

NEGOTIATING THE ETHICS OF TRUST AND ADDICTION IN
CHRONIC PAIN MANAGEMENT

by

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Abstract

Pain is one of the main reasons that adults seek health care, yet the management of chronic nonmalignant pain (CNMP) is framed by epistemological, ontological, ethical, and clinical uncertainties. As a subjective experience, CNMP presents challenges for both patients and health care providers. Opioid analgesics are commonly prescribed for CNMP. However, recent research questioning the long-term benefits of opioids for CNMP and the rapid rise in public health harms from prescription opioid abuse have led to concerns about iatrogenic addiction, drug-seeking behaviour, and medication diversion. Such concerns pose risks to the patient, to the health care provider, and to society, and may threaten the trust that provides the moral foundation of the therapeutic relationship.

Drawing upon an interdisciplinary literature and methods from both bioethics and empirical neuroethics, this in-depth, multi-component single study focused on adults living in an urban setting in the Lower Mainland of British Columbia, Canada. Semi-structured interviews (N=27) were conducted with participants with chronic low back pain to explore their experiences of trust and trustworthiness in CNMP management. Grounded theory analysis of the data yielded four major themes: (1) fidelity and iatrogenic suffering; (2) communicating the invisible and subjective condition of chronic pain; (3) motive, honesty, and testimony; and (4) stigmatized identities. The findings were response-validated by two feedback groups comprising re-contacted interview participants (N=4) and physician specialists drawn from the same setting who care for patients living with CNMP and addiction (N=6).

Qualitative analysis suggests that trust in CNMP management is challenged when patients perceive that their accounts of pain and suffering are considered by health care providers to lack credibility, feel unfairly accused of being deceptive, or sense a combination of both lack of credibility and deception.

The dissertation concludes with a discussion of the practical implications of these findings in the context of the broader health care system, and with a proposal for how a trust-centred ethics of CNMP management can involve greater epistemic humility toward improved patient care.

Preface

No part of the research presented in this document has been published. The UBC Behavioural Research Ethics Board approved the study presented in the dissertation. Certificate number: H12-00227.

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List of abbreviations

5-HT	5-hydroxytryptophan
AIDS	Acquired Immunodeficiency Syndrome
BREB	Behavioural Research Ethics Board
BPI-SF	Brief Pain Inventory-Short Form
CAM	Complementary and Alternative Medicine
CDSA	Controlled Drug and Substances Act
CSA	Controlled Substances Act
CSF	Cerebral Spinal Fluid
CLBP	Chronic Low Back Pain
CNMP	Chronic Nonmalignant Pain
CNS	Central Nervous System
COX-2	Cyclooxygenase-2
DEA	Drug Enforcement Agency
DSM	Diagnostic and Statistical Manual of Mental Disorders
fMRI	Functional Magnetic Resonance Imaging
GABA	<i>gamma</i> -Aminobutyric acid
GLU	Glutamate
HIV	Human Immunodeficiency Virus
HNTA	Harrison Narcotics Tax Act
IOM	Institute of Medicine
IASP	International Association for the Study of Pain

IV	Intravenous
LSD	Lysergic Acid Diethylamide
NE	Norepinephrine
NRM	Nucleus Raphe Magnus
NS	Nociceptive Specific
NRGC	Nucleus Reticularis Gigantocellularis
NSAID	Non-Steroidal Anti-Inflammatory Drugs
MRI	Magnetic Resonance Imaging
ORT	Opioid Risk Tool
pG	Paragigantocellularis
PAG	Periaqueductal Grey
PVG	Periventricular Grey
PSTT	Posterior Spinothalamic Tract
SES	Socioeconomic Status
SD	Standard Deviation
WDR	Wide Dynamic Range
WHO	World Health Organization

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Dedication

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Chapter 1: Introduction

Recent headlines in major news publications that read, “‘I live this life in pain’: Canadians with chronic pain struggle to find help, hope” (Kirkey, 2011, p. headline) and “Addicted to painkillers, unready for help” (Christopher, 2012, p. headline) reflect an increasing public awareness of what many people have dubbed an invisible epidemic of chronic nonmalignant pain (CNMP), and what the Centers for Disease Control in the United States have claimed to be a corresponding epidemic of prescription opioid abuse.

The current state of CNMP in North America is indeed concerning. There are years-long wait lists for treatment centres; minimal health care provider education and training in both pain and addiction; limited evidence for effective long-term treatments; health care provider, patient, and societal worries about the ambiguous moral and medical status of addiction; misleading marketing strategies by the pharmaceutical industry; and the escalating public health problem of prescription opioid abuse. These factors are enmeshed in a complicated history of international narcotic regulatory regimes, policies, and prohibition-era laws that still impact medical procedures and prescribing attitudes and behaviours of health care providers today. In Canada, these complex concerns exist within increasingly fragmented provincial health care systems that operate on a model of acute care medicine focused on curative goals of care, outcomes, and eradication of disease—a medical model that is increasingly unable to meet the complex health needs of the chronically ill. Behind the scenes are research programs that continuously generate new knowledge about the neurobiological and genetic contributors to the development and maintenance of CNMP, and lead to ever-improving treatments, diagnostic, and interventional technologies (Borsook, Sava, & Becerra, 2010; Coghill, McHaffie, & Yen, 2003). At the policy and health systems level, it is becoming clear that more action needs to be taken to address the wider health system issues and the health and social disparities that impact individuals living with CNMP and their families in profound ways (Liberman, O’Brien, Hall, & Hill, 2010; Institute of Medicine [IOM], 2011).

The subjective experience of CNMP includes but goes beyond the neurobiological process of nociception. The experience of pain may contain emotional, social, cultural, and

spiritual elements. The experience of CNMP challenges the limits of language, and defies boundaries of race, class, gender, and culture, but CNMP is not equally distributed amongst members of these groups in society (Anderson, Green, & Payne, 2009; Fuentes, Hart-Johnson, & Green, 2007; Green & Hart-Johnson, 2010; Unruh, 1996). Pain can displace its sufferers from their conventional ways of being in the world, and may shatter deeply held assumptions about it. Pain can threaten the intactness of the self, the sense that one is in control of one's own body, and may challenge widely held Western liberal values of individual autonomy, independence, self-control, and personal responsibility. Pain may expose a *terra incognita* where nothing is quite as it seems, as what was once ordinary becomes abnormal, disorderedly, and chaotic (Jackson, 2005; Kleinman, 1988; Scarry, 1985)

As the social science and popular press literatures show (Heshusius, 2009; Jackson, 1992, 1995; Levy, 2003; Mager, 2013), while the visibility of pain experience from injury may diminish over time, the internal suffering of the individual may be unremitting. Plans and relationships may be disrupted. Activities are often restricted. Patients and families struggle to navigate the health care system; they receive care from a range of health care providers, and receive interventions that may only provide them with short-term relief. Patients may also have to deal with funding applications, government subsidies, and social service agencies. Many of the everyday experiences and encounters people have take on a new meaning for those living in pain. Activities of daily life and socializing with others that were once considered mundane may become arduous. As Scarry (1985) has written, pain is an “unmaking of the world.”

In the highly contentious context of contemporary CNMP management (Butler & Sheridan, 2010; Upshur, Bacigalupe, & Luckman, 2010; Wasan, Wootton, & Jamison, 2005), some health care providers may be hesitant to treat patients with certain classes of medications that carry the risk of serious harms, such as opioid analgesics, when symptoms have no discernable biological abnormality or patients themselves are considered to be at risk for iatrogenic addiction or other harmful behaviours (Friedman, Li, & Mehrotra, 2003). Some patients may constantly deal with health insurance companies over coverage of expensive treatments or long-term disability (Gaskin & Richard, 2012).

The individual living with CNMP is a member of a social group that experiences widespread inadequate pain management and suffering (King & Fraser, 2013; Schopflocher,

Taenzer, & Jovey, 2011). Clinical and social challenges may ensue if the patient's subjective pain experiences are not congruous with the objective clinical framework of modern health care, which, since the rise of modern medicine, has considered pain as a material, visible pathology (Morris, 1998; Rey, 1995; Sullivan, 1998). Tensions between the inherent subjectivity of CNMP and tools of biomedicine can produce feelings of frustration, dissatisfaction, doubt, and distress in health care providers when caring for patients, particularly if the patient also has addictions issues (Barry, et al., 2010; Matthias, et al., 2010). The patient's authenticity and moral character may be questioned. Motive may be questioned when the potential secondary financial or emotional gain or drug-seeking is involved (Matthias, et al., 2010; McCaffery, Grimm, Pasero, Ferrell, & Uman, 2005; Turk, 1996). As Cohen, Quintner, Buchanan, Nielsen, and Guy (2011) state, "when sufferers of medically unexplained disorders (such as chronic pain syndromes) cannot fit into the conceptual frame of biomedicine and therefore cannot meet health professionals' expectations of what constitutes an illness, their personal legitimacy is undermined" (p.1639). Therefore, uncertainty, distress, and frustration may exist on both ends of the therapeutic dialogue in the CNMP context.

As Kleinman (1988), Jackson (1992, 2005) and others have pointed out, the responses of others to a person's pain experiences matter. These responses, with their potential for important losses and gains, are embedded with moral content (Kleinman, 1998, 1999). As Kirkey (2011) notes in her opening article, "...chronic pain is one of the most invisible, undertreated and disbelieved afflictions in Canada." My claim in this dissertation is that this invisibility leads to compromised trust in the narratives of CNMP sufferers, and, by extension, I will argue that perceived distrust is a key moral dimension in that lived experience.

1.1 Situating the dissertation in the fields of bioethics and neuroethics

Although written accounts of ethics in the delivery of health care can be traced to the times of Hippocrates, what has become known as bioethics is a very young field—approximately half a century old. As it is often defined, bioethics is a branch of normative applied ethics that focuses on issues in biomedicine and the life sciences. The German philosopher Jahr (1927), thought to be the originator of the bioethics neologism, put forward his concept of a

Bio-Ethik to extend Kant's moral imperative to all forms of life, and as an ethics devoted to an understanding of lived experience. Bioethics evolved to become the study of the ethical and moral implications of biomedical practice and research, and the implications this knowledge has on and for the clinic, the conduct of health care professionals, health policy, and beyond (Steinbock, 2007).

Bioethics as a field emerged in the 1960s, an era marked by social and cultural transformation. The era that included a greater focus on individual and group rights, including those socially marginalized, led many to question the power and authority of social institutions such as the government, the medical profession, and the law in the governance over individual lives. These social movements prompted the creation of the first bioethics think tanks in the U.S., including the Hastings Center, co-founded in 1969 by Daniel Callahan (Jonsen, 2012), and the Kennedy Institute of Ethics (formerly the Kennedy Institute for the study of Human Reproduction and Ethics), established in 1971 by André Hellegers (Harvey, 2013). The Hastings Center and the Kennedy Institute of Ethics provided an intellectual environment for some of the field's pioneers, including Ramsey (1970) and Pellegrino and Thomasma (1993), who explored ethical issues in patient care, the therapeutic relationship, and the virtues of medical professionals.

Much of the history of bioethics as a formalized area of study comes from the research world and rapid advances in medical science and technology in the 20th century. The Nuremberg Code was established in 1947 in the wake of the atrocities committed by Nazi physicians and scientists on concentration camp prisoners and others during World War II. The years that followed were also plagued by a series of additional scandals in medical research. These scandals include the Tuskegee Syphilis Study in Macon County, Alabama, in which several hundred black men from 1932-1972 were denied treatment for syphilis so that the researchers could study the disease over time, even when penicillin became available in 1947 (Brandt, 1978). From 1956 to 1972 at the Willowbrook State School in New York, children with neurodevelopmental disabilities were infected with the hepatitis B virus (HBV) by medical researchers (Robinson & Unruh, 2008). The study was halted after critics asserted that there was more harm than benefit to the participants after being intentionally infected with HBV, and questions were raised about whether parents felt coerced to consent on behalf of their children so that the children could be admitted to a school with limited space that met

their needs (Robinson & Unruh, 2008). In 1963, three physician researchers from the Jewish Chronic Disease Hospital in Brooklyn, New York, injected live cancer cells into patients without their consent, a situation that raised additional questions about dual-role conflicts of physicians and scientific researchers (Katz, Capron, & Glass, 2003). In the early days of bioethics, some courageous physicians became whistleblowers on their colleagues for experimenting on patients without valid consent (Beecher, 1966). Although there is far more regulatory oversight today, questions about the ethical conduct of research still remain (Elliott, 2012), particularly with socially marginalized and vulnerable populations.

The rapid emergence of novel medical technologies was also a driving force in shaping bioethics (Jonsen, 1998, 2012; Rothman, 2009). New technologies allowed for cures and treatments for ailments that were thought to be incurable. Kidney dialysis, organ transplantation, the polio vaccine, and respirators, among others were some of the life-prolonging innovations that were propelling modern medicine and capturing the attention of the broader public (Jonsen, 1998, 2012). These social, cultural, scientific, and technological shifts raised profound moral questions about the role of technology in medicine and human life, the limits of human life and what lives were considered worthy of technological intervention—in other words, what lives should be saved, particularly in a time of resource scarcity (Childress, 1970). Not only did the rise of technology in medicine change the dynamic between patient and provider, it had a major influence on the public perceptions of trust in health care providers, particularly physicians' ability to protect those made vulnerable by illness and disease (DeVries & Kim, 2008; Pellegrino, 1991).

During this era of social reform, the public became aware of harms to people from scientific research that often lacked adequate informed consent procedures (Brandt, 1978; Robinson & Unruh, 2008; Katz, Capron, & Glass, 2003). There was also an increasing awareness that certain medical treatments and interventions recommended by health care providers might not serve to promote the patient's welfare, but rather serve the financial interests of the health care provider or institution (Rothman, 2009). These social changes motivated a libertarian posture toward health care and research, and the creation of the Belmont Report in 1979 for the protection of research on human subjects, which was followed by the publication of the first edition of the *Principles of Biomedical Ethics* (Beauchamp & Childress, 2009) that same year. These two documents were central in

formalizing bioethics within and beyond the clinical context, where the principles of respect for autonomy, nonmaleficence, beneficence, and justice provide the moral framework. The rise of bioethics in response to research scandals, technology drivers, and changes in the dynamic of the therapeutic relationship led De Vries & Kim (2008) to question whether bioethics is founded upon a social history of distrust.

Much like bioethics was spawned as a response to the developments in science, technology, research, and clinical practice, neuroethics emerged formally in 2002 as a response to the rapid advances in and increasing hype around brain research specifically (Fins, 2011; Illes & Bird, 2006; Marcus, 2002). Research in the neurosciences has helped to clarify some of the neurobiological underpinnings of pain, and has also helped to shed light on the categorical mistake that the body feels pain. For instance, based on research on patients with phantom limb pain, Melzack and Wall (1982) concluded that “We do not need a body to feel a body or a physical injury to feel pain; the brain can generate both experiences” (p.xi). Biomedical models of pain and treatment have become more neurocentric in both epistemology and approach, and neuroethics has responded to these developments by calling for a “neuroethics of pain care” (Giordano, 2009, 2010a). This important approach aims to guide thinking about the role of neuroscience and neurotechnology in pain management practices, and in particular, how knowledge from neuroscience can inform the way pain patients ought to be treated. However, despite these rapid technological developments in science and medicine, uncertainties remain.

1.1.1 Bioethics, chronic illness, and chronic nonmalignant pain: Opportunities for discovery

The bioethics literature on pain management has traditionally focused on malignant, cancer pain and ethical issues in the provision of palliative care (Emanuel, 2001; Pellegrino, 1998). Bioethics scholarship in this area has done much to help minimize barriers to pain relief at the end of life and provide a forum for debate about suffering and human dignity (Emanuel, 2001). Despite the availability of relatively inexpensive pharmacological and non-pharmacological interventions in Western societies, and an increased emphasis in the CNMP discourse on the ethical duty to relieve pain and suffering, there is consensus among pain

experts that CNMP remains inadequately treated (IOM, 2011). However, concerns about the failure to relieve pain and suffering are not only considered unethical; they are also framed as a violation of a fundamental human right (Brennan, Carr, & Cousins, 2007; Lohman, Schleifer, & Amon, 2010). This idea was captured in the First International Pain Summit in 2010, and resulted in the *Montreal Declaration* (International Pain Summit of the International Association for the Study of Pain, 2011).

The inadequate treatment of pain has been identified as a source of public, professional, and political concern (Bostrom, 1997, IOM, 2011). The U.S. Congress declared the year 2001 as the beginning of the “Decade of Pain Control and Research” to address the challenges posed by pain treatment. Even though individual providers may successfully manage their patients’ CNMP needs, there is evidence to suggest that the treatment of pain may be worsening. For example, some CNMP conditions such as low back pain may tend to be overtreated, but this has not translated to improvements or reductions in disability rates on a population level (Deyo, Mirza, Turner, & Martin, 2009). There is a growing awareness that the prevalence of un- and undertreated acute, chronic, and cancer pain is a global health matter requiring urgent attention (International Association for the Study of Pain, 2013; King & Fraser, 2013).

While disciplines such as sociology and anthropology have provided rich insights of individuals and groups living with CNMP, the ethical implications of the findings are largely left unaddressed in their literature. In bioethics, the majority of the emerging discourse has been theoretical; ethical issues are defined, developed, and addressed top-down through clinical and academic discussion (see, e.g., Giordano, 2009; Payne, et al., 2010; Rich, 1997, 2000; Schatman, 2007; Sullivan & Ferrell, 2005). There is still much work to do in the context of assessment and clinical practice, however. In fact, this gap from theory to practice of chronic illnesses motivated Gibson and Upshur (2012) to ask in their editorial, “Where are the bioethicists?” (p. ii), for Christopher (2011) to proclaim, that “it’s time for bioethics to see chronic pain as an ethical issue” (p. 3), and Rich (1997) to argue that bioethics has subjected the phenomenon of pain to a “legacy of silence” (p. 233). This dissertation attempts to heed Gibson and Upshur’s and Christopher’s call, and to contribute meaningfully to the work that is breaking the legacy of silence claimed by Rich.

1.2 Conceptual and empirical opportunities in the ethics of CNMP

The therapeutic relationship has been a main focus of bioethics since the inception of the field, and one of the more controversial issues (Jonsen, 1998; Siegler, 1998). In CNMP, the therapeutic relationship is an area requiring further study as anthropological research has demonstrated that it is among the greatest challenges in health care (Jackson, 2005). Trust has been identified as an essential ingredient for both a strong therapeutic relationship and subsequent positive outcomes in the management of chronic illness (Canlan & Rowe, 2007; Thorne & Robinson, 1988), and trust in patient testimony is a key facet of developing shared goals of care. Accordingly, trust is a concept of great ethical and practical importance in the context of CNMP clinical encounters.

Just as chronic illness and CNMP have largely been overlooked by bioethics, trust has also been little studied in bioethics with few notable exceptions (see, e.g., De Vries & Kim, 2008; Ho, 2011; McLeod, 2002, 2004; O'Neill, 2002a; Rogers & Ballantyne, 2009). Trust may not have been fully explored because of the historical focus in bioethics on acute care-related questions such as withholding and withdrawing treatment, and patient autonomy as it applies to informed consent (O'Neill, 2002a). De Vries and Kim (2008) acknowledge that it is “odd that bioethicists [have] paid so little attention to an issue that is central to their work” (p.377).

Although trust has surfaced as a theme in recent empirical studies on CNMP (Matthias, et al., 2010; Ridd, Shaw, Lewis, & Salisbury, 2009; Upshur, Bacigalupe, & Luckmann, 2010), and in one study exploring the ethics of CNMP among key stakeholders (McGee, Kaylor, Emmott, & Christopher, 2011) trust tends to be portrayed in a generic or generalized way, and has not been a focal point of research. Survey studies have attempted to quantify patient trust in physicians and other health care stakeholders (see: e.g., Hall, Dugan, Zheng, Camacho, Kidd, Mishra, & Balkrishnan, 2001), but these do little to provide in-depth insight into a complex, multidimensional concept. Such survey research focuses on placing trust in others, and does not explore what it is like to be trusted.

Critically, how individuals living with CNMP experience being trusted, distrusted, and articulate how they demonstrate trustworthiness is unclear, and the normative role of trust in the ethics of CNMP is understudied. Studies that explore the experience of being trusted or

distrusted in health care contexts, how patients negotiate trust relations with providers, and the issues and experiences individuals living with CNMP identify as morally and practically important, would provide a major contribution to the developing literature on ethics in CNMP management. While a host of complex factors likely converge to shape the interaction between patient and provider in CNMP management, the central thesis of this dissertation is that tensions in the therapeutic relationship in CNMP management may reflect a more fundamental concern: the absence, or breakdown, of trust.

1.2.1 Notes on style and terminology

In this dissertation, I use the phrases *individuals or patients with CNMP*, or *individuals or patients living with CNMP*, or *individuals or patients suffering from CNMP* as opposed to *CNMP patient* because no two CNMP patients are identical. Even though participants in this study all reported the same condition and share the diagnostic category, their illness experiences and journeys are necessarily unique (Frank, 1997). Moreover, while an individual living with CNMP may be a patient on one or more occasions during the course of a chronic illness, there are many times when the social role of “patient” is not the adopted identity (Zola, 1973). As Conrad and Barker (2010) have pointed out, the patient experience is not necessarily the same as the illness experience.

The terms *narrative* and *story* are used interchangeably. I use the term *health care provider* to include all health care professionals. I refer to specific professionals (e.g., physicians) where appropriate, particularly when the discussion is relevant to the type of provider. For example, only physicians, not for example social workers, can prescribe controlled substances such as opioids.

The term *patient-doctor relationship* is well known in medicine and bioethics (Emanuel & Emanuel, 1992). The relationship is typically understood as an interaction between patient and physician over time. Both the values that underlie the patient-doctor relationship and the models that shape it have long been debated (Childress & Siegler, 1984; Emanuel & Emanuel, 1992). In recent years, the term has also been extended to other health care providers, and in this dissertation, I use the more encompassing term of the *patient-provider relationship*. However, the term relationship in this context may be a misnomer as

an interaction or series of interactions may exist between patient and provider without a relationship ever developing. Acknowledging that there may be no relationship between patient and provider, at times I refer to the *therapeutic dialogue*, which, at times, may be a more accurate portrayal of the clinical practice situation.

When I refer to bioethics as a field, I include neuroethics as well. As I describe in further detail in CHAPTER 5, empirical neuroethics has many of the same overall goals and approaches as empirical bioethics: the exploration of research questions relevant to health care and human behaviour, and the use of descriptive empirical data to inform normative ethical analysis. I use the umbrella term of bioethics for brevity, while acknowledging that neuroethics focuses on the brain and behavioural sciences, and ethical issues related to topics such as consciousness, responsibility, addiction, mental disorder, and the potential benefits and limitations of novel neurotechnologies (see, e.g., Illes & Sahakian, 2011).

1.3 Goals of the dissertation

Using a qualitative, grounded theory approach (Charmaz, 2006; Corbin & Strauss, 1990), I centre the stories of individuals who live with CNMP and attend to the moral dimensions of trust in their narratives, especially in the therapeutic relationship with health care providers. In presenting narrative excerpts from the stories of individuals living with chronic low back pain, my goal is to determine and characterize how dimensions of trust interact in the therapeutic relationship in CNMP management. In keeping with grounded theory analysis, I develop a model of trust from the findings about facts, realities, meanings, and contexts of these individual sufferers' lives. Accordingly, my methodological orientation has pragmatic overtones, largely inspired by the narrative approach to bioethics as described by Zaner (1988, 1991, 1994), Frank (1995, 1997, 2004b), and Brody (2003, 2007) and the medical anthropology of moral experience, particularly as it relates to chronic pain and chronic illness, as described by Kleinman (1988, 1996, 1999).

Narrative and anthropological approaches are consistent with recent arguments supporting the “empirical turn” in bioethics (Draper & Ives, 2007), which draws upon social science research methods to help integrate diverse perspectives into the discourse (Elliott, 1997; Turner, 2003). However, the perspective of the individual living with CNMP as a

guiding voice in the ethics of CNMP is in short supply. Arguing for more integration of the moral concerns of patients with CNMP into the bioethics literature, Benner (2007) reminds us “the chronic pain patient brings a very unique ethical perspective to the process of health care, and this perspective has been too often overlooked by the medical community” (p.15). Understanding the perceptions of patients living with CNMP is important, because improving the treatment, support, and quality care for people living with CNMP in Canada and beyond demands consideration and a deeper appreciation of what it is like to live and even suffer with CNMP. This includes attending to the ways in which individuals narrate how they conduct themselves in the world in relation to the moral dilemmas, judgments, and decisions of everyday life in varied contexts (Kleinman, 1999; Morris, 1991). Such a goal requires that health care providers, scientists, patients, families, and policy makers listen to sufferers’ stories.

The empirical component of my research is primarily focused on an in-depth, single study of patient perspectives about the management of CNMP in the therapeutic relationship. I claim that a rich concept of bioethics in CNMP must encompass the experiences of the individual who lives with CNMP and suffers from it, and the contexts in which the person is embedded. Participants can learn what is morally relevant to them from their lived experiences, and then reflect and articulate what is at stake in different contexts. Participant narratives provide a critical insight into the ethical dimensions of subjective experiences such as pain and suffering. Examining the stories of individuals living with CNMP provides an epistemic infrastructure to this dissertation.

This dissertation brings diverse interdisciplinary scholarship on CNMP and bioethics into one conversation. I follow the neurologist Fields’ (2007) assertion that, “[t]o the extent that we seek to understand the human experience of pain as fully as possible we must address the issue of meaning. This requires constant interchange between neuroscience, the social sciences, and the humanities” (p. 37). This line of interdisciplinary thinking follows the consilience argument made by Wilson (1998) for the “‘jumping together’ of knowledge by linking of facts and fact-based theory across disciplines to create a common groundwork of explanation” (p. 8). Interdisciplinary approaches draw upon knowledge from multiple relevant disciplines and integrate this knowledge into a more thorough understanding of the phenomena under investigation (Newell, 2001). Through the outcomes of research, I hope

that bioethics, and by extension neuroethics, will see pain narratives not just as a priority for the clinic, but for practice guidelines and health care provider training and education as well. The findings will ideally help to guide clinicians, patients, and policy makers in making ethically sound recommendations that reflect what matters most to patients.

Having provided the rationale for the approach I have taken to this dissertation work in CHAPTER 1, in CHAPTER 2, I synthesize different lines of inquiry and provide an account of the inherently multivalent and complex phenomenon of pain. In CHAPTER 3, I examine three moral tensions at the intersection of CNMP and addiction, with a particular focus on prescription opioid abuse. The aim of the chapter is to characterize how prescription opioids and moralized attitudes about addiction in Western societies have influenced the practice, policies, and legislation relevant to CNMP management, and has contributed to a broader climate of distrust. In CHAPTER 4, I further elaborate on the concepts of trust, distrust, and trustworthiness as they are utilized in philosophical, applied ethics, and sociological texts.

In CHAPTERS 5 to 6, I present the methodological design using grounded theory and results from patient interviews and patient and physician feedback groups. In CHAPTER 6, I also present a theoretical model derived from the findings. Through this model, and consistent with the methods I have adopted for this work, I visualize and integrate the results. In the final chapter, CHAPTER 7, I discuss patient and health care provider perspectives on the relationship in CNMP management, contextualize the findings using the model as a guide, acknowledge various assumptions and discuss limitations of the work, and conclude with directions for future interdisciplinary research.

Chapter 2: The question of pain

Pain – has an Element of Blank –

It cannot recollect

When it begun – or if there were

A time when it was not –

It has no Future – but itself –

Its Infinite realm contain

Its Past – enlightened to perceive

New Periods – of Pain (Dickinson, 1976)

The word pain originates from the Latin words *poena*, loosely translated to mean penalty or punishment, and *dolor* which denotes pain, grief, ache, and suffering. Anthropologists, sociologists, psychologists, philosophers, and other observers of and commentators on human life have long asserted that pain is a fundamental feature of human existence (Delvecchio Good, Brodwin, Good, & Kleinman, 1992). Pain, however, is enigmatic; as a subjective experience that is often refractory to objective assessment, pain is elusive. There is no universal pain experience. According to the literary scholar Scarry (1985), pain is the quintessential private experience. Pain has historically held various meanings and significance, shaped by the cultural, religious, intellectual, and political communities of the time (Morris, 1991; Rey, 1995).

What is known about pain in antiquity comes from the texts and philosophies of Ancient Greece and Rome, including the works of Homer, Socrates, Aristotle, Hippocrates in the *Corpus Hippocraticum*, and later Galen. A vocabulary emerged within these works for describing the experience of pain and its significance from both a medical and moral perspective. Regarding the latter, philosophers and physicians suggested that pleasures must be enjoyed and pain must be avoided (Rey, 1995). This is by and large the philosopher Aristotle's (1999, 2008) perspective, in which he defined pain, or *lupē*, as an emotion. Along with pleasure, he considered pain as *epithumia* or an “appetite” (Aristotle, 1999, p. 323). As an emotion, he believed that pain alters judgment. Aristotle witnessed the effect of pain on

human beings and how pain “disturbs and ruins the nature of the sufferer” (Aristotle, 1999, p. 48).

The Roman physician Galen emphasized the role of sensation and perception in pain, particularly the role of touch, and had a major role in classifying and describing different forms of pain based on their types and intensities, many of which resemble metaphorical descriptors used today. These include pains that Galen called *pulsific* (e.g., giving the sense of throbbing, often found in inflammations), *gravative* (e.g., giving the sense of weight), *tensive* (e.g., giving the sense of tension), and *pungitive* (e.g., giving the sense of a sharp point or repeated stabbing). In the Middle Ages, the meaning of pain and suffering took on religious and spiritual significance as enduring physical pain and suffering was considered a divine experience that brought believers closer to God (Rey, 1995). In the Renaissance, the French philosopher Descartes described pain as a reflexive response to a physical, mechanical stimulus—a concept that had wide influence for centuries (Cottingham, Stoothoff, & Murdoch, 1985).

Today the prevailing definition of pain describes, “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (International Association for the Study of Pain [IASP], 2010). The IASP definition that I use as an anchor for the present work is based on similar definitions such as pain is “whatever the experiencing person says it is, existing whenever the experiencing person says it does” (McCaffery, 1968, p. 8). These definitions are not without problems. For instance, the pain that an individual experiences is not necessarily the same as what the individual says he or she experiences. While these definitions emphasize that pain does not have to be linked to a physical, mechanical stimulus and that pain is a subjective experience, the Cartesian legacy remains strong in CNMP management (Cohen, et al., 2011; Sullivan, 2001b). How the health care community understands and defines pain, including accompanying suffering, has implications for how it is or should be treated.

Pain occurs in all age groups, although women and older adults tend to be overrepresented in clinical samples (Moulin, Clark, Speechley, & Morely-Forster, 2002; Unruh, 1996). The higher prevalence in women might be explained by psychosocial factors such as different tendencies to seek health care services in general and for pain specifically (Weir, Browne, Tunks, Gafni, & Robers, 1996). As well, recent research suggests that there

may be important underlying biological-sex differences between males and females in pain sensitivity (Fillingim, King, Ribeiro-Dasilva, Rahim-Williams, & Riley III, 2009; Mogil, 2012a).

As the Institute of Medicine (2011) Report *Relieving Pain in America* emphasizes, the role of pain is purposeful—it is critical to survival and human flourishing. Pain may be a biological warning sign or alarm of tissue damage, infection, or future harm. The noxious qualities of pain may have the adaptive advantage of motivating organisms to engage in self-preservation, such as moving away from the danger, seeking rest, and for humans, seeking medical attention. From this evolutionary perspective, pain might be construed as a biological good, or *eudynia*. Indeed, not being able to experience pain can be dangerous and even fatal. In Melzack and Wall's (1982) seminal work, they describe the case of Miss C., a woman who had a congenital insensitivity to pain due to a genetic mutation encoding the growth factor receptor necessary for the survival of sensory neurons, and died at age 29 from infections and extensive skin and bone trauma.

2.1 Definitions of the pain experience

Pain experiences are assessed clinically by duration and source. Historically, these experiences were demarcated by one of two categories, acute pain and chronic pain, although recent efforts—such as the IASP definition—attempt to provide a definition of pain that encompasses both acute and chronic pains. For the purposes of this dissertation, I will adhere to these distinctions, but recognize that there is variability in the definition of pain in the theoretical and empirical literature (Von Korff & Miglioretti, 2005).

Acute pain may persist for up to three months, and typically arises from acute injury or disease process. The pain is usually most intense at the onset of injury and subsides as healing occurs (Casey, Greenberg, Nicassio, Harpin, & Hubbard, 2008). Acute pain may also be recurring with alternating painful and pain-free episodes (IASP, 2010). It may transition to chronic nonmalignant pain (CNMP) if it is inadequately treated, or if there is a diminished responsiveness to some therapies (Casey, et al., 2008; DeLeo, 2006).

CNMP is currently defined by the IASP as prolonged and persistent pain lasting at minimum three to six months in duration, but many sufferers live with CNMP for much longer

periods of time (IASP, 1994). CNMP may be associated with chronic tissue pathology (e.g., arthritis) or the pain may exist beyond an expected healing period for an acute injury.

As described by Casey, et al., (2008) acute and CNMP differ in both temporality and in kind. CNMP without an obvious cause or origin may signify disease. Since CNMP is often incurable, many people live encumbered by their chronic condition. It is at this point where pain no longer serves an adaptive role for the organism; pain is no longer good or useful as the pain has become *maldynic*, or pain without purpose (Giordano, 2007a, 2011).

CNMP can take many forms that may or may not have a known origin or discernible organic cause. Examples include low back pain, neuropathic pain, fibromyalgia, migraine, and tension-type headache (Fishman, Ballantyne, & Rathmell, 2010). Even in cases for which there was originally an identifiable pathology, the pathology may resolve but pain may persist in absence of any evidence of nociceptive stimulus due to neuroplastic changes in the CNS that promote ongoing pain after the initial injury (Woolf, 2011). Conditions in which pain is an associated symptom may include diabetic neuropathy, arthritis, and Acquired Immunodeficiency Syndrome (AIDS). CNMP may arise out of injury, a co-occurring chronic disease, psychological trauma, or complications from surgery.

Symptoms associated with CNMP conditions are often accompanied by reduced mobility, loss of energy and strength, disrupted sleep patterns, and other health and mental health comorbidities (McCracken & Iverson, 2002). These sequelae of CNMP can lead to loss of identity and role functioning, ability to work, financial burdens, and complicate treatment for other conditions. Studies consistently suggest that patients report a low quality of life with CNMP (Lamé, Peters, Vlaeyen, van Kleef, & Patijn, 2005; Hunfeld, et al., 2001; Terwindt, Ferrari, Tijhuis, Groenen, Picave, & Launder, 2000). CNMP may also adversely impact family members, friends, and colleagues close to the patient, or those directly involved in the care of the patient (Katzman & Geppert, 2008).

2.2 Prevalence and economic costs

CNMP has been defined using diverse methods, questions, and samples from different geographic areas and time frames making published data on prevalence difficult to compare (Boulanger, Clark, Squire, Cui, & Horbay, 2007). While statistics vary, the literature indicates the high global prevalence of pain. In a large-scale telephone survey of 15 European countries and Israel, authors Breivik, Collett, Ventafridda, Cohen, and Gallacher (2006) revealed that moderate to severe CNMP occurs in approximately 19% of adults. An Australian study by Blyth, March, Brnabic, Jorm, Williamson, and Cousins (2001) found the prevalence of CNMP to be 17.1% in men and 20% in women. The European study used six months as a minimum for CNMP, while the Australian study used three months as a minimum. In the United States (U.S.), CNMP affects approximately 25% of people (IOM, 2011); in Canada, given the rapidly aging population, one out of every three Canadians is expected to be affected over the next two decades (Moulin, Clark, Speechley, & Morely-Forster, 2002). In all of these studies, there was a much higher prevalence in older adults. In the US, it is often reported that more people experience CNMP than heart disease, diabetes, and cancer combined (National Center for Health Statistics, 2006; Tsang, et al., 2008).

CNMP is associated with increased use of health care resources, and individuals seek out care in a variety of public and private health care contexts (Turk, 2002; Loeser, 1999). Authors from the Canadian STOP-PAIN project found that the mean monthly cost of care was \$3,112.00 CAD, with 95% of those costs accounting for out-of-pocket expenses, private and third-party insurance, and time costs (Guerriere, et al., 2010). Gaskin and Richard (2012) estimate that the annual economic costs of CNMP in the U.S. falls between USD \$560-635 billion, which includes USD \$61.2 billion per year in lost work productivity (Stewart, Ricci, Chee, Morganstein, & Lipton, 2003). The cost of CNMP in the U.S. exceeds that of the six most expensive diagnoses (Tsang, et al., 2008).

2.3 Chronic low back pain

Chronic low back pain (CLBP) is the most prevalent CNMP condition (Hardt, Jacobsen, Goldberg, Nickel, & Buchwald, 2008; National Center for Health Statistics, 2006), and low

back pain is one of the oldest medical afflictions. The Egyptian *Edwin Smith Papyrus* suggests physicians provided treatments for low back pain in Ancient Egypt (Brandt-Rauf & Brandt-Rauf, 1987), and remedies for back pain are also documented in the *Corpus Hippocraticum*. Much like today, healing was offered largely for symptomatic relief (Allan & Waddell, 1989). During the Renaissance, low back pain or *lumbago* was classified as a buildup of rheumatic phlegm and was treated in the same way as other rheumatic diseases. Allan and Wadell (1989) state that chronic back pain historically did not receive the status of a disability¹: “it seems unlikely that simple backache was easily accepted as a reason for chronic disability in ages dominated by epidemic infections, limited food supply, and a life expectancy of less than 40 years” (p. 9).

In the nineteenth century, medical and folk perspectives on low back pain began to shift. The Scottish physician Brown (1828) was the first to propose that back pain was due to changes in the spine and nervous system, and considered back pain a disease caused by what he called “irritation of the spinal nerves.” Spinal irritation was a condition more “peculiar to females” (p. 131), and had a major influence on how CLBP was perceived and defined in the ensuing decades. Many physicians were dissatisfied with the symptom vagaries of spinal irritation, which resulted in a staunch opposition to the diagnosis (Brown, 1828). It was not until a rise in back injuries due to the Industrial Revolution and nationwide railway construction specifically that a new cultural framing of back pain emerged, mainly in men: a neurological and psychological condition known as railway spine (Allan & Waddell, 1989; Keller, 1995). Both spinal irritation and railway spine were initial attempts to construct a disease model of CLBP and forms the basis for pain management today (Waddell, 1996). In this way, CLBP is a modern illness largely brought on by the Industrial Revolution and the advent of compensation legislation in the industrialized world. These historical processes shifted the emphasis of treatment away from approaches focused on disease eradication to a clinical management philosophy based on independence and functionality.

Today, CLBP is considered a subset of CNMP and is an umbrella term of a diverse number of painful lower back conditions. Approximately 90% of people with CLBP have non-

¹ Disability has historically been associated with various socio-cultural and normative meanings. Some are discriminatory and associated with a deficit model of human functioning.

specific or idiopathic CLBP, that is, pain that cannot be reliably attributed to a recognizable pathology and is often intermittent (van Tulder & Koes, 2002). While prevalence estimates are difficult to determine, a meta-analysis estimated that the lifetime prevalence of CLBP is approximately 23%, and is most likely to occur in the 45-64-year age range (Balagué, Mannion, Pellisé, & Cedraschi, 2012). Low back pain is one of the main causes for absence from the workplace (Andersson, 1999) and demands extensive use of health care resources (Picavet, Struijs, & Westert, 2008). Although definitions of disability are not often provided, disability due to CLBP increased exponentially from the latter half of the 20th century, with approximately 10% of the population considered disabled by CLBP. The disability framing of CLBP is having a major impact on public health systems (Waddell, 1996; Balagué, et al., 2012). However, these statistics need to be put in context: they are often projections from worker compensation boards or disability insurance collectors. In Canada, patients who report back pain have the highest overall degree of health service utilization among adults less than 60 years of age (Rapoport, Jacobs, Bell, & Klarenbach, 2004).

2.4 Pain as a biopsychosocial phenomenon

Given the phenomenological complexities of pain, there has been a paradigm shift in pain theory, research, and practice over the past several decades. This shift is characterized by the adoption of a pain model, known as the biopsychosocial model, that situates the subjective experience of pain as emergent from convergent biological, psychological, spiritual, and social systems (Gatchel, Peng, Peters, Fuchs, & Turk, 2007; Waddell, 1987). The contemporary biopsychosocial model of pain draws upon the multidisciplinary concept of *total pain* advocated by the hospice and palliative care pioneer Cicely Saunders (Richmond, 2005), “influenced as much by personal values and cultural traditions as by physiological injury and disease” (Post, Blustein, Gordon, & Neveloff Dubler, 1996, p. 348). Social and structural factors, such as political and economic systems, also shape notions of health, illness, and behaviour (Engel, 1980). Under this model, pain management ought to reflect and recognize the relative influences of these multiple interacting systems on patient health and well-being (Craig & Versloot, 2011; Giordano & Schatman, 2008b; Quintner, et al.,

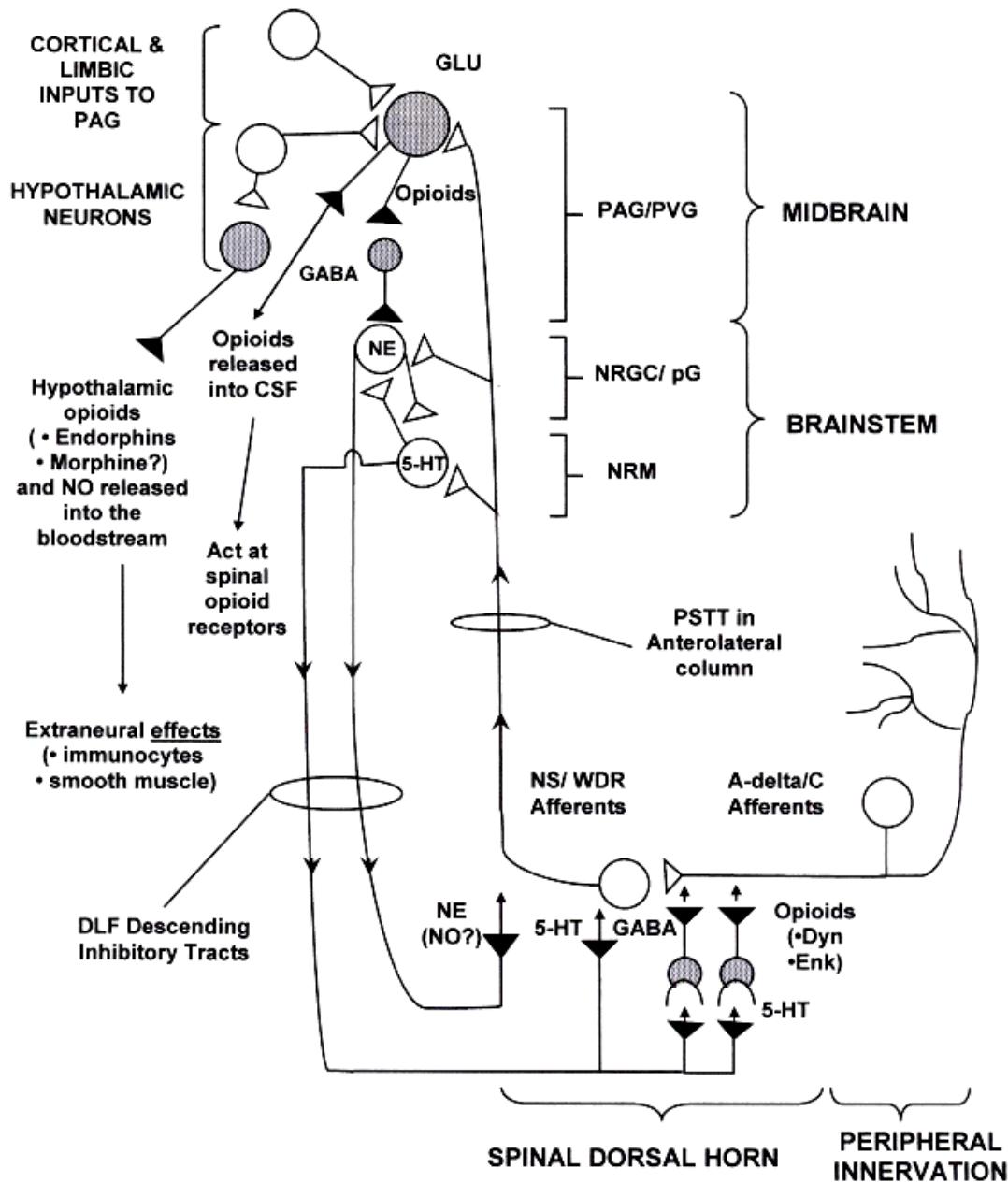
2008). The discussion that follows summarizes some of the multifaceted and intertwined contributors to the CNMP experience in greater detail.

2.4.1 Neurophysiology and genetics

Descartes is credited as the first to argue for the centrality of the brain in pain perception, as is documented in his 16th-century account of phantom limb pain: “pain in the hand is felt by the soul not because [pain] is present in the hand but because [the soul] is present in the brain” (Cottingham, Stoothoff, & Murdoch, 1985, p. 284). Although the soul is no longer implicated, contemporary neuroscience research continues to focus on the roles of the CNS and peripheral nervous system (PNS) in pain.

Neuroimaging research demonstrates a widely distributed network activated by nociceptive or anti-nociceptive mechanisms (Borsook, Sava, & Becerra, 2010). Nociceptors are located in peripheral nerve terminals of certain types of fibres activated by noxious stimuli. Nociception is the neurobiological process of encoding noxious stimuli, and is the precursor for the experience of pain (IASP, 2011; Saab, 2012). How pain operates in the CNS and PNS is, at present, conceptualized by the neuromatrix theory of pain (Melzack, 1999, 2001; Mosely, 2003). This theory is built upon Melzack and Wall’s (1965) postulate about a gating system in the CNS that opens and closes when pain messages are transmitted to the brain. If the gates are open, the perception of pain is greater than if they are closed. The theory further asserts that the perception of pain emerges from signal exchanges on at least three levels of the neuroaxis: peripheral, spinal, and supraspinal areas of pain processing (DeLeo, 2006; Melzack, 1999). The perception of pain relies on the integration of multiple inputs (i.e., sensory, visual, cognitive, emotional, and signals from the stress-regulation system) and produces an output of an individual-specific neuromatrix—a neurosignature of “nerve impulses” (Melzack, 2001, p. 1379). The primary relay station is the spinal cord, which projects to the anterior cingulate cortex, insular cortex, thalamus, and the primary (SI) and secondary (SII) sensory cortices. These cortical regions are concerned with the localization and affective aspects of pain respectively. The ascending pain signals are modulated at each relay station prior to being synthesized into pain perception. A schematic of the pain pathways is shown in FIGURE 1 below.

Figure 1: Pain pathways



Schematic diagram of afferent (nociceptive) and efferent (anti-nociceptive) pathways involved in pain and pain modulation, indicating sites and neurochemical substances involved in intraspinal, supraspinal and descending mechanisms. From Giordano (2005), used with permission of the author.

Descending inhibition is also involved in the perception of pain. The descending, inhibitory pathway projects from the dorsal columns of the spinal cord and terminates at the dorsal horn. Here, neurotransmitters such as noradrenaline (NA) and serotonin (5-HT) and the endogenous opioids are released to provide anti-nociception (Serpell, 2006). Certain opioid analgesics (please see 2.6 TREATMENTS FOR CHRONIC PAIN below) simulate the activity in these anti-nociceptive circuits (Wager, Scott, & Zubieta, 2007). Burdensome consequences of pain such as lack of sleep, anger and stress can reduce neurotransmitter and endogenous opioid production; therefore, permitting more pain signals to reach the cortex.

Pain that becomes clinically intractable CNMP occurs because the nervous system has not returned to a non-pathological baseline state after a brief healing period (Saab, 2012; Woolf, 2011). The re-modeling of neural networks in the CNS, particularly those involved in nociceptive primary afferent nerve fibres (Kayser, Idänpää-Heikkilä, & Guilbaud, 1998), may create a type of wind-up phenomenon where the CNS becomes sensitized by the somatosensory neurons in the dorsal horn of the spinal cord. Known as central sensitization (Woolf, 2011), pain thresholds are lowered and an individual may become hypersensitive to stimuli, such as a light touch, that would not otherwise be painful. This creates a pain state known as *allodynia*. An individual may also perceive pain to be disproportionate to the level of noxious stimulus, leading to a phenomenon called *hyperalgesia*. When there are long-lasting modifications in excitability of these primary afferent nociceptors, pain sensitivity may spread to non-damaged or initially non-painful areas of the body (Reichling & Levine, 2009). Central sensitization has been observed in neurons of brain structures associated with pain perception, such as the rostral ventromedial medulla, rostral and mid-anterior cingulate cortex, nucleus of the thalamus, and the amygdala (Saab, 2012; Woolf, 2011). The phenomenon of central sensitization suggests that the nervous system does not necessarily need to depend on input from noxious stimuli for the experience of CNMP to occur. The role of glia cells has become increasingly important in understanding the pathophysiology of central sensitization, as glia may have both a contributory and protective functions (DeLeo, 2006; Milligan & Watkins, 2009).

Advances in functional magnetic resonance imaging (fMRI) research—a technique that measures brain activity by detecting changes in blood oxygen levels—are shifting the understanding of pain from a sensory and emotional experience to a condition or “disease” of

the CNS (Borsook, Sava, & Becerra, 2010). At present, CNS changes are observed in pre-clinical animal models and human pathology post-mortem research, because spinal cords in living human beings cannot be ethically biopsied for research.

Recent research has also explored the genetic contributions to CNMP states (Edwards, 2006; Mogil, 2012b; Sorge, et al., 2012). Studies with animal models have yielded valuable insights into the molecular underpinnings of pain sensation, particularly those derived from knockout mice studies. Research in humans to date has elucidated the role of genetic risk factors for the development and persistence of CNMP, and genetic contributions to sensation, cognition, emotion, and behaviours involved in pain perception. LaCroix-Fralish, Austin, Zheng, Levitin, and Mogil (2011) have identified at least 358 genes believed to be relevant to pain and analgesia. Mogil (2012b) has observed wide genetic variability in the development of CNMP syndromes, and related analgesic responses to drugs such as opioids and NSAIDS. Continued research that seeks to understand the role of gene-environment interactions may lead to better CNMP management using existing resources and new therapeutic targets (Mogil, 2012b).

Preliminary animal research has also suggested a possible role of epigenetic mechanisms in the onset, persistence, and potential relief of CNMP states (Denk & McMahon, 2012; Géranton, 2012). Epigenesis is the “processes that lead to stable and/or heritable changes in gene function without any concomitant DNA sequence changes” (Denk & McMahon, 2012, p. 437). In other words, changes in gene function occur during the developmental process and course of life and may be passed on to future progeny through changes in DNA folding that alters gene expression.

2.4.2 Psychological considerations

The neurophysiological processes of CNMP impact emotion and cognition, and so the high levels of comorbidity between CNMP and psychiatric disorders are therefore not surprising (Dersh, Gatchel, Polatin, & Mayer, 2002; Fishbain, Cutler, Rosomoff & Rosomoff, 1998; Gatchel, 2004). Some authors have characterized CNMP as a disorder that occurs on a spectrum with comorbid cognitive and emotional manifestations (McWilliams, Cox, & Enns, 2003; Wurzman, Jonas, & Giordano, 2008) that include anxiety, depression,

somatization, fear, addiction, anger, and deficits in learning and memory. Such psychopathology, alone or in combination, may also predict opioid abuse and drug use in patients with CNMP (see, e.g., Edlund, et al., 2010a, 2010b, 2010c for the TROUP study; Manchikanti, et al., 2007). What is more, it is well established that there is a high prevalence of severe physical (i.e., embodied) and psychological pain among people who inject drugs, particularly opioids (see, e.g., Fischer, Rehm, Brissette, et al., 2005). The psychological, emotional pain and suffering experienced by adults who inject drugs is correlated with the high rates of trauma and post-traumatic stress disorder (PTSD) in this population, especially for those street-involved (Chilcoat & Breslau, 1998; Torchalla, Strehlau, Li, Linden, Noel, & Krausz, 2013).

Psychological phenomena may directly affect the nervous system and thus contribute to pain flare-ups. Thus, through psychological manipulation of these manifestations, pain intensity may diminish.

There is a wealth of evidence that expectations and beliefs about pain influence the way pain is experienced. During WWII, Beecher (1946) observed that soldiers wounded in battle tended to report much lower levels of pain than severely injured civilians. He offered two interpretations of his findings. First, the subjective experience of pain is not necessarily correlated to the degree of tissue damage, a perspective that was years beyond his time. The second interpretation includes the meaning the wounded soldiers attribute to their injuries and pain, and the context in which they find themselves. He suggested that some soldiers might have found relief from their injuries, as they were then able to leave the battlefield and the danger associated with it.

According to research supported by the World Health Organization (WHO), individuals living with CNMP are four times more likely to experience depression and anxiety (Gureje, Von Korff, Simon, & Gater, 1998). CNMP may produce maladaptive coping mechanisms, feelings of helplessness, hopelessness, and reduced self-esteem. The experiences of pain and suffering may depend on the relative influence of the patient's psychological health, previous pain experiences, the meaning the patient attributes to the pain, attitudes and beliefs about treatment, and beliefs the patient has about his or her own ability to cope (Serpell, 2006; Lamé, et al., 2005). Quality of life in CNMP is associated with beliefs about the pain rather than its reported intensity (Lamé, et al., 2005) and, as Waddell,

Newton, Henderson, Somerville & Main (1993) describe, fear-avoidance beliefs of future pain may be more disabling than the pain itself.

2.4.3 Social and cultural considerations

The biopsychosocial model recognizes that a register of social norms that govern the boundaries of permissible expression also influences private and public experiences of pain and associated pain-related behaviours. Indeed, as Morris (1991), Kleinman (1992), and others state, the views people have about pain in general, their own pain, and pain management are historically and socially based. If a specific or set of pain behaviours is congruent with a societal or cultural view of how people should behave when in pain, sufferers may receive attention, sympathy, compensation, and sick role legitimization (Helman, 1994). Accordingly, some individuals may learn to display certain behaviours in order to achieve a desired response. These secondary gain behaviours depend upon the cultural formulations of the societies in which pain is experienced (Rey, 1995).

In reference to culture, Free (2002) describes it as “a set of societal rules and standards developed over time and shared by the members of a particular society” (p.143). Culture may include broad notions such as Western and Eastern culture, and also those of social institutions, such as the cultural systems of biomedicine and pain management (see, e.g., Crowley-Matoka, Saha, Dobscha, & Burgess, 2009). Diverse cultural systems use varying sets of explanatory models to understand health, illness, and healing (Kleinman, 1978). For example, in many Western cultures, childbirth is regarded as a painful, distressing experience; a perspective that is not universally shared (Melzack, 1976).

Language and metaphor to describe diversities of pain experiences are also culturally varied. A frequently cited ethnographic study by Oknuki-Tierney (1981) who examined pain experiences among the *Sakhalin Ainu* of Japan, discovered that headache pain is classified as a terrestrial or aquatic animal, with varying features of thermo-tactile chills, sound, and touch. In terms of sound for terrestrial animals, bear headaches imitate the heavy footsteps of a bear; deer headaches simulate the galloping sounds of a musk deer; dog headaches resemble the noise when a canine is gnawing on a hard object; and woodpecker headaches have the experiential feature of a woodpecker drumming into a tree trunk. For the aquatic

animal-headaches of octopus, crab, and lamprey, the experiences of thermo-tactile chills are almost always present to varying degrees.

2.4.4 Social structural factors

Many health problems have social structural foundations (Raphael, 2004) that can be related to gender, socioeconomic status (SES), ethnicity, and race in influencing how pain is perceived, experienced, and expressed (Anderson, Green, & Payne, 2009; Fuentes, Hart-Johnson, & Green, 2007; Green & Hart-Johnson, 2010; Unruh, 1996). It has been well documented that health inequalities exist between socially advantaged and socially disadvantaged groups, and the experience of pain is no exception. For example, a community-based telephone survey of 3982 American individuals by Krueger and Stone (2008) revealed that lower income and less education were correlated with a higher incidence and severity of pain. Members from these populations are doubly disadvantaged as they receive poorer treatment for the pain that they are more likely to experience: as other studies from the United States demonstrated, those who are economically disadvantaged or members of racial and ethnic minorities are less likely to access pain care, and tend to receive lesser quality pain care when they do (Anderson, Green, & Payne, 2009; Lebovits, 2005). A mixed-methods study by Morrison, et al., (2000) found that 25% of pharmacies in non-white neighbourhoods in New York City carried opioid analgesics as compared to 72% of pharmacies in predominantly white neighbourhoods, with pharmacists in non-white neighbourhoods citing fears related to regulations with regard to disposal, illicit use, fraud, low demand, and theft. While many factors are at play, treatment disparities in racialized populations arise from patients' distrust in health care, physicians, and other health care providers, and previous negative experiences with the health care system (Blanchard & Lurie, 2004).

Although people typically do not choose to experience pain, for many, pain is an unavoidable burden placed upon them by poverty and barriers in accessing health care. Such structural, systemic conditions may have consequences for suffering and relief. A study by Hwang, Wilkins, Chambers, et al., (2011) found that stress due to living in shelters and lacking stable living environments, the inability to afford over-the-counter and prescription

medications, and poor sleeping conditions were barriers to CNMP management among street-involved individuals such as the homeless.

Governments play a critical role in shaping the discourse and content of pain management. Following the end of former U.S. President George H.W. Bush's "Decade of the Brain" in 1999, in which efforts were made to enhance public awareness of the neurosciences through enhanced public and private funding and research infrastructure, then-U.S. President Bill Clinton declared the 2000s the "Decade of Pain Control and Research". This declaration was motivated by concerns that pain treatment had long been a neglected public policy priority, which was problematic given the increasing social and economic burdens CNMP has on the population. Like the "Decade of the Brain", the "Decade of Pain Control and Research" included an extension of public and private research funding and capacity, and shaped how knowledge is produced, implemented, and received by the patients, families, clinicians, and others from the policy level to the clinic.

2.4.5 Suffering

Many kinds of pain bring about suffering, but the meaning of suffering is difficult to define. Philosophers have expressed different opinions. For example, the French philosopher Levinas (1988) referred to suffering as useless. Nietzsche, in whose writing pain was a fixture, believed that the hallmark of a human being is the capacity to suffer (O'Sullivan, 1996). Singer (1975/2002) argued that since human and non-human animals are sentient beings, they have the capacity to suffer. This capacity, Singer argues, demands that we take the beings' interests in not suffering into account.

The relief of suffering is a duty of physicians. The duty of beneficence states that physicians have an obligation to promote the patient's welfare while having a concurrent obligation of nonmaleficence to not cause harm. The implication is that suffering is bad and ought to be relieved, and that the relief of suffering is a moral good. This perspective is consistent with a simplified utilitarian ethos that seeks to maximize happiness and minimize suffering. However, it does raise the question, as Carnevale (2009) has pointed out, as to whether suffering is something that can be objectively assessed by another. The answer, Carnevale argues, will have significant implications for clinical practice: patient suffering, in

the present or future, is a key criterion in substitute decision-makers² considerations of an incapacitated patient's best interests regarding the potential benefits and drawbacks of a potential therapeutic course (Buchanan & Brock, 1990; Carnevale, 2009).

Cassell (2004) argues that the subjective nature of suffering—like pain—makes it challenging to address with the tools of objective medicine. Aside from palliative contexts where symptom management rather than disease eradication is the goal, Cassell (2004) contends that focusing on disease where chronic illness is concerned may obfuscate key features of suffering:

People in pain frequently report suffering from pain when they feel out of control, when the pain is overwhelming, when the source of the pain is unknown, when the meaning of the pain is dire, or when the pain is apparently without end (p.35).

On Cassell's account, pain and suffering are phenomenologically distinctive yet dimensional, and the experience of suffering is intensely personal: it is perceived “as a threat to persons' continued existence—not merely to their lives but their integrity as persons” (p. 36). These discussions about suffering are inextricably tied to the concept of human dignity, particularly in discussions of end-of-life and palliative care. In such contexts, physicians are understood to have a duty to relieve patient's pain and suffering as a means to promote their dignity at the end of life (Kuhl, 2002; Pellegrino, 1998).

Turk and Wilson (2009) write that pain and suffering are two distinct, but inseparably linked concepts and their congruence is often incorrectly implied in the literature. For example, the “insular cortex is activated … in patients suffering from chronic back pain” (Baliki, et al., 2012, p. 3), “…the complex process of stigmatization of chronic pain sufferers” (Cohen, et al., 2011, p. 1640), and “[s]eventy-five million Americans suffer persistent pain” (Peppin, 2009, p. 493). Most people are resilient in terms of their CNMP conditions and are able to function in the world despite their pain, so it may be incorrect to assume that they are necessarily suffering (Turk & Wilson, 2009). While Turk and Wilson (2009) reason that pain is not a necessary condition for suffering, they acknowledge that

² A substitute decision-maker is an individual appointed by the patient or a legal body to give or refuse consent to treatment on behalf of a patient who lacks the capacity to make the treatment decision.

suffering can exacerbate pain, pain-related suffering does indeed occur, and that health care professionals ought to assess for both. Likewise, recent literature questions the ontological distinctions between pain and suffering by suggesting that underlying neurobiology between these two constructs is the same regardless of cause or context (Moskowitz, 2011).

Writing from an anthropological perspective, Kleinman (1992) defines suffering as “the result of processes of resistance (routinized or catastrophic) to the lived flow of experience” (p.174). For Kleinman, suffering occurs when an individual perceives pain to threaten the activities of daily life, but then resists that threat. Kleinman’s resistance is thus conceptually similar to Cassell’s threat of intactness (Cassell, 2004). In this way, both Cassell and Kleinman’s definitions make room for the suffering associated with depression and feelings of demoralization. However, while Cassell and others describe suffering as a subjective individual experience, Kleinman seeks to portray suffering as being embedded in social life. Kleinman further argues that suffering is “both an existential universal of human conditions and a form of practical and, therefore, novel experience that undergoes great cultural elaboration in distinctive local worlds” (p.174). I have noted earlier that the experience of pain is dependent on cultural influences, and thus on Kleinman’s account, the experience of suffering is also shaped by sociocultural inflections. Drawing a meaningful line between pain and suffering is challenging, therefore, because the psychosocial suffering as described by Kleinman and others may present as pain in a somatized form (Sullivan, 2001a).

2.5 The context of chronic pain management

Historically, pain management was not considered a clinical specialty or a distinct area of academic inquiry, as pain was considered a symptom of something else rather than a problem in itself. Since the mid-20th century, however, a new specialization called pain management emerged (Baszanger, 1998). Pain management lies primarily within the realm of science and biomedicine, although individuals may seek out naturopathic, homeopathic, and other complementary and alternative medicine (CAM) treatments and remedies.

In Canada, pain management typically occurs in the office of the primary care physician, who may be a family doctor or general practitioner. While CNMP is one of the main reasons that people seek treatment in primary care (Gureje, Von Korff, Simon, & Gater,

1998), one study by Picavet, Struijs, and Westert (2008) indicated that less than one-third of patients reporting CLBP had contact with their family doctor in the preceding year, and even fewer had contact with a medical specialist or a physiotherapist. One explanation for this finding is that the patients may have underreported their pain, or the physician did not consider the complaint serious enough to register it in the study (Picavet, Struijs, & Westert, 2008). While one primary care provider generally delivers the main care for CNMP, a range of health care providers such as chiropractors, physiotherapists, acupuncturists, massage therapists, occupational therapists, psychologists, and others are often involved concurrently.

Seeking care for CNMP depends on the meanings the individual attributes to his pain; the availability, accessibility, and expectations of treatment; and the social norms particular to that illness (Mechanic, 1977; Morris, 1991). The patient living with CNMP occupies a peculiar place within the health care context and in particular, in today's modern medicine, which is focused on cures for ailments, rather than on chronic illness management (Kleinman, 1988, 1992; Oprea, Braunack-Mayer, Rogers, & Stocks, 2010; Thorne & Robinson, 1988).

2.5.1 Subjectivity, the clinicopathological framework, and narrative

Since the beginning of the 19th century and the development of clinical biomedicine, the qualitative and subjective aspects of pain have posed challenges for physicians. There have been many unsuccessful attempts to discover an objective indicator that "would remove the ambiguities inherent in [pain] symptoms" (Rey, 1995, p. 99) and many of the issues that emerge in pain management.

The subjective nature of CNMP makes it an invisible condition that may exist without any discernible biomedical injuries, such as in some cases of fibromyalgia or non-specific low back pain, and thus makes it difficult to treat in the clinicopathological framework of modern health care. Dating back to 18th and 19th century France and the rise of modern medicine, the clinicopathological framework is both a philosophy of health care and an explanatory tool, characterized by the view that all symptoms and health complaints are caused by discoverable, visible pathological lesions (Saint-Maur, 2012). The clinicopathological framework is, in Foucault's (1963/2010) terms, the clinical "gaze": an

approach, a language, and a way of seeing that governs the care of the ill. The clinicopathological framework became central to the developing scientific medical approach that privileges observable over unobservable phenomena. Pain, in the clinicopathological framework, is expressed by a predictable relationship between tissue pathology or nociceptor activity and clinical presentation that is universally generalizable (Sullivan, 1998). The clinicopathological framework is central to neuroscientific investigations of chronic pain, for example, which seek to identify and represent neuropathological lesions in the brain and spinal cord through modalities such as functional neuroimaging (Davis, Racine, & Collett, 2012; Sullivan, Cahana, Derbyshire, & Loeser, 2013).

In the absence of objective measures of pain, providers must determine the patient's pain indirectly, relying on observation, comprehensive history taking, and patient testimony. However, relying on testimony is challenging; language alone is often inadequate for an individual to articulate what it means to live in pain (Biro, 2010; Scarry, 1985). Indeed, there have always been plenty of metaphors to describe pain, but these often do not do justice in describing what it is like to be in pain (Frank, 1991). As the poet Woolf (1967) wrote, "The merest school girl, when she falls in love, has Shakespeare or Keats to speak her mind for her; but let a sufferer try to describe a pain in his head and language at once runs dry" (p. 194). Instruments that use descriptive adjectives based on the experiences of pain patients, such as the McGill Pain Questionnaire (Melzack, 1975), help patients to express their pain in metaphorical language.

Once patients share the meaning of their pain and use language to describe it to their providers and loved ones, CNMP is no longer a private experience: pain becomes a public, shared experience acquiring meaning from dialogue (Biro, 2010; Sullivan, 2001a; van Hooft, 2003; Wittgenstein, 1953). If the individual believes that the pain is inexpressible to others, particularly to a health care provider, he or she may become isolated. Such psychological isolation may increase the intensity of the pain experience and contribute to feelings of uncertainty and doubt (Biro, 2010; Frank, 1991).

The emphasis on language and narrative in CNMP management may be challenging for some health care providers when patients report intense pain and suffering and there is no evidence of objective pathology. The inconsistent relationship between pathology and perceived pain has also been established in the research literature. For example, in a seminal

paper, Jensen, Brant-Zawadzki, Obuchowski, Modic, Malkasian, and Ross (1994) demonstrated only a weak association between lumbar abnormalities on magnetic resonance imaging (MRI) scans and low back pain. The authors found that patients who had bulges or protrusions in the lumbar spine did not necessarily report low back pain. Even if abnormalities can be demonstrated via tools such as MRI, the extent of the objective pathology may not correspond to its perceived severity by the patient. As a subjective experience, pain constructs an ontological divide between the reality of the individual experiencing the pain and the reality of those who observe the individual. Even with the advent of neuroimaging in which research attempts to verify pain functionally as well as structurally, these realities are unbridgeable; “[i]n the end, all we have is the word of the sufferer” (Biro, 2010, p. 133). But as I discuss in later sections, words by themselves do not establish its veracity.

2.6 Treatments for chronic pain

During the mid-19th century, opioids were the front-line treatment for acute pain, but the use of opioids and other anesthetics for more intractable conditions was not as widespread (Meldrum, 2003). If the patient was in pain, the patient was considered to be healthy; pain was a sign of healing. Since then, treatment philosophies among physicians and public attitudes toward pain relief have changed. Much has been influenced by the profitable pharmaceutical industry and the domination of prescription and non-prescription pharmaceuticals such as the opioid analgesics and non-steroidal anti-inflammatory drugs (NSAIDs). Non-prescription analgesics are advertised across the full spectrum of popular media, and are sold in pharmacies and corner stores alike. In the U.S., the cost estimates of prescription analgesics purchased by adults 18 years or older amount to approximately \$28.2 billion USD annually (Soni, 2009), and non-prescription analgesics accounted for an additional \$2.6 billion USD annually (Anonymous, 2007).

Despite the array of treatments for pain available in high-income countries, CNMP remains a challenge and long-term relief can be elusive. Treatment responses vary among individuals even for CNMP of similar categories, and many pharmacological treatments lose their effectiveness with increased use as tolerance to the medications develops, although

some patients may stay at the same dose for years. Treating CNMP can be time-consuming and frustrating for health care providers and patients alike, as no singular approach or intervention has been found to be effective across all CNMP conditions. As Goldberg (2010) stated, CNMP is not treated any better today than it has been over the last several decades.

Most individuals living with CNMP tend to use NSAIDs such as aspirin, ibuprofen, acetaminophen, and naproxen (Clark, 2002). In recent decades, several new analgesics have been made available by prescription including synthetic opioids like morphine, methadone, oxycodone, and hydromorphone. However, the abuse of oxycodone and other prescription opioids has been a growing concern in North America, with rapid rises in associated morbidity and mortality (please also see CHAPTER 3). Drugs such as gabapentin and pregabalin, which were originally developed as anticonvulsants, have some demonstrated effectiveness in treating chronic neuropathic pain (Moore, Wiffen, Derry, & McQuay, 2011). Similar reports have been made concerning the cyclo-oxygenase (COX-) 2 inhibitors such as celecoxib (Celebrex®) and rofecoxib (Vioxx®). Merck withdrew the latter in 2004 because of undisclosed safety issues concerning the increased risk of heart attack and stroke. Updated versions of anesthetic blocks, implantable devices, such as spinal cord stimulators, and neurosurgical procedures have also been invented and improved.

There are adverse side effects and the potential for long-term harm associated with any kind of treatment for CNMP. Given the increased risks associated with invasive surgical procedures (Fritzell, Hägg, Nordwall, 2003), some patients with low back pain might instead opt to continue to use pharmacological interventions. Pharmacotherapy options pose the risk of neurotoxicity, gastrointestinal concerns from NSAIDs, a high abuse potential associated with prescription opioids, and the associated problem of opioid-induced hyperalgesia. Opioid-induced hyperalgesia is the paradoxical state of nociceptive sensitization that may emerge after long-term use of opioid analgesics where the individual becomes hypersensitive to painful stimuli (Lee, Silverman, Hansen, Patel, & Manchikanti, 2011). Additional adverse effects of long-term NSAID and other anti-inflammatory use may include renal impairment, particularly among the elderly (Gooch, et al., 2007). The potential short- and long-term harms resulting from the side effects of these drugs are not benign. However, as with all treatments, the risks of harms must always be weighed against the potential benefits (Ong, Lirk, Tan, & Seymour, 2007).

People may seek CAM approaches to relieve pain in addition to biomedical ones. Examples of CAM for CNMP include acupuncture, massage therapy, chiropractic treatment, yoga, osteopathy, herbs and supplements, energy healing, prolotherapy, and biofeedback (Fleming, Rabago, Mundt, & Fleming, 2007). While there is not a strong scientific justification for many CAM modalities, they are nonetheless considered part of comprehensive CNMP management strategies (Tan, Craine, Bair, et al., 2007; Ulett, Han, & Han, 1998). For example, a recent meta-analysis of acupuncture suggests that the therapeutic benefits for CNMP are only modest in comparison to placebo or sham acupuncture (Vickers, et al., 2012).

During World War II, the anesthesiologist and pain management pioneer Bonica (1953) proposed that the best treatment for CNMP required the collaboration of disciplines. His hypothesis was confirmed, and current evidence suggests that pain clinics that involve specialists from diverse disciplines such as medicine, anesthesiology, psychology, psychiatry, occupational therapy, and physical therapy, are most effective in treating CNMP (Flor, Fydrichc, & Turk, 1992; Guzmán, Esmail, Karjalainen, Malmivaara, Irvin, & Bombardier, 2001; Marcus, 2009). Pain clinics vary in philosophy and approach, however: some clinics are oriented toward the underlying physiological causes of pain while others focus on behavioural cues and triggers (Baszanger, 1998).

Still, very few pain specialists and multidisciplinary pain clinics are available to meet the escalating need of those who live with CNMP. In Canada, for example, Peng, et al. (2007) found that 80% of multidisciplinary pain management clinics are concentrated in major urban centres, with no clinics in the province of Prince Edward Island, or the Yukon, Northwest, or Nunavut Territories. Wait times to see a specialist for CNMP can take up to six months from time of referral (Lynch, et al., 2008), and wait times are on average longer than one year for more than one-third of publicly funded clinics, with geographical and other barriers preventing access (Peng, et al., 2007). These barriers have contributed to the demise of multidisciplinary pain centres in North America. The evidence for the effective of these centres has not been harnessed to support and sustain their existence (Schatman, 2007).

Aside from pain medicine training for anesthesiologists, many physicians in North America receive little to no training in pain treatment, nor have the time or resources in order to address these concerns appropriately (Goldman, 1991; MacDonald, Hébert, & Stanbrook, 2011; Watt-Watson, et al., 2009). Many primary care physicians report that they do not feel

confident in addressing patients' CNMP needs and concerns (Librach, 1993; Upshur, Luckmann, & Savageau, 2006).

Chapter 3: Moral tensions about addiction in chronic pain management

“Gone, gone, the damage done.”

Young (1972)

Since the 1990s, the escalation in the prescribing rates of extended-release formulations of short-acting opioid analgesics for CNMP has been associated with a steady rise in prescription opioid abuse and related harms, considered to have reached epidemic levels in North America (Compton & Volkow, 2006; Dhalla, Persaud, & Juurlink, 2011; Office of National Drug Control Policy, 2011). Abuse includes consumption of opioids without a prescription, taking more opioids than prescribed, using for reasons other than prescribed, intentionally mixing opioids with alcohol or other drugs, or crushing or liquefying the preparation in order to achieve a high from the euphoric properties of the drug (National Institute on Drug Abuse, 2011).

The evidence of population-level harms challenges earlier claims made by a number of researchers, clinicians, and pharmaceutical manufacturers that opioid use for patients with CNMP is appropriate, safe, and effective, and that there is little potential for addiction or medication diversion, except for individuals who are currently addicted or have been in the past (Passik & Weinreb, 2000; Passik & Kirsch, 2004; Portenoy, 1996a). Population-level harms also challenge moral claims about the tragedy of un- and undertreated CNMP, which was a critical factor in launching pain medicine into the medical and political spotlight in North America (Rich, 2005b, 2010). The controversial treatment of CNMP using opioid analgesics presents health care providers with a clinical and ethical dilemma: providers have an ethical duty to relieve pain and suffering while upholding the duty to not cause harm to their patients. These conflicting obligations are emphasized in the IASP’s (2005) *Ethical Standards for Pain Management and Research* that states, “... any pain above moderate levels can be physically and psychologically harmful. Preventing or alleviating such pain is not merely a matter of charity or doing good (beneficence), but carries a duty to prevent harm (nonmaleficence)” (p. 1). The use of opioid analgesics for long-term CNMP management has emerged as a controversial topic, shaped by a host of intertwining political, historical, social,

moral, and clinical forces (Crowley-Matoka & True, 2012; National Advisory Committee on Prescription Drug Misuse, 2013; Office of National Drug Control Policy, 2011; Sullivan & Howe, 2013). In this chapter, I review the major literature relevant to addiction in CNMP management, and argue that the social, moral, political, and regulatory history of prescription opioids, including moralized attitudes about addiction, have converged to create three intertwining moral tensions that threaten the moral foundation of the therapeutic relationship.

3.1 Opiates and opioids

The opiates are the alkaloids that are extracted from opium, the white juice that is removed from the opium poppy (*papaver somniforum*) and include morphine, codeine, thebaine, and papaverine. Opioids are peptides—either exogenous such as heroin, oxycodone, or methadone, or endogenous such as dynorphin or endorphin—and bind to receptors in the brain, spinal cord, and gastrointestinal tract (Julien, 2001; Trescot, Datta, Lee, & Hansen, 2008). Opiates such as morphine, and opioids such as diacetylmorphine (heroin), oxycodone, oxycodone, and methadone, are commonly referred to as painkillers or narcotics³. As central nervous system (CNS) depressants, opiates and opioids produce effects that include analgesia, sedation, reduced gastrointestinal motility, and euphoria (Trescot, Datta, Lee, & Hansen, 2008). Prescription opioids include formulations such as codeine, methadone, and oxycodone, which are synthetic and semi-synthetic derivatives of opium and morphine that have been manufactured as medications. These drugs are available in regulated doses in forms such as pills, syrups, injections, transdermal patches, and suppositories.

3.2 Opioid prescribing in the historical context⁴

Opioids have long been known to have beneficial therapeutic uses. Treatments for pain using opium and opium derivatives have existed since the time of the Sumerians (approximately

³ The term narcotic is derived from *narke*, the Greek word for stupor or numbness. Originally associated with inducing sleep, the term later became associated with opioids such as morphine and heroin (Julien, 2001). The term is often reserved for legal contexts, and discouraged from pharmacological contexts.

⁴ For detailed scholarly treatments of this topic beyond the scope of this dissertation, please see, e.g., Berridge (1999), Courwright (2001), Harding (1988), and Spear (1994).

3400 BCE; Booth, 1999). Throughout the ages, Hippocrates, Galen, and many Arabic physicians and Chinese practitioners used opium to treat pain in those who sought their care. Concoctions such as laudanum (alcohol and opium) became popular in the 17th century and were prescribed heavily by physicians including the well-known English physician Thomas Sydenham (Berridge, 1978).

Recreational consumption of opium was noted in early 19th century Britain and, among the most celebrated literary narratives on opium consumption, De Quincey (1886) extolled the virtues of opium for many benefits, including the relief of his chronic gastric pains. The complicated political history of the opium trade between China and Britain is well-documented. There was a stigmatizing and racist view among many British that only the Chinese were predisposed to opium addiction (Berridge, 1978, 1999; Harding, 1988). Up until the late 19th century, and aside from the views of the British toward the Chinese, recreational or medicinal opium use was not considered a moral problem.

In the 18th and early 19th centuries, physicians generously prescribed opium and morphine to their patients, which often resulted in iatrogenic, or medically induced, addiction (Courtwright, 2001a, Lindesmith, 1968). The majority of people who developed an iatrogenic opioid addiction during this era were white, middle- and upper class middle-aged housewives (Courtwright, 2001a). These women used opium recreationally and were also prescribed opium and morphine for various forms of neuroses and the pain associated with dysmenorrhea.

Moral attitudes toward addiction and drug use began to shift at the beginning of the 20th century in the U.S. As the prevalence of cocaine and opium consumption increased, use of these drugs became associated with criminalized and immoral activity among those considered to be in the lower classes such as African Americans, Hispanics, and Chinese immigrants (Courtwright, 2001a, 2001b). However, as white working-class Americans began to develop addiction-related problems with opium use, authorities decided legal measures were necessary to control the marketing and distribution of opioids. Opioids came to be considered an illicit and dangerous drug consumed only by morally corrupt drug addicts. The passage of the 1914 *Harrison Narcotics Tax Act* (HNTA) in the U.S. changed both the legal and moral status of opioids.

The HNTA made it illegal for physicians to prescribe opioids such as morphine for substitution addiction treatment. Physicians became the ethico-legal gatekeepers of this medical resource, and could lose their license and face criminal prosecution for imprudent prescribing (Ballantyne & Mao, 2003; Courtwright, 2001a; Meldrum, 2003). The HNTA and similar regulations in other jurisdictions created a particular kind of dependency of the patient on the prescriber as a gatekeeper from whom opioids could be accessed. In the wake of the HNTA, the clinical encounter and the resulting dialogue between health care providers and the patient living with CNMP began to take on an entirely different social and moral meaning⁵.

The distribution and use of opioids today are tightly controlled and regulated, as they are Schedule I drugs under the *Controlled Drugs and Substances Act* (CDSA; *Controlled Drug and Substances Act*, 1996) in Canada and Schedule II drugs under the *Controlled Substances Act* (CSA; *Controlled Substances Act*, 1970) in the United States (U.S.). These drugs have recognized therapeutic uses, but also have a high potential for harm. The CSA emerged as a federally legislated response to former U.S. President Nixon's declared War on Drugs, which was an escalation of prohibitionist drug policies dating back to the HNTA (Baum, 1997). The War on Drugs permitted law enforcement officials to have a central role in U.S. drug policy, specifically the U.S. Drug Enforcement Agency (DEA). The practices and policies of the DEA are central to the enforcement of drug abuse and diversion. In a sociopolitical context framed by the War on Drugs, many physicians became uncomfortable prescribing opioid analgesics for CNMP and feared criminal prosecution (Rosenberg, 2007; Schmidt, 2005). Canada's legislation and federal National Anti-Drug Strategy have less direct ties to the U.S. War on Drugs, but are still heavily influenced by it in terms of the emphasis on law enforcement initiatives (DeBeck, Wood, Montaner, & Kerr, 2009). The CSA and CDSA state that the drugs listed under the Act have the potential for abuse, regardless of whether they are deemed an illicit drug.

⁵ It is important to acknowledge that the HTNA and other 20th century developments paved the way for increased federal oversight of opioids in the United States, including agencies such as the Drug Enforcement Agency (DEA) and the Food and Drug Administration (FDA). These two federal agencies have had a major role in the U.S.-led “War on Drugs”.

3.3 The moral case for increased opioid prescribing

Concerns about prescription opioids, addiction, and associated behaviours considered aberrant such as drug-seeking, diversion, and prescription drug abuse are often blamed on a current trend in the liberal prescribing behaviour of physicians (Dhalla, Persaud, & Jurrlink, 2011; Sullivan & Ferrell, 2005; Van Zee, 2009). However, concerns about high rates of opioid prescribing are not a new phenomenon. In the years following the HNTA, because of over-prescribing, opioids such as morphine became heavily regulated and long-term use was only authorized for those at the end of life (Courtwright, 2001a). Given the success of opioids in the palliative and hospice context in reducing pain and suffering, improving quality of life, and promoting the dignity of the patient, health care providers, researchers, and advocates in the 1980s and 1990s began to argue that prohibitionist-era regulatory barriers should be eased and opioids should be extended for use in non-cancer pain. Pain management leaders such as Melzack (1990) and Portenoy (1996a, 1996b) made the moral case that CNMP causes needless pain and suffering, and CNMP patients have the right to benefit from opioid treatment as well.

These arguments occurred concurrently with national campaigns by the American Pain Society, the Veterans Health Administration (VHA) and Joint Commission on Accreditation of Health Care Organizations (JCAHO) to consider pain as the “5th Vital Sign” alongside with blood pressure, pulse, respiration, and temperature (American Pain Society, 1999; Department of Veterans Affairs, 2000; Phillips, 2000). Health care providers were required to administer a 1-10 Likert pain scale and collect quantitative pain scores when meeting with their patients. The compassionate aim had awareness at its heart: pain should be identified and characterized, monitored, and managed. To date, however, a study by Mularski, et al. (2006) suggests that the 5th Vital Sign initiative has not yet translated into better quality pain management: while health care providers may be routinely documenting their patients’ pain intensity, appropriate treatments are not necessarily being offered.

Increased opioid use for CNMP was also spurred by medical concerns regarding the adverse safety profile of long-term use of nonsteroidal anti-inflammatory drugs (NSAIDs) and cyclooxygenase-2 (COX-2) inhibitors for CNMP, particularly among older adults; NSAIDs did

not produce sufficient analgesia for many with intractable pain (Solomon, Rassen, Glynn, Lee, Levin, & Schneeweiss, 2010).

Advocates for more generous use of opioids added that patients with CNMP suffer needlessly because of unsubstantiated fears and prejudices about addiction (Jovey, et al., 2003; Porter & Jick, 1980). These authors and others (e.g., Portenoy, 1996a, 1996b; Portenoy & Savage, 1997) emphasized that addiction, prescription opioid abuse, and medication diversion in patients with CNMP is atypical. In the 1990s and 2000s, pharmaceutical manufacturers marketed opioids for CNMP aggressively by claiming that the risk of addiction was greatly reduced with extended-release formulations such as Oxycontin than short acting formulations, which had historically been prescribed. These new release mechanisms allowed for the drug to be steadily absorbed by the body, thereby reducing the likelihood of addiction (Gudin, 2013).

In the 1990s and 2000s, health care providers, researchers, and leaders in pain management frequently cited two papers to reinforce the empirical claim that addiction and related harms is rare in CNMP management. The first paper was a brief communication by Porter and Jick (1980) who claimed that addiction is found in only four out of 11,882 patients who receive an opioid analgesic for pain while in hospital. In Purdue Pharma L.P educational materials for Oxycontin, the company cited this brief communication asserting that the rate of addiction in patients with CNMP who are treated with opioids is less than one percent, and overdoses are extremely rare (Purdue Pharma L.P., 1998). The second paper, a small retrospective case study by Portenoy and Foley (1986), suggested that only two patients with CNMP out of 38 had a problem with prescription opioids, and both patients had a prior history of drug abuse.

The central message was that opioids are non-addictive when appropriately prescribed by a physician and that iatrogenic addiction and opioid abuse were limited to those previously addicted or a population believed to be at risk of addiction (Portenoy, 1996a; Savage, 1996; Tennant, Robinson, Sagherian, & Seecof, 1988). The widely held myths and assumptions about addiction risk were considered a barrier to achieving optimal pain relief. Advocates claimed that the literature overestimated the potential harm of iatrogenic addiction and abuse and underestimated the clinical and quality of life benefits of pain relief from opioid analgesics (Fishbain, Cole, Lewis, Rosomoff, & Rosomoff, 2008;

Passick & Weinreb, 2000; Savage, 1996). Others, such as Lynch (2013), suggested that people who use opioids without a prescription are self-medicating because of inadequate pain management and are not actually abusing these drugs.

There was an additional moral basis underpinning the push for more liberalized prescribing: since addiction and related harms such as medication diversion was understood to be rare in patients with legitimate pain, a larger net benefit to the population was presumed. For instance, Heit (2001) argued that “[i]t is better that 1% of patients obtain opioids for non-agreed upon medical use than to have 99% of patients suffer from pain when medications are readily available to treat them” (p. 27). The liberalized use of opioids for CNMP was endorsed by leading North American pain societies, and consensus statements were published supporting the supervised and careful use of opioid therapy in patients with CNMP (American Academy of Pain Medicine and the American Pain Society, 1997; Jovey, et al., 2003). Indeed, these statements swayed public perception that prescription opioids are legitimate medications and safer than illegal drugs, and helped providers view opioids for CNMP more favorably than in the past (National Advisory Committee on Prescription Drug Misuse, 2013).

Bioethicists have also contributed to the moralized discourse of liberalized opioid prescribing. Since there was the presumption that long-term opioid use for CNMP was clinically beneficial, some scholars argued that withholding opioids from patients suffering from CNMP is tantamount to harm and a threat to patient dignity (Pellegrino, 1998; Rich, 2000). These arguments equated the prescription of opioids with the health care provider’s duty to relieve pain and suffering (Cohen, Jasser, Herron, & Margolis, 2002; Rich, 2000). Many health care providers who refused or hesitated to prescribe opioids due to concerns about addiction risks were considered “opiophobic” by their colleagues (Morgan, 1985). The studies discussed here and the confluence of factors described earlier, provided a hybrid empirical-moral foundation for much of the culture of pain treatment in North America for decades.

Today, prescription opioids are among the most widely prescribed drugs in North America, and Canadians are the second highest per capita consumers of prescription opioids worldwide (International Narcotics Control Board, 2013). These North American consumption rates are in stark contrast to several countries from the global south, many of

which do not have access to opioid analgesics even for intractable cancer pain (World Health Organization, 2007). The prevalence of untreated malignant pain is considered a scourge of international proportions, and narcotics regulation is one component of this complex problem (King & Fraser, 2013).

3.4 Potential medical and social benefits and harms associated with prescription opioids

3.4.1 Potential medical and social benefits

The health care community and policy makers have long supported the therapeutic value of opioids for short-term pain relief and cancer pain relief at the end of life. As noted earlier, it is in these contexts that the evidence for compassionate use of opioids is most compelling and that the ethical arguments for relief of pain and suffering are accepted (Emanuel, 2001; Fohr, 1998).

Opioids are prescribed for many types of short-term and persistent pains, with the explicit purpose of analgesia and improvement of quality of life and independence, not intoxication, pleasure, or euphoria. There is evidence that prescription opioids may provide benefit for relief of certain types of short term pain, such as post-operative pain, and perhaps even for short-term relief of CNMP (Grady, Berkowitz, & Katz, 2011). A randomized trial by Moulin and colleagues (1996) involving a nine-week course of morphine therapy for chronic musculoskeletal pain demonstrated an increase in analgesia and reduction in pain intensity relative to a placebo. On an individual patient level, specific benefits to opioid therapy for CNMP may include improved functional independence, participation in society including the ability to return to the workforce, and improved social relationships (Passick & Weinrib, 2000).

3.4.2 Potential medical and social harms

Population-level benefits of long-term opioid therapy have been difficult to demonstrate convincingly (Sullivan & Howe, 2013). Concerns of prescription opioid abuse in this context were initially brought to the attention of the broader public and regulatory authorities as the Oxycontin or “hillbilly heroin” scandal was emerging in the United States (Van Zee, 2009). Oxycontin was initially approved “for the treatment of moderate-to-severe pain lasting more than a few days” (United States General Accounting Office, 2003, p. 1). Soon after the release of Oxycontin on the market, it was discovered that the patented extended-release mechanism could be dismantled if the pill was chewed or crushed, and the potency of the drug increased when snorted or injected. Purdue was eventually ordered by the courts to pay \$634.5 million in fines for intentionally misleading the public and physicians about the addiction and abuse risk of Oxycontin as compared to other pain medications (U.S. v. Purdue Frederick Co., Inc, 2007; Zimmerman, 2007). One broader implication of this outcome is that if physicians and patients do not know the risks of medications because of potentially misleading information by pharmaceutical manufacturers, it is even more difficult for physicians to know how to prescribe or decide how much and how long patients should be taking the medications.

There are concerns with the evidence that is used to support the claims about the addiction and other safety risks of long-term opioid therapy. The well-cited Porter and Jick (1980) letter mentioned earlier failed to describe their methods in any meaningful detail and did not discuss whether a previous history of addiction was assessed. The patients in this study were hospitalized and, therefore, cannot be generalizable to typical patients in the community. These patients may have only used opioids for a limited period of time and only within a hospital context. In the Portenoy and Foley (1986) study, the doses of morphine prescribed to patients were far less than what might be today. This raises questions about present-day clinical relevance. Other early studies of opioids for CNMP that did not report rates of addiction (e.g., Tennant, Robinson, Sagherian, & Seecof, 1988) have been cited by researchers to reinforce the benefits and safety of opioids as opposed to their supposedly minimal risks of harm (see, e.g., Fishbain, Cole, Lewis, Rosomoff, & Rosomoff, 2008). The presence of substance use disorders is critical as patients who have pre-existing substance use

disorders are more likely to have challenges with prescribed opioids and receive long-term opioid therapy (Edlund, et al., 2010a; Edlund, et al., 2010b; Edlund, et al., 2010c).

Amid these changes in the pain field, a body of data began to emerge that challenged—and in some cases convincingly refuted—the claim that prescription opioid abuse and addiction were rare in patients with CNMP. Martell and colleagues (2007) estimated that aberrant medication-taking behaviours that may be interpreted as signs of opioid abuse occur in up to 24% of patients with CNMP who are prescribed opioids. A review of studies by Højsted and Sjøgren (2007) found that the prevalence of opioid addiction reported in the scientific literature broadly ranges from 0% to 50%. Inconsistencies across studies in terms of the definition of addiction and the subpopulations studied complicate the interpretation of this report. In a random sample of outpatients receiving opioid therapy in a large U.S. health system, Boscarino, et al. (2011) calculated that the rate of the DSM-5 category of Opioid Use Disorder is found in approximately 35% of patients. Recent Canadian data suggest that using prescription opioids without a prescription occurs in approximately 4.8% of the population, and 0.4% use prescription opioids for the purposes of intoxication (Shield, Jones, Rehm, & Fischer, 2013). Another study suggested that the frequency of opioid use disorders is four times higher in primary care CNMP samples than in the general population (Fleming, Balousek, Klessig, Mundt, & Brown, 2007). These numbers are similar to addiction rates associated with other drugs, such as alcohol and tobacco (Health Canada, 2012). Drug craving—considered to be the *sine qua non* of addiction—has been reported in patients with CNMP who do not meet DSM-IV criteria for substance dependence and are receiving opioid therapy regardless of pre-determined risk for opioid abuse (Wasan, et al., 2012).

Evidence for the effectiveness of long-term use of prescription opioids in CNMP management is limited and raises questions about potential harms (Von Korff, Kolodny, Deyo, & Chou, 2011), thereby posing ethical concerns for prescribing physicians. For example, a systematic review of opioid treatment for chronic back pain indicated that prescription opioids might be effective in the short term, but effectiveness for use over 16 weeks is less clear (Martell, et al., 2007). Randomized trials of prescription opioids for CNMP are typically short-term efficacy studies. They tend to exclude participants who are considered at high risk for opioid abuse or other adverse events, and provide lower doses than what would be typically given in clinical practice (Chou, Ballantyne, Fanciullo, Fine, &

Miaskowski, 2009; Juurlink & Dhalla, 2012). Because the focus of opioid clinical trials is on efficacy, assumptions about long-term safety are made as they pertain to the risk of addiction. Longer-term studies assessing iatrogenic addiction and abuse are extremely limited in the published literature, and those that exist tend to have methodological weaknesses such as extremely high dropout rates in experimental groups, which raise questions about internal validity (Katz, 2005).

The marked increase in opioid prescription and abuse has been associated with a host of related clinical and public health harms, and raises more ethical concerns. In Canada, individuals—adolescents in particular—tend to access non-prescribed prescription opioids through various means of diversion, such as from family, friends, double doctoring, or the black market (Fischer & Argento, 2012). Emergency room visits due to adverse effects of prescription opioids have increased in the last decade, as has the number of prescription opioid-associated overdoses (Dhalla, Mamdani, Sivilotti, Kopp, Qureshi, & Juurlink, 2009; Warner, Chen, Makuc, Anderson, & Miniño, 2011). Fatal overdoses involving prescription opioids, particularly morphine, are highly correlated with doses that exceed recommended prescribing guidelines (Fischer, Jones, & Rehm, 2013; Gomes, Dhalla, Paterson, & Jurrlink, 2011). Moreover, if some individuals who are taking prescription opioids are not accessing them through their primary care physicians or pain specialists, and if these individuals are not engaged in addiction treatment, it is possible that they may turn to alternative sources such as heroin or other street-available prescription opioids such as fentanyl (Center for Disease Control, 2008).

The potential harms of long-term prescription opioid use are not limited to addiction, abuse, and death. Additional medical harms may include fractures, respiratory depression, opioid-induced hyperalgesia, constipation and bowel obstruction, neuroendocrine dysfunction, and cardiovascular problems (Ballantyne & Mao, 2003; Vuong, Van Uum, O'Dell, Lutfy, & Friedman, 2010). Accordingly, health care providers are put in a precarious position: they need to be concerned not only with the potential medical and social harms prescription opioids might have on the patient and others, but also with the potential professional and legal consequences they might face as well. Such consequences also include concerns about health care provider safety. A recent Canadian study by Saveland, Hawker, Miedema, and MacDougall (2014) found that family physicians who prescribed controlled

substances, are at risk of experiencing physical or verbal abuse by patients who seek these drugs, namely opioids.

3.5 Moral tensions

The use of opioids for CNMP is a contentious, often ideologically driven therapeutic topic with complex social, political, regulatory and medical histories, and occurs in a challenging clinical and regulatory climate. Recent data on the limited long-term effectiveness of opioids for CNMP and the population-level harms they can cause (Chou, et al., 2009; Martell, et al., 2007) further complicate the relationship between pain, suffering, and ethical practice. The central ethical dilemma concerns the medical and ethical risks incurred by the potential harms of omission and commission (see, e.g., Fins, 1999). I argue that the controversy over prescription opioids and addiction in CNMP management can be framed by the following three central tensions: (1) the conceptual models used to understand addiction, specifically the behavioural, brain, and brain disease models; (2) the ambiguous moral status of prescription opioids as both a good medication and a harmful drug; and (3) the contrast between the good patient who takes legitimate medications and the difficult addict who abuses them.

3.5.1 Moral tension (1): The behavioural, brain, and brain disease models of addiction

There are several models that have been used historically to describe addiction. However, there are inconsistencies both within and across the models. Below I explain the three models of addiction as they are most commonly described in the literature.

The behavioural model of addiction is perhaps the oldest view of addiction in medical, philosophical, and lay discourses (Foddy & Savulescu, 2010). Often called the moral model of addiction, the phenomenon of addiction is described as a weakness of the will, and assumes that addicted individuals compulsively desire to use psychoactive drugs and that they eventually lose control over their drug use even in the face of negative consequences. Such consequences may be loss of employment, disengagement from or conflicts within personal relationships, difficulty maintaining housing, and health problems

(Russell, 2011). Loss of control is a threat to the Western liberal notion of the autonomous individual who chooses to give in to their weak will and lose the capacity to be autonomous; this consequence is what makes addiction an issue of moral concern. While the moral model and behavioural model are often synonymous, the former has roots in religious perspectives and the latter emerged from early theories of psychology (Courwright, 2001b; Courtwright, 2010).

In the context of CNMP management, where the use of opioids has been normalized, the behavioural model of addiction assumes that if an individual develops an iatrogenic addiction or engages in aberrant behaviours associated with prescription opioid abuse, it is because the individual is either not taking their medication responsibly or is addicted (Heit, 2001). What conditions might be necessary or sufficient for responsible medication taking is neither well defined nor understood, but it is typically thought of in terms of how well a patient follows the instructions of a prescribed medication regimen. Specifically, responsible medication taking is understood by how compliant or adherent patients are with the prescription regimen as determined by their health care provider (Conrad, 1985). Responsible use of medication often incorporates more than taking the medication as prescribed; additional criteria can be the reliance on one physician to prescribe opioids and one pharmacy to obtain them, storing pain medication in a secure location, not caching or diverting medications, keeping appointments with the physician, and agreeing to random urine drug screening.

Over the last several decades, research in addiction neuroscience has attempted to unravel the brain systems, mechanisms, and biological processes involved in craving, reward, dependence, and withdrawal (Volkow & Li, 2004; Volkow, Baler, & Goldstein, 2011). Researchers aim to demonstrate that drugs of abuse produce pleasure by releasing neurotransmitters such as dopamine within the reward system of the brain. These drugs of abuse are thought to hijack the neural circuitry for natural rewards such as food or sex, and propel addicted individuals to continue to use drugs in the face of negative social and occupational consequences (Dackis & O'Brien, 2005). It is the differences in neurobiology and neurophysiology that distinguish an “addicted brain” from a normal “nonaddicted brain” (Volkow, Baler, & Goldstein, 2011, p. 600) and therein lies the brain model of addiction. For instance, an “addicted brain” may have impairments in the pre-frontal cortex, a brain region

associated with executive function, impulse control, volition, and the ability to understand and appreciate the consequences of decisions. This distinction is made in contrast to the behavioural model of addiction, which defines addiction based on a patient's aberrant behaviours and physicians' clinical judgment.

The brain model of addiction is closely related to the brain disease model of addiction, and the latter extends its reach into the domain of ethics. The brain disease model states that addiction is a chronic, relapsing brain disease that emerges from the prolonged effect of drugs on the human brain (Leshner, 1997; Volkow & Li, 2004). Addiction is located inside the brain, but caused by harmful drugs that disrupt the normal healthy brain and propel the individual into a pathological state. A motivation of contemporary disease-based models is to reconfigure addiction within a biomedical framework and away from the behavioural model (Hyman, 2007).

Advocates for the brain disease model argue that framing the language in terms of disease (i.e., addiction is not the individual's fault) will bring about clinical and public health benefits, such as minimizing barriers to accessing care, facilitating greater investment in research and treatment, and promoting less punitive drug policies (Buchman, Skinner, & Illes, 2010; Gartner, Carter, & Partridge, 2012; Hyman, 2007). One particularly strong, compassionate motivation of the brain disease model is its attempt to combat the harmful effects of stigma, discrimination, and moral opprobrium that have historically been associated with people who are addicted to drugs (Leshner, 1997; National Institutes of Drug Abuse, 2001; Volkow & Li, 2004). The brain disease model emerged from broader historical and social processes to medicalize addiction and mental disorder that formally dates back to Rush (1823), who provided an alternative to the moral perspective on alcoholism promoted by the church (Jellinek, 1960; Levine, 1978).

Despite the scientific authority of both the brain model and brain disease model, the conceptual framing of addiction as a brain disease has not strongly shaped the discourse and practice of CNMP management, which largely operates from a behavioural model of addiction. Keane and Hamil (2010) summarize this point:

the therapeutic gaze of pain medicine and its commitment to ameliorating the suffering of its patients [through the use of prescription opioids] has led it to

see addiction as a set of problematic and harmful behaviours that are independent from the effects of drugs on the brain (p. 54).

From this perspective, addiction in CNMP management is a pathological psychological/behavioural condition as opposed to the neurophysiological phenomenon involving neuroadaptation. In CNMP management, iatrogenic addiction is not an expected or intended outcome when opioids are involved. If opioids are truly safe and effective when taken as prescribed, as proponents argue, then their long-term use cannot be conceptually associated with the increased risk of addiction. Moreover, from a neurobiological perspective, the brains of patients with CNMP who are dependent on opioids and access their prescriptions in a medical context are neurobiologically similar to individuals who are dependent on opioids and access their supply from illicit contexts (Keane & Hamill, 2010). Addiction in the context of CNMP management is a characteristic of problematic individual behaviour, rather than a characteristic of drugs or of brains.

The three models of addiction all explain certain aspects of the addiction phenomenon, but one problem with each of them is that they neglect the role of social factors. In particular, the social determinants of health are overlooked with the behaviour, brain, and brain disease models of addiction. Social determinants of health are not consequences of drug use, but rather socially driven conditions that affect drug use behaviours and overall health and well-being (Galea & Vlahov, 2002). Factors such as socioeconomic status, unstable housing, unemployment, education levels, legal system involvement, and poverty are all well-established risk factors for addiction. They influence health disparities and the degree to which an individual is able to mobilize and access resources to achieve goals and adapt to adverse situations (Raphael, 2004). The social and health inequalities faced by many individuals living with addictions have a cumulative and interactive effect on well-being, and are associated with ethical concerns such as injustice and disadvantage (Powers & Faden, 2006). The evidence suggests that prescription opioid use is higher in those socially disenfranchised, such as street-involved drug users, Aboriginal groups, and those in the forensic system (Fischer & Argento, 2012). Attention to the social determinants of health may help in the prevention and treatment of prescription drug abuse and addiction, and may help in reducing the harms of these drugs.

Since the brain disease model of addiction does not emphasize the role of the social

determinants of health, moral explanations of addiction may become the default when issues of iatrogenic addiction or prescription drug abuse arise. Western societies place a significant emphasis on individual rights, responsibilities, and self-control, and so there may be a tendency to conceive of addiction from the behavioural/moral model described earlier, which blames the individual for presumably valuing short-term pleasures over other social and occupational responsibilities. Accordingly, attention may be disproportionately focused on the behaviour of the individual without situating the behaviours within the individual's social context, or even the highly addictive properties of certain medications. This is particularly important in the context of CNMP management in which the social determinants of health (i.e., psychosocial factors) have been well established as important to contributors to the onset and persistence of pain.

3.5.2 Moral tension (2): Good medication/harmful drug

Derrida (1993) states that Plato's notion of the *pharmakon*—a substance that is both at once a beneficial medicine and a harmful poison—shapes the relationship human beings have to the substances classified as drugs. Prescription opioids, along with other drugs such as methylphenidate, methadone, nicotine replacement therapies, and cannabis, are examples of the ambiguous status of the pharmakon as both good, compassionate medicines and harmful, dangerous drugs.

The use of opioids for analgesia has long had therapeutic value, but the association of prescription opioids with addiction and high rates of prescription drug abuse and related notions of irrationality, lack of control, and crime have created social anxieties about the use and abuse of opioids (Meier, 2003; Meldrum, 2011). Given the public health data on prescription opioid abuse and the brain disease model, the legitimacy of long-term opioid therapy as a beneficial non-addictive therapeutic agent is thus called into question.

Providing an adequate definition of a drug is challenging given that drugs used in a medical context are considered legitimate and, unlike street drugs, issues of legality and social permissibility are less relevant (Keane, 2002). Opioids such as heroin are illegal and possession is punishable by law, while opioids such as morphine can be legally prescribed by physicians to relieve pain due to acute health conditions, as well as ease pain and suffering at

the end of life. However, possession and use of morphine for non-medical purposes is prohibited, and legal penalties may ensue for physicians who indiscriminately prescribe. It is the very complex social and medical nature of opioids, a drug embedded in a long history of definitions of addiction and substance dependence from medical, legal discourses and practices, which produces uncertainty about defining safe, effective, and morally responsible use (Keane, 2002, 2008). As one U.S. Drug Enforcement Agency (DEA) agent observed, “[t]hey [prescription opioids] don’t have the stigma of heroin or cocaine … because it’s something doctors use, it doesn’t have the same risks associated with those other drugs” (Zimmerman, 2007, paragraph 16). In other words, prescription opioids in a medical context are perceived as safe, while heroin, an illegal drug is not considered a medication and is perceived as dangerous. Conceptually and ethically distinguishing medications that provide benefit and cause harm is central to this tension.

The moral boundaries between good medication and bad drugs are further blurred as these distinctions are bound up with the ethics and politics of desire, excess, and pursuit of unendorsed pleasure. The literature distinguishes legitimate use of prescribed opioids for physical pain relief and the illegitimate use of prescribed opioids to produce euphoria or relieve emotional pain (Heit, 2001; Portenoy, 1996b; see also Bell & Salmon, 2009). However, patients with CNMP taking opioids have reported intoxicating euphoric effects of the medications (Zacny & Gutierrez, 2008). Euphoria is a rewarding embodied state associated with illicit drugs and thus creates unease in medical contexts, as drug-induced euphoria and other non-therapeutic pleasures are antithetical to the proper use of medications whose purpose is to produce analgesia and improve functionality. Despite the expected psychoactive response to opioid-derived compounds, feelings of euphoria in a CNMP management context are considered to be a risk factor for iatrogenic addiction (Bieber, et al., 2008). It is not just about how the artificially produced pleasure invites moral disapproval (Derrida, 1993), but rather how pleasure-seeking may lead to other aberrant drug-related behaviour. There is also a growing body of evidence that suggests that, at the neurobiological level, there is overlap in areas corresponding with physical and emotional pain, which occur in areas associated with high μ -opioid receptor binding potential (Baumgartner, et al., 2006; Eisenberger, 2012). The public health and social impact of prescription drug abuse has done

much to destabilize the perception of opioids as safe and beneficial medications, and further moralize the debate over opioid analgesic use in CNMP management.

3.5.3 Moral tension (3): Good pain patients/difficult addicts

The third moral tension regarding the use of opioids and addiction in CNMP management emerges between two allegedly distinct kinds of patients: the good pain patient and the difficult addict. The good pain patient—an accepted social identity—is health seeking and rational, takes medication for CNMP responsibly, and reaps the benefits of the treatment process and the therapeutic relationship. The neurologist Fields states in the context of CNMP management, “there is very much the concept of the ‘good patient’—the patient who doesn’t complain, who just does what he or she is told and they get better” (Rosenfeld, 2003, p. 100). The difficult addict is considered a contested or “spoiled” (Goffman, 1963/1986) identity; this individual tends to abuse legitimate medications, and is deceptive and irresponsible (Fry, 2010; Fry & Buchman, 2012; Wasan, Wootton, & Jamison, 2005). Such patients can be very frustrating for health care providers to care for, and providers who convey negative emotions to these patients may encourage distrust in the therapeutic relationship (Jamison, 2010). For the distinction between patient types to be maintained, it is important to successfully identify patients with predispositions to addictions so they do not transition from a good patient to a difficult addict (Keane, 2013).

The classification of good patients and difficult addicts is made by moving from a descriptive process that attempts to establish the ontological reality of pain, to a normative process that makes a moral statement regarding the legitimacy of patient testimony (Cronje & Williamson, 2006). Questions about classification systems are timely given the new DSM-5 categories of Somatic Symptom and Related Disorders and Opioid Use Disorder, which replaced the DSM-IV categories of Pain Disorder and Opioid Dependence and Opioid Abuse, respectively (APA, 2013). In DSM-5, these formerly separate categories are collapsed. This change poses a challenge for CNMP management as the diagnostic categories about the ontology of pain have become ambiguous (please see APA, 2013, section 300.82). Patients on a stable dose of opioids may be incorrectly labeled as having an opioid use disorder, which may in turn influence the interactions they have with their provider (Giordano, 2010b).

Giordano (2010b) further notes, these new categories “may implicitly ascribe pain to a psychological malady and may bias clinicians against the use of opioids—or not treating such patients altogether for fear of incurring medico-legal sanction” (p. 72). Being identified as a good patient or difficult addict is thus also related to nosological descriptions and the current state and conduct of pain care. Likewise, these new categories may raise concerns about the trustworthiness of some patients who meet the new diagnostic criteria for a disorder, and whether certain patients should be trusted to take their medications safely. National guidelines are available to assist providers in determining the risk of addiction in patients in which opioid therapy is considered (Chou, et al., 2009; Furlan, Reardon, Weppler, 2010).

In the literature, individuals with addictions are often marginalized in discussions of beneficial CNMP management (Bell & Salmon, 2009). As one article states, “when prescribed *for the right patients*, the long-term use of opioids does not necessarily result in *problems* of tolerance, physical dependence and addiction” (Adriaensen, Vissers, Noorduin, & Meert, 2003, p. 44; emphasis added). While the data reviewed earlier on the medical and social harms of opioid use for CNMP do not necessarily support this claim, the target patients in this context are the good patients, such as those who do not present with addictions, and seek opioids only for pain relief. By implication, those who have addictions are the difficult patients who seek drug-induced euphoria, pleasure, or may have non-medical motivations with their medication.

Patients with CNMP and addictions are often considered difficult due to aberrant behaviours. Aberrant behaviours, such as drug-seeking or diversion, may place a strain on the therapeutic relationship, and the difficult patient designation is likely to prejudice current and future therapeutic interactions (Fiester, 2012; Miksanek, 2007). Indeed, overly paternalistic accounts may assume that addicted individuals are almost always incapable of making decisions about what is in their own best interest (see, e.g., Caplan, 2008). However, concerns about responsible use of medications in addicted populations tends to underestimate the evidence that not taking medications as prescribed is also common in the general population (DiMatteo, 2004; Glombiewski, Nestoriuc, Rief, Glaesmer, & Braehler, 2012). Patients may be non-adherent for many reasons; some patients may have decided that taking medications

is not in their interests because of, for example, side effects, costs of the medication, or concerns of being labeled as an addict.

This moral distinction between good pain patients and difficult addicts is reflected at the institutional level and reinforced among public knowledge dissemination efforts. For example, in the U.S., the DEA created a museum exhibit “to educate and increase public awareness” (DEA Museum and Visitors Centre, 2012) on prescription drug abuse. The title of the exhibit, “Good Medicine, Bad Behavior: Drug Diversion in America” reflects the complex moral identity of both prescription drugs and the individual who takes such drugs. From the title of the exhibit, it seems the DEA does not challenge the neuropharmacological risks involved in the use of prescription opioids, and instead focuses on the morally reprehensible individual who has abused good medications and contributed to widespread social harms.

The condition of pseudoaddiction in CNMP management complicates the tension between good patients and difficult addicts. Weissman and Haddox (1989) defined pseudoaddiction as an “iatrogenic syndrome” (p. 363) produced by the undertreatment of pain with opioids. These authors claimed that patients who were sub-optimally medicated with opioid analgesics might demonstrate behaviours that resemble real addiction. The behaviours may include doctor shopping, dose escalation from non-medical sources, early refills, feigned lost prescriptions, or “desperate acting out” (Passik & Kirsh, 2004, p. 291). If the problematic behaviours are pseudoaddiction, they should resolve once the pain is adequately controlled with more opioid medication (Fishman, Wilsey, Yang, et al., 2000; Nicholson & Passik, 2007; Weissman & Haddox, 1989). Accordingly, pseudoaddiction can only be diagnosed after the patient has received a sufficient escalation in dose of opioids. The patient with legitimate CNMP is morally excused for aberrant addiction-related behaviour as she is insufficiently medicated.

Based on an analysis of the clinical and academic pain management literature, Bell and Salmon (2009) write that pseudoaddiction is a term reserved mainly for individuals from privileged socioeconomic backgrounds and real addiction is a label more readily applied to disenfranchised populations—populations that are more often assumed to struggle with addiction and mental disorders. However, individuals with a current or history of addiction cannot ever be labeled a pseudoaddict. Because addiction is part of the patient’s illness

narrative, any aberrant behaviour is considered suspect (see, e.g., Heit, 2001; Portenoy & Savage, 1997). Herein lies the source of the tension between good patients and difficult addicts with respect to pseudoaddiction: The behaviour of someone with an addiction is inseparable from his stigmatized social identity as an addict, and, therefore, cannot receive the clinical explanation afforded by the diagnosis of pseudoaddiction (Keane & Hamill, 2010).

The construction of pseudoaddiction as a bone fide diagnosis is considered “an important step forward in pain management” (Passik & Kirsh, 2004, p. 291), and is endorsed by international pain management organizations (e.g., American Society of Addiction Medicine, 2001). Aberrant behaviours are consistent with clinical experience in patients with legitimate pain who are prescribed opioids, and so the concept has good face validity among many providers (Passik & Kirsch, 2004; Portenoy, 1996b). Pharmaceutical companies that manufacture opioids for the treatment of CNMP are receptive to the concept as well; such companies have long claimed that fears about addiction are a barrier to effective pain treatment.

Despite the enthusiasm for the concept in the CNMP literature, pseudoaddiction was based only on a case report of 38 patients without further empirical support. After almost two decades of use, even the most initially ardent supporters of the concept concede that pseudoaddiction has not been empirically demonstrated (Nicholson & Passik, 2007). It is unclear why pseudoaddiction has maintained such prominence in the CNMP management and addiction discourse when the empirical foundation is weak at best.

3.6 Negotiating the three moral tensions

The three moral tensions that I have discussed underpin addiction in CNMP management and present ethical challenges for clinical practice. The challenging climate of CNMP management involving opioids thus places providers in an ethical quandary, as providers are committed to promoting patient welfare, but are also committed to not do harm to their patients and others (Geppert, 2007). However, fulfilling these ethical duties in the context of CNMP management does not mean that opioid analgesics ought to be prescribed. Even in the context of a moral right to pain treatment (Lohman, Schleifer, & Amon, 2010), given the medical and social

harms described in this chapter, a moral right to pain treatment does not necessarily imply a right to opioid therapy. If there is an ethical duty to provide pain relief, this should include effective non-pharmacological pain modalities as well (Sullivan & Ferrell, 2005). Non-pharmacological interventions may even be prioritized depending on the potential for harm of other interventions and the resources that may be required. Opioids are only one treatment option in the clinical armamentarium of the physician. Opioids are not a panacea. Questions remain about the duty to provide pain relief, particularly when complete analgesia or relief of all forms of pain and suffering is not always a realistic option, and given health care provider obligations to do what is medically necessary to restore normal species functioning (Daniels, 2001; Sullivan, 2001a; Kaufman, 2009).

Health care providers must be acknowledged for their diligence. They are expected to adhere to evidence-based practices and guidelines; however, the evidence that forms the basis of many guidelines around opioid management in CNMP has recently been questioned. Compounding this problem is the fact that there is no consensus on how to effectively reduce opioid-related harms, so providers often rely upon their own clinical experiences and moral intuitions (Dhalla, Persaud, & Juurlink, 2011; Geppert, 2004).

Because a physician prescribes opioids, the locus of power in the decision-making process in CNMP management with opioids lies with the prescribing health care provider (Ballantyne, 2007). Accordingly, it is incumbent on the prescribing physician to assess the harm-benefit calculus as it pertains to the individual patient. Various screening instruments, such as the widely adopted Opioid Risk Tool (ORT; Webster & Webster, 2005), have been proposed to assist providers in prescribing decisions and help identify patients who are at a high, moderate, or low risk of addiction or drug abuse with long-term opioid therapy. However, tools such as the ORT are fraught with methodological problems. These include the tool not being validated in a separate population, lacking face validity, and patients who were labeled “moderate” risk developed one or more aberrant behaviours after one year (Juurlink & Dhalla, 2012). Moreover, the evidence that such tools help reduce the risk of opioid-related harms is limited (Von Korff, Kolodny, Deyo, & Chou, 2011), and a recent study suggested that the ORT did not predict moderate to severe aberrant drug-related behaviour in patients receiving long-term opioid therapy for CNMP (Witkin, Diskina, Fernandes, Farrar, Ashburn, 2013). There are also important ethical concerns with the use of screening tools,

such as inadvertently denying people living with addictions treatment for their pain, and stigmatizing some as addicted or at risk, which may adversely affect the therapeutic relationship (Meltzer, Hall, & Fins, 2013). Accordingly, the clinical practice has been to identify risky problematic patients as opposed to prohibition of risky, problematic drugs.

Although opioids are prescribed by physicians and consumed by patients, health care providers and patients should not be the only ones who bear the responsibility for prescription opioid abuse. Considering the social determinants of health, those integral in minimizing the harms of prescription opioids include the wider health care community, health care organizations, prescription opioid manufacturers, policy makers, governments and others (National Advisory Committee on Prescription Drug Misuse, 2013). The responsibility for minimizing the harms of opioid use must be a shared responsibility, as the locus of responsibility relative to the harms of prescription opioid use matters ethically as it is connected to issues of fairness (Russell, 2011).

The ethical concerns described in this chapter are not limited to the three moral tensions discussed. There may be a constellation of additional social harms linked with long-term opioid therapy for CNMP that patients may identify as ethically salient. Research that explores the perception of harms by patients receiving opioid therapy may help fill this gap in practice understanding.

The complex social, moral, political, and regulatory history of prescription opioids that contextualize the moral tensions surrounding addiction in CNMP management may threaten the moral foundations of the therapeutic relationship, which is based on trust (Ho, 2011; Pellegrino, 1991; Rogers & Braunack-Mayer, 2004; Zaner, 1991). Threats to the covenant of trust in the therapeutic relationship may disproportionately impact those with stigmatized identities such as addicts, whose testimonies may be met with suspicion. Indeed, in the context of CNMP and addiction management, Geppert (2004) writes that “belief and trust in the integrity and credibility of the patient” (p.162) is often neglected. As noted in CHAPTER 1, trust is a concept that has received limited treatment in bioethics and even less so in the discourse of CNMP management. In the next chapter, I explore the moral value of trust, including the related concepts of distrust and trustworthiness and their application to health care.

Chapter 4: Why trust matters

Доверяй, но проверяй (Trust, but verify).

- Russian proverb

4.1 On trust and distrust

Trust is a central value that underpins human relationships; it is pervasive in daily life—it is the glue between the micro and macro levels of society (Luhmann, 1988). Trust is a common term in folk parlance yet there is little conceptual clarity about what trust is as formal definitions vary in the literature. In clinical care, trust is a binding feature in the patient-provider relationship (Zaner, 1991, 1998; Pellegrino, 1991).

Many different conceptualizations of trust are described in the literature. Some authors state that trust is an affective or emotional attitude that depends on a person's good will and motivations toward another, with the belief that a trustee is competent and will follow through with an expected action or predicted set of behaviours significant to a trustor (Baier, 1986; Hardin, 2002; Jones, 1996). Others argue that good will does not capture the motivational component of trust. Accordingly, authors such as McLeod (2002, 2004) argue that when a person is trusted, the trustor does not expect the trustee to be motivated by good will, but rather has the normative expectation that the trustee will act with moral integrity. Tobin (2011) and Hawley (2012) state that trust involves the reliance upon someone else to meet a moral commitment. The cognitive model of trust suggests that trusting may be a conscious or instrumental judgment of the trustworthiness of a potentially trusted individual, institution, or group (Gambetta, 1998; Hawley, 2012).

People are trusted with advice, items of monetary and symbolic value, intimate secrets, health, time, and so forth. This is what some have described as the triadic-relation of trust, where A trusts B with regard to C (Hardin, 2002), or x entrusts Y with z (Baier, 1986). Here, C and z are considered trust objects, and trust objects are typically things of value—something that matters to the trustor. Norms of trust suggest that people trust others with objects of value and give discretionary powers to the trustee because of the expectation that the trusting relationship will be of benefit. Accordingly, granting discretionary powers

involves some degree of risk, as the trustor becomes vulnerable to the trustee (Rogers & Ballantyne, 2009).

If an individual is ignorant about the motivations of another individual, group, or institution toward his or her interests or well-being, the individual may be agnostic about trust in the relationship (Ullmann-Margalit, 2004). Trust is not an all-or-nothing property; it is discriminatory and occurs on a spectrum (Baier, 1986). Returning to the triadic relation of trust just described, A may trust B with respect to C, but not necessarily with respect to D.

Trust is distinguished from related concepts such as dependency and reliance (Baier, 1986; Jones, 1996; O'Neill, 2002a). For instance, while trust may involve choice, for dependency, choice is often highly constrained (Meyer & Ward, 2009). Baier (1986) argues that trust is distinguished from related concepts such as reliance based on the attitudes about betrayal. Feelings of betrayal when trust is broken are contrasted with emotions such as aggravation or disappointment if an inanimate object is unreliable (Baier, 1986; Hawley, 2012). Individuals may also be relied upon but not trusted (Baier, 1986). It is the difference between betrayal and emotions such as disappointment that give trust its moral valence.

Trust is not always explicit or volitional and is at times placed without critical reflection (Adolphs, 2003; O'Neill, 2002a, 2002b). Being reflective and reasoning through every action, interaction, and judgment is not necessarily practical; individuals do not always reflect upon and check strategies for trusting, withholding trust, or evaluating trustworthiness. Research in cognitive psychology suggests that trusting others and making judgments about the trustworthiness of others often rely upon rapid and automatic cognitive processing that is largely influenced by facial cues and other heuristics (Stirrat & Perrett, 2010). These may include stereotypic and problematic beliefs about skin colour, accent, acknowledged expertise based on judgments, internalized social norms, and emotional reactions to the interaction (Adolphs, 2003; Engell, Todorov, & Haxby, 2010; Origgi, 2012; van't Wout & Sanfey, 2008; Willis & Todorov, 2006). Past experiences of placing trust may inform the individual whether or not placing trust again in similar contexts will be advantageous (Gordon & Platek, 2009). Accordingly, when trust is placed without some degree of caution, harm can potentially follow. Misplaced trust makes a person vulnerable to betrayal (Baier, 1986) and may damage the sense of self-respect (McLeod, 2002, 2004). Trust is a phenomenon that is at stake for individuals “who have important things to lose, to

gain, and to preserve” (Kleinman, 1998, p. 362). It is an important component of daily encounters with others and provides some predictability and certainty. As Luhmann (1979) wrote, if human beings operated with a complete absence of trust, it would be impossible to “get [...] up in the morning” (p. 4).

Trust, like other moral commitments, demands that individuals act with good will toward others with whom they are engaged in specific kinds of relationships (McLeod, 2004). The expectation of good will and reciprocity may reflect the existing social norms about trust. For instance, trust relations tend to be stronger in kith and kin networks than less familiar interactions (Barber, 1983; Churchland, 2011). These networks represent the close relationships that Putnam (2000) and Hardin (2002, 2004) describe as “thick trust”. By contrast, interactions with those less familiar are described as “thin trust”, and are not necessarily bound by strong relational commitments (Baier, 1986; Peter & Morgan, 2001; Putnam, 2000; Schwartz, 2009). While trust is entrenched in human relationships, it may also be extended to social and political systems such as institutions, health care systems, and governments (Gilson, 2003; Luhmann, 1979; Mechanic, 1998).

Distrust exists when the belief is held that B will not act in A’s best interest (i.e., B does not bear good will toward A or consistently demonstrates a lack of moral integrity), or when the domain-specific competence of B is questioned (Hall, Dugan, Zheng, & Mishra, 2001; Hardin, 2004; Ullmann-Margalit, 2004). Distrust, like trust, can be conceived in terms of a triadic relationship, where A distrusts B regarding some trust object C, or A distrusts B with trust object C, but not D. Distrust may either be conscious or a result of automatic cognitive processes (Hawley, 2012).

The factors that shape an individual’s distrust of others are often based on past personal experiences (Giddens, 1991), and the relative influence of gender, age, social class, and ethnicity (Ward & Meyer, 2009). While it may be assumed that trust is good and ought to be cultivated, and that distrust is bad and ought to be avoided, distrust may actually safeguard against harms rather than cause them (Hardin, 2004). For example, where oppression is a common experience of daily life, a distrustful stance by members of an oppressed or disenfranchised group may protect against further exploitation, particularly when they have repeatedly experienced forms of injustice. The reasonableness of placing or withdrawing trust depends on certain social contexts and relationships (Potter, 2002; Tobin, 2011).

Just as trust can be misplaced, distrust, too, can be misplaced or imprudent in some situations, and potentially even harmful. For instance, the trustor may hold certain moral prejudices about the motivations and moral integrity of certain groups of people based on culturally powerful stereotypes (Fricker, 2003, Larson, 2004). Accordingly, if A holds a certain prejudice against the social group to which B belongs, this may cause A to question the credibility of B's testimony, and perhaps even the trustworthiness of B. Such biases may, reflectively or unreflectively, influence A to undermine B in his or her capacity as a provider of knowledge (Fricker, 2003, 2007).

4.2 From trust and distrust to the virtue of trustworthiness

Being a trustworthy person is a character virtue (Potter, 2002; Zagzebski, 1996).

Trustworthiness matters because when person A places trust in B, A is assessing the trustworthiness of B with respect to factors such as competence, intentions, interests, and motivation (Baier, 1986; Hardin, 2002; Jones, 1996). Assessments of trustworthiness also matter because the outcome will influence how much discretionary power A will give to B to promote the welfare of A, with the expectation that A will not be harmed in the process (Potter, 1996; Rogers, 2002). This process of assessing trustworthiness depends on whether placing trust is a one-time event or an ongoing process. If it is the latter, there is a feedback loop occurring through which one makes an assessment based on previous experiences. With each experience, and depending on the circumstances, the trust relationship and the reciprocal sense of individual trustworthiness may change (Potter, 2002).

Like trust and distrust, trustworthiness can be either discrete or general. A trustworthy person may be the kind of person who can be counted on for one valued good, but not for another. As Potter (2002) contends, A will only be entrusted with something that matters to B if B considers A trustworthy to some degree. Potter (2002) further contends that full trustworthiness requires that the individual go beyond being trustworthy in discrete situations. Those who are trustworthy in a general sense are those "who can be counted on, given who one is in relation to diverse others, to have the right feelings toward the right sorts of things, to deliberate and make choices, and to act from a trustworthy disposition" (Potter, 2002, p. 25).

4.3 Dimensions of trust and distrust in health care

4.3.1 Trust in health care

The provision of health care is grounded in trust and the trustworthiness of its professionals and institutions, and yet trust may be taken for granted in therapeutic relationships (Ho, 2011; Pellegrino, 1979, 1991). Health care has historically operated from a paternalistic model of the therapeutic relationship where the health care provider, practicing chiefly from the duty of beneficence, holds the power in health care decision-making (Jonsen, 1998; Veatch, 1979). As medical experts, health care providers are traditionally thought to know what is best for the patient (Beauchamp & Childress, 2009; Sherwin, 1998). Following the civil rights movement in the U.S., and informed by the evolution of medical jurisprudence, the latter half of the twentieth century saw the rise of a consumer choice model of the therapeutic relationship. This new trend privileged individual autonomy, choice, and voluntary informed consent (O'Neill, 2002a; Wolpe, 1998). These social developments were driven in part by increasing distrust of authority, as Western populations realized that external factors, such as financial incentives to health care providers, researchers, and institutions, were negatively influencing clinical judgments (de Zuleta, 2007; Rothman, 2009). The increasing availability of other clinical options due to advancing technologies has also provided different alternatives for patients with the same condition. The concept of patient-centred care emerged as the desired ethical ideal, and patients became viewed as active and capable participants in their health care rather than passive recipients (Jonsen, 1998; O'Neill, 2002a). This shift in power dynamics ultimately affected the trust relationships patients had with their health care providers and the health system generally (de Vries & Kim, 2008; O'Neill, 2002a).

The nature of the patient-provider relationship involves disparities in knowledge, vulnerabilities, and power (Rogers & Ballantyne, 2009; Sokolowski, 1991). For instance, as Ho (2011) describes, a health care provider is sought based on his or her epistemic authoritative status—the expert knowledge, skills, and ability possessed to address the specific health concern. Providers have obtained qualifications giving them socially

sanctioned expert status, and expert status implies technical competence (Calnan & Rowe, 2007; Goldman, 2001; Hawley, 2010). Since health care providers are expected to abide by certain norms and ethical codes of conduct of the profession (Sokolowski, 1991), expert status also implies *prima facie*, professional trustworthiness. Indeed, health care institutions provide reasons to encourage public trust: institutions have developed professional licensing procedures, board certifications, and other regulations (Shapiro, 1987). Most patients and families do not have the necessary knowledge to assess the technical competence of health care providers, or have the ability to judge the various medical instruments, medications, or diagnostic tests recommended by providers (Ho, 2011). With various norms and codes of conduct in place, patients and families are likely to believe what their health care provider says because they trust the source of information (Ho, 2011; Marewski & Gigerenzer, 2012).

In therapeutic relationships, the trust object is health and it is placed within the discretionary power of the health care provider (Rogers, 2002; Rogers & Ballantyne, 2009; Rogers & Braunack-Mayer, 2004). While there is usually shared identification of the good—the patient's health and well-being—it is the relational asymmetries between provider and patient that can make the patient vulnerable to the discretionary power of the health care provider (Canlan & Rowe, 2007; Ho, 2011; Rogers & Ballantyne, 2009). Most patients believe that their physicians recognize their interests as primary and act to promote these interests (Mechanic, Ettel, & Davis, 1990), even if their interests may or may not overlap with those of the provider (Ullmann-Margalit, 2004). As medical experts, patients are also likely to trust the scientific and technical competencies of their health care provider.

Contemporary health care is characterized by uncertainty (Fox, 2000). Complexities of diagnosis, uncertainty regarding the veracity of symptoms, lack of evidence-based treatments, unclear courses of action, and challenges in communication all affect the ability of patients and providers to tolerate uncertainty (Dogra, Giordano, & France, 2007; Fox, 2000; Lillrank, 2003). With the lack of certainty that is inherent in health care, patients who have even less medical knowledge than professionals may have or feel the need to adopt higher levels of trust with health care providers (Calnan & Rowe, 2007). Nonetheless, if a patient places trust in a provider without some degree of caution or assurance of competence or good will, patient well-being can be threatened (Calnan & Rowe, 2007; Gilson, 2006). The ways in which patients place trust in health care providers might affect their assessment of

the possibilities of medical error or the benefits, risks, and limitations of modern medical science and technology, and render them more or less vulnerable to the possibility of iatrogenic harm (Entwistle & Quick, 2006).

Both health care providers and patients must epistemically trust many others in the health care system for care delivery. Schwab (2008) argues that epistemic trust in the process and in others is unavoidable and necessary, and gives an example of a patient being given a negative human immunodeficiency virus (HIV) test result. Neither the provider nor the patient can know for certain if the test was run correctly, falsified, or misinterpreted; both provider and patient are placing epistemic trust in the technical competence and good will of the person who drew the blood, the technician who ran the test, and many others who were involved in relaying the information throughout the health care system. This reality creates relations of epistemic dependency, or a need to trust not only the knowledge claim but also the process in which those claims are derived (Hardwig, 1985; Scheman, 2001; Schwab, 2008; Tobin, 2011).

The empirical literature suggests that patients tend to identify trust as a key component of the therapeutic relationship; the benefits of patient-provider interactions are greater when patient and provider trust each other (Ridd, Shaw, Lewis, & Salisbury, 2009). Trust is central to an effective therapeutic relationship (Dibben & Lena, 2003), and is an important quality indicator of the therapeutic relationship (Safran, Taira, Rogers, Kosinski, Ware Jr., & Tarlov, 1998). Trust correlates with patient satisfaction in the provider (Thom & Ribisi, 1999), adherence to treatment, loyalty and continuity with the health care provider (Roberge, Beaulieu, Haddad, Lebeau, & Pineault, 2001), and it increases the likelihood of accessing health care and disclosing information (Calnan & Rowe, 2004). Indeed, therapeutic trust tends to be stronger in longer-term therapeutic relationships than shorter ones (Calnan & Rowe, 2007; Kao, Green, Davis, Koplan, & Cleary, 1998). Nonetheless, a study by Mechanic and Meyer (2000) found that, despite acknowledging the benefits of trust in health care relationships, patients tend to have difficulty articulating specifically how they make trust calculations, and often refer to intuition or gut feelings.

4.3.2 Distrust in health care

Health care providers have historically enjoyed a high level of patient and public trust, owing to society's perception of medicine as a valued profession (De Vries & Kim, 2008; O'Neill, 2002a). However, discussions on the erosion of public and patient trust in medicine and health care institutions (O'Neill, 2002a, 2002b) have identified social developments that have contributed to distrust. These include the dominance of individual patient autonomy in Western health care, neo-liberalism in Western democracies, the continued rise of for-profit health care, and a general decreasing confidence in medical experts and the authority of medical science and institutions (O'Neill, 2002a, 2002b; Ward, 2006; Williams & Popay, 1994). These factors have led to reports about the increasing number of questions that patients ask about their clinicians' calculations about benefits and harms (Allsop, 2006; Crawford, 2004; Williams & Canlan, 1996).

From the public opinion polls, O'Neill (2002b) argues that generalized trust in medicine has transitioned to a "culture of suspicion" (p. 18). The role of popular media and reporting of professional misconduct is central to this trend. This includes high profile public cases such as the Shipman scandal in the UK (BBC News, 2004), for example, Australian pop singer Kylie Minogue and her alleged breast cancer misdiagnosis (see discussion in Meyer & Ward, 2008), continuous reports of the high rates of death from medical errors (Giese, 2012), and financial conflicts of interest between physicians and the pharmaceutical industry (Reuters, 2011). Most relevant to the present discussion are media reports of physicians who have been charged in the overdose deaths of their patients after they prescribed well-known opioid analgesics (Blackwell, 2011).

Patient distrust in health care providers may also stem from an overall distrust in the health care system (Giddens, 1990; Ward & Meyer, 2009). Patients may have had negative past personal experiences with certain providers or the medical profession, or are aware of the historical legacy of negative experiences of members from their sociocultural group. Indeed, patient trust in their health care providers is lower in ethnic minorities and those with chronic illnesses (Armstrong, Ravenell, McMurphy, & Putt, 2007; Gordon, Street Jr, Sharf, & Souchek, 2006). For example, both Gamble (1993) and Washington (2006) have reported that many African-Americans distrust health care providers and the health system, which is

partly explained by a history of medical exploitation, research scandals such as the Tuskegee Syphilis Study, and widening health disparities in the African-American population. When professionals' good will cannot be ascertained based on one's experience, distrust of health care providers and the health system can be rational.

4.3.3 Health care provider trust in patients

The health care context is one in which trust relations are particularly fragile (Pellegrino, 1991), and once trust in health care providers has been broken, it is difficult to re-establish (Hupcey & Miller, 2006). From this perspective, trust may be considered "the scarcest of medical resources" (Illingworth, 2002). While the literature on trust in health care mostly focuses on patients' trust in health care providers, the reciprocal question of whether or not health care providers ought to trust their patients is as ethically important a question (Miller, 2007; Rogers, 2002).

As discussed earlier, patients may trust their health care providers because patients are confident in their medical, technical, or scientific competence and their good will. However, the competence and good will definitions of trust manifest differently for health care providers trusting patients. The moral significance of placing trust in patients, overall, is central to the discussion (and as I discuss shortly, such trusting relationship may also have therapeutic benefits). For instance, by trusting the competence⁶ of a patient—patient testimony, the ability to adhere to a specific treatment plan, or competence in the general sense—a health care provider demonstrates a commitment to consider the patient as a moral agent who is able to direct his or her own care and to do so in keeping with personal values and interests (Rogers, 2002; Rogers & Braunack-Mayer, 2004). Likewise, the health care provider may trust the good will of the patient in terms of the patient's motives for seeking care, and that the patient does not intend to deceive the health care provider. Such commitments highlight the ideal manifestation of trust in therapeutic interactions because "it demonstrates a sharing of power and respect for the patient's knowledge and virtue" (Peter &

⁶ I do not use the term competence here to refer to possessing legal decisional capacity as it is often defined in health care legislation regarding the ability of the patient to give or refuse consent for treatment, placement, or personal assistance services.

Watt-Watson, 2002, p. 67). Placing trust in competence and good will facilitates cooperation and benefits the provider who may feel that responsibility for decision-making can be shared (Rogers, 2002). Hardin (2002) refers to trust in this way as “encapsulated interests”—the provider is vested in fulfilling the patient’s trust.

Trust may be challenged for health care providers when individuals are viewed alongside the values of larger groups to which they belong, and accompanying societal beliefs, assumptions, and prejudices (Miller, 2000). Certain groups, particularly those that are disenfranchised, may be seen as being less competent or less trustworthy in a broad sense than non-disenfranchised groups (Peter & Watt-Watson, 2002; Miller, 2000). This distrust is both moral and epistemic (Peter & Watt-Watson, 2002; Tobin, 2011). Accordingly, there may be a heightened climate of suspicion surrounding patients with pre-existing vulnerabilities, such as addictions (Merrill, Rhodes, Deyon, Marlatt, & Bradley, 2002; Miller, 2007; Rogers, 2002). If a provider distrusts a patient’s competence or good will, an additional burden may be placed on the existing health complaint that the patient has to shoulder. Misplaced trust in certain disenfranchised patients may create barriers in access to certain forms of health care in addition to other existing barriers (Rich, 2000; Gilson & Joranson, 2002). Communication, discussions about goals of care, and engagement in treatment may all be affected (Rogers & Braunack-Mayer, 2004).

Still, health care providers can have ethically justifiable reasons to distrust some patients for certain aspects of their care, especially if the patient does not exhibit competence or demonstrate good will. In such circumstances, misplaced trust in patients may bring about harm to the patient, provider, and possibly others (Rogers & Braunack-Mayer, 2004). Assuming a position of distrust with some patients, therefore, may well protect against clinical and public health harms (Chesney, 2003). In some situations, misplaced trust can have societal impacts as well. As stewards of finite resources in a publicly financed health care system, health care providers are obliged to determine how resources such as medications are justifiably distributed (Beauchamp & Childress, 2009). In British Columbia, for example, HIV medications are covered for medically insured citizens under the provincial medical service plan (British Columbia Ministry of Health, 2013). Patients who may not be trusted to adhere to their anti-retroviral medications may potentially increase the risk of harm to others—by transmitting drug-resistant forms of HIV—and a more trustworthy patient might

derive more benefit and minimize the possibility of harms to others. In these situations, providers are faced with the difficult task of assessing the competence and good will of their patients, which patients can be trusted not to misuse their medications, and under what conditions it is wise to place trust in them (Tobin, 2011). For health care providers, deciding to trust or distrust certain patients is affected by the micro-level therapeutic relationship, and the meso and macro institutional, professional, legal, and political contexts in which that therapeutic relationship is situated (Gilson, 2006; Miller, 2007; Schwartz, 2009).

4.4 Trust, distrust, and trustworthiness in CNMP management

4.4.1 Certainty, objectivity, and subjectivity

Kleinman (1988) states that “[i]f there is a single experience shared by virtually all CNMP patients it is at some point those around them—chiefly practitioners, but also at times family members—come to question the authenticity of the patient’s experience of pain” (p.57). Such questioning is associated with concerns about certainty as it relates to objectively unverifiable symptoms. Scheman (2001) refers to this phenomenon in relation to scientific objectivity as trustworthiness: objective judgments of clinical medicine are understood as judgments that can be rationally trusted. In the CNMP management context, scientific objectivity as trustworthiness raises questions about who or what should be trusted and under what circumstances (Scheman, 2001; Tobin, 2011).

Victor and Richeimer (2005) summarize this epistemic uncertainty as follows: pain “is a less objective, and therefore, in the clinician’s eyes, a less ‘trustworthy’ symptom than a broken bone or torn ligament” (p. 385). Because pain does not necessarily have a corresponding physical signal, the patient’s testimony about their pain may not be considered epistemically competent, particularly in cases where the perceived severity of pain as reported by the patient seems far from a reliable account (e.g., the provider’s clinical expertise indicates that this individual is malingering). Where uncertainty exists, health care providers may feel limited to address the patient’s CNMP needs or may be suspicious of the patient’s good will or motivations for seeking care (Barry, et al., 2010; Matthias, et al., 2010). To avoid bringing about harm to patients and others, providers may resort to distrust

of patients whose pain symptoms cannot be objectively verified (Victor & Richeimer, 2005). Where their experience is perceived to lack credibility, the patient might perceive the presumed scientific objectivity of medicine to be valued more than their own lived experience (Rich, 1997; 2000). These negative interactions may contribute to the perception by patients that they are being stigmatized and questioned as a trustworthy source of information (Marbach, Lennon, Link, & Dohrenwend, 1990; Osborn & Smith, 1998).

Green, et al. (2003) have documented that the credibility of the patient's report of pain is more likely to be questioned in marginalized populations, thereby raising questions of social justice. For example, as discussed in CHAPTER 2, the burden of CNMP-related suffering is greater for patients from disadvantaged socioeconomic groups than for patients from more privileged socioeconomic groups. Some health care providers may be more suspicious of certain requests of individuals from marginalized populations, such as requests for an increased dose of addictive pain medications (Barry, et al., 2010). Likewise, a patient from a marginalized population may be suspicious about what the provider thinks of a request, and how his or her moral character is being evaluated (Govier, 1997). This may be particularly relevant for patients who in previous health care interactions were accused of exaggerating their pain or malingering. Patients may feel confused and doubtful, and both parties may be wary of the other, fostering mutual mistrust (Merrill, et al., 2002; Miller, 2007). What may occur is an undermining of the quality of the therapeutic interaction, and a risk of inadequate CNMP management (Kenny, 2004; Librach, 1993). Inadequate treatment of CNMP can lead to significant negative consequences, as patients may doctor shop or withdraw from care entirely (Parsons, et al., 2007).

Uncertainty about the treatment of CNMP and worries about the potential harms arising from iatrogenic addiction, drug-seeking, abuse, and diversion have come to dominate the discourse around treatment and shape CNMP management (Bell & Salmon, 2009; Sullivan & Ferrell, 2005; Rich, 2000). These worries are based in the uncertainties that come with addiction, and may in some circumstances be warranted given the dramatic rise in harms from prescription opioid abuse, as described in CHAPTER 3. The theme about the connection between uncertainty in CNMP management and trustworthiness is revisited in later chapters.

4.4.2 Chronic nonmalignant pain: A special case for the study of trust

Given the challenges and complexities of CNMP and the therapeutic relationship between patients and physicians, it is not surprising that Rich (2010) states, “in no other aspect of patient care has the fundamental role of trust in the clinician-patient relationship become more of a pivotal issue” (conclusion section, last paragraph). Since the subjective nature of CNMP causes uncertainties in the context of presumably objective clinical medicine, instead of automatically placing trust in patients, some authors argue that the responsibility of demonstrating trustworthiness lies with the patient with CNMP rather than the health care provider (Richeimer & Case, 2004; Victor & Richeimer, 2005). Yet, in most other therapeutic interactions, patients do not bear such a heavy burden of proof (Rich, 2005). Whether patients bear any reciprocal moral obligations in the therapeutic relationship is an important ethical question (English, 2005; Giordano, 2007b).

The empirical literature on trust discussed in the current chapter largely examines how individuals and the public at large trust generically; the findings tend to be abstracted from the contexts in which individuals might trust or distrust certain other individuals, groups, or institutions for various reasons. The qualitative experience of being trusted or distrusted, including interrelated issues such as motives for seeking care and testimony of pain symptoms, merits further exploration. As discussed in CHAPTER 1, trust has received little treatment in bioethics and even less attention in the context of CNMP management. Research that provides an in-depth account of trust that is both descriptive and normative, and places an explicit focus on its role in CNMP management, is an important place for inquiry. It is this gap in research and practice that I turn to next.

Chapter 5: Methods

In this chapter, I shift my focus from a review of the literature and background theory to the empirical research conducted for this dissertation. I situate the work in the context of qualitative research, empirical neuroethics, and grounded theory methodology.

5.1 Research questions

My goal is to answer the following central research question:

What is the role of trust in CNMP from the patient's perspective?

Four sub-questions will inform the answer to the central research question:

- 1) How do patients living with CNMP experience trust in their relationships with primary care physicians and specialists?
- 2) Do these patients seek to demonstrate trustworthiness; how do they do so, and why?
- 3) How do patients living with CNMP and receiving primary care and specialist services value trust?
- 4) How do patients living with CNMP understand and describe relationships between CNMP and addiction-related behaviours?

5.2 Methodological and theoretical approach

5.2.1 Qualitative research

Qualitative research is a collection of methods that privileges the acquisition of new knowledge about the lived experiences of and interactions of and between individuals and groups. In their seminal text, Denzin and Lincoln (2008) define qualitative research as,

a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that makes the world visible. These practices...turn the world into a series of representations including fieldnotes, interviews, conversations, photographs, recordings and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach

to the world. This means that qualitative researchers...attempt to make sense of, or to interpret phenomena in terms of the meanings people bring to them (p. 4).

The goal is to develop “thick descriptions” of experience (Geertz, 1973; Denzin, 1989) that are socially, culturally, and historically contingent, and captured at a particular moment in time. Qualitative research designs are particularly well-suited to capture elements of experiences that are especially hard to objectify (Galvagni 2011), such as that of pain that is inherently subjective and demands interpretation (Frank, 2004a; Galvani, 2011; Morris, 1991).

I couple the qualitative approach with the contemporary discourse of empirical neuroethics, which has the same overall objectives as empirical bioethics⁷, but focuses on challenges specifically related to the central nervous system. In both cases, previously fragmented social science research methods and philosophically grounded applied ethics are tightly linked (Borry, Schotmans, & Dierickx, 2005; Hedgecoe, 2004; Solomon, 2005). Empirical neuroethics supports both quantitative measures and qualitative explorations of phenomena such as attitudes and behaviours, beliefs and perceptions, procedures, policies, and common practices. It is well suited to inquiries about health care environments, and has been applied to neuroethics topics such as perspectives of individuals diagnosed with depression or bipolar disorder on the role of neuroimaging in shaping notions of selfhood (Buchman, Borgelt, Whiteley, & Illes, 2013), patient and scientist views of addiction as a brain disease (Hammer, Dingel, Ostergren, Partridge, McCormick, & Koenig, 2013), treatment decision-making in spinal cord injury (Eijkholt, Kwon, Mizgalewicz, & Illes, 2012), and neurocognitive enhancement (Fitz, Nadler, Manogaran, Chong, & Reiner, 2013). Empirical neuroethics data enrich the understanding of an ethical issue or concept under investigation by building upon foundational premises and assumptions, describing key components of ethical theory, uncovering new ethically-relevant issues, revisiting and sometimes revising normative arguments, and assessing both the process and outcomes of

⁷ In this dissertation, I use the term empirical neuroethics interchangeably with empirical bioethics, and distinguish it from other usages of the term empirical neuroethics that seek to understand the neural basis of human moral behaviour (see, e.g., Illes, 2007; Northoff, 2009).

policies that have ethical objectives (Frith, 2010; Parker, 2009; Sugarman, Pearlman, & Taylor, 2007).

In contrast to conceptual, normative ethical analysis that tends to reason deductively by top-down approaches such as the Beauchamp and Childress (2009) principlism paradigm, empirical neuroethics studies allow for reasoning from the bottom-up: data from empirical neuroethics research are descriptive, provide epistemological and methodological tools for empirically accessing the social world (Borry, Schotmans, & Dierickx, 2005; Haims, 2002; Hoffmaster, 1992), and can help anticipate ethical challenges at the interface of advances in brain-related science (e.g., Illes and Bird, 2006). Haims (2002) discusses the interdisciplinary nature of empirical ethics and the role of qualitative social science research methods in the following manner:

the social sciences have more to contribute than just ‘the facts’. The social sciences see legal and ethical issues as primarily social issues and, because of this encompassing perspective, can contribute not only to the understanding of ethical issues but also to the understanding of the social processes through which those issues become constituted as ethical concerns (Haims, 2002, p. 91).

This dissertation research is an example of what Draper and Ives (2007) refer to as “social science *in* bioethics” (p. 323; italics in original), which aims to use empirical qualitative data to inform normative ethical analysis. The rationale for taking this approach is based in the claim that normative reasoning should not rely upon the intuitions or moral judgments of the researcher alone, but rather should be informed by the descriptive accounts of those with the lived experience of the phenomenon of interest. These accounts are what Lindemann Nelson (2001) refers to as “normative self-disclosure[s]” (p. 25), accounts through dialogue that reveal what matters to participants and the values they uphold (Frank, 2004b).

To transform the descriptive narrative data I acquired from interviews and feedback group into a normative ethical analysis, I applied a combined version of two complementary empirical bioethics approaches: the Network Model with Third Person Moral Experiences (de Vries & van Leeuwen, 2010) and Narrative Equilibrium (Brody, 2003). Both approaches are based on the model of philosophical ethical reflection known as wide reflective equilibrium (WRE), as described by Rawls (1971/1999) and later Daniels (1979). In the

original philosophical version of WRE, the philosopher engages in a deliberative process in which coherence is sought among a set of moral intuitions or judgments, moral principles, and background theories. After reflection, beliefs about an intuition or judgment are revised. Coherence is achieved by testing existing moral principles and background theories against variations of a particular case, and then refining and specifying the theories to accommodate judgments about those variations (Daniels, 1979). De Vries and van Leeuwen and Brody build upon Rawls and Daniels' philosophical approach. In their WRE empirical bioethics model, themes derived from the grounded theory about, for example, the experiences of participants, are compared and contrasted with background theories from philosophy and sociology. They argue that, in this way, the normative, coherent conclusion that is reached at the end of an empirical bioethics study is supported both theoretically and empirically: the model integrates the background theories relevant to the research questions and the empirical data yielded from lived experiences.

5.2.2 Grounded theory: Classical approach

Grounded theory guides the general design and analytic approach to the present research. Within the domain of qualitative research, the classical approach to grounded theory is based on the seminal texts of Glaser & Strauss (1967) and Corbin and Strauss (1990). Grounded theory describes both a method and the product of inquiry: it is the iterative process of cycling between qualitative data, such as interviews and analysis, and simultaneously focusing the data and strengthening the theoretical aspects of the analysis (Bryant & Charmaz, 2007; Corbin & Strauss, 1990). Grounded theory is,

inductively derived from the study of the phenomenon it represents. That is, it is discovered and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon. Therefore, data collection, analysis and theory stand in reciprocal relationship to one another. (Corbin & Strauss, 1990, p. 23).

When applying grounded theory to a research problem, the researcher develops an explanatory theory of a social process that is grounded in the descriptively rich data acquired from participants in a particular context (Charmaz, 2005; Corbin & Strauss, 1990; Creswell, 2007). In this way, grounded theory provides a practical, analytic interpretation of how the

microcontexts of people's local worlds⁸ (Charmaz, 2005; Kleinman, 1992) help to shape ensuing questions and processes (Charmaz & Belgrave, 2012).

Grounded theory is based in the Chicago School of sociology (Glaser & Strauss, 1967), which combines the philosophical theories of phenomenology (Sokolowski, 2000; Spiegelberg, 1994) and symbolic interactionism (Blumer, 1969/1986) with its emphasis on social processes, with empirical tools such as in-depth interviews and participant observation. Through analysis, grounded theory emphasizes the relationships among data-generated concepts, categories, and themes.

The notion of theory in grounded theory is different from a scientific theory, for example, which is defined as a system of propositions united by a common subject matter that has been supported by repeated observation and testing, and modified based on new evidence (Bunge, 1999). The focus of a social science grounded theory, therefore, is much narrower than a scientific theory that strives for universality. Grounded theory is more closely related to the specific studied world; the emphasis is on theory generation, as opposed to conceptual description or theory verification (Creswell, 2007). Kearney (2007) explains the unique role of theory in grounded theory in that it "does not simply posit that A always leads to B, but...the degree to which A leads to B and what that relationship looks like depends on a range of factors that influence A, B, and the relationships between them" (p.128).

As the analytic approach in grounded theory is inductive rather than deductive, the researcher continually interrogates the data and refines the developing theory. In a grounded theory interview study, researchers tend to be concerned with gaining "theoretically plausible" (Charmaz & Belgrave, 2012, p. 351) accounts from participants rather than verifying the degree of accuracy of stories. Qualitative researchers who focus on narratives are interested in how discourse and metaphors in particular create, define, and shape the experiences of participants (Wetherell, Taylor, & Yates, 2007). The synthesis of narratives minimizes the effect of potentially misleading participant accounts (Charmaz & Belgrave, 2012). This does not mean that researchers are uncritically accepting the personal narratives

⁸ In CHAPTER 1, I introduced Kleinman's anthropological concept of "local worlds," which may consist of places, spaces, and institutions in which human beings inhabit or interact with one another and their environment.

that participants share in qualitative research contexts, however. For instance, there are culturally defined permissible and impermissible stories that people tell about their experiences, as narratives may reflect the moral public discourse on the health issue more so than what might have been true for them (Segal, 2005).

Critics have claimed that the term grounded theory is often equated with non-descript qualitative research, as researchers who claim to be using grounded theory methods typically focus on the analytic aspects and tend to neglect several important methodological components such as the actual theory (Suddaby, 2006). Indeed, while many interpretations and applications of grounded theory are available (see, e.g., Bryant & Charmaz, 2007), the unifying feature across these interpretations is the focus on theory generation.

5.2.3 Constructivist grounded theory

Charmaz (1990, 2005, 2006) proposed a social constructivist interpretation of grounded theory in order to overcome what she perceived to be the limitations of the Glaser, Strauss and Corbin approaches. Charmaz's approach was developed to "study social psychological themes which cut across diverse chronic illnesses" (Charmaz, 1990, p. 1161), and it is this interpretation that is specifically adopted for the research presented here.

The constructionist element of Charmaz's grounded theory approach is derived from a long intellectual tradition in sociology that stresses the sociocultural, historical, and political aspects of phenomena as opposed to any inherent fixed properties those phenomena may possess. The theory of social constructionism states that knowledge, reality, and social meanings that are attributed to various phenomena develop through processes and activities among people in a particular social context (Berger & Luckmann, 1966). Positing that the experience of reality is socially constructed, a social constructionist account places a strong emphasis on subjective experience. It examines the individual, social, political, and cultural meanings of the experience and how individuals in various social contexts construct their identities through their narratives: "people constitute and are constituted by the stories that they live and the stories that they tell" (Neimeyer, 1993, p. 226).

To a social constructionist, first-person accounts are not solely unique experiences or simply mirror social, economic, and political forces and ideologies. The forces and the

rhetoric of health, illness, and medicine as a social institution, for example, shape the experience of illness and the resulting clinical practice and policy efforts (Segal, 1997, 2005). From a social constructionist perspective, reality is not fixed awaiting discovery by the researcher out in the world. Rather, individuals who act and respond to others within the world construct multiple realities. In research settings, and grounded theory specifically, this knowledge of reality is co-constructed by the researcher and the participants (Charmaz, 2006). Taken to its logical extreme, social constructionism contends that reality itself is socially constructed and there is no such thing as an objective reality. In this dissertation, I do not presume that reality is entirely socially constructed. Similar to a biopsychosocial perspective, I think of these processes as “interactions” (Hacking, 1995, 1999) rather than just social constructions. For instance, Hacking (2006) states that humans are biosocial beings, i.e., both biological mammals and social animals. The identity of groups of people are characterized in biological and social ways, with both the biological and the social interacting with others, including the environments and communities that groups of people create and develop.

Charmaz (2005, 2006) argued that classical iterations of grounded theory lacked interpretive, reflexive, and social constructionist elements, and fail to consider the impact of power and macro-level forces on micro interactions. To fill this gap, Charmaz advocated for integration of the Chicago School approach drawn from empirical sociology, and its emphasis on symbolic interactionism, with prior methods. On Charmaz’s account, qualitative data are situated in a particular time, place, culture, and context, and also reflect the social and epistemological positions of the researcher (Charmaz, 2006; Charmaz & Belgrave, 2012). Charmaz (2005, 2006) views grounded theory as a methodological tool, rather than a prescriptive system. The attention to intertwining contexts makes this approach appropriate for studying the moral content of CNMP experiences.

In other research approaches from more positivist traditions, *a priori* categories, codes, and definitions are applied to the data. In other words, the researcher attempts to fit the data into a previously defined concept. With grounded theory, no *a priori* or preconceived categories are applied, as the categories and codes emerge from the data.

Since no *a priori* categories are applied to the data in a grounded theory study, there has been some debate concerning the role and purpose of the literature review in grounded

theory (McGhee, Marland, & Atkinson, 2007). Even Charmaz (2006) cautions against the use of a literature review until the end of the project. She argues that interpreting data through the lens of a pre-existing theory, literature, or set of ideas contaminates the grounded theory process. I departed from this recommendation, however, given the importance and requirement of obtaining scholarly expertise on the literature on CNMP, addiction, and relevant concepts from moral philosophy before embarking on the project. I also had to ensure that the research questions I posed had not already received empirical treatment, and that I could make a novel contribution to the field. I reviewed the literature for this dissertation during all stages of the research process—conceptualization, project development, data collection, analysis, and writing. Since my research objectives pertain to patient perspectives of trust in the CNMP management therapeutic relationship, I relate the literature on patient and health care provider perspectives on the therapeutic relationship in CNMP management in CHAPTER 7, in order to contextualize my findings with the existing literature.

5.3 Methods

5.3.1 Participant inclusion and exclusion criteria

To explore the role of trust in CNMP from the patient's perspective, participants had to meet the following inclusion criteria: English-speaking; adults between the ages of 35-64; self-reported CNMP in the low back region for two years or longer; and, under the care of a primary care physician for pain management. Participants could have reported CNMP in multiple anatomical locations, but the lower back was the required primary relevant complaint. The age inclusion criterion was chosen for the high prevalence of pain in this range (Schopflocher, Taenzer, and Jovey, 2011). The low back was the focus as pain in this location is the most frequently reported complaint for CNMP in Canada (Boulanger, et al., 2007; Schopflocher, Taenzer, & Jovey, 2011). Older adults were excluded because of their additional health and psychosocial concerns. Those on workplace disability were excluded because of the potential bias from the primacy of the “sick role” during the claims process (Glenton, 2003; McCluskey, Brooks, King, & Burton, 2011).

5.3.2 Recruitment

Participants were recruited by print advertisement from primary care practice clinics, community health centres, and physiotherapy clinics across the socioeconomically diverse neighbourhoods of Vancouver’s Lower Mainland. A recruitment advertisement also appeared in the Pain BC March 2012 newsletter, and two print advertisements ran for one week each in the Vancouver weekly publication *Georgia Straight* on May 17th, 2012 and July 19th, 2012. Other study recruitment advertisements were posted online in the Volunteer section of the Vancouver Craigslist website (<http://vancouver.en.craigslist.ca/vol/>), and on the Vancouver Coastal Health Research Institute’s website (<http://www.vchri.ca/>). Upon contacting the researcher, all interested candidates participated in a telephone screening call to determine eligibility (APPENDIX A). There was no predefined sample size. Following Creswell (2007), the target was 20 to 30 interviews for expected saturation of thematic categories in grounded theory analysis. The study took place between March 30th, 2012 and December 5th, 2012.

5.3.3 Sampling

Consistent with grounded theory methods, recruitment sampling as well as data collection and analysis were conducted as an iterative process. There were two sampling phases: (1) purposeful sampling of participants and (2) theoretical sampling.

5.3.3.1 Purposeful sampling

Purposeful sampling is a non-probabilistic sampling method in which individuals are invited to participate in a study based on rigorously determined inclusion/exclusion criteria. To ensure heterogeneity of the sample—a deliberate and desired feature to yield both overlapping and diverging descriptions of patterns of experiences—the strategy of maximum variation sampling was applied by recruiting from diverse socioeconomic neighbourhoods and clinical sites in Vancouver’s lower mainland (Creswell, 2007; Sandelowski, 2000; please see 5.3.2 RECRUITMENT above). This method assures the representativeness of the small non-

random purposeful sample (e.g., n = 30 ±10) to the general views of the population of interest by ensuring a diversity of ages, genders, and socioeconomic groups from a target population. A total of 36 individuals responded during the 8-month period of open recruitment. Guided by the analysis unfolding in parallel with recruitment and interviewing, 23 individuals who responded to the announcement of the study met inclusion criteria and seven individuals did not meet inclusion criteria. Two individuals who met inclusion criteria did not attend the interview. Accordingly, 21 individuals were interviewed during this first stage of the study. Potential participants who contacted the researcher after the first 21 participants and met inclusion criteria were notified that they would be placed on a waiting list.

5.3.3.2 Theoretical sampling

To elaborate and refine the categories of the emerging theory derived from the analysis of the first 21 patient participants, six additional respondents were interviewed. These represented all on the waiting list and, therefore, all who responded and met inclusion criteria ultimately had the opportunity to participate.

5.3.4 Consent

To be enrolled in the study and provide informed consent, participants had to demonstrate an understanding of the purpose of the research, its risks and potential benefits, and that participation is completely voluntary. Patient participants were assured that the researcher is not connected to any treatment team, and that enrollment would in no way affect their care. They were also reminded that it would not move them ahead on any waitlist for treatment. Participants were given an opportunity to read the consent form without time pressure, and a copy of the consent form was provided to participants who requested it ahead of time. Participants who were enrolled and interviewed by telephone were similarly engaged in a discussion about consent, followed by a verbatim reading of the informed consent form. These participants provided verbal consent.

Since the side effects of certain medications used in CNMP management may affect cognition and emotions, as might certain drugs of abuse, a high level of vigilance was maintained to the participants' responsiveness during the interviews to ensure that there was no significant adverse effect on them or potentially on the downstream integrity of the data. Participants were also reminded that they could withdraw from participation or refrain from answering any questions if they did not feel comfortable.

All patient participants were invited to be re-contacted for a future feedback group. Feedback group participants were asked to refrain from disclosing the contents of the discussion outside of the focus group, while acknowledging that absolute confidentiality could not be guaranteed.

5.3.5 Demographics questionnaire

Prior to each interview, all patient participants completed a demographics questionnaire. These questions encompassed variables such as gender, employment status, education, age, sociocultural and ethnic background, and related personal and family medical history. Please see APPENDIX B.

5.3.6 Brief pain inventory-short form

All patient participants then completed the Brief Pain Inventory-Short Form (BPI-SF; please see APPENDIX C) upon enrollment in the study. The BPI-SF is a well-validated self-report questionnaire that provides measure of pain severity, its interference in daily life, pain location and medications (Keller, Bann, Dodd, Schein, Mendoza, & Cleeland, 2004). Initially developed to assess cancer-related pain (Cleeland, et al., 1994), the BPI-SF uses a continuous assessment scale from 0 to 10. It provided a quantitative dimension to complement the qualitative narratives. The BPI-SF was administered prior to the research interview and took approximately five minutes to complete. Each BPI-SF item was read aloud and the researcher recorded responses for participants who required reading assistance or who participated by telephone.

5.4 Interviews

5.4.1 Interview guide

The patient interview guide (see APPENDIX B) was developed following the tenets of grounded theory and qualitative interview guide development (Charmaz, 2006; Kvale & Brinkman, 2009). In particular, the guide was structured to include open-ended questions, intermediate questions, and ending questions that specifically probed for the concept of trust in the patient experience with CNMP. Open-ended questions are broad questions aimed at yielding rich descriptions of the phenomena of interest; intermediate questions are structured to attempt to gather more precise descriptions; and ending questions are posed late in the interview, when the goal is for participants to summarize their thoughts and indicate which aspects of the phenomena discussed are most important (Charmaz, 2006; Kvale & Brinkman, 2009). Given addiction-related issues in pain management, participants were also probed for their views toward drug-seeking behaviours, medical diversion, and prescription drug abuse. Interview questions were framed according to the symbolic interactionist underpinnings of grounded theory as described above, and were written to explicitly gain access to a rich and deep understanding of the moral meanings participants attribute to their actions and experiences in a pain management context.

The interview guide was vetted with members of the dissertation committee, experts in qualitative research design and implementation, and physician experts who care for patients with pain and addiction concerns prior to finalization and study execution.

5.4.2 Semi-structured interviews

Interviews were conducted at a pace that fit the needs of the participant, and were up to 90 minutes in duration. Participants were interviewed either in a private conference area at the University of British Columbia (UBC), at a location convenient for them, or by telephone. When the interview was conducted offsite, such as in a participant's home, a research colleague accompanied me. Other locations were coffee shops, the participant's

place of employment and, in one case, a community centre. Three interviews were conducted over the telephone following procedures for directed conversations described by Lofland & Lofland (1995) and Kvale & Brinkmann (2009).

All interviews were audio recorded. Throughout the course of the interview, participants were invited to recount and elaborate on the story of their CNMP, with a particular emphasis on how pain affects their everyday interactions, trust relationships with health care providers and others, and attitudes toward various forms of treatment. At the completion of the interview, all participants received a \$10 gift card to a coffee shop. Transcripts were deidentified immediately after the interviews.

5.4.3 Feedback group guides

The same process was applied to develop the feedback group guides as for the interview guides (see, APPENDICES A and D) and they were developed, vetted, and refined with the PhD supervisory committee and associated experts.

5.4.4 Feedback groups

Two feedback groups were conducted to collect different types of information. One group comprised a sample of interview participants and the second group comprised physicians who care for patients with CNMP and addictions. Feedback groups are considered a form of member checking or respondent validation (Lincoln & Guba, 1985) that enable the researcher to refine data analytic categories and minimize misinterpretation. The goal of member checking is not to obtain objective truth, but rather analytic depth and accuracy. It further allows participants to be involved in the process of reflection, ethical deliberation, and analysis (Widdershoven, Abma, & Molewijk, 2009). It is a process of co-constructing data, consistent with constructivist and interpretivist research methods. In keeping with Morgan (1997), a small sample was assembled for each group, as “small groups are more useful when the researcher desires a clear sense of each participant’s reaction to a topic” (p. 42).

5.4.4.1 Patient group

A feedback group of $n = 4$ patient participants was conducted after all the patient interviews were completed. They formed a post-interview, self-selected group. Participants were invited to an hour-long feedback group in a private conference room at UBC. They were asked to provide reactions individually to descriptions of the emerging themes of the study presented by the candidate, and then engaged in dialogue with the other participants. I facilitated the patient feedback groups and a research assistant documented field notes. At the completion of the patient feedback group, participants received a \$10 gift card to a coffee shop, and were compensated \$5 to cover the costs of transportation.

5.4.4.2 Physician group

To capture the health care provider side of the patient-provider dyad, a feedback group of $n = 6$ physicians who care for patients with CNMP and addictions was conducted. The physicians who were invited to participate in the feedback group were drawn from the research team's professional network. Physicians were invited by phone or email, which included a pre-defined phone script describing the purpose of the study and feedback group, the date and time, and contact information for follow up (APPENDIX D). I presented the patient themes, based on the patient interviews and the patient feedback group, to the physician group. The physician group responses were then used to further refine the patient themes. The resulting four patient themes are presented in CHAPTER 6: FINDINGS. The physician feedback group was carried out in keeping with principles of emergent design, a common practice in qualitative research (Lincoln & Guba, 1985), which allows for refinement to a study as the research unfolds, including additional data collection and analysis.

The same procedure was followed for the physician group as for the patient group, except that the thesis supervisor and co-supervisor served as additional note-takers and observers. The physician participants received lunch in appreciation for their time and expertise.

5.5 Analysis

The specific goal of the data analysis was to explore the role of trust in the experience of CNMP management from the perspective of the patient. The broader analytic goal was to understand the ways in which participants experience and understand their situations and apply the various aspects of the experiences with meaning (Charmaz, 2006; Charmaz & Belgrave, 2012). Thus, the approach is to synthesize narrative fragments of multiple interviews to generate a collective story, in this case, of trust in the experience of the therapeutic relationship and CNMP (Charmaz, 2006; Charmaz & Belgrave, 2012). The final analysis synthesized the interview data generated from both the purposeful and theoretical sampling phases of the study.

Interview transcriptions and analysis were managed in the qualitative data software program NVIVO 9 (QSR International, 2012). Analysis began as soon as data were collected and was an ongoing process as new interviews were conducted. Emerging concepts were incorporated into each ensuing interview (Charmaz, 2006).

5.5.1 Coding procedures

5.5.1.1 Open coding

I engaged the three inductive phases of grounded theory to fluidly code the data as the method dictates: initial (or open) coding, focused coding, and axial coding. These phases move from a detailed level of analysis to more conceptual integration (Bryant & Charmaz, 2007; Spencer, Ritchie, & O'Connor, 2003; Please see FIGURE 2 below). The process of coding “involves interacting with the data (analysis) using techniques such as asking questions about the data, making comparisons between data...deriving concepts to stand for those data, then developing those concepts in terms of their properties and dimensions” (Corbin & Strauss, 2008, p. 66).

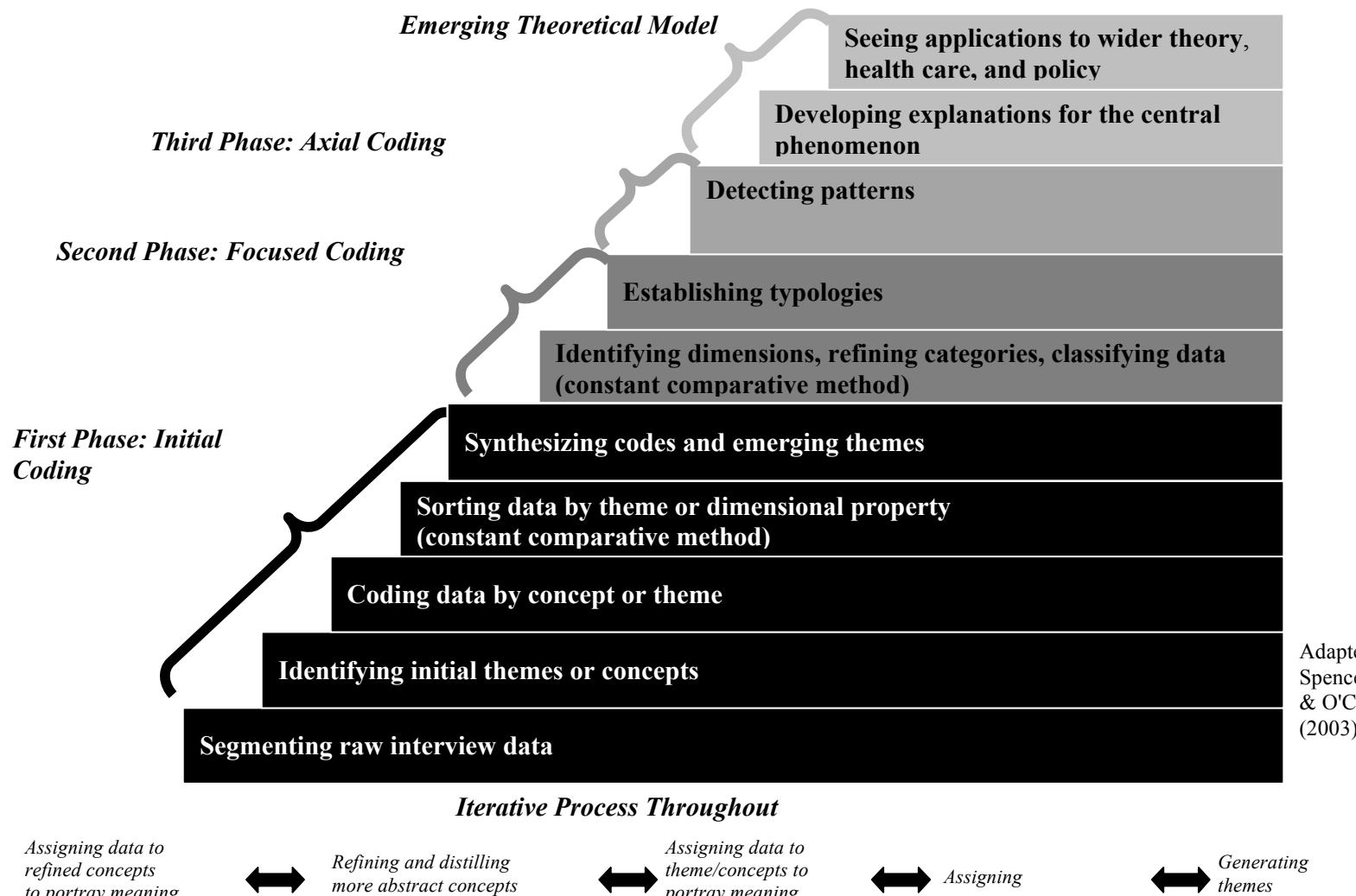
During the initial analytic phase, I undertook a close reading of the data: listening to the recordings, reading the transcript of an interview several times to become familiar with the interview, and open coding. In this phase, a second coder also worked in parallel with but

also independently from me to segment the raw data into broad thematic categories. We then further independently approached the transcript word-by-word, creating *in vivo* codes where useful (Charmaz, 2006). These codes “preserve participants’ meanings of their views and actions in the coding itself” (Charmaz, 2006, p. 55).

Open codes in the initial analytic phase are intended to be provisional, but they are supported by evidence from the text, explain ongoing interpretations, and are relevant to the core themes (Charmaz, 2006; Glaser & Strauss, 1967). The categories may also have sub-categories, or dimensional properties that represent multiple aspects of each category. We utilized the constant comparative method to attend to the interrelationship between emergent categories and other information (e.g., instances, events, theoretical propositions; Glaser & Strauss, 1967; Charmaz, 2006). Theoretical saturation was achieved when all categories were fully developed in terms of properties, dimensions, and variations (Corbin & Strauss, 2008; Creswell, 2007) and no new themes emerged.

After the initial open coding phase, the two coders compared analyses and disagreements, and then came to a consensus on the initial codes. The thesis supervisors were available to adjudicate any enduring disagreement, but this option was never needed. Consensus helped set the stage for further phases, as the coders achieved consistency in the approach to the analysis. The grounded theory also emerged in this early phase of analysis through the process of memoing, which links analytic notes such as emerging thoughts, ideas, queries, and preliminary propositions about the developing theory throughout the coding process (Charmaz, 2006; Corbin & Strauss, 1990; Lempert, 2007). As a narrative tool, memoing actively situates the researcher in the analyses (Charmaz, 2006; Corbin & Strauss, 1990).

Figure 2: Process of grounded theory data analysis



5.5.1.2 Focused coding

During the focused coding stage of analysis, I determined which codes were analytically salient on the basis of the most significant initial codes and categorized them in larger thematic chunks (FIGURE 2). Through this process, I developed a collective story from the interrelationships of initial codes and questioned such interrelationships (Charmaz, 2006; Corbin & Strauss, 2008; Creswell, 2007). Through the constant comparative method, I separated and synthesized the large volume of data into a conditional matrix (Charmaz, 2006). This process leads to a visualization of the central phenomenon—a category that holds the most conceptual salience by virtue of its prominence across all interviews. The most saturated theme was then put in the context of other thematic categories emerging from the data, and discourse in the literature.

5.5.1.3 Axial coding

Axial coding relates categories to subcategories and brings segmented data back together with the goal of describing the studied experience more in-depth (Charmaz, 2006). The procedure involves the selection of one of the open coding categories and positioning it within a visual model or figure. For the purposes of this study, I placed the central phenomenon of perceived distrust identified in the previous analytic phase and explored causal conditions (categories of conditions that cause perceived distrust), actions/interactions (how participants respond to issues, events, or problems), and consequences (what happens based on the outcomes of the actions and interactions) (Corbin & Strauss, 1990, 2008; Creswell, 2007).

Transcripts for the feedback group were analyzed using the constant comparative method of grounded theory (Charmaz, 2006; Glaser & Strauss, 1967). The analysis of the patient feedback group was incorporated into the findings from that group.

5.6 Rigour

Qualitative methods require that a researcher pursue and report rigour by implementing several approaches and/or demonstrating certain values throughout the research process

(Davies & Dodd, 2002; Krefting, 1991). To meet this requirement, I engaged a second coder for data analysis. Multiple coders provide a mechanism for crosschecking coding strategies and interpretation of results (Barbour, 2001; Lincoln & Guba, 1985). The replication of results by independent researchers or inter-rater reliability is not the main analytic objective. Rather, multiple coders provide a platform for discussion through the examination and discussion of competing explanations, and interpretations, and eventually consensus. I also used member checking or respondent validation to verify the findings. Finally, the physician feedback group served as a mechanism for data triangulation, through which a validation of the convergence of the data, analysis, and conclusions was tested (Denzin, 1989).

5.7 Research ethics

The study adhered to the recommendations provided by the 2nd edition of the *Tri-Council Policy Statement* on ethical conduct for research involving humans (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010), and the protocol for conducting research at Vancouver Coastal Health Research Institute. Consultation with appropriate health care facilities and units took place prior to participant recruitment. Behavioural research ethics board (BREB) approval was obtained from the UBC, and institutional approval was gained from the Vancouver Coastal Health Research Institute.

Each participant was assigned an alphanumeric code, which was kept separate from their data, and which was viewed and listened to only by members of the research team. Hard copies of the transcripts and audio files were kept in a locked cabinet in the office of Dr. Illes, the Principal Investigator. Given that a discussion of their CNMP experiences could have been distressing for some participants, information about supportive services was made available at the time of the interview, or sent to the participant in advance. Additionally, because individuals living with CNMP often face barriers in accessing treatment, a list of online and local resources was provided to access services for healthcare, mental illness, addiction, and CNMP.

Chapter 6: Findings

6.1 Demographics of the participants

6.1.1 Individual patient interviews

Twenty-seven interviews with 17 women and 10 men were conducted between March 2012 and October 2012. TABLE 1 presents the sample characteristics of these patients.

Fourteen participants self-identified as belonging to two or more sociocultural and ethnic backgrounds, eight as Canadian, European descent or White, and three identified as Aboriginal. One individual self-identified as Métis. Two participants declined to answer this question. The average age was 54.3 years with standard deviation (*SD*) of 7.31, ranging from 36 years to 63 years. Eight participants achieved a professional or graduate-level degree, five obtained an undergraduate university degree or college diploma, nine participants completed some college or university courses, one participant completed high school, and four did not complete high school.

Participants reported living with CNMP for a mean of 14.4 years with a *SD* of 11.31, ranging from two years to 45 years. They reported receiving care from their current primary care provider for a mean of 6.1 years with a *SD* of 5.34, ranging from one year to 25 years.

Fourteen participants indicated a history of at least one mental health problem. Participants had the option of reporting multiple mental health problems. Depression was reported by eight participants, anxiety was reported by four participants, and bipolar disorder was reported by three participants. Participants had the option of reporting a history of multiple drug use problems. Ten participants reported a history of problem use of at least one drug. Six participants reported a history of problems with cocaine/crack cocaine, five with alcohol, five with cannabis, five with heroin, and four identified problems with other drugs such as morphine, methadone, tobacco, and lysergic acid diethylamide (LSD).

The mean Pain Severity Score on the BPI-SF was 5.5, with a *SD* of 2.02. The mean Pain Interference Score was 6.4, with a *SD* of 1.9. These scores indicate that participants' pain falls within the moderate pain range.

6.1.2 Patient feedback group

Of the patient interview pool, four participated in the feedback group. The participants were all women. The average age was 56.5 years, ranging from 53 to 59 years. Two participants were employed full-time, and two were unemployed. The unemployed participants were receiving BC Employment Assistance, and Provincial Disability payments, respectively. One participant attended some college, and two participants achieved a college diploma; one achieved a Master's degree. None reported problems with drug use; three reported a history of mental illness. Participants had been receiving treatment for their pain from their current primary care provider for an average of 11.25 years, ranging from two to 25 years, and reported living with CNMP for an average of 17.5 years, ranging from seven to 25 years.

6.1.3 Physician feedback group

Five men and one woman participated in the physician feedback group, representing the specialties of family medicine (n=1), internal medicine (n=2), and psychiatry (n=3). All physicians have experience treating patients with both CNMP and addictions, and were on staff at the same large urban hospital in the lower mainland of British Columbia.

Table 1***Patient sample characteristics***

Variable	Total
Gender (n=27)	
Female	17
Male	10
Employment status (n=27)	
Unemployed	15
Full-time	9
Retired	3
Relationship status (n=27)	
Single	11
Common-law or married	8
Separated or divorced	5
In a relationship	3
Highest level of education achieved (n=27)	
Professional or graduate degree	8
University degree or college diploma	5
Some college or university	9
High school diploma	1
Some high school	4
Age (M, SD) (n=26)[^]	54.3 (7.31)
Sociocultural and ethnic background (n=25)	
Multiple or other	14
Canadian, European descent, or White	8
Aboriginal	3
Years with chronic pain (n= 26)* (M, SD)	14.4 (11.31)
Years with current primary care provider (n=24)[§] (M, SD)	6.1 (5.34)
Personal history of drug use problems (positive) (n=26)	10
Personal history of mental health problems (positive) (n=24)	14
Family history of drug use problems (positive) (n=24)	10
Family history of mental health problems (positive) (n=21)	8

Total n in parentheses reflects the number of responders. When n < 27, the remaining participants declined to answer the question.

[^]n=1 participant did not respond to the question, but met the age criterion for inclusion in pre-interview screening.

*n=1 participant did not respond to the question, but met the CNMP criterion for inclusion in pre-interview screening.

[§]n=2 participants did not respond to the question, but met the established relationship with a primary care physician criterion for inclusion in pre-interview screening.

6.2 Recordings

Approximately 29 hours of qualitative data were obtained for analysis across all interviews and feedback groups.

6.3 Patient interview findings

Four themes emerged directly from the analysis of the semi-structured interviews and patient feedback group, and reflect the dimensions that influence trust in CNMP from the perspective of the patients: (1) fidelity and iatrogenic suffering; (2) communicating the invisible and subjective condition of chronic pain; (3) motive, honesty, and testimony; and (4) stigmatized identities. The themes, and sub-themes where relevant, are presented in the order of their prominence based on theoretical saturation. All participant names have been changed to pseudonyms here. Gender was preserved for reporting.

6.3.1 Theme (1): Fidelity and iatrogenic suffering

The first theme reveals situations in which patient participants believed that their best interests were not respected. This dominant theme was raised by 85% (n=23) of the patient interview participants, and was also a theme discussed in the patient feedback group. For many participants, when trust in the therapeutic relationship was threatened, iatrogenic suffering followed and the vulnerability of the patient increased. The concept of iatrogenic suffering relates to the unintentional harm that can result from negative interactions between providers and patients (Kuhl 2002). In the context of the present findings, both fidelity and iatrogenic suffering influences trust in the therapeutic dyad in terms of how patients perceived the interpersonal competence of the health care provider.

6.3.1.1 Threats to fidelity in CNMP management

Threats to fidelity in the context of CNMP management were reported in the form of perceived abandonment, lack of care, empathy, and respect. For example, participant

EDMUND found it difficult to accept the statement from his family doctor that nothing could be done to address the needs of his chronic back pain:

EDMUND: I found that my family doctor for a while, I was going every month, and she was like, ‘There’s nothing I can do’... it’s hard to believe that a doctor would run out of options.

EDMUND described that when his family doctor told him “there’s nothing I can do,” he interpreted this statement as, “there is nothing I intend to do”. He recounted that this caused him to feel emotionally abandoned by his physician, itself a perceived injury to the trust relationship. EDMUND further suggested that his physician’s perceived indifference was a way for his physician to avoid dealing with the CNMP she did not feel competent to address:

EDMUND: So, I think she’s over, maybe, her knowledge or what she knows.

Accordingly, EDMUND believed that his provider did not have the competence to address his pain or the interest in promoting what matters to him in the context of his suffering.

Several other participants also perceived a lack of empathy and recognition from their health care providers. SUSAN recounted how she believed her primary care physician repeatedly ignored her when she went to his office for an appointment:

SUSAN: You could just tell that he just didn’t believe me that I was in as much pain as I was. He was just very unsympathetic. He would literally walk away while I was in the middle of a sentence. Literally [laughs], you know?

For participants such as SUSAN, the sense of being ignored exacerbated her pain and suffering.

HANNAH, a young Aboriginal woman who lives with multiple pain concerns and reported a history of intravenous (IV) heroin use, recalled several encounters with her health care providers when she requested prescription analgesics and was refused. She believed that her medical needs were not seen as important:

DANIEL: And when you ask for certain medications the doctors won't ... ?

HANNAH: They just look at me, laugh, and say no.

DANIEL: No? How does that make you feel?

HANNAH: Mad and angry, you know, like they, they expect me to live like this, even though I didn't ask to be born like this and I didn't ask to be hit by any types of vehicles. I always tell them, imagine being put in my shoes, being hit by two cars and being born with minor scoliosis. Can we trade shoes for a day [laughs]?

The colloquial phrase, “put yourself in my shoes,” has important moral overtones in terms of empathy. HANNAH described that the negative stereotype of a drug-using Aboriginal person makes her seem untrustworthy to health care providers. She believed that this compromises caring and respect, and leads to inadequate treatment.

Both SUSAN and HANNAH expressed feeling disrespected in these interactions: SUSAN's, “he would literally walk away,” and HANNAH's, “they just look at me, laugh.” From their perspective, the failure to be recognized for their vulnerability was a threat to the fidelity of the therapeutic relationship.

Participant PATRICIA offered a counter-narrative to many of the participants in this study with respect to fidelity and trust. She believed her doctor communicated that he trusted her by conveying empathy and belief in her pain experiences:

PATRICIA: My doc is really great, you know, and he has been very empathetic. He believes that I have pain. He's been there all the way for me. And, you know, even when I go in for my flare-ups he'll go, “Do you need to be off work? Are you okay?” Like, just like that! Bam ... And so he's a – and I know you're going to blur this out – but he's the director of a regional for palliative care, so he knows about pain, [laugh] right. So, he's a really good doc actually, yeah.

The positive therapeutic relationship recounted by PATRICIA reflects her trust in her physician's technical competence—“he knows about pain”—his expertise “he's the director of a regional for palliative care”—and his interpersonal competence to how he conveys empathy and belief in her testimony.

SUSAN also felt that her physician trusted her because her physician assumes good will in their therapeutic relationship:

SUSAN: I've come to really appreciate her [my physician] ... And she trusts me, you know? Like, she'll give me a large bottle of Ativan 'cause she just knows I'm not going to take a lot, right? She deals with you on...deals with people on a[n] individual basis, whereas these pharmacists up here go, like, 'Well, we have on our records that you have three pills left, so we won't fill this prescription.' I mean, come on, right?

In situations such as this, and like the one PATRICIA describes above, trust in the therapeutic relationship is directly related to trust that patients feel physicians display about their ability to self-manage medications that have a high abuse potential.

6.3.1.2 Iatrogenic suffering

NELL expressed how she perceived that her health care providers failed to imagine her experience from her perspective and respond empathically. NELL told a story about a recent experience at her community health centre that may be described as iatrogenic suffering:

NELL: I would walk in crying about my body, about my pain, about the swelling of my body, about how painful it was, and they [doctors, nurses, social workers] would chitchat, move, you know, go back to whatever room they'd go back to and come back and say, 'Yeah, well, we'll see you next week.' What? ... is there nothing you ... like, is there any other kind of painkiller you can...is there something else you can give me that I don't have to feel this wrecked, this emotional, debilitating, void, dark?

Like EDMUND, NELL described the sense of abandonment as a key piece in her suffering; she described feeling ignored when her health care providers told her they did not have any more treatment options. Similar to SUSAN and HANNAH'S narratives, NELL indicated that she did not believe that her health care providers recognized her suffering and she desired to pursue what mattered to her, that is, emotional and medical support for relief of her pain and suffering.

MARIAN reported how similar interactions with her providers threatened her well-being and worsened her suffering. This, in turn, eroded her trust in the medical profession:

MARIAN: It's demoralizing, it's demoralizing. I get to the point where I have distrust for people in authority, for the medical profession ... I get into a funk that might be called depression or anxiety, but I call it, I get contemptuous.

JEAN-PAUL's sense of vulnerability was related to the unavoidable dependency on his health care provider that he described, and his perception of how he was treated during clinical appointments. He described an encounter with his physician during which he was told that if he came back too early for a prescription refill he would be banned from the clinic. JEAN-PAUL referred to this experience as abuse:

JEAN-PAUL: It was probably the most stressful thing I've been through in my life ... What form of abuse am I going to get [today]? And you don't expect to be helped, and that starts to really get to you ... I felt hopeless, like I was never, ever going to get better.

JEAN-PAUL, who has a history of addiction to alcohol and prescription medications, provided long statements about how he had no choice but to stay with this physician because all the others had fired him as a patient. JEAN-PAUL did not trust his current physician because he did not believe that his physician would do whatever was necessary to help him get the care he believed he needed. The experience of distrust contributed to his suffering. In order to protect himself from this sense of abuse, and minimize the impact of his suffering, JEAN-PAUL reluctantly accepted that he needed to rely on his physician, even though he did not trust him.

6.3.2 Theme (2): Communicating the invisible and subjective condition of chronic pain

Communicating the experience of CNMP as an invisible, subjective condition was the second dominant theme that emerged from the analysis of the semi-structured interviews and patient feedback group. The second theme was discussed by 56% (n=15) of the patient interview participants, as well as by members of the feedback group. It describes how participants perceived the ways in which their health care providers evaluated their ability to communicate their pain needs, namely to convince their providers of the legitimacy of their pain. The ability to communicate the subjective pain experience is related to the perceived trust that providers place in their patient's character, and the level of competence they attribute to their patient's ability to self-assess. Participants such as BERTRAND spoke directly about this commonly described phenomenon:

BERTRAND: You know what, [when] a person actually is in pain, he knows himself ... you know, you can't read a book by its cover.

The challenge to communicate the legitimacy of the pain experience is compounded by its sheer invisible nature, which contributes to suspicion by others that the pain may not exist:

PHILIPPA: I think one of the hardest things with chronic low back pain is people don't understand what they can't see. It's so hard. It's so difficult.

FRIEDRICH had similar sentiments to PHILIPPA, and compared the pain he experiences from his visibly severed finger lost in a work accident, to his invisible chronic low back pain that lacks identifiable pathology:

FRIEDRICH: ... [it's] the visual aspect of things, they see the finger gone. It's gone. It's easy, you know, it's not there no more. But they don't see the injuries in my back, you know what I mean? I try to explain that to them and then just, like, they just pass it off ... if people don't see it, they don't recognize it.

The narratives of participants such as PHILIPPA and FRIEDRICH suggest that the absence of a visible condition puts them in a disadvantaged position when they tell their stories of pain and suffering. PHILIPPA reported that family, friends, and her health care providers often accused her of exaggerating her pain, whereas FRIEDRICH felt that his employer did not believe that he was in as much pain as he claimed.

Part of both the invisibility and subjectivity of pain is that language to describe it can be elusive. ELISABETH described this challenge as a language barrier:

ELISABETH: I think it's like a whole language barrier thing ... you don't know you have this chronic pain syndrome, and you don't have language ... like you asked me for a metaphor and I couldn't give you one.

EDMUND also conveyed his frustrations about the language of pain:

EDMUND: I want to believe that she [my physician] knows [laughs] what kind of pain I am in. That's why she keeps prescribing the pills. But, I mean ... if I could convince her that my pain is ... where my pain is and if I could explain it better ...

ELAINE reported that her physician was discounting her story and her experience. ELAINE stated that she was frustrated that she could not convince her physician that she was in pain and was experiencing great suffering:

ELAINE: Last time I went to the doctor, I just put my hands up in the air and I said, I don't even know what to say for myself anymore 'cause I don't know how to get heard.

ELAINE's perception that she was not heard caused her to feel silenced when interacting with health care providers unless she gave her providers the answers that they expected. She did not believe her provider trusted her ability to articulate or even understand her pain needs:

ELAINE: Doesn't matter how I speak it out, they have their own opinion ... even I had a doctor tell me that some of the tests that he saw, 'Well, that doesn't hurt.' Well, it does hurt. I'm in pain. 'No, you're not in pain.'

Participants also often described that they felt dismissed as malingeringers, or accused of experiencing psychogenic pain. EMMA recounted a story to this effect about her mother who also experiences CNMP:

EMMA: I know cases that doctors think [pain] is psychological. Oh yes, heard many times.

DANIEL: What do you mean?

EMMA: Doctors think it's psychosomatic ... My mother, doctors didn't believe her. They said it's psychological. And she went to one place and the doctor just gives her a bang on her back or something.

PHILIPPA reported that she has struggled for years to convince her primary care physician that she was experiencing excruciating chronic low back pain that was not responding to any treatments. PHILIPPA stated that she would request diagnostic investigations each time she went for a clinical appointment, and these requests went ignored for years. It was not until PHILIPPA was to undergo back surgery that a magnetic resonance imaging (MRI) of her lower back indicated sciatica. The MRI made her formerly invisible pain objectively visible, which came as a relief to PHILIPPA because of how her provider responded:

PHILIPPA: That went a long ways for me, that he [my doctor] believed me ... I'd had surgery and it was on the MRI and everything was visible. I felt so much better when that happened. It just sort of reinforced what I guess I believed.

MARIAN reported a positive therapeutic relationship with her physician, and provided a counter-narrative to PHILIPPA. MARIAN spoke about how her physician made her pain visible and legitimate in a way that was not dependent on medical technology:

MARIAN: So [pain is] not something that people don't see. The presentation of pain is there. Certainly, Dr. S, in 2005, was the first person to legitimize that it was a physical pain. It was not imagined. He explained it to me. He explained that I had to go to these special physiotherapist sessions. It had weakened my core and my pelvic floor.

For MARIAN, the experience of pain was legitimized and linked to her anatomy; she had visible, physical pain and it was real. In that therapeutic relationship, MARIAN also felt validated.

PATRICIA, a health care provider herself, provided a counter-narrative of a different kind. Having received care from her physician for approximately seven years, PATRICIA felt confident that her physician believed that her experience of pain was legitimate:

DANIEL: So, how do you know that he [your physician] believes that you're in pain?

PATRICIA: He just believes me, I don't know, he gives me drugs [laughs], but he knows that I don't really abuse them, you know what I mean? Or at least I don't know I just, I think he believes I'm in pain.

In this context, PATRICIA feels that she does not have to convince her physician that her pain is legitimate. Feeling believed and supported by her physician was a main component of her positive therapeutic relationship, which for PATRICIA was reflected in her physician prescribing her drugs.

6.3.3 Theme (3): Motive, honesty, and testimony

This prominent third theme was raised by 44% (n=12) of patient interview participants, and also discussed in the patient feedback group. The third theme reflects situations where participants believed that their health care providers were suspicious of their intentions for seeking care. Participants stated that they were often uncertain as to whether their health care providers believed they were telling the truth about their pain experiences or about aberrant addiction-related behaviours. The participants, from whom the quotes were drawn for this section, all reported a history of drug use.

6.3.3.1 Motive and honesty

Participants described the sense that they were perceived as untrustworthy when they were accused by their health providers of lying, being dishonest about treatment adherence, or of promulgating falsehoods. For many participants, accusations were related to motives for seeking care:

DANIEL: So, how do you feel when you get a letter that says you're drug-seeking, double-doctoring?

SIMONE: Horrible, outraged, just humiliated. You know, it's being falsely accused is one of the worst feelings you can have, you know, to be—to be accused of doing something you not only didn't do, but so vehemently believe is wrong, that's not you ... And you just become so outraged. But then you can't stay in a state of outrage. So you become depressed, humiliated, beaten down completely—that's it. Those are the three words that sum it up.

Like many participants in the study, LUDWIG's story demonstrated that health care providers are often skeptical about patients' treatment-seeking motives. This particular patient participant attributed the accusation to prejudices toward people addicted to illegal or prescription drugs:

LUDWIG: When I was in [hospital] just a couple of weeks ago for a pretty severe infection, the ambulance drivers just took one look at me and it was, like—the look in their eyes was like, 'Oh, he's just a junkie looking to get stoned.' They didn't believe that I was actually suffering and in pain. They thought I was faking it completely ... I was actually pissing blood, and I was

in severe pain, but for over an hour, they left me in that pain before they injected me with medications to control the pain that I was in. For that extra hour, I was forced to suffer in Emergency before they would give me any pain medication.

MARTHA, a participant with an addiction to alcohol and who lives in one of Vancouver's lowest-income neighbourhoods, also believed that health care providers did not always take her to be honest about her treatment intentions:

DANIEL: And what is it like discussing your pain with your doctor?

MARTHA: I think he listens to it and then ignores what I have got to say about it.

DANIEL: So, why would he ignore it?

MARTHA: I just feel like he don't think I'm telling the truth, or I'm looking for something.

MARTHA'S "something" was prescription opioids.

Similar to LUDWIG, JEREMY, a self-reported cannabis and crack cocaine user living in subsidized housing, recognized the sense that health providers found him untrustworthy because of his poverty, pain, and drug addictions. He recalled an encounter when his physician refused to believe he was telling the truth about his Oxycontin use, and accused him of medication diversion:

JEREMY: It [Oxycontin] does nothing. So I wasn't taking them, I was just chucking them in the garbage ... I'm going to give them back to him so I won't be accused of putting them on the street. So I got another urinalysis and I said, 'There's nothing in there.' And he [doctor] says, 'You want me to believe you're throwing them in the garbage?' And I said, 'Yeah.' Because that's what I was doing with them. 'Well I wouldn't believe that for a second,' he said ... There's that mistrust, that I might as well be a liar.

JEREMY expressed that he felt mistrusted because his physician did not believe he was telling the truth. During this segment of the interview, JEREMY went over to the cupboard, took out his unopened blister packs of Oxycontin, and put them in front of me on the table:

JEREMY: ... here they are sitting in front of you. Here, I'm not throwing them in the garbage anymore. They're not going on the street. You [physician] can

f***ing have them. And I get so frustrated ... He makes up his mind ... what can I do to convince him?

It was as if JEREMY needed to prove to me, the researcher, that he was not lying about diverting his medication.

6.3.3.2 Credibility of testimony

In other situations, patient participants reported that their credibility as an informant was questioned:

ONORA: If it's a doctor I've never met before who's looking me up and down and going, 'Well I don't, you know, your makeup's on perfect, you're dressed nicely, I don't see any sign of pain. I virtually think you're lying.'

MARIAN echoed similar frustrations in that she believed she was not seen as a trustworthy informant, and that any contributions she made about the direction of her care was seen to lack credibility:

MARIAN: It's like, it doesn't really matter what comes out of my mouth. Really, it doesn't.

Like many participants in this study who reported a history of addiction, IMMANUEL described that he is often treated unfairly when he goes to the emergency room (ER) because of his prior visit history. IMMANUEL admitted that he has a reputation in a particular ER in the Lower Mainland for drug-seeking prescription opioids, but stated that when he is not seeking drugs and does require emergency care, his testimony is not seen as credible. IMMANUEL told a story about a time several years ago when he was escorted from the ER when he presented with a broken jaw after a fight:

DANIEL: Has anything like that happened recently?

IMMANUEL: Every time I go [to the ER] they do the same thing.

DANIEL: So, every time you go to the hospital they kick you out?

IMMANUEL: For this problem ... They don't answer me; just tell me to get the

f***k out ... It is bad, you know, and I f***kin' don't know what to do to tell you the truth.

IMMANUEL's story highlights how a health care provider's evaluation of patient trustworthiness is informed by components such as motive and testimony (Victor & Richeimer, 2005). Based on the information IMMANUEL provided, it is understandable why the ER staff may have been suspicious of his story and how, reciprocally, he felt distrusted by them.

Especially in contexts such as CNMP management where medical uncertainty or ambiguity is a particular challenge, patients may not be seen as credible informants. This materialized for ELAINE, who felt that her opinion and knowledge of her own experiences were not as credible as her physician's:

ELAINE: I think she's [physician] trying—she's trying very hard to work with me. But she still—instead of me being able to say to her, 'Listen, I'm pretty aware and I know what I need.' All doctors tell me what I need ... When I just sat there for an hour telling you what's going on, and then you tell me no, this is what's going on. You know, like, it's depression. No, it's not. I wasn't in this pain before the car accident. I know the pain from the car accident. I know what I've been through. I know how I feel, and I'm tired of them looking at me going, 'No, this is what we're going to do.'

The sub-theme of *credibility of testimony* raises important questions about expertise and what kind of information—and from whom—is considered trustworthy. SUSAN raised questions about the locus of expertise, and asked the ethical question of whose expertise should matter:

SUSAN: People don't want the person who's suffering to be the expert. It seems like whoever's suffered whatever experience, they get to not be the expert ... whether it be chronic pain or PTSD [post-traumatic stress disorder] or child abuse or drug addiction or any of these things, it's always the outsider who gets to be the expert and decide cause and effect and impact and all of this, where obviously, the expert is the person who's been through it, in my opinion.

SUSAN reported that she often found it upsetting that what information she felt she had to contribute to discussions with her health care providers were often dismissed as lacking credibility. Accordingly, she felt distrusted. SUSAN believed that even though she has been

living with CNMP for over five years, she perceived that her health care providers treated her as if she did not have the capacity to make relevant contributions about her CNMP management strategies.

Not all participants expressed the belief that health care providers failed to find their testimony credible. PHILIPPA offered a counter-narrative, and explained that after initially feeling distrusted by her physician, she felt supported by her physician in the face of an disruptive physiotherapist who questioned her credibility as a trustworthy patient. PHILIPPA had been accused of malingering:

PHILIPPA: And then he [the physiotherapist] phoned my doctor and said that I was faking this and that I had done this and—I know my doctor just—he just [pause] fought back at him, or argued with him and told him off ... That, that was not possible and that [pause] ... he just fought for me I would say.

DANIEL: How do you feel about it, that your doctor fought for you?

PHILIPPA: I feel good. I feel good that he believed me ... And that he told this person off ... and said, more or less, ‘How dare you treat my patient like that?’

PHILIPPA reported a positive experience because the person whose expertise mattered—her health care provider—advocated for her and validated her story. In similar situations in which the participants described that providers believed their stories, this belief communicated trust and moral support.

6.3.4 Theme (4): Stigmatized identities

The final dominant theme reflects the implications that stigmatized social identities, such as being an addict or a patient with CNMP, can affect participants’ perceptions of trust relations with health care providers. This theme was discussed by 44% (n=12) of patient interview participants, and was also discussed in the patient feedback group.

MARIAN told her story about the challenges that she and other patients with chronic conditions face when trying to find a family doctor, and how it took several attempts until one family doctor accepted her as a patient. She stated that constantly being turned down by physicians because of her chronic pain disability was a form of stigma and discrimination:

MARIAN: I went to other doctors, and in one situation, there was a sign saying 'New doctor, interviewing patients,' and they're actually interviewing the patients on whether or not they will take them.

DANIEL: Right. Right. Right.

MARIAN: So, I was actually turned down. So, when people say they've been turned down by their doctor, I believe them because I was turned down by three places here.

DANIEL: Because you have chronic pain?

MARIAN: Because I'm a person with disability, and I have chronic conditions of fibromyalgia, um, [inaudible] problems. I'm a chronic patient.

DANIEL: And, so, how do you feel about that?

MARIAN: [Pause] Well, it's a pretty hard situation to be in, and it dismisses you. I must be a fairly hard person. I mean, after all, [laugh] ... Patients, you must have some degree of exaggeration or whatever ... They [physicians] just assume that there must be a problem of some kind and that I must be exaggerating it. And I have to say that I'm not, this is not uncommon, you know, as I got to know other people ... I'm thinking, wow, they were turned down at this clinic too, you know, and, or I will hear about such and such a doctor and his response, and I'm thinking, wow ...

This perceived discrimination affected MARIAN'S global trust in health care providers and the health system.

Participant SIMONE is a person living with chronic low back pain who also has a past history of addiction. She summarized her experience with the imprinting of a double spoiled identity:

SIMONE: If you have ever had an alcohol or drug issue no matter how far in the past it was and how much you dealt with it, if you mention that to any doctor that is dealing with your chronic pain, and your painkillers, they will forever brand you an addict or an alcoholic and in doing so, will completely change the way they approach you with the medicine and their whole attitude and outlook.

Similarly, ELAINE disclosed her frustrations concerning encounters with her health care providers, which she described as stigmatizing. She argued that because she had a past

history of alcoholism and was asking for increasingly higher doses of prescription opioids for pain relief, she was perceived as a relapsed addict who was drug-seeking:

ELAINE: I asked a doctor one time, ‘What am I doing that’s wrong?’ And he says, ‘You present like a drug addict.’ And I’m, like, what? Because of I’m in so [much] pain, I need something to help me. And because of saying that, it makes me a drug addict rather than a woman who’s in pain.

Like SIMONE, what was most troubling for ELAINE was that her presentation as a drug addict was not only a barrier to a trusting relationship with health care providers, but also a barrier to securing what she perceived to be necessary treatment. LUDWIG explains his own experience with perceived stigma and distrust:

LUDWIG: Before I became a drug addict—I guess you would call it now, legalized drug addict—before they started me on the opiates, I didn’t have a real problem in the hospitals. I didn’t have so many bad looks or nurses had no problem walking away leaving stuff in sight. But now that whenever I’m in a doctor’s room, office, or the hospital, it’s like they close the door, they close the drawers, they don’t leave you alone. If they do leave you in alone, they open the door so they can keep an eye on you. Kind of like they don’t trust you anymore.

While identities such as drug addict or pain patient are considered stigmatized identities, the use of certain medications can also be stigmatized. Methadone—a synthetic opioid used to treat CNMP—is stigmatized because of its association with the treatment for heroin addiction:

SIMONE: They [my physicians] tried to get me on a methadone, too, and I just absolutely refused. I said I will suffer to the [umph] before I ever agree to that ... And because once you’re on methadone for chronic pain, you are immediately assumed to be a recovering street heroin addict because so many doctors don’t know it’s for chronic pain ... they think you’re the lowest scum of the earth. So, as soon as you say, ‘I’m on methadone,’ they just freak out.

The stigmatization of methadone use was enough for SIMONE to refuse it as an analgesic for her pain because, like many other participants, associations with a stigmatized identity of a drug addict is connected with being an untrustworthy person.

6.3.5 Summary of findings from the patient participants

The findings from the individual patient interviews combined with the patient feedback group are summarized in TABLE 2 below. Overall, the narratives suggest that the epistemic hierarchy between health care providers and patients has a significant impact on the way that patients are perceived to be trustworthy informants about their pain experiences. In light of this, perceived credibility and trustworthiness is morally important in encounters with health care providers as it mitigates the power dynamic and this hierarchy.

Table 2	Summary
<i>Patient participant themes</i>	
1) Fidelity and iatrogenic suffering	Lack of trust in the interpersonal competence of the provider, and perceived lack of respect for best interests.
2) Communicating the invisible and subjective condition of chronic pain	Perceived tensions between invisible, unobservable pain, subjective experience, and trust in patients' reports.
3) Motive, honesty, and testimony	Perceived suspicions of ulterior motives and dishonesty in seeking care, such as drug-seeking or double-doctoring.
4) Stigmatized identities	Impact of stigma in the interpretation of participant narratives.

6.4 Physician feedback group

The findings from the physician feedback group provide a complementary perspective to those from the individual patient interviews and group feedback. Three dominant themes emerged from the analysis of the reflections of this group on the data acquired from the patients: (1) the challenges of the practice context; (2) central moral obligations; and, (3) challenges to the therapeutic relationship. The findings presented below represent a

synthesized account of the feedback group discussion following the principles of grounded theory described in CHAPTER 5. The themes are presented in their order of prominence in the analysis; specific quotes are drawn from the discussion to highlight the main thematic areas.

6.4.1 Theme (1): Challenges of the practice context

All participating physicians (n=6) highlighted the often adversarial clinical practice context in which care is delivered for patients living with CNMP and addictions. They recalled several difficult interactions and the impact these interactions have on their approach to care:

DR. JOHN: When we talk about as physicians our accumulative experiences, the things that we remember are the times that we got burned, right. And so, because you tend to remember the bad things more, they maintain more prominence and you become more worried about being burned. You may get burned one in 100, but that one in 100 is enough to burn an impression in your mind that makes you wary of all patients potentially.

The metaphor of being burned was frequently used to describe the broad context of CNMP and addiction management, and the worries that physicians shared both about bringing and avoiding iatrogenic harm to patients. Such past negative experiences with certain patients proved to be distressing for physicians, especially when physicians believed they had been doing the best that they could to promote the patient's welfare, but later found out they had been deceived by the patient. The physicians described situations in which patients obtained a prescription for opioids under false pretenses in order to support their addiction or divert medications to others:

DR. PATRICK: Just the being lied to when you really trust a patient and you feel like you're trying to help them. And then you find out that you're being lied to. I had a patient that I saw in residency and a couple of years later saw in the jail and they'd been diverting the medication that my preceptor had been [prescribing]. I had no idea ...

While concerning, it was not necessarily the deception itself that was most distressing to physicians; it was the harm that did or potentially could occur to the patient or others as a result of their decisions.

6.4.2 Theme (2): Central moral obligations

Eighty-three percent (n=5) of physicians emphasized throughout the discussion, that the central moral obligation in medicine is to do no harm to the patient; a duty enshrined in the Hippocratic Oath. However, because of the potential risks of opioid therapy, including harms to others such as medication diversion, physicians stated that their moral obligations to do no harm extend beyond the patient:

DR. PATRICK: When we're prescribing a potentially abusive or divertible medication, our responsibility is not just to that patient, but to anyone else that that drug could be diverted to.

DR. RONALD underscored this point and specified that the patient, the physician, and society are all harmed by untrustworthy patients:

DR. RONALD: What we're talking about here is being burned in the sense that our patient ends up getting really, really sick and that's a problem ... We have a responsibility to be careful with prescribing these medications, so when we get burned, society gets burned, patients get burned, you know.

The other physicians also suggested that because of the power given to them to prescribe potentially harmful substances, they bear an extended obligation to be accountable to both the patients and the communities they serve.

6.4.3 Theme (3): Challenges to the therapeutic relationship

The third dominant theme follows directly from the first two and reflects how the combination of the challenging practice climate of CNMP and addiction management and central moral obligations uniquely influences the therapeutic relationship. All physician participants (n=6) discussed this theme throughout the course of the feedback group.

Physicians in the feedback group did not necessarily see their role as a collaborative partner per the customary model of the physician-patient relationship, but rather in a defensive role of interrogator. They expressed that distrust of patients with CNMP and addiction issues is actually beneficent and justified in that it protects the patient and society from harm:

DR. HENRY: In most doctor/patient relationships we learn to listen to the patient and accept their testimony; there's a dual purpose happening here [when pain medicine is involved] where we have to listen to the patient's testimony, but in some instances, to be quite honest, we are interviewing the patient as if we are a police officer or a lawyer and we're trying to find flaws in their story. And we're looking behind to see what the potential for them telling untruths are. So there is a different relationship here.

Skepticism about the trustworthiness of patient testimony is clearly intertwined with the ontological, moral, and clinical uncertainties surrounding CNMP:

DR. PATRICK: We have all had experiences where patients have been misrepresenting their physical findings and there's been a discrepancy between what they report and what we see. And, unfortunately, it is a very distrustful relationship inherently.

Complicating matters is that the profound subjectivity of pain is often incompatible with the tools of biomedicine. As discussed earlier, the clinicopathological framework that is central to modern health care is the treatment philosophy in which the health care providers were trained:

DR. RENÉ: I feel this as a physician, when I see a patient who has, you know, a pathological fracture on an X-ray ... if there's something objectively definable it does change the way that I approach the patient. And I'm embarrassed to admit that, but I think that it's important that we look at ourselves and recognize that.

Physicians expressed deep uncertainties about the subjectivity of pain, and how they struggle with these uncertainties especially when there is a discrepancy in goals of care and the conditions under which they feel patients ought to be trusted. This phenomenon emerged in narratives that suggested that experiences with untrustworthy patients might translate into a self-distrust of one's own competencies:

DR. JOHN: I've learned not to trust my own interpretations, so I've learned that I'm not always an excellent assessor of the validity of what the patient's telling me.

The consensus among the physician group was that being in a position of personal uncertainty might lead to a disposition of distrust with future patients who display aberrant

behaviours or who are believed to have a history of addiction. The physicians acknowledged that when they found themselves questioning the trustworthiness of the patient's story, they often felt unclear about how to proceed ethically. Working with potentially untrustworthy patients in a contentious practice climate is not a scenario for which the physicians felt they received much education:

DR. HENRY: How do you deal with it when what the patient wants isn't in the patient's best interests, for example, or how do you deal with a situation where you don't trust the patient or have evidence why you should not trust the patient? That's a disruption in the classic patient/physician relationship that ... we have almost no training in.

Several physicians endorsed a no-nonsense attitude when incongruence exists between what the patient desires or believes to be in his or her own best interests (e.g., high dose opioids), and what the physician believes:

DR. RONALD: Every week I deal with somebody, I admit somebody, and literally I have to distrust what they tell me because if I write down on the chart and order what they tell me to order I'll kill them. And doctors have lost their jobs, on my ward, over that issue.

They further described, however, a commitment to be neither antagonistic or to have an adversarial relationship with their patients. Nonetheless, some physicians maintained that an antagonistic attitude might be mitigated by strong, pre-existing trust relationships between patient and physician:

DR. JOHN: I think the other thing that's important is both the patient's perspective and the physician's perspective in these issues is largely affected by what is the nature of the relationship between the two before issues around pain medications is involved. So, if the only interaction with the patient is around pain medication, you don't have a foundation of trust to start with, both from the physician's perspective and from the patient's perspective.

The physicians stated that they are on a firmer ground to discern the trustworthiness of patient testimony if there is an established therapeutic relationship. DR. JOHN elaborated on the "foundation of trust" between patient and physician, calling it a "bank of good will," a metaphor endorsed by members of the feedback group:

DR. JOHN: If you're the family doctor or long-term psychiatrist or internist who's known them [the patient] for 10 years and now they've developed a pain problem, you already have a bank of goodwill both ways.

6.4.4 Summary of findings from the physician participants

The findings of the physician feedback group are summarized in TABLE 3.

Participants in the group were forthcoming about their uncertainties, vulnerabilities, and past challenges when treating patients with both CNMP and addiction issues despite their expertise. The themes highlight the challenging, precarious context in which CNMP and addiction care is delivered, and the challenges they face in terms of fulfilling their ethical duties to promote patient well-being and avoiding harm. The practice climate is one in which physicians must not only prevent harm to the patient, but be accountable to the broader community as well.

Table 3 <i>Physician feedback group themes</i>	Summary
1) Challenges of the practice context	Uncertain context of CNMP management presents challenges to the delivery of care.
2) Central moral obligations	Risks of opioid therapy may harm the patient and potentially others, making it difficult to fulfill ethical duties.
3) Challenges to the therapeutic relationship	Interchanging roles between collaborator to interrogator in the therapeutic relationships.

6.5 Analysis and interpretation

In keeping with grounded theory, the next step in the analysis is to derive a theoretical model based on the findings of the interviews and feedback groups. This model centres on how trust is challenged, and distrust is perceived, unifying the saturated themes in the open and focused coding phases of analysis and the preponderance in the axial coding stage (please see CHAPTER 5). The social processes that underlie the central phenomenon of perceived distrust—perceived identity prejudice and perceived accusations of deception—further support and provide richness to the model.

6.5.1 The central phenomenon of perceived distrust

Perceived distrust in CNMP management explains how participants construct the meanings of their experiences of distrust in their therapeutic relationships. Perceived distrust occurs when the patients perceive: a) a lack of credibility about their stories of pain and suffering by health care providers; b) unfair accusations of being deceptive; c) simultaneous identity prejudice and accusations of deception. Perceived distrust has less to do with narratives of the experience of pain and more about how the patient perceives and negotiates his or her relationships and treatment with health care providers. The phenomenon is associated with patient perceptions of being at a disadvantage with health care providers. This perception may be due to a place of vulnerability: a history of addiction, the need for help to relieve pain and suffering, and lack of medical expertise. The consequences of disadvantage are that the patient may believe that the health care provider does not take reports of pain and suffering seriously or intend to promote their best interests. The findings from the physician participants validate this central phenomenon, and further situate the explanation in the importance of avoiding harm. Such universal precautions for prescribing have been discussed before in the context of pain management (Gourlay, Heit, & Almahrezi, 2005).

6.5.2 Theoretical foundation for perceived distrust

The central phenomenon of perceived distrust in CNMP management shares theoretical foundations with Fricker's (2003, 2007) account of epistemic injustice. Fricker argues that people may be wronged in their capacity as givers of knowledge—informants—and that a distinctive kind of injustice occurs when a listener's (or “hearer's” in Fricker's terms) prejudicial stereotyping causes the listener to attribute a reduced level of credibility to a speaker's testimony than they otherwise would have given. The injustice is particularly concerning when there is insufficient evidence to support an attribution of reduced credibility. For example, a patient is accused of lying about diverting prescribed opioids, despite the lack of evidence that demonstrates that diversion occurred. This unfair accusation is what Fricker refers to as *testimonial injustice*. While Fricker focuses on the harms that the

listener inflicts on the speaker, the model derived from the findings of the present study is concerned with the implications of perceived harms from the perspective of the speaker. The model is not based on any assumptions about whether prejudicial stereotyping or other harms actually occurred in the clinical encounter for patients or physicians who participated in this research.

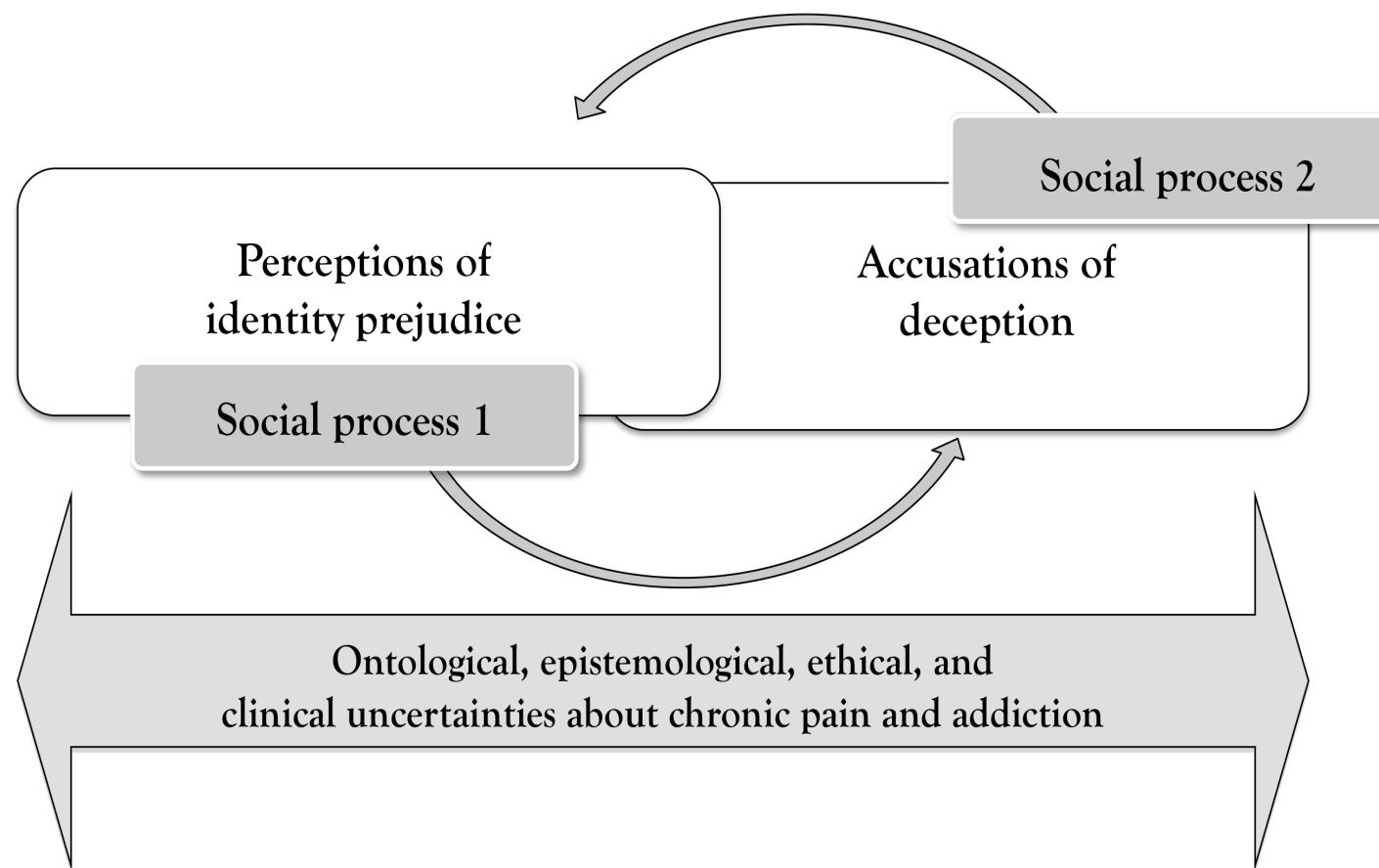
In the context of the findings, patient participants reported that the listener was often but not always a physician, and the speaker (i.e., the informant) was the participant in the role as a patient. In other health care scenarios, the informant may be a family member, friend, or the patient's substitute decision-maker⁹. In the therapeutic dialogue between patient and health care provider, each person adopts the role of listener and speaker. While the discursive exchange is critical to all health care interactions, the analysis indicates how testimony and narrative are central to perceived distrust, especially since CNMP management depends largely on the patient's self-assessment and narrative of symptoms and experiences. From a narrative ethics perspective, patients tell stories as a mechanism to make sense of right or wrong, good or bad, just or unjust in situations that are anything but clear or simple (Brody, 2003; Charon & Montello, 2002). Narrative is ethically important in health care insofar as it is the beginning of the dialogue between patient and provider that forms the moral foundation of the therapeutic relationship (Brody, 2003; Charon, 2006; Frank, 1995).

6.5.3 Social processes underlying perceived distrust

The analysis of patient participant accounts revealed two primary social processes underlying perceived distrust: (a) perceived identity prejudice; and (b) perceived accusations of deception. These social processes may exist independently or in combination (FIGURE 3). They are associated with participant perceptions of injustice and occur in CNMP management, a context shaped by ontological, epistemological, ethical, and clinical uncertainties involving therapeutic relationships that are often considered adversarial (see, e.g., Crowley-Matoka & True, 2012; Jackson, 2005).

⁹ A substitute decision-maker is an individual appointed by the patient or a legal body to give or refuse consent to treatment on behalf of a patient who lacks the capacity to make the treatment decision.

Figure 3: Relationships between perceptions of identity prejudice and accusations of deception, the two independent social processes underlying perceived distrust in CNMP management. Possibilities for their interaction are illustrated by the overlap of the boxes.



6.5.3.1 Perception of identity prejudice (Social process 1)

The first social process of the model refers to situations in which participants believed that they were not seen as trustworthy because of a prejudice held by the health care provider. Recall the stories by SIMONE, JEREMY, ELAINE, LUDWIG, and others who believed that their social identity as drug addicts caused health care providers to question the credibility of their claims of pain, suffering, intentions, and actions. This perceived identity prejudice (Fricker, 2007) might unfavorably bias the health care provider's judgment of the patient's narrative.

The process of identity prejudice is intertwined with patient *Theme (3): motive, honesty, and testimony*, and *Theme (4): stigmatized identities*. For identity prejudice to occur, heuristics are invoked to assess the trustworthiness of another individual. Heuristics are simple mental strategies that individuals use to scan information in order to make faster and ideally more accurate decisions, particularly in cases where uncertainty exists (Tversky & Kahneman, 1974). In the present study, patient participants perceived that identity prejudice occurred in absence of evidence of past untrustworthiness. This component of the model mainly applies to the perceptions of patients from socially disenfranchised groups, especially those living with mental illness and addictions. Patients who are members of these disenfranchised groups have various stigmas, negative attitudes, and assumptions directed toward them, and have historically been excluded from meaningful dialogue with health care providers because their narratives have been seen as lacking credibility or untrustworthy (Goffman, 1963). The adversarial interactions further influence distrust in therapeutic encounters and may reflect tensions that relate to the notion of social hierarchy. For example, there may be tensions related to the social hierarchy between health care providers and patients from socially disenfranchised groups, as such groups typically share different socioeconomic backgrounds from each other (Crowley-Matoka, Saha, Dobscha, & Burgess, 2009).

Identity prejudice is closely aligned with stigma, and stigma is known to be a barrier to adequate forms of pain relief (Shah & Diwan, 2010). CNMP becomes part of a stigmatized identity because of the association of CNMP with undesirable stereotypes such as being

disabled, lazy, attention seeking, and often having medically unexplained symptoms (Holloway, Sofaer-Bennett, & Walker, 2007; Jackson, 1992; Slade, Molloy, & Keating, 2009). The stigmatized social identity of the addicted person is one who is weak-willed, out of control, untrustworthy, non-adherent, and socially deviant (Keane, 2002; Reith, 2004). Indeed, being addicted to drugs is seen as being more blameworthy for symptoms when compared to people diagnosed with other illnesses (Corrigan, Kuwabara, & O'Shaghnessy, 2009). Addicted individuals are frequently subjected to negative social attitudes across a variety of social institutions and from various actors within those institutions, including physicians (Baldacchino, et al., 2010; Meltzer, et al., 2013). Individuals living with CNMP and addiction often internalize the stigma directed toward them (Lennon, Link, Marbach, & Dohrenwend, 1989; Meldrum, 2011), which suggests that broader social structures inflict a kind of systemic oppression on individual self-identities.

Perceived identity prejudice in CNMP management is supported by past qualitative research associated with trust and integrity of testimony. A study on public trust in health care by Calnan and Sanford (2004) suggests that a major influence of trust in the patient-provider relationship is the patient perception that health care providers take their testimony to be credible. It has been shown previously that not being believed or taken seriously is a common experience among those with CNMP (Clarke & Iphofen, 2005; Jackson, 1992; Osborn & Smith, 1998; Toye & Barker, 2010; Werner, Steihaug, & Malterud, 2003).

Kleinman (1992) writes, what is “[a]bsolute private certainty to the sufferer, pain may become absolute public doubt to the observer. The upshot is often a pervasive distrust that undermines family as well as clinical relationships” (p. 5). A desire to avoid pervasive distrust may be what really matters to patients living with CNMP, as they strive for their claims to be considered trustworthy.

A significant harm that may result from holding and not correcting an identity prejudice is that the health care provider may fail to notice, or may attribute less weight to an important piece of knowledge communicated by the patient. This knowledge may be explicit or enmeshed within the dialogue and go undetected. In some cases, the overlooked knowledge and failure of recognition contributed to the patient *Theme (1): fidelity and iatrogenic suffering*. For this theme, if patients believed that they had been given less credibility than they deserve based on an identity prejudice, patients may feel unfairly

distrusted. The potential practice-based harms of perceived distrust may result in the experience of lower quality care, the failure to have pain and suffering addressed, an inability to enjoy the benefits of a trusting therapeutic relationship, and a barrier to accessing treatment in the future.

6.5.3.2 Perceived accusations of deception (Social process 2)

The second social process described in the theoretical model concerns situations in which patient participants stated that they were unfairly accused of being dishonest and acting deceptively. This component reflects the influence of the history of drug prohibition and the current climate of distrust in which CNMP management operates, as reflected in physician feedback group *Theme (1): challenges of the practice context*. The analysis pinpoints two scenarios where patient participants reported being accused of acting deceptively and how it affected their trust relations with their providers. The first relates to perceived accusations of malingering, and the other relates to perceived accusations of being dishonest about aberrant behaviours associated with addiction, such as drug-seeking and diversion.

Malingering is the “intentional production of false or grossly exaggerated physical or psychological symptoms, motivated by external incentives” (American Psychiatric Association, 2000, p. 683). Such external incentives may include drug-seeking or disability compensation. Patients may be accused of somaticizing, malingering, or faking their pain when they seek monetary compensation for their condition. They can also be accused of malingering when there are suspicions about secondary gain, when the pain is refractory to treatment, or when the patient’s reports of pain and suffering are inconsistent or disproportionate with what is considered a normal response to that particular pain condition.

These tensions may also arise when patient reports of pain are incongruent with the ability of the provider to diagnose the pain. This challenge reflects the epistemic hierarchy between health care providers and patients with CNMP, given that the objective tools of modern health care are considered superior ways of knowing the body and oneself over subjective testimony (Ho, 2011; Jackson, 2011). As Rhodes, McPhillips-Tangum, and Klenk (1999) observe about the problem of the invisible in chronic back pain, “a true representation

of the situation...cannot be trusted to words alone" (p. 1193). Recall those situations in the findings where participants felt that their self-confidence about their experiences was discredited until their reports of pain were deemed proportionate with evidence demonstrating a visible pathology. As a result, the patient may not perceive himself or herself to have the competence to be a legitimate contributor to the decision-making process, including discussions about health care.

Despite the expectation of malingering among some health care providers (Kleinman, 1988; Williams, 2002), the evidence suggests that malingering is not easily detected in the clinical setting due to high false-positive rates (Bianchini, Greve, & Glynn, 2005). Because of the stigma associated with malingering, patients with unexplained chronic low back pain may go to great lengths to avoid the harmful repercussions of this stereotype and avoid being seen as untrustworthy (Toye & Barker, 2010). As mentioned previously, when participants perceive that their credibility has been deflated, they may not necessarily see themselves as moral equals. Accordingly, a deflation in moral status due to an unfair credibility deficit may be perceived as a combined epistemic and moral harm.

Patients may be at risk of bearing a greater burden of the harms from a distrustful therapeutic dialogue, and this is especially true for those with pre-existing vulnerabilities such as addictions. In the case of a patient with a current or past history of addiction, the request for highly addictive pain medications such as opioids may reinforce the stereotype of the deceitful drug-seeker who should not be trusted (Keane, 2002; Fry, 2010; Fry & Buchman, 2012). Drug-seeking is defined as a manipulative behaviour to secure prescribed opioid analgesics to support an existing addiction, abuse medications, or divert to the street (McCaffery, Grimm, Pasero, Ferrell, & Uman, 2005). As Clark and Treisman (2011) state, "[i]n patients with known substance use disorder, continuing complaints of pain are routinely regarded simply as drug-seeking behavior" (p. 2). As represented by ELAINE's and LUDWIG's narratives, the patient with an addiction may come to believe that he or she is not seen as someone who is in pain or suffering, but rather as someone who intends to deceive the provider. Patients with addictions who are actually suffering in pain may be at a double disadvantage by the expectation that their stories raise red flags and should be regarded with suspicion. Recent research with residents in internal medicine suggests that they tend to demonstrate less regard for patients with substance use disorders (Meltzer, et al., 2013), and

that there is a mutual distrust between health care providers and patients addicted to opioids: providers are concerned about being deceived and patients believe that they are badly treated and stigmatized (Butler & Sheridan, 2010; Merrill, Rhodes, Deyo, Marlatt, & Bradley, 2002).

Physicians in the feedback group described cautionary tales of patients who they encountered that intended to deceive them in order to secure access to opioids to support their addiction. This is also a violation of trust in the therapeutic relationship and one that is not always easy to detect (Jung & Reidenberg, 2007). In a study of substance use disorders in patients receiving opioid therapy for CNMP in a primary care setting by Fleming, et al. (2007), 46% of patients with positive toxicology results denied using illegal drugs, even when they were guaranteed anonymity by the researchers. While there may be several explanations for this finding, including that the patients may not have trusted the researchers to keep their remarks confidential, some patients do intend to mislead health care providers. It could be imagined from the perspective of physicians, as described in the feedback group, that trusting the testimony of the patient with a history of addiction may bring about harms to the patient, the physician, and possibly others. For example, the College could reprimand a physician if the physician frequently increases a patient's dose of opioids and the patient tragically overdoses. The physician must decide whether she can trust that the patient is not being deceptive about his pain symptoms, and thereby not taking advantage of the physician who compassionately attends to the patient's pain and suffering.

Starting from a practice philosophy of patient-centred care (Fiscella, et al., 2004), it could be argued that health care providers ought to believe and trust patient narrative and not assume deceptive intentions and untrustworthy testimony until proven otherwise. But, as portrayed in the clinical discourse on CNMP management and the themes from the physician feedback group, the current epistemic and ethical climate in CNMP does not encourage a default disposition of trust. In fact, the context of CNMP management has created a clinical situation where benevolent health care providers are worried about avoiding and bringing about harm to the patient and others, while some physicians are being urged to be on the lookout for deceptive patients (Johnson, 2012). Nonetheless, expecting that patients intend to deceive health care providers could potentially bring about further harms and suffering to the patient. A study by Poole and Craig (1992) demonstrated that health care providers, when primed to expect that patients reporting pain were being deceptive, underestimated the level

of the patient's pain. This context of CNMP management may facilitate interactions in which trust and support are substituted with suspicion, accusation, distrust, and resentment that might make any sort of dialogue based in empathy and compassion unattainable (Kleinman, 1992). The difficult question for health care providers becomes whether the potential increased pain and suffering outweighs the potential benefits of assuming a position of distrust with certain patients and the potential harms a distrustful stance may prevent.

6.5.3.3 Possibilities and implications for the interactions of Social process 1 and Social process 2

The findings suggest that perceived distrust arises from the two social processes, perception of identity prejudice (1), and perceived accusation of deception (2). However, an interaction effect is also possible (FIGURE 3). Interviews from participants HANNAH, ELAINE, and JEREMY provide examples of such cases. HANNAH is an Aboriginal woman with a history of IV drug use and intractable chronic pain; all of which are considered stigmatized identities. HANNAH reported that health care providers systematically dismiss her requests for pharmacological assistance with her pain. She believes this dismissal occurs because of an identity prejudice in which she is assumed to be deceptive: as an Aboriginal IV drug user, HANNAH is presumed to be dishonest about her motives for seeking care (e.g., drug-seeking), and her preferences about what are in her medical interests are presumed to lack credibility as well. Participant ELAINE stated that she did not believe her health care provider took her pain complaints seriously because of her past history of alcoholism and that she was told she presents like a relapsed, drug-seeking addict. Despite reported years of sobriety, the stigmatized identity of an addict was reinforced when she requested opioid analgesics. Accordingly, ELAINE was not seen as trustworthy. She believed that her health care providers did not trust her ability to know what should be in her medical best interests. Participant JEREMY, who reported polydrug use, stated that he was wrongly accused of lying about diverting prescription opioids. He believed he was considered untrustworthy because of a prejudice his physician allegedly held toward drug addicts and those living in poverty. As a result, JEREMY believed his physician did not trust the veracity of his testimony and felt his credibility was deflated. Whether or not HANNAH, ELAINE, and JEREMY actually suffered an

identity prejudice, had ulterior motives in seeking care, or both together cannot be known. Regardless, the narratives they offered provide examples of an interaction of the two social processes, which may have led to a breakdown of trust in the therapeutic relationship.

6.6 Summary

In this chapter, I presented the four main themes that emerged from the individual patient interviews and feedback group, and the three main themes that emerged from the physician feedback group. Consistent with grounded theory analysis, I presented a theoretical model based on these themes. The model centres on the phenomenon of perceived distrust when trust is challenged, and describes two primary social processes underlying perceived distrust: perception of identity prejudice (1) and perceived accusation of deception (2). These social processes are associated with participant perceptions of injustice and undermined credibility in their interactions with health care providers.

Chapter 7: Discussion and conclusions

“*Whatever* matters to human beings, trust is the atmosphere in which it thrives.”

Bok (1999) [emphasis in original].

In this dissertation work, I sought to answer the empirical ethics question: *What is the role of trust in chronic nonmalignant pain (CNMP) management from the patient’s perspective?* In addition, I pursued the answers to four sub-questions:

- 1) How do patients living with CNMP experience trust in their relationships with primary care physicians and specialists?
- 2) Do these patients seek to demonstrate trustworthiness; how do they do so, and why?
- 3) How do patients living with CNMP and receiving primary care and specialist services value trust?
- 4) How do patients living with CNMP understand and describe relationships between CNMP and addiction-related behaviours?

The study built upon past interdisciplinary explorations of CNMP, trust, and addiction and, through in-depth analysis of interviews and feedback from patients and physicians, the findings provide new understandings of the role of trust in the therapeutic relationship in the management of this illness. Overall, they highlight patients’ perceptions both of trustworthiness and challenges to trust in CNMP management. They also highlight the ethical duty that underlies the responses of health care providers to their patients with CNMP, especially when uncertainty exists around the medical and addiction history of the patient or if the provider has been deceived in the past. Distrust is a key moral dimension and arises when patients perceive:

- a) a lack of credibility about their stories of pain and suffering by health care providers;
- b) unfair accusations of being deceptive; or
- c) simultaneous identity prejudice and accusations of deception.

Trust and distrust interactions are further shaped by the health care system in which the relationships are lived, at least insofar as the health care system in which this study was conducted, and by social structural factors. Taken together, such new understandings of the role of trust in the therapeutic interaction in CNMP management can provide a pathway to prevent “distrust [from] becoming the reigning paradigm” (Rich, 2010, p.151).

I discuss the research findings in-depth in the next sections, and situate them in the context of past academic writings as well as contemporary dialogue in pain autopathographies and CNMP blogs. I then discuss the implications of the findings in the context of the broader health care system, describe limitations and areas for future research, and conclude with ideas for how an ethical transformation in CNMP management can involve greater epistemic humility toward improved patient care.

7.1 Situating the findings in the empirical literature

7.1.1 Patient perspectives

Over the last two decades, there has been increasing attention in the empirical literature to patient perspectives that reflect the lived experience of CNMP, and the therapeutic relationship in particular (see, e.g., Toye, Seers, Allcock, et al., 2013). To understand the ethical implications of the findings presented here, it is critical to situate them in this past body of academic work. For example, research on patient-provider interactions in CNMP management has shown that patients struggle to have their pain concerns legitimized by their health care providers, often in response to how the providers convey their beliefs about the legitimacy or severity of the pain (Dewar, Gregg, White, & Lander, 2009; Frantsve & Kerns, 2007; Kleinman, 1992; Lillrank, 2003; Nettleton, 2006; Tait & Chibnall, 1997; Werner & Malterud, 2003). Struggles to demonstrate legitimacy may occur if the patient embraces a biomedical explanatory model about pain while the health care provider adopts a psychogenic perspective (Kenny, 2004). A small qualitative study by Clarke (2008) suggests that patients tend to be relieved when their health care providers accept their stories of pain, and when patients do not have to find additional ways to prove the reality of their pain.

Ethnographic research demonstrates that patients rely on strategies such as embellished descriptions or “social performances” (Brodin, 1992, p. 79) in order to communicate their feelings of demoralization, the legitimacy of their pain, and to establish their competence in self-assessment and self-management (Brodin, 1992; Kleinman, 1988). In order for patients to demonstrate competence, which is a key dimension of trust, they must have effective communication skills (Hall, Dugan, Zheng, & Mishra, 2001). Here, patient interview and feedback group *Theme (2): communicating the invisible and subjective condition of chronic pain*, reifies patients’ concerns about legitimacy, and extends it to encompass trust in their integrity and self-management competencies. It also illuminates the challenges and limitations of language as a tool of expression about the experience of pain that cannot be visualized.

A recent study by Upshur, Bacigalupe, and Luckmann (2010) examined the views of patients with CNMP and their satisfaction with their primary care provider. The authors conducted 17 focus groups with a total of 72 participants. They found that patients with CNMP reported more satisfaction with their provider when they felt that they were listened to and trusted, and they reported less satisfaction when they perceived that they were thought of as drug-seekers or that their pain symptoms were discounted. This latter point is consistent with the combination of *perception of identity prejudice (Social process 1)* and *perceived accusations of deception (Social process 2)*, described in CHAPTER 6.

A phenomenological interview study by Vallerand and Nowak (2009) explored the lived experiences of 22 adults before and after receiving opioid therapy for CNMP. Participants reported a stark contrast between life before and after opioid therapy. Desperation and loss of functioning characterized life before therapy, and a deep appreciation for regained functional capacity and a fear of losing the treatment regimen characterized life after therapy. In a second paper from the same study, Vallerand and Nowak (2010) reported that patients face many hurdles when receiving long-term opioid therapy, which include stigma; attitudinal barriers from family, employers, and colleagues; and health system barriers such as regulatory guidelines and costs of medication and health insurance. The patient narratives reported in *Theme (4): stigmatized identities*, are supported by the findings of the latter Vallerand and Nowak study as they pertain to stigma, and provide a deeper understanding of how stigmatizing experiences influence trust relations.

7.1.2 Health care provider perspectives

While patient accounts have received increased attention in social science research on CNMP, health care provider attitudes in the context of CNMP are less well described. In one study, Rogers (1999) explored perspectives on the moral value of beneficence among 21 general practitioners and 17 patients who reported low back pain. General practitioners identified that acting for the good of the patient—fulfilling the moral duty of beneficence—includes integrating their own professional expertise with the non-medical expertise of patients. Non-medical expertise includes the patient's self-knowledge about his or her own illness experience. The physicians in the feedback of the current study group did not explicitly discuss the duty of beneficence nor did they discuss the non-medical expertise of patients. Rather, as described in physician feedback group *Theme (2): central moral obligations*, physicians stated that their central moral duty was nonmaleficence—the *prima facie* obligation to do no harm to the patient and others.

A recent qualitative study by Matthias, et al. (2010) examined American health care provider perspectives on the patient-physician relationship in CNMP management. Health care providers reported striving for productive patient-provider relationships, but because of various difficulties they encountered caring for patients living with CNMP, their experience was sometimes “frustrating, overwhelming, and ungratifying” (p. 1692). Further, health care providers reported that trust was necessary to a successful therapeutic relationship, and distrust occurred when pain could not be reliably determined, or when patients were suspected of opioid diversion. The themes derived from the physician feedback group, specifically those related to *Theme (1): challenges of the practice context* and *Theme (3): challenges to the therapeutic relationship*, are consistent with the results from the Matthias, et al. (2010) study. A narrative study of Swedish general practitioners' therapeutic relationships with CNMP patients (Kristiansson, Brorsson, Wachtler, and Troein 2011) similarly revealed that physicians attempt to be empathic and to empower their patients, but find it difficult to do so when the patient's pain is unresponsive to different interventions.

When the focus of the therapeutic relationship becomes the misuse or abuse of prescription drugs, health care providers may adopt distrustful attitudes towards patients with

CNMP. In a qualitative study with 19 physicians, Baldacchino, Gilchrist, Fleming, and Bannister (2010) found that physicians were often reluctant to prescribe opioids to patients with a history of substance abuse, fearing addiction, misuse, or medication diversion. Physicians reported that they did not trust their patients, and considered these patients “guilty until proven innocent” (p. 272). Such concerns may be warranted, as a study by Wenghofer, Wilson, Kahan, et al. (2011) found that 42% of primary care physicians in Ontario treated at least one patient who experienced an adverse event related to prescribed opioids in the year prior to completing the survey. Consistent with the themes of the physician feedback group, an ethnographic study by Crowley-Matoka and True (2012) found that physicians narrated “getting burned stories” (p. 702) about their patients with CNMP. Such stories described certain patients who deceived the provider and were able to obtain a prescription for opioids. Situations where health care providers feel deceived may compromise their expressions of empathy (Banja, 2006, 2008) and may lead to a disfavourable attitude toward these patients (Halpern, 2007). The physician feedback group *Theme (2): central moral obligation* findings resonate with those of past studies, and demonstrate their relevance to an entirely new population, that is in an urban cohort serviced by a provincial health care system.

Butler and Sheridan (2010) discovered similar concerns in their qualitative exploration of New Zealand primary care providers and their attitudes toward patients who misused prescription drugs. The authors found that primary care providers tended to stigmatize patients who had a past history of prescription drug abuse, but were more sympathetic to patients who developed iatrogenic prescription over-use problems. In another study (Barry, et al. 2010) using modified grounded theory methods specifically, perceived barriers and facilitators to opioid therapy for CNMP among 23 primary care physicians were explored. The findings suggested that physicians tended to negatively characterize patients with CNMP and addictions, and reported a lack of interest in providing opioid therapy to this population.

7.2 Situating the findings in chronic pain autopathographies and blogs

To better understand the research findings in the context of the broader patient-driven discourse on CNMP, I used an inductive analytic approach characteristic of interpretive description (Thorne, 2008; Thorne, Kirkham, & MacDonald-Emes, 1997) to explore how the findings compare to the experience of trust in CNMP as represented in published CNMP autopathographies and blogs. Autopathographies are autobiographical accounts of the hopes, fears, and anxieties about illness and corresponding treatment (Hawkins, 1999). Consistent with narrative analyses and individual case reports by Dekkers (1998) and Steinhaug and Malterud (2008), I randomly selected five CNMP autopathographies representing 33% of relevant titles from the return of searches on the websites <http://www.amazon.ca> and <http://books.google.ca> using the terms “chronic pain narrative” or “chronic pain autobiography” (TABLE 4). Relevant CNMP blogs were identified through the website BlogRank using the keyword search “pain” and selecting type “blog name” (BlogRank, 2012). I randomly selected five blogs from this pool, representing 14% of relevant titles from the search return (TABLE 5). The search term “trust” was entered into the blog search field to identify relevant entries. The intent here was not to conduct a separate analysis from the interview and feedback groups, but rather to provide extra breadth to the principal methods of inquiry used through collateral sources (Thorne, 2008; Thorne, Kirkham, & MacDonald-Emes, 1997). This type of triangulation in qualitative research can help to facilitate deeper understanding of the phenomena under study (Denzin, 1989).

Table 4

Chronic pain autopathographies reviewed (of 15 relevant titles returned in the searches)	
1	Chronic Pain Anonymous. (2012). <i>Stories of hope: Living in serenity with chronic pain and chronic illness</i> . Scottsdale, AZ: Chronic Pain Anonymous Service Board.
2	Greenhalgh, S. (2001) <i>Under the medical gaze: Facts and fictions of chronic pain</i> . Berkeley, CA: University of California Press.
3	Heshusius, L. (2009). <i>Inside chronic pain: An intimate and critical account</i> . Ithaca, NY: Cornell University Press
4	Levy, Carol Jay. (2003). <i>A pained life: A chronic pain journey</i> . Bloomington, IN: Xlibris.
5	Mager, D. (2013) <i>Some assembly required: A balanced approach to recovery from addiction and chronic pain</i> . Las Vegas, NV: Central Recovery Press.

Table 5***Chronic pain blogs by BlogRank (of 35 returned in the search)***

	Title	Uniform Resource Locator (URL)
1	How to cope with pain	http://www.howtocopewithpain.org/blog/
2	Chronic pain and ramblings	http://chronicpainramblings.blogspot.ca/
3	Dancing with pain	http://dancingwithpain.com/blog/
4	Shauna's life in pain	http://www.shaunaslifeinpain.blogspot.com/
5	Chronic pain journal	http://chronicpainjournal.wordpress.com/

7.2.1 Chronic pain autopathographies

The small sample of autopathographies provided rich insights into the lives of individuals living with CNMP that are consistent with the narratives analyzed for this dissertation. The autopathographies described stories of identity transformation and personal changes before and after the onset of pain (see, specifically, Chronic Pain Anonymous, 2012, Levy, 2003, and Mager, 2013). The authors described how they struggled to convince health care providers, family members, colleagues, and friends that their testimonies were credible, especially when there was no medical explanation for their suffering. Greenhalgh (2001), Heshusius (2009), and Levy (2003) found it difficult to convince others of the legitimacy of their pain, similar to the narratives described by patient *Theme (2): communicating the invisible and subjective condition of chronic pain*. At some point in each authopathography, authors reported feeling stigmatized and distrusted. They reported that their testimonies were frequently dismissed, considered irrelevant, inarticulate, or epistemically inferior to the perspectives of health care providers (Greenhalgh, 2001; Heshusius, 2009; Levy, 2003). Mager (2013) reported internalizing addiction-related stigma, and found that the stigma of his addicted identity strained many of his social and professional relationships, including his interactions with members of the health care system. Such perspectives are consistent with patient *Theme (4): stigmatized identities*.

Themes of health care provider abandonment were common in the autopathographies. Authors described a deep desire for health care providers to partner with them in their pain

and suffering. Some authors trusted their health care providers to promote their well-being, but this trust shifted to mere reliance when the authors' pain and suffering did not improve or when they felt that their health care provider did not respect their medical interests (Greenhalgh, 2001; Heshusius, 2009). Levy (2003) experienced the harms of misplaced trust and lack of informed consent when her surgeon did not adequately disclose the potential risks of an experimental neurosurgery that left her face partially paralyzed. Levy's pain increased and she wrote that she suffered more as a result. The experiences of these authors and their relationships with their health care providers are consistent with the dominant patient *Theme (1): fidelity and iatrogenic suffering*.

Greenhalgh (2001) and Heshusius (2009) reported that they grew to distrust allopathic medicine when interventions failed to relieve their pain and suffering, and described turning to naturopathic and homeopathic remedies. In other autopathographies, hope for recovery followed by intermittent periods of despair was a common thread (Chronic Pain Anonymous, 2012; Levy, 2003). All authors described the medical, social, relational, occupational, and financial hardships they endured—sometimes for decades at a time—in order to achieve a diagnosis. And yet, misdiagnosis was common (Greenhalgh, 2001; Heshusius, 2009; Levy, 2003). Mager (2013) chronicled his recovery from both addiction and CNMP. He described various forms of aberrant addiction-related behaviours such as opioid abuse. Participants in the physician feedback group stated that they have a moral obligation to prevent such behaviours, because of the harm that may come to the patient and potentially others. To fulfill this obligation, the physicians suggested that a disposition of distrust should be adopted with certain patients. These perspectives are described in physician *Theme (2): central moral obligations* and *Theme (3): challenges to the therapeutic relationship*. The way in which these authors negotiated health care provider and health system trust is an implicit thread undergirding all of the autopathographies examined.

7.2.2 *Chronic pain blogs*

Hope was a dominant theme in the CNMP blogs, and, unlike the autopathographies and my research findings, unsympathetic encounters with health care providers and others were not an emphasis. Blogs tended to offer readers strategies for managing pain and relationships

(*How to Cope with Pain, Dancing with Pain*), and provided a space for readers to comment on author (hereinafter, “blogger”) postings. For certain blog entries, bloggers used the online format in a similar manner to the autopathography. For instance, bloggers personally reflected on their pain disability, illness experiences, and the purpose that pain has in their life (*Chronic Pain Journal, Shauna’s Life in Pain*). Bloggers would describe, sometimes in great detail, the impact CNMP has on their health and overall well-being (*Chronic Pain Journal, Dancing with Pain*). Trust was a minor, but still relevant theme. Bloggers wrote about the development of self-trust even in the face of the skepticism of others (*Dancing with Pain, How to Cope with Pain*). Another blogger wrote, “I am too jaded to trust yet another treatment plan” (*Chronic Pain Journal*, February 13, 2013), and yet another reflected on disappointment that her treatments were repeatedly unsuccessful. Finally, in text that truly departed from the narratives collected for this study, two bloggers wrote about a trust in God or a higher power as a pain coping mechanism (*How to Cope with Pain, Chronic Pain Ramblings*).

7.3 Broader social context of health care delivery

7.3.1 Individual patient autonomy, consumer choice models of health care, and trust

In the current study, patient participants tended to equate being perceived as untrustworthy with not receiving expected or requested therapy, namely prescription opioids. When patients perceived that they were accused of being untrustworthy, it was potentially damaging to the therapeutic relationship from the patient’s perspective. One interpretation of this observation is that the delivery of health care in Canada operates within an ethico-legal framework rooted in the primacy of individual autonomy, an important value in North American culture (Sherwin, 1998; Wolpe, 1998). Individual autonomy has had a major influence on the rise of consumer choice models of the therapeutic relationship in North America (Azetsop & Rennie, 2010; Wolpe, 1998). In consumer choice models, health care professionals are considered providers of a health service and patients are consumers of health services. The health care provider gives the patient the relevant information required

for informed consent, and the patient decides the interventions he or she wants the health care provider to deliver (Emanuel & Emanuel, 1992).

Consumer choice models uphold a crude form of respect for autonomy as a primary value assuming that patients have the best knowledge of their own health needs and thus should be allowed to make decisions according to their own values and beliefs (Beauchamp & Childress, 2009). Under this model, patients may presume that their health care providers would trust their health complaints and intentions. The rise of informed consent and consumer choice models in the mid-20th century have constructed the therapeutic relationship as contractual, mimicking the economic transactions of a consumer society (Wolpe, 1998).

Nonetheless, this economic contract model is in tension with the medical profession's social contract with society, where reciprocal obligations and expectations on both medicine and society describe the nature of the relationship (Cruess & Cruess, 2008). Chronic pain management operating within a consumer choice model may put increasing pressure on health care providers to submit to patient demands for high-risk medication regimens such as opioids or invasive surgical procedures, while fearing legal retribution and other health system pressures (Turk & Okifuji, 1997). A consumer choice model that operates within a social system that imposes a high value on respecting patient autonomy may, in some circumstances, conflict with the health care providers' ability to exercise cautious clinical judgment and utilize their expertise to practice according to their professional values (Giordano, 2008; Giordano & Schatman, 2008a).

Consumer choice models of the therapeutic relationship influence perceptions of patient autonomy and trust in another related way. O'Neill (2002a) argues that, since the mid-20th century, patient autonomy and the focus on informed consent have increased at the expense of trust in the therapeutic relationship. Individual patient autonomy is prioritized even when patients are vulnerable and require the help of competent others (O'Neill, 2002a). The rhetoric of patient autonomy under a consumer choice model of health care may have given the impression that patients can request desired interventions from their health care provider or challenge medical authority. However, with the inherent power hierarchy in the therapeutic relationship aside, the *prima facie* duty of nonmaleficence requires health care providers to refrain from providing interventions that they believe to be harmful. As O'Neill (2002a) states, "the autonomous agent is not actually going to be allowed to determine his or

her own treatment” (p. 26). Patients who hold the consumer choice model and forfeit trust in their providers may become dissatisfied with their care if the providers deny their care demands or dismiss their suggestions (Jamison, 2010). In the current study, patients may have interpreted that their providers did not trust them when they rejected their treatment demands for prescription opioids. Even if the provider’s dismissal of the patient’s request came from the well-meaning intention to promote patient welfare, participants may have perceived their providers’ actions to be paternalistic. This may have been the case particularly if the patients thought they were not seen as credible informants and thus were not invited to be part of a collaborative dialogue about their care.

7.3.2 *Clinical objectivity as trustworthiness*

The proposed theoretical model of perceived distrust is situated in a schism between subjectivity and clinical objectivity in CNMP management (Foucault, 1963/2010; Morris, 1998; Rey, 1995; Saint-Maur, 2012). Scheman (2001) argues that objectivity is important for grounding knowledge claims because it provides rational reasons to trust and guidance on what or whom one can wisely trust. Clinical indicators of pathology are considered objective and scientifically authoritative, as they presumably portray a picture of the natural world unbiased by social and cultural factors or the values and interests of the health care provider (Datson & Galison, 2007). The historical subjectivity-objectivity tensions in CNMP management have potential implications on the therapeutic relationship. For example, without clinically objective indicators of CNMP, health care providers may adopt a defensive or acquiescent practice in order to investigate the patients’ history and motives before placing trust wisely.

The research findings suggest that, in the context of a clinicopathological framework in CNMP management, patients’ self reporting may not be given epistemic credibility. This can be concerning, since patients may suffer epistemic and moral harms when their pain complaints do not match the objective pathology (Hill, 2010; Sullivan, 1998; Quintner, et al., 2008). As Foley, an eminent pain physician and researcher, commented, “[pain] is a subjective experience, and that we professionals tend to objectify it, and when we can’t, we minimize it. This is a serious problem for the patient with pain” (Rosenfeld, 2003, p. 114). In

addition to the lack of objective instrumentation to diagnose pain (Borsook, 2013), the culture of modern science and health care and its continued emphasis on the need to make subjective pain visible may have contributed to large-scale inadequate treatment efforts for CNMP sufferers (Goldberg, 2014).

Scientists and health care providers are not the only ones who seek to provide an objective explanation of pain. As discussed earlier, patients struggle to prove to themselves and others the objectivity of their pain, namely that the pain is real, visible, and legitimate. Legitimizing pain through clinical objectivity is one situation where the desire to be seen as a trustworthy informant is tied to notions of the sick role (Glenton, 2003). Initially described by Parsons (1951), the sick role includes behaviours based on people's illness and suffering. It permits them to be relieved from particular role duties and obligations, to receive certain benefits, and to act according to certain normative expectations. While individuals may have illness behaviours without a diagnosis, to achieve a medically sanctioned sick role the medical profession must legitimize the patient's pain by either establishing that the pain is real through formal pain assessments or by trusting the veracity of the patient's testimony. For example, in order to be eligible for disability financial compensation or transit service for people with disabilities, the medical profession must legitimize the pain. Kristiansson, et al. (2011) discovered that physicians who believe the source of the patient's pain to be psychosomatic (i.e., not real) as opposed to biological are less trusting of their patients' testimony and are less willing to authorize a "sickness certificate" for insurance purposes or disability compensation.

Given the desire for objective representations of pain, health care providers, scientists, patients, and families are looking to emerging research that applies modalities such as functional magnetic resonance imaging (fMRI) to overcome subjectivity and correct the stigma that has historically been associated with CNMP. However, there are important limitations of current neurotechnologies in classifying pain states and bridging the subjective-objective chasm in CNMP management (Giordano, 2012; Giordano, Abramson, & Boswell, 2010). Making an ethical case for the use of tools such as fMRI in CNMP management, Davis, Racine, and Collett (2012) explain that "[w]ithout a method for objective validation, patients can be dismissed as malingerers, exaggerators, or as having a mental health issue as opposed to actually experiencing pain" (p. 1555).

Davis and colleagues are also careful in noting that there remain serious limitations with fMRI technology, and that clinicians need to be cautious of the enormous impact its misuse can have. However, the quest for objective validation reveals some professionals' worries about the role of subjective testimony in CNMP management, and their desire for more personalized approaches to pain care (Giordano, Benedikter, & Boswell, 2011), and reliably distinguish trustworthy from untrustworthy patients. This point about reliably distinguishing patients was raised by some of the participants in the physician feedback group, as patient narratives are often considered to be epistemically inferior to objective clinical data (Scheman, 2001). The emphasis on finding objective tools to validate pain also suggests that those who possess the scientific competence to use diagnostic technologies such as fMRI and interpret their results are considered more credible and authoritative interpreters of the pain experience than the patients.

7.4 Implications for the clinical setting: Repairing trust and demonstrating trustworthiness

The findings of this dissertation highlight the reciprocal normative expectations of the therapeutic relationship in CNMP management. This clinical implication can be summarized by what Frank (2002) calls “how can they act like that” (p. 15) stories. Such stories represent breakdowns in the therapeutic relationship on both sides. The health care provider and the patient have both common and competing concerns, which may lead to misunderstandings, antagonism, and distrust, as each party is participating in the therapeutic relationship based on incongruous moral visions of care. Normative expectations about how the other ought to act shape how trust functions in that therapeutic relationship (Walker, 2006). The stories told by the participants in this dissertation serve as a reminder that trust relations are of concern to both patients and health care providers, as threats to trust affect patient-provider communication patterns in profound ways.

From a patient care perspective, it is important to understand the implications of the proposed model of perceived distrust as it pertains to patients' beliefs they have suffered an injustice and had their credibility undermined. For instance, perceived injustice may predict work disability in individuals with CNMP at their one-year follow-up (Sullivan, Adams,

Horan, Maher, Boland, & Gross, 2008), and poor health and mental health recovery trajectories (Sullivan, Scott, & Trost, 2012). An interpretive phenomenological analysis by McParland, Eccleston, and Osborn (2011) demonstrated that patients with CNMP tend to report concerns about inequality and unmet care needs, which impact how they rate their quality of life.

The findings of this dissertation can inform clinical practice when the credibility of patient narratives might be called into question and trust in the therapeutic relationship may be diminishing, non-existent, or damaged. Certainly, health care providers and patients should not uncritically accept the credibility of the other's testimony and trust its veracity. As discussed, placing trust unreflectively in a context framed by uncertainty can bring about harm. Ethically, however, it is necessary to maintain or repair trust relations whereby patients and health care providers have an appropriate environment to co-develop care plans according to patients' medical interests. Informed by the literature and findings of this dissertation, I argue below that health care providers ought to repair damaged or lost trust in the therapeutic relationship by striving toward a disposition of epistemic humility. I argue that the responsibility for epistemic humility and repairing damaged or lost trust falls more heavily on the health care provider than on the patient given the inherent power hierarchy in the therapeutic relationship. However, I also contend that patients, as participants in a relationship, also have responsibilities to demonstrate veracity and trustworthiness. Patient participation in the therapeutic dialogue has both epistemological and ethical importance.

7.4.1 Epistemic humility and health care providers

In the health care context, epistemic humility is an approach that calls for partnership and dialogue between patient and health care provider in a deliberative decision-making process (Buchman & Ho, 2013; Ho, 2009, 2011). Being epistemically humble means recognizing that medical judgments are always accompanied by uncertainty (Schwab, 2012). Appreciation of such uncertainty requires health care providers to adopt a disposition, or an attitude, that allows room for balancing clinical information, professional judgment, and patients' perspectives. Epistemic humility is intentionally collaborative, as "both the HCP [health care provider] and patient are counting on each other in investigating a full picture of

the patient's experience and determining the most appropriate management strategies" (Ho, 2011, p. 117). While health care providers have vast medical knowledge, they do not have direct access to their patients' experiences. In search of the most appropriate clinical approach, epistemic humility requires an inquiry into the patient experience. For example, the health care provider can invite the patient to tell her story, and embrace a willingness to incorporate the patient's narrative into her professional worldview (Atkins, 2000). Epistemic humility does not require a rejection of health care providers' clinical expertise. Rather, it recognizes the limits of clinical knowledge and expertise in determining the most appropriate care plans, especially where there is uncertainty or incomplete knowledge about the patient's situation. Accordingly, epistemic humility is a commitment to continuous responsiveness to the patient's experience and recognition of the uncertainties and limitations of applying clinical knowledge and expertise to decision-making (Frank, 2004c; Ho, 2011; Upshur & Colak, 2003). It is a process and practice that allows for repairing damaged trust and demonstrating professional trustworthiness.

Given that social characteristics of the patient may influence physician judgments about the claims of patients with CNMP (Tait & Chibnall, 1997), a curious, morally self-reflective stance is critical to epistemic humility. By acknowledging the value of the patients' perspectives and providing patients with a constructive means of participating in their care decisions, a commitment to epistemic humility may help to minimize the power asymmetry in the therapeutic relationship. Such commitment may also enhance the self-efficacy of socially disadvantaged patients by facilitating the knowledge, skills, and confidence needed to address their own health concerns (Lorig & Holman, 2003).

Epistemic humility also requires health care providers to critically evaluate the implicit assumptions inherent in the clinicopathological framework, especially as this framework categorically privileges certain kinds of knowing over others (e.g., the objective MRI results over the subjective patient testimony). Greenhalgh (2001) observed in her CNMP autopathography that even though health care providers are not the experts about the patient's own complex illness narratives, they generally place their scientific and medical narratives in an epistemically higher position than patients' narratives.

Medical knowledge is a socially privileged kind of knowledge. While medical information today has proliferated on the Internet, most patients do not have the specialized

clinical knowledge and skills to discern between good and bad evidence, or apply volumes of online information to their specific situation. The necessity of such expertise and skill places health care providers in an epistemically privileged position to decide how the patient should manage their CNMP (Ho, 2009, 2011; Rogers & Ballantyne, 2009). Nonetheless, patients with CNMP have lived with their pain for many years and often have extensive experiences with multiple therapies and interventions. These individuals become knowledgeable about their condition and the effectiveness of various care plans. Perpetuating the established epistemic hierarchy and neglecting the patient's story and expertise may communicate the message that people living with CNMP—especially when they are also living with addictions and mental illnesses—do not have an epistemically and morally equal claim in negotiating their care plan.

In addition to acknowledging patients' lived experiences, a health care provider who aims for epistemic humility can also reconsider the concepts and paradigms that drive the discourse and practice of CNMP management, including underlying epistemic and ethical assumptions. These discursive concepts include binary terms often used in CNMP such as objective/subjective, legitimate/illegitimate, real/unreal, normal/abnormal, and the dichotomies underpinning the moral tensions discussed in CHAPTER 3: brain disease/moral condition, good medication/harmful drug, and good patient/difficult addict. Health care providers can also examine how continued use of such binary terms may continue to deflate the credibility of people with CNMP, particularly those with mental illness and addiction issues. One important part of contesting the use of these binary terms in clinical practice is for health care providers to be cognizant of how such terms may work as explanatory tools to prematurely discredit the patient's story and dismiss the patient's credibility as a trustworthy informant (Cohen, et al., 2011; Fricker, 2007). By recognizing that the line that separates binary terms is blurry, health care providers can critically evaluate and modify mistaken dichotomies accordingly.

7.4.2 The patient's role in demonstrating trustworthiness

The findings of this dissertation are consistent with reports in the literature that the therapeutic relationship is asymmetrical in terms of knowledge, skills, and power. However,

these disparities do not mean that the moral responsibilities are one-sided. A social contract model of health care that extends to the therapeutic relationship implies that patients have responsibilities as well.

Patient involvement in collaborative management of a chronic condition is central to good therapeutic outcome (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997), and past discussions have called for increased patient responsibility for the management of chronic pain (Bodenheimer, Wagner, & Grumbach, 2002; Jansen, 2001). Since health care providers have no direct access to the patient's subjective experiences of pain and suffering, it is incumbent on the patient to truthfully communicate her experiences, symptoms, and expectations for treatment. Patients need to be honest about their health care and medication histories, as well as their motives for seeking treatment. They also need to recognize and disclose any potential harm that may come to others (e.g., medication diversion). By being committed to an honest therapeutic dialogue, health care providers may trust the veracity of the patient's testimony. It may also help providers to appreciate the severity, quality, and meaning of the patient's pain in the context of his or her life, and to provide appropriate care accordingly (Giordano, 2007b).

To contribute knowledge about their care needs and benefit from health care providers' clinical expertise, patients ought to discuss their preferences as these relate to the risks and benefits of treatment options. It is, however, important to note that a patient with decisional capacity has the moral and legal right to decide to not participate in specific discussions about care plans. To aspire for epistemic humility, patients ought to be open to treatments, interventions, management strategies, and provider interpretations about their condition that the patient may not have considered. Although patients are not obligated to accept any recommended treatments that do not fit their goals and values, they must inform the health care provider if they may not or will not adhere to accepted interventions (Brody, 2004; Giordano, 2007b). This is both ethically and clinically important in terms of preventing potential harm to the patient (e.g., painful withdrawal symptoms) and displaying trustworthiness: the patient demonstrates that she can be trusted to take her medications safely and is competent to self-manage. Patients who aim for a disposition of epistemic humility demonstrate respect for the health care provider's knowledge, virtue, and moral agency, and establish that they trust the health care provider's intent to provide pain care

according to their medical interests (Giordano, 2007a, 2007b; Giordano & Schatman, 2008b, 2008c). This demonstration of epistemic humility fulfills reciprocity in the clinical relationship (Giordano, Abramson, & Boswell, 2010), which is an important component of values-based medicine (Fulford, 2008) and goal-directed health care (Waters & Serpina, 2006).

7.4.3 Potential challenges in motivating epistemic humility

There are several potential challenges in motivating health care providers to adopt an attitude of epistemic humility in CNMP management. The first challenge relates to the conflicting obligations health care providers face in providing care for patients living with CNMP, especially when the patient is also living with addiction and mental illness. As Geppert (2007) explains, many physicians struggle to treat CNMP and prevent addiction in the midst of mixed messages from the government, professional organizations, and the media. Such inconsistent messaging about addiction risks creates more uncertainty for health care providers; in providing compassionate and adequate treatment, health care providers also need to prevent iatrogenic addiction and medication diversion (Geppert, 2004; Katzman & Geppert, 2008). These conflicting duties pose a problem for epistemic humility when health care providers are inclined to adopt a default position of distrust with some patients due to past deceptive encounters where patients managed to obtain opioid prescriptions for inappropriate purposes. The physicians in the feedback group described such scenarios.

The second challenge is that epistemic humility requires the health care provider to be empathic and compassionate in inviting the patient to tell his or her story. Physicians have historically been taught to remain emotionally detached from patients, as subjective empathy was believed to be an impediment to clinical objectivity (Halpern, 2001). Bearing witness to patient stories of pain and being responsive to them requires training and skill (Charon, 2006), and even well-intentioned health care providers may not have the necessary clinical-emotional competencies. Recommendations to enhance empathy in clinical practice range from increasing humanities content in undergraduate medical education (Geppert, 2008; Peterkin, 2008) to exposing medical students to classical texts, poetry, the arts, history, and philosophy (Shapiro, Morrison, & Boker, 2004). However, these programs have shown

limited evidence of beneficial long-term impacts (Ousager & Johannessen, 2010; Wershof, et al., 2009).

A third challenge in motivating epistemic humility is that caring for patients with CNMP can be time-consuming, frustrating, and stressful. Many providers are overworked and overburdened, and they increasingly feel the economic pressures of efficiency (Braddock & Snyder, 2005; Dugdale, Epstein, Pantilat, 1999; Giordano, 2008). Opportunities to hold compassionate and empathic dialogues regarding the patient's pain concerns in an emotionally charged context can be limited. In short office visits, "physicians are expected to form partnerships with patients and their families, address complex acute and chronic biomedical and psychosocial problems, provide preventive care, coordinate care with specialists, and ensure informed decision-making that respects patients' needs and preferences" (Fiscella & Epstein, 2008, p.1843). Taken together, these factors may present obstacles in health care providers being able to fully pursue and commit to epistemic humility.

Patients also face barriers in demonstrating trustworthiness and adopting a stance of epistemic humility. Some may not have the cognitive capacity to be epistemically humble, given how CNMP-associated suffering can threaten the intactness of the person, including self-identity (Cassell, 2004). Moreover, during bad pain flare-ups or sedation from medications, patients may not be able to actively participate in a collaborative process. The impact of multiple chronic morbidities including psychopathology on patients' ability to be epistemically humble must be acknowledged (Manchikanti, et al., 2007; Wurzman, Jonas, & Giordano, 2008). To complicate matters further, the aforementioned factors may impair the patients' capacity to tell their whole story. The latter considerations do not obviate patient responsibility in the therapeutic relationship. Rather, they contextualize the lived experience of the patient with CNMP.

Not all patients desire to be active participants in their care in the way I have described, and not all patients will be capable of being full participants. As discussed, patients have responsibilities to demonstrate trustworthiness, such as being honest about their medical and psychosocial histories, as well as being honest about their motives for seeking treatment. Both the patient's and the health care provider's perspectives are necessary in constructing appropriate care plans. The patient's lived experience ought to be in an

epistemic equilibrium with the specialized clinical expertise of the health care provider. By attending to these considerations, patients may be able to contribute to the discussion and their care may be a legitimate two-way collaborative approach.

7.5 Limitations

While I used well-established qualitative methods and applied grounded theory rigorously to this work, the study has recognizable limitations. All are captured by two general categories: 1) transferability of the findings, and 2) veracity and tone of the narratives. I focus on these here.

7.5.1 *Transferability of the findings*

While quantitative research attempts to test hypotheses, examine cause and effect, and generalize experimental results from a representative sample of participants to the larger population, qualitative research focuses on making sense of processes, people's experiences, and the social structures that contribute to these experiences. Qualitative research is most helpful for studies at the individual level, and allows for extrapolations of results to other similar situations (Lincoln and Guba, 1985). The responsibility to judge whether results are transferable is left to the reader, not the researchers of the original study, however (Golafshani, 2003; Lincoln & Guba, 1985). Transferability might occur, for example, if a reader has similar experiences as reported in a study, or even if the results resonate with past experiences. Qualitative research also does not represent an "unalloyed subjective truth" (Bury, 2001, p. 281); the assumed benefit of narratives, from either a small purposive sample as used here or larger ones, create a context-dependent form of knowledge.

Transferability of findings can be affected by the location of the original study. This dissertation research was conducted in the city of Vancouver, British Columbia, which has been the site for much research on addiction given Vancouver's open drug use community in the Downtown Eastside (DTES) neighbourhood (Linden, Mar, Werker, Jang, & Krausz, 2012). Many of the patient participants who reported addiction histories live in Vancouver's

DTES, one of the most socioeconomically impoverished neighbourhoods in Canada (City of Vancouver, 2012). Individuals tend to be stigmatized and may be exposed to crime, trauma, and other forms of injustices (Linden, et al., 2012; Torchalla, et al., 2013). Accordingly, the findings of the current study are not necessarily reflective of all patients who live with CNMP in other geographical areas and social contexts. Similarly, the findings from the physician feedback group represent physicians who were recruited from one particular regional health authority and who tend to care for patients with the profile above.

Considerations for transferability also concern the limitation of the study to English-speaking participants. Given the important role of language in the experience of CNMP, and the importance of communicating pain through language, this is a key imperative for future work. Culture is similarly an unexplored element. Further, the perspectives of older adults (\geq 65 years old) who are disproportionately affected by greater rates of CNMP (American Geriatric Society, 2002) were not captured. Likewise, adolescents and children who live with CNMP were excluded, as were the narratives of family members and caregivers of people living with CNMP whose own perspectives can illuminate the important issues discovered here.

7.5.2 Veracity and tone of the narratives

While trust has been linked to autonomy and beneficence in philosophical (O'Neill, 2002a; Pellegrino & Thomasma, 1993) and empirical ethics research (Rogers, 1999), its role in CNMP management has not been widely explored in the past. It is possible that confounding factors, such as the role of denial in addiction, may have shaped how patient participants understood their behaviours (see, e.g., Howard, McMillen, Nower, Elze, Edmond, & Bricout, 2002). In the present study sample, 37% of patient participants reported a current or past drug use problem. It is possible that some participants could have been using drugs in a problematic way, but did not acknowledge or report it as such. Twelve-step or mutual aid programs such as Alcoholics Anonymous (AA) are helpful in supporting individuals in their recovery once they have overcome denial, as AA is based on the hypothesis that addicted individuals cannot trust themselves with their own illness (Alcoholics Anonymous, 2013; Kelly, Humphreys, & Youngson, 2004). It is unknown

whether any participants in this study were attending any AA or similar Narcotics Anonymous (NA) support groups.

The stories participants told about their CNMP and care experiences might also have been shaped by conversations with fellow patients with CNMP, pharmaceutical advertisements, and popular sources that describe what it is like to be in and live with pain. Indeed, the public and institutional discourses about a health condition can shape the personal experience of that condition (Segal, 2005; Graham, 2011). Other factors that may have shaped participant stories include status quo and social desirability biases, which include the boundaries of what is and is not appropriate to divulge to a health care provider or a researcher about the CNMP experience (Frank, 1995; Morris, 2001; Riessman, 1990).

I assumed for the purposes of this dissertation that the stories participants chose to tell are true representations of what they believe has happened, as I do not have evidence to doubt or to confirm their veracity. If I were to presume that participants were intentionally misleading me in their testimony, I would be committing a testimonial injustice. Therefore, the theoretical model I have proposed in CHAPTER 6 can only be a first step, even while it lays the foundation for future work. What participants stated as evidence of their experience may be true for them as they perceived it, but it might also be misleading or untrue.

Participants may also be mistaken or naïve to the complexities of the therapeutic encounter. Throughout the analysis and writing, I asked myself what counts as the conditions for an authentic narrative and how much the CNMP narratives in this dissertation should be used to illustrate the individual's lived experience. What is more, I attended only to what Brody (2003) calls a "time-slice" (p. 69) of the narrative being told by the participant, and this portion is a small part of their larger life narrative that was not shared with me due to the limited scope of the research questions. Being able to grasp the moral meanings of trust, distrust, and trustworthiness embedded in these pain narratives cannot expose the totality of participants' life experiences, nor was this the primary goal of the work.

Finally, the tone of the participant accounts was generally negative about therapeutic interactions and may thus represent one end of the patient population spectrum with CNMP. Although some patient participants with CNMP reported trusting therapeutic relationships with their health care providers, and reported benefits such as return to the workforce and social functioning, these participant accounts were scarce in comparison to reports of poor

functioning and adversarial therapeutic relationships. Patients with predominantly good experiences may not have responded to the recruitment efforts because they do not see the necessity of discussing positive relationships. Accordingly, there may have been a self-selection bias to participate (Olsen, 2008).

7.6 Study contributions and directions for future research

This dissertation brings together diverse interdisciplinary scholarship on CNMP, addiction, ethics, and social science research. It contributes to the growing literature in bioethics that considers the clinical context as a hybrid epistemic-ethical space. It is also the first empirical neuroethics study to provide an in-depth examination of trust, distrust, and trustworthiness in CNMP management, and is part of ongoing efforts within neuroethics—including my own past work—to bring the narratives of stakeholders into an upstream ethics discussion (e.g., Buchman, Borgelt, Whiteley, & Illes, 2013), and to improve the ethical delivery of health care in a vulnerable population. The resulting theoretical model of perceived distrust is pragmatic and naturalistic. It is pragmatic insofar as the theoretical model acknowledges the real clinical, ethical, moral, and public health challenge of CNMP, and is sensitive to the multidimensional facts, realities and contexts of CNMP management; it is naturalistic, following Walker (2009), as it is “socially inquisitive, politically critical, and … empirically nourished but also … does not privilege institutionally organized natural and social scientific knowledge but embraces also the experience of individuals in personal, social and institutional life” (p.5). The naturalistic aspect of the model was additionally achieved by incorporating the narratives of patients with CNMP into normative ethical analysis. Finally, the findings of this dissertation draw attention both to the feasibility and need for further research to explore the process of trust in and its impact on diverse aspects of patient care. Multi-morbidities, the increasing age of the population, cultural diversity, efficiency pressures, among other variables, all put pressure on a health care system largely designed for acute care issues and form the imperatives for future research. In its current form, the health care system is not sustainable in meeting the needs of the chronically ill (Wagner, Austin, Davis, Hindmarsh, Schaefer, & Bonomi, 2001).

Through this research, I answered the central research question, *What is the role of*

trust in CNMP management from the patient's perspective?, by demonstrating that trust is foundational to the therapeutic relationship, and a negotiated social process in CNMP management. To answer sub-question 1, *How do patients living with CNMP experience trust in their relationships with primary care physicians and specialists?*, I demonstrated that many patients in my sample experienced trust in its negative form as distrust. This phenomenon is shaped by two social processes that underpin the experience of CNMP management: perception of identity prejudice (Social process 1) and perceived accusations of deception (Social process 2). To answer sub-question 2, *Do these patients seek to demonstrate trustworthiness; how do they do so, and why?*, I established that, for patients in this study, the demonstration of trustworthiness is of instrumental and practical importance: patients reported that they would be prescribed medications that have a high risk of harm, such as opioid analgesics, only if their testimonies were perceived as trustworthy by their health care providers. To answer sub-question 3, *How do patients living with CNMP and receiving primary care and specialist services value trust?*, I showed that trust is valued by patients for the way that it enhances the quality of the therapeutic interaction and fosters collaboration in treatment decision-making. Finally, to answer sub-question 4, *How do patients living with CNMP understand and describe relationships between CNMP and addiction-related behaviours?*, I demonstrated that patients understand addiction-related behaviours as an impediment to receiving optimal treatment. Patients in my study who live with addictions described identity prejudice and perceived accusations of deception, adverse social phenomena that they felt compromised the ability of health care providers to act in their best interests.

Future research that explores both positive patient perspectives and a broader capture of physician perspectives will provide a more comprehensive understanding of how both negotiate their trust relationships in CNMP management. A longitudinal approach that follows the therapeutic relationship and patient adherence to treatment, pain control, and satisfaction with care can track the nature of trust over time. Future research can also examine whether the level of health care provider uncertainty about the patient affects how the provider decides to place or withdraw trust. A training program that focuses on building epistemic humility in health care providers can be evaluated, and patient trust in this context measured. Finally, the nature and role of trust in CNMP can be evaluated in other populations such as

intravenous drug users. Here, the role of social structural factors such as homelessness and poverty can be critically evaluated for their role on shaping trust relationships.

7.7 Conclusion

Twenty-six years ago in the *Hastings Center Report*, Jennings, Callahan, and Caplan (1988) outlined significant ethical challenges posed by the broad spectrum of chronic illnesses, including CNMP. The authors argued that the individualistic discourse of American medicine, and the dominance of a curative medical model in Western health care, results in a narrow focus on cure versus care. The prevailing discourses of bioethics, and neuroethics as well, have followed the acute care-curative emphasis of Western health care and have, aside from psychiatry and explorations of chronic mental illness (Bloch & Green, 2009), been largely unconcerned with the ethical issues raised by other chronic conditions.

The Western cultural focus on curative models has led to important developments in medical treatments and technologies. While such advances have extended life for people living with incurable medical conditions, such conditions, now in chronic form, are often accompanied by, or can result in, intractable chronic pain. Multidisciplinary pain clinics notwithstanding, an acute care model of health service delivery is not well suited to individuals with chronic biomedical and psychosocial morbidities. Given that patients with addictions and mental illness also tend to be socially disadvantaged, it is less likely they will engage in treatment and thus face greater barriers in accessing evidence-based care (Galea & Vlahov, 2002). What is more, contemporary acute health care systems tend to privilege individuals who have higher health literacy, self-management capacities, and self-efficacy, factors less prevalent in disadvantaged patients (Fiscella & Epstein, 2008; Fiscella & Shin, 2005). The negative impact of care is likely to have a greater burden on socially disadvantaged patients and contribute to an ongoing climate of distrust. Accordingly, a trust-centred ethics of CNMP needs to be consistent with a health care model that considers the needs of socially disenfranchised patients, which include addressing inequalities in access to and outcomes of care.

In discussing the role of biomedical culture in pain management, Crowley-Matoka, et al. (2009) suggest that the norms embedded in one's culture may seem common sense because norms are part of the everyday experience. This common-sense view could be one reason why the Institute of Medicine (IOM; 2011) in the United States has called for a "cultural transformation in the way that health care providers and the public view pain, and its treatment" (p. 4), and why others have argued that the current health care system has failed those who live with CNMP (Giordano, Schatman, & Höver, 2009). The challenges of CNMP as described in this dissertation—from bench to clinic to policy—are the product of tensions across several aspects of the health care system that converge on the therapeutic relationship. To rectify these system issues, a cultural transformation for CNMP management ought to focus on an ethical transformation as well, which includes a critical examination of how society writ large faces and responds to the pain, suffering, and vulnerability of others. Although the IOM refers to effective pain management as a moral imperative of health care providers, the analysis here suggests that an ethical transformation of CNMP ought to go beyond health care providers and achieve consensus and collaboration among all relevant stakeholders. Striving toward a collaborative culture in CNMP management will provide the opportunity to attend to both patient and health systems' concerns, and cultivate trust across individuals, health systems, and institutions.

A central implication of my analysis is that any efforts to ethically transform care for those with CNMP will fail to have relevance if patient narratives are not given due attention alongside the views of the recognized epistemic community comprised of health care providers, scientists, and policy makers. Given the inherent vulnerability of being a patient, a trust-centred ethics of CNMP management ought to start with empowering the patient first. Empowerment will ensure that patient values are appreciated and perspectives and priorities heard. As highlighted by the discussion of epistemic humility, patients have an important role to play in the collaborative process of knowledge creation. Patient advocacy groups, such as Patients Canada, have attempted to bring the voice of patients into health care debates (Patients Canada, 2013). An ethical shift for CNMP management, with trust at the centre, ought to be informed by the growing body of interdisciplinary research in CNMP management and the stories of CNMP sufferers. Such an evidence-based strategy may affect clinical practice by helping to minimize the epistemic hierarchy between health care providers and

patients, and build a community of mutual trust through expressions of trustworthiness and good will.

The treatment of CNMP in biomedical contexts raises important and complex questions about the goals of health, the ends of health care, the ontological statuses of illness and disease, the moral limits of treatment, and the ethical foundations of evidence-based healthcare policy and practice guidelines (Cassell, 2004; Gibson & Upshur, 2012; Jennings, Callahan, & Caplan, 1988). This does not mean that pre-clinical and clinical research should not seek ways to prevent or even cure CNMP. Rather, the emphasis on care plans and health outcomes at the clinical level can be re-oriented. A commitment from health care providers in shifting the conversation away from pain severity and opioids and toward a model focused on long-term prevention, quality of life, functionality, and mutual trust, is one approach toward a more sustained moral engagement in CNMP management. Chronic care models arguably promote patient-provider and provider-health team trust because such models have the potential to increase multidisciplinary collaboration and lead to beneficial outcomes (Oprea, Braunack-Mayer, Rogers, & Stocks, 2010). Biopsychosocial models of care have been similarly proposed to address CNMP. There is evidence that Bonica's 1960s-era advocacy for comprehensive multidisciplinary approaches to CNMP management is beginning to penetrate some areas of the field, as multi-modal approaches to CNMP management are becoming increasingly more common (please see CHAPTER 2).

The perspectives of those with lived experience can offer credible viewpoints in order to promote quality of care, good health outcomes, and health care policies. Existing clinical guidelines in CNMP management may not sufficiently capture patients' perspectives, values, and priorities (Upshur & Tracy, 2008), which, as this research and the existing literature have demonstrated, may be at odds with the perspectives of health care providers and with existing drug laws and policies. The trust-centred ethics I am proposing for CNMP management can help researchers and health care providers—from the solo health care provider in the community to multidisciplinary teams in hospitals—focus on how CNMP narratives are told and learn to wisely place trust. This does not suggest that a unified or master pain narrative is required, but rather that there is an opportunity for the inclusion of multiple perspectives and experiences in the development of practice guidelines and priority setting for health and social policy. Incorporating patient perspectives in practice guidelines has been recently

recommended in the context of evidence-based medicine (Montori, Brito, & Murad, 2013) as it demonstrates that the broader health care community highly values the patient experience, which may help fortify patient and public trust in pain management broadly. Whether incorporating patient perspectives increases public trust at the macro level, cultivating and sustaining trust at the micro level is indeed an important empirical question.

In some ways, the suggestion that a trust-centred ethics of CNMP ought to include listening to the patient and incorporating patient/family perspectives, values, and priorities might appear to be too simple or obvious. Despite calls for improved patient-provider communication in CNMP management and in therapeutic relationships more generally, there is considerable evidence that communication patterns in the therapeutic relationship remain an ongoing challenge (Cannarella Lorenzetti, Jacques, Donovan, Cottrell, & Buck, 2013; Mira, et al., 2013; Ommen, et al., 2008; Stewart, Brown, Boon, Galajda, Meredith, & Sangster, 1999). More research and integration of narrative-based understandings of care into health care provider education is thus an important next step.

Ethically, it is critical that the discourse and practice of CNMP management do not continue to marginalize the voices of those who are considered to reside outside of the accepted epistemic community. If health care providers accommodate the stories of patients with CNMP, it may signify a commitment to epistemic humility in the therapeutic relationship and demonstrate that these individuals are valued members of the epistemic community. This may help build trust in therapeutic encounters. By striving for epistemic humility, the social meaning of CNMP can be revealed and can serve to enrich the rapid advances in the genetics and neuroscience of CNMP, and in other areas of research in chronic pain. Perhaps most importantly, providing a moral lifeline with patients on their pain and addiction journeys is one way to demonstrate trustworthiness and good will, cultivate well-placed trust, and ultimately improve patient care.

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Appendix A: Participant recruitment advertisement and telephone screen protocol

VCHRI#: V12-00227

Research Study on Chronic Low Back Pain and the Patient-Doctor Relationship

Researchers at the University of British Columbia are interested in your views about living with chronic low back pain and the patient-doctor relationship.

You may be eligible to participate if you are an adult:

- Diagnosed with chronic low back pain for 2 years or longer
- Between the ages of 35 – 64
- Currently receiving treatment for chronic low back pain from a primary care physician (family doctor)
- Not currently receiving disability payments from your employer or from Workers Compensation BC.

The study will involve a 5-min questionnaire and a 60-90 min in-person interview at a time that is convenient for you either at UBC Hospital or at a location of your preference. You will receive a \$10 gift certificate for participating.

This research study is being conducted in fulfillment of the requirements for the PhD degree at the University of British Columbia.

If you would like more information about this research study, please contact Daniel Buchman, PhD Candidate, at [REDACTED] or [REDACTED].

Research ID:

Telephone Screen Protocol

I have some questions to ask you in order to determine your eligibility for our research study. We ask everybody who is interested in participating the same questions. May I proceed?

1. Do you speak English fluently?

- a. Yes... → Continue to assess English-speaking abilities throughout screening procedure.
- b. No...THANK AND TERMINATE

2. How old are you today?

- a. Between 35 – 64...
- b. If < 34...THANK AND TERMINATE
- c. If > 65...THANK AND TERMINATE

3. Do you have chronic pain?

- a. Yes...
- b. No...THANK AND TERMINATE

4. Do you have chronic malignant (e.g., cancer) pain?

- a. Yes...THANK AND TERMINATE
- b. No...

5. Where is your chronic pain *primarily* located?

- a. Low back...
- b. Another anatomical location...THANK AND TERMINATE

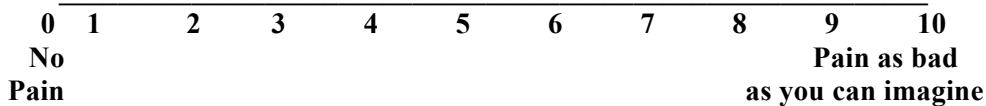
6. For how long have you lived with your low back pain?

- a. [Enter number if > 2 years]: _____
- b. THANK AND TERMINATE IF < 2 years or "DON'T KNOW" or REFUSED.

7. Are you currently an in-patient on a chronic pain treatment unit?

- a. Yes...THANK AND TERMINATE
- b. No...

8. Please rate your pain by indicating on a scale of 0 – 10 where 0 is "no pain" and 10 is "pain is as bad as you can imagine" that best describes your pain on the AVERAGE.



9. Do you see a primary care physician (e.g., family doctor/general practitioner) for pain management?

- a. Yes...
- b. No...THANK AND TERMINATE

10. Are you receiving workers compensation board payments or disability payments from your employer?

- a. Yes...THANK AND TERMINATE
- b. No...

Appendix B: Demographics questionnaire, patient semi-structured interview guide, and patient focus group guide

Research ID#: _____

1. DEMOGRAPHICS

The following are questions about your background and your and your family's mental health and drug use history. Please remember that the answers you give are confidential, and you do not have to answer any question that you do not want to answer. We are asking everyone who participates the same questions.

a) What is your age today (in years): _____

b) How do you identify your gender: _____

c) What is your current marital or living status?

- i) Single
- ii) Married
- iii) Separated
- iv) Divorced
- v) Common-law
- vi) Widowed
- vii) Refused

d) What is your highest achieved level of education?

- i) None
- ii) Elementary school
- iii) Some high school
- iv) High school
- v) Some College/University
- vi) College Diploma
- vii) Undergraduate University Degree
- viii) Master's Degree or equivalent
- ix) Professional or Postgraduate Academic Degree
(e.g. LLB, JD, MD, PhD)
- x) Refused

e) How would you describe your social and cultural background?

f) Are you currently (circle all that apply):

- i) Employed full-time
- ii) Employed part-time
- iii) Volunteering
- iv) A student
- v) Working at home
- vi) Not currently employed
- vii) Receiving Employment Insurance
- viii) Receiving BC Employment and Assistance
(Income Assistance)
- ix) Receiving Canada Pension Plan (CPP)
- xi) Other (please describe): _____
- xii) Refused

2. HEALTH DEMOGRAPHICS

- a) **How long have you been living with chronic pain?**

_____ Years _____ Months

- a) **Do you have a personal history of mental health problems, such as attention-deficit/hyperactivity disorder, obsessive-compulsive disorder, bipolar disorder, schizophrenia, anxiety, or depression?**
- i. Yes
 - ii. No
 - iii. Do not know
 - iv. Refused

If yes, please specify: _____

- b) **Do you have a personal history of drug use problems, including alcohol, illegal drugs, prescription medications, or over-the-counter medications?**
- v. Yes
 - vi. No
 - vii. Do not know
 - viii. Refused

If yes, please specify: _____

- c) **Do you have a family history of mental health problems, such as attention-deficit/hyperactivity disorder, obsessive-compulsive disorder, bipolar disorder, schizophrenia, anxiety, or depression?**
- ix. Yes
 - x. No
 - xi. Do not know
 - xii. Refused

If yes, please specify: _____

- d) **Do you have a family history of drug use problems, including alcohol, illegal drugs, prescription medications, or over-the-counter medications?**
- xiii. Yes
 - xiv. No
 - xv. Do not know
 - xvi. Refused

If yes, please specify: _____

b) **How long have you been receiving treatment for chronic pain from your current primary care physician/GP?**

_____ Years _____ Months _____ Weeks

INTERVIEW GUIDE

ADDICTION, TRUST, AND WHAT REALLY MATTERS: PERSPECTIVES OF PATIENTS WITH CHRONIC PAIN

RESEARCH ID# _____

DATE ____/____/2012
D D M M YYYY

TIME ____ : ____ AM/PM

INTERVIEWER INITIALS _____

1. CHRONIC PAIN – ILLNESS EXPERIENCE

I will now turn the audio recorder on. In this section, we'll spend some time talking about your experience living with back pain. Please remember that the answers you give are confidential, and you do not have to answer any question that you do not want to answer. [Turn audio recorder on].

- c) Please tell me how and when your pain started.
- d) Please tell me how your pain impacts your life on a day-to-day basis.
- e) People who live with chronic pain sometimes find it difficult to convince others that they are actually in pain. Has this ever happened to you?
 - i. If yes: Can you please tell me more about that?
 - ii. If no: Can you please tell me how others know that you are in pain, and why you don't think you've had difficulty convincing others.

INTERVIEW PROBES

- The *meaning* participants attribute to their pain
- Does the participant feel like they are *suffering*?
- Impact of pain on relationships (e.g., workplace, family, friends, romantic partners), vocational, and recreational activities
- What aspects of the participant's *testimony* convince/do not convince others about their pain experience?
- Has the participant ever had the experience that they were *mistrusted* about their reports of pain? Do they feel their *credibility* was undermined? By whom?

2. RELATIONSHIP WITH PRIMARY CARE PHYSICIAN OR GP

I am now going to ask you about your clinical relationship with your primary care physician or GP. Please remember that your answers are confidential and will not affect the health care you are currently receiving or health care that you might receive in the future.

- f) Please tell me about your clinical relationship with your primary care physician or GP.
- g) People who live with chronic pain sometimes find it difficult to convince their primary care physician or GP that they are actually in pain. Has this ever happened to you?
 - i. If yes: Can you please tell me more about that?
 - ii. If no: Can you please tell me how your GP or primary care physician knows that you are in pain, and why you don't think you've had difficulty convincing your GP or primary care physician.
- h) Does it matter to you that you have a trusting relationship with your

primary care physician or GP? Why or why not?

- i) **Can you please tell me about a *good* experience that you had with your primary care physician? Can you tell me about a *bad* experience?**

INTERVIEW PROBES

- Does the participant feel that their doctor *believes* them when they report their pain symptoms?
- Has the participant ever felt *wronged* by their physician?
- Has the participant ever felt that their physician is compassionate? Empathic?
- Does the participant feel that their primary care physician is (scientifically/medically/technically) *competent* to address their pain needs?

3. TREATMENT/MEDICATION

The next questions are about your experience with **treatment** for chronic pain. This may include experience with various medications, or experience with complementary treatments such as psychological therapies, acupuncture, TENS, prolotherapy, yoga, massage, chiropractic, physiotherapy, or other treatments or remedies, interventions, activities, or healing practices that I did not mention.

- l) **Please tell me about your experience with treatment for your pain.**
- m) **Have you ever encountered difficulties receiving prescription medication when you needed it?**
 - i. **If yes:** can you please tell me about an experience where it was difficult to be prescribed pain medication? How did you handle the situation?
 - ii. **If no:** How do you communicate to your primary care physician or GP that you need more pain medications?

INTERVIEW PROBES

- Does the participant feel their pain is adequately treated by their primary care physician? Undertreated? Overtreated?
- Strategies/resources the participant uses when he/she does not get the medication he/she needs

4. TREATMENT CONT'D: ADDICTION

- n) **Sometimes, people find other ways to manage their pain, using strategies, therapies, alcohol or other drugs that were not necessarily prescribed by their physician. Has this been your experience?**
- o) **In one research study, 70% of Canadians taking pain medication reported that they were worried about becoming addicted to their medications. What do you think about that?**

- p) **Has your primary care physician or GP ever discussed issues associated with addiction with you? Have you brought up these issues to them on your own?**
- i. If yes: Please tell me more about that discussion; how often do you discuss these issues? What are the main concerns? Context?
 - ii. If no: have issues of addiction and chronic pain ever crossed your mind?
- q) **Some primary care physicians have stated that they sometimes find it difficult to determine whether a patient is in need of more pain medication or is “drug-seeking”. What do you think about that?**

INTERVIEW PROBES

- What is the participant's perceived legitimacy of his or her pain self-management strategies?
- Self-stigma and public stigma toward addicted individuals
- Attitudes toward prescription drug abuse/misuse
- Opioid diversion

5. Concluding Section

- a) **What is most important for you with regards to your chronic pain treatment?**
- b) **Do you have any other comments or concerns about trust, chronic pain, or addiction?**
- c) **Is there anything you would like to add that we have not discussed here?**

Thank you for participating in the interview.

###

PATIENT FOCUS GROUP GUIDE

ADDICTION, TRUST, AND WHAT REALLY MATTERS: PERSPECTIVES OF PATIENTS WITH CHRONIC PAIN

DATE / /2012
D D M M YYYY

TIME : **AM/PM**

INTERVIEWER INITIALS _____

Welcome everyone to the focus group. Your participation is greatly appreciated. Today, I will be presenting the findings of the research project that you all participated in. I would like to keep this discussion flowing, so please raise your hand at any point in time if you have a question or comment to make.

We are interested in what really matters for you in your treatment for chronic pain. We are particularly interested in your thoughts on our research findings that might be considered to be right or wrong, good or bad, just or unjust. These words are often what we refer to as part of ‘morality’ or ‘ethics’.

In this first part, we will be discussing how participants felt when the right thing was done and also, when they felt wronged.

1. SPECTRUMS OF RIGHT-WRONG

- 3. What do you think people are saying about their experiences where they felt the right thing was done?**
- 4. What do you think people are saying about their experiences where they felt wronged?**
- 5. Are there other interpretations that we have not discussed?**

POSSIBLE PROBES

- Are there any other chronic pain experiences people have had where they felt the right thing was done/the wrong thing was done?
- What does the group think about some individuals being accused as a ‘drug seeker’?

2. SPECTRUMS OF GOOD-BAD

In this second section, we will be discussing experiences that people have that are both good and bad.

- a) **What do you think people are saying about their good experiences?**
- b) **How do you understand what are people saying about their bad experiences?**
- c) **Are there other interpretations that we have not discussed?**

INTERVIEW PROBES

- What do people think about the need to be in control of one’s own health?
- What do people think about the way their health care providers communicate with them?

3. SPECTRUMS OF JUST-UNJUST

In this third section, we will be discussing experiences that people have that are both just, or fair, and unjust, or unfair.

- a) **What do you think people are saying about their experiences where they felt that they were treated fairly?**
- b) **How do you understand what are people saying about their experiences of being treated unfairly?**
- c) **Are there other interpretations that we have not discussed?**

INTERVIEW PROBES

- What does it mean for a health care provider to treat his or her patient fairly?
- Some people do not have the money to pay for different kinds of treatments. What do people think about that?

4. SPECTRUMS OF TRUST-DISTRUST

Here, we will be discussing how people spoke about issues of trust with their health care providers, and also times where they felt distrusted.

- a) **What do you think people are saying about their experiences where they felt that they were trusted?**
- b) **What do you think people are saying about their experiences where they felt that they were distrusted?**
- c) **Are there other interpretations that we have not discussed?**

INTERVIEW PROBES

- Do the experiences discussed here resonate with you? Why or why not?
- Does trust matter in relationships with health care providers? Why or why not?

5. Concluding Section

- d) **What are your final thoughts about what was discussed here today?**
- e) **Do you have any other comments or concerns about trust, chronic pain, or addiction?**
- f) **Is there anything you would like to add that we have not discussed here?**

Appendix C: Letter of permission to use the Brief Pain Inventory-Short Form, and Brief Pain Inventory-Short Form

T [REDACTED] F [REDACTED]

Department of Symptom Research
[REDACTED]

February 1, 2012

Mr. Daniel Buchman
University of British Columbia
[REDACTED]
[REDACTED]

Re: Authorization to use the Brief Pain Inventory

Dear Mr. Buchman:

I am pleased that you have considered using the Brief Pain Inventory[®] (BPI) in your upcoming study.

- The study description you provided seems to be congruent with the intended use of the BPI. You are hereby granted permission to use it in your upcoming study. Please note that:
- Your use of the BPI is limited only to the study specified above; to use the BPI in additional studies, you must reapply online at www.mdanderson.org/departments/prg > Symptom Assessment Tools > The Brief Pain Inventory (BPI).
- You are permitted to reproduce the copy of the BPI that is included with this Letter of Authorization; however, you must not remove the copyright notice.
- The BPI may not be modified or translated into another language without the express written consent of the copyright holder; Charles S. Cleland, PhD. Failure to comply may result in legal action. Permission to alter or translate the instrument may be obtained by contacting me at [REDACTED] or by mail
- We would greatly appreciate your sending us a summary of your study results after the completion of your project, so that we can continue to evaluate the performance of our instrument.

Sincerely,



Charles S. Cleland, PhD
McCullough Professor of Cancer Research and Chair
Department of Symptom Research

STUDY ID #:----- **DO NOT WRITE ABOVE THIS LINE** -----

Brief Pain Inventory (Short Form)

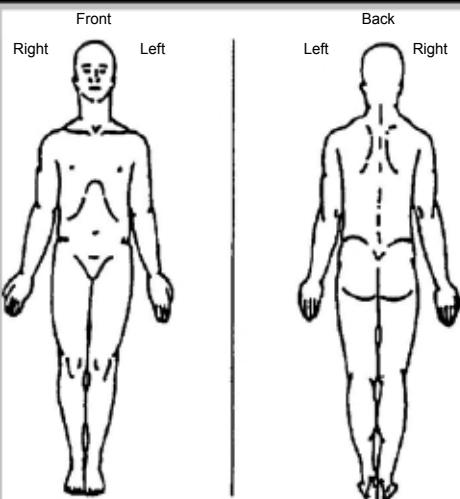
Date: _____ / _____ / _____
Name: _____

Time:

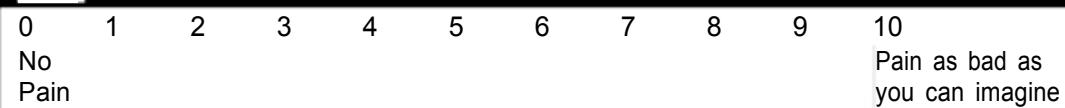
1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

1. Yes 2. No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



3. Please rate your pain by circling the one number that best describes your pain at its worst in the last 24 hours.



4. Please rate your pain by circling the one number that best describes your pain at its least in the last 24 hours.



5. Please rate your pain by circling the one number that best describes your pain on the **average**.



6. Please rate your pain by circling the one number that tells how much pain you have right now.



STUDY ID #: _____

DO NOT WRITE ABOVE THIS LINE

Date: _____ / _____ / _____

Time:

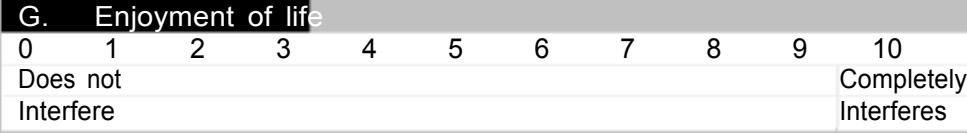
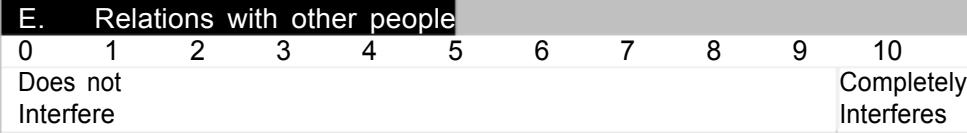
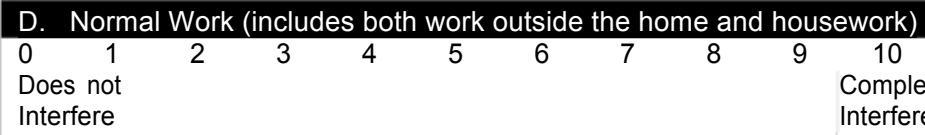
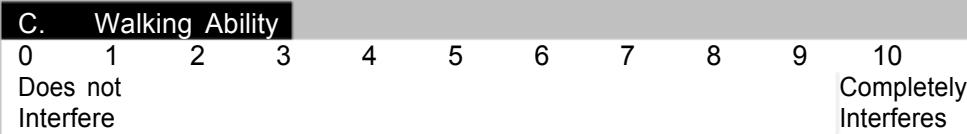
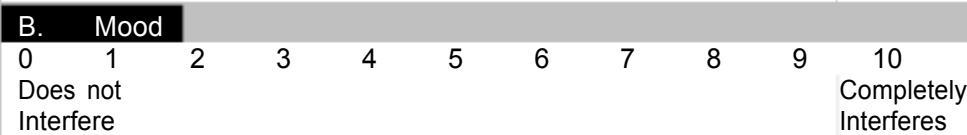
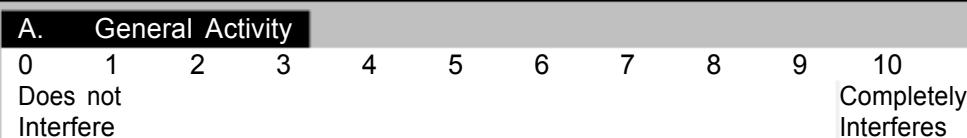
Name: _____

7. What treatments or medications are you receiving for your pain?

8. In the last 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
No Relief Complete Relief

9. Circle the one number that describes how, during the past 24 hours, pain has interfered with your:



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Pain Research Group

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Appendix D: Telephone and email script for potential physician expert panel participants, and physician panel guide

Telephone and Email Script for Potential Physician Expert Panel Participants

September 15, 2013

Dear Dr. _____,

As a physician who cares for patients living with chronic nonmalignant pain and addiction issues, I would like to invite you to take part in an expert panel for my PhD research, "Addiction, Trust, and What Really Matters in Chronic Pain Management". This research is being conducted under the supervision of Dr. Judy Illes, Professor of Neurology and Dr. Anita Ho, Professor of Applied Ethics at UBC.

In the expert panel, I will present to you and other physicians findings from the first part of my study that elicited the perspectives of patients with chronic pain on their views toward the therapeutic relationship with health care providers. The panel will engage in a confidential discussion about the findings from the patient interview portion of the research. I am interested in your feedback on the findings of the research and options for future directions and your views will be aggregated and reported as results in the dissertation.

The expert panel will be conducted on **September 26th, 2013 at 12:30pm in Dining Room 1 & 2 at St. Paul's Hospital in Vancouver**. The expert panel will last one hour. Lunch will be served.

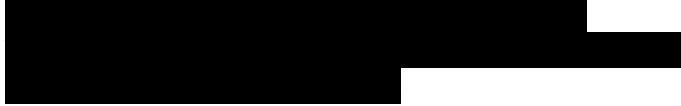
If you are interested in participating in the expert panel, please respond to me, Daniel Buchman, PhD candidate, at [REDACTED] or [REDACTED]. If you are unable to participate in the expert panel on September 26 but would still like to participate, please contact me and we will find time for a face-to-face or telephone interview.

A consent form will be available for your review at the expert panel; however, I would be happy to send you a consent form in advance if you wish. Please do not hesitate to contact Daniel Buchman at [REDACTED] or [REDACTED] if you have any questions.

Sincerely,

Daniel Buchman, BA, MSW
Interdisciplinary Studies Graduate Program, University of British Columbia
[REDACTED]

Judy Illes, Ph.D.
Canada Research Chair in Neuroethics and Professor of Neurology
Department of Medicine, Division of Neurology, University of British Columbia



Anita Ho, PhD
Associate Professor, W. Maurice Young Centre for Applied Ethics
University of British Columbia



PHYSICIAN PANEL GUIDE

**ADDICTION, TRUST, AND WHAT REALLY MATTERS IN
CHRONIC PAIN MANAGEMENT**

Welcome everyone to the expert panel! Your participation is greatly appreciated. Today, I will be presenting the findings of my dissertation research that explored how patients who live with chronic nonmalignant pain view their relationships with health care providers.

As practicing physicians who care for patients living with chronic pain and sometimes addiction issues, I am interested in your responses to the research findings and your suggestions for future research directions.

Any questions? Okay. We'll move ahead now.

I interviewed 27 patients living with chronic low back pain, and then verified the data with four who returned for a feedback group session. I collected and analyzed the interview data and the feedback group data using a method called grounded theory. This qualitative research method allows for themes to emerge directly from the data. A second coder worked independently from me on the data analysis and our results were compared and contrasted. Discrepancies were solved by discussion and consensus. No discrepancies required a tiebreaker from one of the two supervisors of this research. Overall, over 28 hours of data were analyzed. There were five themes that emerged dominantly, and several themes that emerged non-dominantly. By dominant, I mean that these themes were the most saturated after the second coder and I aggregated the data into large thematic clusters. Saturation refers to the process in which the independent coder and myself found the most amount of supporting evidence for these themes directly in the data and no new relevant information emerged after each successive interview.

The non-dominant themes tended to have a positive valence, and included situations where participants felt that their health care providers advocated for them, where participants felt in control of their health and chronic pain care, and where participants perceived that they had developed a trusting therapeutic relationship with their health care provider and were enjoying the benefits of improved care and functionality. The five dominant themes tended to be more negative in tone. Today I want to focus on the five dominant themes because they represent the crux of the findings.

The five dominant themes are:

1. **Subjectivity and the clinicopathological method:** this theme represents the tensions that arose between the participant's subjective experience of pain and what has been called the clinicopathological method of modern health care, which often relies on objective indicators to explain disease processes. When participants believed that their subjective experience of pain did not align with this objective perspective, participants perceived that their claims to pain were not taken seriously, or seen as trustworthy.
2. **Iatrogenic suffering and non-recognition:** this theme emerged when participants' perceived that they unfairly endured more suffering because their providers did not recognize their experiences as legitimate or that their provider conveyed a lack of empathy, respect, and compassion for their suffering.

3. Feeling wronged: the third theme is represented participants' perceptions of injustice and unfairness. Participants felt wronged by others, especially by health care providers, when they perceived that they were accused of being deceptive (i.e., not trustworthy) by engaging in aberrant behaviours associated with prescription opioids, such as drug-seeking or opioid diversion.

4. Stigmatized social identities: Participants perceived that their social identities, for instance as a drug addict, influenced their health care providers' assessment of the trustworthiness and their capacity to make contributions to goals of care discussions that would be taken seriously.

5. Credibility and testimony: The fifth theme connects the previous four themes. Participants perceived that they were not seen as a credible and trustworthy informant about their pain and suffering. Perceived lack of credibility and undermined testimony was associated with the perception that they were not considered knowledgeable in their own experiences, and that their stories were often presumed to be irrelevant when placed alongside their health care providers' assessment.

[Discussion]

DIRECTIONS FOR FUTURE RESEARCH

Based on the discussion today, what are your suggestions for next steps for this research?

CONCLUDING SECTION

Is there anything you would like to add that we have not discussed here?

In summary, here are the main points that I heard from this discussion...