IN THE HANDS OF STRANGERS: THE MYTH OF CHOICE AND SELF-DETERMINATION FOR CHRONIC PAIN PATIENTS IN ONTARIO

A DISSERTATION SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

GRADUATE PROGRAM IN SOCIOLOGY
YORK UNIVERSITY
TORONTO, ONTARIO
NOVEMBER 2017

Abstract

This study aimed to better understand and explain the lived experience of chronic pain patients within Ontario primary health care settings, their perceptions of self-determination, and the impact on their capacity to self-manage their condition and health-related quality of life.

Through in-depth interviews with 23 chronic pain (CP) patients, this research establishes an emergent theme of alienation as a key sensitizing characteristic of the experience of the research participants.

Self-Determination Theory suggests the management of pain is most effective when patients have a sense of agency and some measure of influence in their own health care. This view is consistent with the current provincial government policy of promoting Patient Centred Care (PCC).

The results of this study suggest that CP respondents experience feelings of alienation in the management of their condition. This experience is evidence of a lack of self-determination created by the inability of the health care professionals to effectively put into practice PCC.

Dedications

To my son, Frederick and my sister, Mariana

Acknowledgements

A number of people contributed to the completion of this doctoral dissertation. I would like to express my deeply felt gratitude to all of them.

I am extremely grateful to Dr. Brenda Spotton Visano, my advisor, and, Dr. Livy Visano, my second advisor and member of my thesis committee. This dissertation would not have come to its completion if not for their support, encouragement, guidance, and mostly for their unending patience and willingness to make themselves available to help me for over a decade.

Completing this dissertation was in no small measure made possible because of the genuine direction, vast knowledge, unreserved enthusiasm and support that Dr. Brenda Spotton Visano offered at all times. She has supported me not only by providing research advice over several years, but also emotionally during my journey. I cannot imagine having had a better advisor and mentor for my Ph.D.

Besides my advisors, I would like to thank the rest of my thesis and examination committees: Dr. Merle Jacobs, Dr. Linda Muzzin, Dr. Jay Goulding and Dr. Naomi Couto, for their encouragement, insightful comments, and questions. Special thanks to Dr. Linda Muzzin, for her valuable suggestions and concise comments on my thesis.

Similarly, profound gratitude goes to my personal coach and boundless cheerleader, Eva Marquez: because I owe it all to you. Many Thanks!

To my forever devoted, encouraging and always optimistic late friend Birnie Floyd, who believed in me and longed to see this achievement come true: I deeply miss you, and our late-night chats and laughter. Wherever you are, amigo mio, know that I made it.

I am grateful to Peter Mueller, who has been a truly dedicated mentor. I am particularly indebted to him for providing his knowledge and expertise, as well as unqualified moral and emotional support. Peter’s contribution to my academic and professional life throughout this pursuit has been beyond generous.

I want to thank Dr. Anthony Winson for his support, and especially for sharing his expertise so willingly throughout my work.

I also want to acknowledge Ms. Annette Shaffer, who was kind enough to undertake the editing work; Ms. Kathryn Robinson for her support through some rough periods in the thesis journey; and, Rob de Grosbois for his assistance.

Last but not least, I want to thank my family. Their presence made this journey easier.

Thank you all for your encouragement!

TABLE OF CONTENTS

Chapter One: Introduction

Chapter Two: Literature Review

Chapter Three**:** Methodology

Chapter Four: Data Analysis

Chapter Five: Interpretive Analysis

Chapter Six: Self Determination Theory (SDT)

Chapter Seven: Discussion and Conclusion

LIST OF TABLES

LIST OF FIGURES

1. Chapter One: Introduction

This research explores the key factors that impact the sense of empowerment and health-related quality of life of chronic pain sufferers and the extent to which these factors are addressed by health care providers and the Ontario health care system. It further examines the contradictions between the lived experience of people with chronic pain and stated Ontario health care policies, strategies, and treatment approaches and practices.

1.1 Background

Chronic pain (CP) is the single biggest cause of disability in Canada (more than diabetes or heart disease) (CPC, 2015), and the largest invisible epidemic in the world (Webster, 2015). More than one in five (or 20 percent) Canadians suffer from CP. Children are not spared and the prevalence of pain increases with age. Chronic pain prevalence is approximately 33 percent in those over 55 years old, with 38 percent of institutionalized seniors experiencing CP on a regular basis (Moulin et al. 2002; Schopflocher et al., 2011; CPC, 2015).

Chronic pain is a strong independent predictor of increased health resource use (Webster, 2015; Foreman, 2014). This disease costs the health care system and the economy more than cancer, heart disease and HIV combined (CPC, 2015). Indeed, the annual cost of chronic pain to Canadian taxpayers is estimated to be as high as $62 billion (von Baeyer, 2011). Further, chronic pain estimates place direct health care costs for Canada to be more than $6 billion per year and lost productivity costs related to job loss and sick days at $37 billion per year (Phillips and Schopflocher 2008; Jovey et al. 2010). "More than 71% of chronic pain sufferers are still in pain for 12 or more hours per day despite having tried, on average, 2.4 different treatments (Prud'Homme, 2015:3). Chronic pain is associated with a lower quality of life than chronic lung or heart disease (CPC, 2015; Schopflocher and Jovey, 2010).

Furthermore, research on opioid (narcotic) related deaths in Ontario found that pain medication-related deaths in Ontario have increased and that most of those who died had visited a physician within 9-11 days prior to death (office visits and emergency room visits respectively). Their final encounter with a physician involved a mental health or pain related diagnosis. Almost a quarter of those cases were determined by the coroner to be suicides (Dhalla et al., 2009; Gomes et al., 2011). Another study released by the Ontario Drug Policy Research Network stated that in 2013, 638 people died from opioid overdoses – a rate of about one death for every 20,000 residents in the province. Thirteen percent of those fatal overdoses were suicides. Between 2009 and 2013, statistics show that in Ontario, there were 2,879 deaths from opioid overdoses. In 2014, hospital records indicate about 3,200 opioid-related emergency department visits in Ontario, which resulted in 1,620 patients being admitted to hospitals (Finestone et al., 2016).

Treatment and Management of Chronic Pain in Ontario

There is no specific framework for chronic pain management either at the national or the provincial level (Palmer, 2016). Instead, chronic pain falls vaguely within the Ontario strategy for the prevention and management of chronic diseases Ministry of Health and Long-Term Care (MOHLTC, 2007).

A general feature of chronic conditions is their influence on functional abilities and other aspects of quality of life. Successful disease management, particularly when dealing with chronic conditions, is largely based on providing treatments that mitigate the impact of disease on an individual's quality of life. Further, as restoration of health is not always possible, the effective treatment of chronic diseases, and in this case, chronic pain, is largely dependent on the capacity of individuals to successfully engage in self-management of their condition (Wagner et al., 1996; 2002, 2011).

Extant research and several theories, such as Self -Determination Theory (Ryan and Deci, 2008; Williams et al., 2010), Self -Regulation Theory (Bandurra, 2005; Muraven and Baumeister, 2000; Baumeister et al., 2000 and 2007; Brownlee et al., 2000; Cameron and Leventhal, 2003; Schwarzer et al., 2011) and Empowerment Theory (Aujoulat et al., 2007; Small et al. 2013; Park et al., 2015) suggest that chronic diseases, including CP, are most successfully treated in a multidisciplinary pain program, where the goal is to empower and support individuals in pain to function better through education and self-management strategies and supports (Larson and Lubkin, 2001).

Chronic disease treatments and management programs call for patient-centred criteria, along with biophysical measures in order to meet patients' bio-psychosocial needs (IOM, 2001; Hanna, 2010; MOHLTC, 2012, 2014, 2015). The Ontario Chronic Disease Prevention and Management (CDPM) Strategy endorses these criteria and clearly states that "clients are part of the care team and engaged in shared decision-making" (MOHLTC, 2007:14).

Knowledge Gap

Patient -centred care is better conceptualized in relation to the notion of self-determination. Self-determination, the capacity to have input, choice and make decisions about care and treatments, has been found to be a particularly strong predictor of how motivated a person with chronic illness is to adhere to prescribed therapeutic plans and successfully partake in self-management plans and activities (Zikmund-Fisher et al., 2010, Ryan and Deci, 2008).

To that end, the Ontario CDPM Strategy requires that health care professionals endeavour to 'empower individuals to build skills for healthy living and coping with disease by emphasizing the individual's (and families') central roles in their health and as a member of the care team, engaging them in shared decision-making, goal-setting and care planning and fostering all mechanisms, supports, technologies and strategies that may facilitate the full integration of individuals as active participants in their care and the achievement of successful health outcomes (MOHLTC, 2007). Accordingly, strategies, programs, and services, whether clinical or environmental, must be geared to minimizing the impact of chronic illness on functional abilities, and to provide patients with the treatments, tools, techniques, knowledge, emotional and physical supports and empowerment to work with their strengths and to continue to effectively adjust to newly developing situations (Wagner and Groves, 2002; MOHLTC, 2007).

Notwithstanding the fact that patient-centered care has become a central aim for national health care systems in many western countries, including the U.S. (Moore et al., 2016) and Canada (Zikmund-Fisher et al., 2010), patient experience surveys (Gondek, 2016; Schoen et al., 2011) and health sector-wide assessments (Zikmund-Fisher et al., 2010; Fredericks et al., 2012; Sullivan 2016) indicate that this objective is far from being achieved. With regard to chronic pain, strategies at the system and organization levels have seen some improvement in certain settings and levels of care, such as palliative care, rehabilitation and long-term care centres, pain clinics, and particularly in nursing practices. However, at the primary care outpatient level, patient-centered care continues to be the exception rather than the rule (Dorrett, 2013; Havas et al., 2017; Housden et al., 2017; Bower et al., 2011; Arnold et al. 2016, Fried et al. 2011).

In Ontario, providing effective pain management care to improve health outcomes and/or the quality of life of chronic pain patients, continues to be an elusive goal, with devastating consequences for individuals, their families and the economy (Action Ontario, 2011, 2016; CPC, 2015). The current system for chronic pain care is uncoordinated and unbalanced, leaving many Ontarians misdiagnosed, inadequately or under-treated, and suffering. (CPC, 2015).

This thesis attempts to shed light on the gap between the Ontario Government's stated strategies and policies regarding the treatment of chronic pain and the lived experience of chronic pain sufferers.

1.2 Thesis Statement

A growing and aging population has progressively led to a staggering increase in the prevalence and incidence of arthritis (Health Canada, 2013), chronic pain (CPC, 2015), and other chronic diseases (MOHLTC, 2007, 2015). Research supports the critical importance of an individual's self-determination and full participation in their own health care for improving the quality of life for individuals with chronic pain (Wagner, 2006; Ryan and Deci, 2008). Promoting effective self-management of long-term health conditions can determine whether they live efficaciously or with disability, pain and dependence (Wagner, 2006). The Ontario health system has been committed to increasing patient engagement to minimize chronic diseases' staggering demand on health resources and reduce health care costs. It also acknowledges the need for, and value, of person/patient-centred strategies to empower patients and increase their self-determination (MOHLTC, 2007, 2010, 2015), yet little has changed for chronic pain patients (Ontario Action, 2011; CPC, 2015). There is a lack of empirical evidence to determine how effective Ontario's interventions are with respect to improving the ability of patients to self-manage their condition or increase their quality of life. Learning more about the relationship between Ontario medical models and client self-determination might help explain Ontario's high failure rate in providing effective pain management care. To assess the actual experience of self-determination and decision-making capacity by patients with chronic pain, and understand the ways in which they might feel empowered or unsupported by the health care system, a qualitative grounded theory exploratory study is needed.

1.3 Research Objectives

The principal objective of this research was to investigate the lived experience of people with CP, mainly within primary health care settings, and their perceptions of self-determination and health-related quality of life. As an additional objective, this study also examines the extent to which there is symmetry between what Ontario health care policies and strategies suggest should be offered to clients in order to increase self-determination, a sense of empowerment and control, capacity to make decisions and influence the treatments, and the care they actually receive as demonstrated in the narratives of the chronic pain sufferers interviewed. The extent to which there is a dichotomy is tested by this research and interviews with 23 CP patients.

The specific research questions this thesis addresses are as follows:
Within current primary health care settings in Ontario,

- To what extent do individuals with chronic pain perceive a sense of control and capacity to influence the treatment and management of their condition?
- What elements of health care practice enable or impair the CP patient's sense of empowerment and self-determination?
- How do those elements impact the biology and lives of patients?

1.4 Methodology

This thesis uses the Grounded Theory (GT) approach. GT begins with a research situation. Within that situation, the researcher's task is to understand what is happening and how the players manage their roles. What most differentiates GT from much other research is that it is explicitly emergent. It does not test a hypothesis. It sets out to find what theory accounts for the research situation as it is. In this respect, it is like action research: the aim is to understand the research situation. The aim, as Glaser states it, is to discover the substantive knowledge implicit in the data.

This a descriptive and exploratory study with the purpose of gaining a deeper insight of people's perceptions of situations and behaviours that either advance or impede/deter individual capacity to feel empowered and to influence, have input, or self-determination about their treatment and management of arthritis-related chronic pain within the primary health care setting.

Thus, this dissertation is an exploratory qualitative study about the perceived degree of power individuals with chronic pain have to determine choices and decisions regarding the treatment and management of their condition and the consequent effect on their well-being and quality of life. A key feature of exploratory research is that it allows for social phenomena to be investigated with minimal *a priori* expectations as a means to render explanations of these phenomena (Lincoln and Guba, 1985). GT is meant to provide information about the processes and outcomes of health-related programs and services (dealing with chronic pain) to be applied to the assessment of planning, implementation or funding of those programs (Smith and Glass, 1987).

GT is used in this study to examine chronic pain patients' experience of their power to engage in and influence the care afforded to them and the impact on their perceived health-related quality of life. Then, the components of Self-Determination Theory[1] (Ryan and Deci, 2000), autonomy, competence, and relatedness, are used to organize the issues that patients identified as most influential to their sense of empowerment, including those factors that influence their capacity to make choices around self-management of their chronic pain condition and the impact on their wellbeing.

Finally, Critical Theory concepts are used to make sense of the fact that newer approaches espoused by the Ontario health care system have done little if anything to bring about change in medical practice to increase individuals' sense of empowerment. In doing so, this study examines the reproduction and permanence of health inequities through power dynamics and command relations, hidden processes of prejudice and ideology that permeate contemporary healthcare, issues of alienation, surveillance, choice as an ideological and legitimatory device "allowing for

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[1] SDT is a macro theory of human motivation and personality that refers to people's inherent growth tendencies and innate psychological needs. This theory focuses on motivation underlying the choices an individual makes without external influence and interference. SDT is concerned with the degree to which people's behaviors are self-motivated and self-determined (Ryan and Deci, 2002).

the political attribution of deviance to those who willfully fall short of acting responsibly, namely, in conformity with structured cultural norms" (Brannen and Nilsen, 2005).

1.5 Significance of This Study

Over 7 million Canadians suffer from chronic pain, yet the need for efficient, effective, qualitative and timely care for those with CP continues to be unaddressed (Cooper, 2015, Reitsma et al., 2012, Boulanger, 2007). Continuous and widespread system failure to provide adequate pain relief for acute pain occurrences has routinely resulted in a greater number of populations developing chronic pain conditions (Jovey et al., 2003; CPS 2002; Boulanger at al., 2007; Daher 2010, IASP 2012).

The findings of the current research can help advance the disability and chronic pain medical field's understanding of how pain sufferers are best supported in achieving self-determination, autonomy and control over the management of their condition; how these goals are sometimes impaired by medical praxis; and, provide valuable information for researchers and health care practitioners as they implement and evaluate interventions to promote patient empowerment and self-determination.

As such, these findings might be of importance to advancing the medical field's understanding of the importance of promoting self-determination in patients with long term conditions, and developing strategies that can better support individuals with chronic pain in living a more efficacious life that can and will enrich their quality of life.

This study also adds to the 'chronic pain' and 'patient/person-centred care model' bodies of literature, by providing new and unique understanding of structural barriers to success in delivering quality care to CP patients, how these barriers operate and their impact on the health status and quality of life of the patient. Further, by revealing the forces constraining clinical relationships and the provision of care, this study can assist in advancing the dialogue between health care stakeholders to increase the effective management of this condition and the level of satisfaction and quality of life of patients.

The findings also provide a detailed and in-depth insight into the perceptions and needs of CP patients in their interactions with the primary health care system.

The most significant contribution of this study is the substantial knowledge arising from the application of grounded theory methodology in this research, which provides a new lens for viewing the lived experience of CP patients, and offers an abundance of details through many accounts rich in information that allow the mapping of the process of empowerment and disempowerment as experienced/lived by CP patients within the medical system and the consequences to their lives.

Organization of This Study

Chapter One introduces the problematic of inadequate pain management care in Ontario and the importance of patient self-determination to effectively manage this condition. The context of the study, research statements, objectives, questions and significance of the study are also outlined in this chapter.

Chapter Two furnishes a critical overview of the literature relevant to this research. Miller and Cabtree note that the literature must present those relevant concepts, assumptions, and expectations that can assist in identifying key conceptual domains that guide the interview process (1999). Accordingly, the literature presented in this chapter offers a background to the context against which the research questions are organized. This chapter also presents clinical manifestations, etiology, prevalence and burden of arthritis and chronic pain. In addition, current clinical models in primary care, and provincial policies and strategies for the treatment and management of pain are discussed. Further, this chapter offers an account of Self-Determination theory and its relevance to the analysis of the level of control and empowerment offered in the current Ontario medical model to those with chronic pain.

Chapter Three provides a comprehensive explanation of the interpretive methods of inquiry and analysis methods that furnished the foundation for the qualitative approach adopted in this dissertation. It centers on the choice of methodology and its suitability for this type of research, and presents the background and justification for using grounded theory to attain further understanding of CP sufferers' lived experiences.

Chapter Four presents the several categories that emerged from the data analysis contained and the different thematic subcategories. These correspond to a process of identifying those mechanisms present in the interaction between the CP patient and the health care system that either hindered or facilitated the individual's capacity for choice, control, and self-determination in the treatment and care of their condition.

Chapter Five provides an interpretive analysis of the core category of alienation. This analysis of the many accounts of patients' lived experiences is rich information that allows the mapping of the process of alienation as experienced by the patient within the medical system and the consequences to their health status and lives.

Chapter Six presents the results of applying the components of Self-Determination Theory (autonomy, competence, and relatedness) to organize the issues that patients identified as most influential in their capacity to make choices around self-management of their condition and the medical care received.

Chapter Seven provides a summary of the research project, a discussion of the findings and their interpretive analysis with reference to previously published knowledge. Alienation as a distinct consequence of a medical model that fails to translate to praxis the strategies, policies, and guidelines that define patient centred care and the complex structures that contribute to this failure are delineated. Conclusions, implications, significance, and limitations of this study are then presented. The chapter ends with recommendations for further research.

Chapter Two – Literature Review

2.1 Issues in Defining Pain

Everybody experiences pain. It's an inextricable part of human experience. The International Association for the Study of Pain (IASP) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Bonica,1979:249). This concept of pain borrows from Merskey's earlier pain definition: "An unpleasant experience that we primarily associate with tissue damage or describe in terms of tissue damage or both (Merskey, 1964 in Bonica, 1979:252)."

Pain is always a subjective multifaceted experience. However, pain is not always tied to tissue damage or any other pathological cause. In some cases, people report pain that is caused by psychological reasons, or that is not directly caused by an identifiable biological marker. Also, pain is always unpleasant and different from sensations that are not comfortable, but not unpleasant (Merskey and Bogduk, 1986). Pain can cause extreme aversive reactions, and it can inhibit complex thought and other feelings. It can obliterate language, and has a strong resistance to objectification (Scarry, 1985). People's experiences of pain are different and therefore not reductive. Pain is a sensory experience in that it is a sensation, which can be felt in an area of the body or many areas. However, pain is also an emotion, since it can affect the way people experience life and their bodies (Merskey and Bogduk, 1986).

Because the ability to clinically assess and measure pain objectively is rudimentary at best and far from ideal, whatever a person says about the experience or sites of pain, intensity, quality, or feeling, must be taken at face value and is until today the only measure clinically acceptable (Merskey and Bogduk, 1994).

Chronic Pain

'Chronic pain' is pain that has lasted for a long time. Clinically, the distinction between acute and chronic pain has conventionally been arbitrarily determined by an interval of time since onset; the two most universally used markers being 3 months and 6 months since onset (Turk and Okifuji, 2001), with some experts and researchers placing the transition from acute to chronic pain at 12 months (Main and Spanswick, 2001). Others term pain as acute when it lasts less than 30 days, *chronic* if it's of more than six months duration, and *subacute* when it lasts from one to six months (Thienhaus and Cole, 2002). Another approved definition of *chronic pain*, requiring no arbitrarily fixed durations is "pain that extends beyond the expected period of healing" (Fishman et al., 2009:14; Turk and Okifuji, 2003:18), or occurs at intervals, commonly lasting between months and years, or is related to a chronic pathology (Bonica in Lubkin and Larsen, 2011).

Whereas acute pain is a sensation activated in the nervous system in response to a possible injury and as a warning to the need to take care of oneself and is often treatable (Bonica, 1979), chronic pain persists or progresses over a long period, often for years; and is usually not responsive to medical treatments (IASP, 1986).

Conventionally, pain that persists for 3 months or longer is considered chronic. The IASP defines chronic pain as pain which has persisted beyond normal tissue healing time, taken, in the absence of other criteria, to be 3 months (IASP, 1986). Purves et al. provide a more inclusive definition: "current continuous or intermittent pain or discomfort which has persisted for more than 3 months, with recent or frequent seeking of treatment or use of analgesic medication (1998)." Emmelkamp and van Oppen simply based the definition of *chronic* on pain duration solely by labelling pain as chronic when it lasts more than 3 to 6 months (1993).

Whether intractable or recurrent, chronic pain, even when mild, can become so pervasive that it becomes a condition in and of itself, requiring daily management (Jeffrey and Lubkin, 2002).

The difference between acute and chronic pain is most relevant for management, since the treatment of acute pain focuses on the cause (including repair of damage) and treatment of chronic pain focuses on the effects (Troup, 1996; Rosen, 1996), including the effect of prolonged pain on the central nervous system, since there is some evidence that the transition from acute to chronic pain alters patients' neurophysiology (Osterweis et al., 1987). In chronic pain, the maximization of function and management of suffering and psychological factors which loom large with this condition (anxiety, depression, and stress), disability and socio-economic problems are also prioritized (Caudill et al., 1991).

It is not uncommon for individuals with chronic pain to present an absence of the body's adaptive physiological and automatic responses (Fishman et al., 2009).

Chronic pain can be continuous, intractable, intermittent or recurrent. Usually, chronic pain will necessitate daily management, even when rated mild to moderate in intensity. This is due to its pervasiveness. Indeed, the ever-present nature of this pain controls much of the afflicted individuals' lives (Dansie, E. J., and Turk, 2013; IASP, 1986).

Malignant and Non-Malignant Pain

Chronic pain conditions are termed as malignant when associated with potentially or progressive terminal illnesses such as cancer, and non-malignant, when not connected to a terminal illness yet unresponsive or difficult to control through pain management therapies and treatments. Non-malignant chronic pain has also been called chronic benign pain or intractable pain. The latter presents a predicament to those who treat it, as well as those who experience it. This type of pain no longer serves the function of protecting the body as in acute pain episodes. However, its etiology, causes, nature, and purpose elude health care providers and patients alike. Pain has also been categorized as eudynia and maldynia depending on the 'rightness and badness' of these conditions, with eudynia having a physiological function of evoking responses and behaviours that may benefit the survival and well-being of the organism, and maldynic pain going beyond any positive behaviour or purpose and persisting even when it does not engage recuperative mechanisms, and hence inducing maladaptive and destructive effects (Morries, 1991).

Regularly, health professionals tend to under-treat pain (Breitbart et al., 1996:79). Despite the awareness of the necessity of increasing the knowledge and expertise of primary and other health care professionals, many have a poor understanding of pain assessment and management (Sloan et al., 1996). Clinically, health providers are more invested in identifying and treating the underlying condition that might be the origin of pain rather than pain itself (Clarke et al, 1996). Health providers are found to experience a high degree of frustration when pain does not respond to therapeutic interventions or with clients who do not manifest symptoms of their pain. This is complicated by the invisibility of pain, lack of clear etiology, biologic models of care, and the relative impossibility of measuring pain (Fishman et al., 2009).

Transition to Chronic Pain: The Interface Between Acute and Chronic Pain

Prevailing theories posit that prolonged experience of acute pain in which long-standing changes are seen within and external to the central nervous system (CNS) creates chronic pain with a histological and pathological basis (Ready, 1998). Indeed, chronic pain development after surgery, injury and short illness likely occurs as a result of complex biochemical and patho-physiological mechanisms (Voscopoulos and Lema, 2010).

Key indicators that signal risk of transition from acute to chronic pain are: pain that is present 3 to 6 months, has no etiology, has a duration longer than expected time to tissue healing, or lasts well beyond the resolution of an underlying process. There is an intimate relationship between passivity; post-traumatic stress syndrome and mood disorders such as depression, fear of pain, anxiety; external locus of control; sleep disorders and disturbances; and chronic pain (Canadian Pain Society, 1998; Schellinck et al., 2012).

Nociceptors or nociceptive nerve fibers are receptors which are cells which transmit information about pain to the brain. When tissues are damaged, they release enzymes which excite these nociceptors. Pain that lasts for long periods leads to persistent activation of nociceptive transmission to the dorsal horn which may induce a wind-up phenomenon. This can induce pathological changes that lower the threshold for pain signals to be transmitted. Furthermore, it may cause non-nociceptive nerve fibers to respond to pain signals. Non-nociceptive nerve fibers may also be able to generate and transmit pain signals. In chronic pain, this process is difficult to reverse or eradicate once established (Vadivelu, 2005).

Chronic pain of various and diverse etiologies has been defined as a disease affecting brain structure and function. Abnormal anatomical (Geha, 2008) and functional connectivity, even during rest (Baliki, 2008; Tagliazucchi E, 2010), in areas associated with the processing of pain has been detected through the use of magnetic resonance imaging. Indeed, relentless pain can result in gray matter loss, although this is reversible when the pain is resolved (May, 2009; Wideman et al., 2011).

These structural changes can be explained by the phenomenon known as Neuroplasticity. In the case of chronic pain, it spawns a somatotopic representation of the body that is inappropriately rearranged following peripheral and central sensitization. Such maladaptive transformation leads to the experience of *allodynia* and/or *hyperalgesia*. Allodynia refers to pain arising from a stimulus that does not normally provoke pain, and hyperalgesia refers to magnified or increased pain intensity from a stimulus that normally provokes pain (see complete definitions, IASP, 2014[2]). The altered brain activity of those who endure a chronic pain condition has been revealed and measured through the use of electroencephalograms (EEG) suggesting pain-induced neuroplastic changes (Jensen, 2009).

2.2 Theories of Pain

Several theoretical frameworks have emerged in an effort to explain the physiological basis of pain though none yet completely explains the phenomena associated with the perception of pain and the exact factors that influence it. These theories are important since they provide various models in which pain can be understood, diagnosed and treated. Indeed, pain theories usually apply to pain management strategies, and are the drivers of therapeutic modalities (surgeries, medications, exercise, and massage) used to facilitate tissue healing and reduce pain.

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[2] **Definitions: Allodynia***Pain due to a stimulus that does not normally provoke pain.
Note: The stimulus leads to an unexpectedly painful response. This is a clinical term that does not imply a mechanism. Allodynia may be seen after different types of somatosensory stimuli applied to many different tissues. It is important to recognize that allodynia involves a change in the quality of a sensation, whether tactile, thermal, or of any other sort. The original modality is normally nonpainful, but the response is painful. There is thus a loss of specificity of a sensory modality. *http://www.iasp-pain.org/Taxonomy?navItemNumber=576#Allodynia*
The term *allodynia* was originally introduced to separate from hyperalgesia and hyperesthesia, the conditions seen in patients with lesions of the nervous system where touch, light pressure, or moderate cold or warmth evoke pain when applied to apparently normal skin. *Allo* means "other" in Greek and is a common prefix for medical conditions that diverge from the expected. *Odynia* is derived from the Greek word "odune" or "odyne," which is used in "pleurodynia" and "coccydynia" and is similar in meaning to the root from which we derive words with *-algia* or *-algesia* in them. http://www.iasp-pain.org/Taxonomy?navItemNumber=576#Allodynia, *accessed on July 23, 2016*

Hyperalgesia* Increased pain from a stimulus that normally provokes pain.
Note: Hyperalgesia reflects increased pain on suprathreshold stimulation. This is a clinical term that does not imply a mechanism. For pain evoked by stimuli that usually are not painful, the term *allodynia* is preferred, while *hyperalgesia* is more appropriately used for cases with an increased (augmented) response at a normal threshold, or at an increased threshold, e.g., in patients with neuropathy. It should also be recognized that with allodynia the stimulus and the response are in different modes, whereas with hyperalgesia they are in the same mode. This distinction should not be confused by the fact that allodynia and hyperalgesia can be plotted with overlap along the same continuum of physical intensity in certain circumstances, for example, with pressure or temperature. Current evidence suggests that hyperalgesia is a consequence of perturbation of the nociceptive system with peripheral or central sensitization, or both, but it is important to distinguish between the clinical phenomena, which this definition emphasizes, and the interpretation, which may well change as knowledge advances. Hyperalgesia may be seen after different types of somatosensory stimulation applied to different tissues.
(http://www.iasp-pain.org/Taxonomy?navItemNumber=576#Pain) accessed on July 23, 2016

Affect Theory

Affect Theory posits that pain is an emotion and not a sensation. It suggests that pain is an emotional quality which influences every sensory event (Melzack and Wall, 1991) and is closely connected to Bonica's so-called 'fourth theory' about pain which differentiates the neurophysiological perception of pain from the cognitive aspects of the response to pain as determined by socio-cultural contexts and previous personal experience (Nathanson, 1994). In other words, this theory is based on a sharp distinction between emotion as a mental state (i.e., the cognized perception and interpretation of affect), and affect as the biological substrate of emotion.

Affect is defined as a hard-wired, physiological response that will in due course manifest as emotion, and the experienced emotion itself. Emotions are thus considered intricate "co-assemblies" of affect, concept, and memory-pattern, established along lines that culture and personal experience make available (Tomkins in Nathanson, 1994). As such "*Affect* is biology; *emotion* is biography (Nathanson, 1994:50)."

Tomkins refers to nine different affects. Two positive affects (interest-excitement and enjoyment), are offset by six decidedly negative affects (fear-terror, distress-terror, distress-anguish, anger-anguish, anger-rage, and shame-humiliation), all of which may be halted instantly by surprise-startle, an affect which is too brief to have either a positive or negative affect flavor. Together, the nine known affects comprise a system, related to the nervous system on one hand, and to various other physiological systems – i.e., the circulatory, musculo-skeletal, digestive and reproductive systems – on the other (Nathanson, 1994: 65-70). Tomkins (1962) emphasizes that each affect functions as an amplifier that calls attention to anything with which it becomes associated or "co-assembled" (Tomkins in Nathanson,1994).

Although pure somatic pain is strongly related to distress, its nature is quite distinct. Similar to so-called drives (i.e., the human body's specific needs for oxygen, water, food and sex), specific receptors throughout the body send messages of pain which will subsequently trigger the distress affect. Unlike the affects, but akin to drives, pain carries specific information about what is hurting. In a manner comparable to the affects though, pain is inherently evaluative and motivating. We tend to engage in any necessary and possible action to stop the pain. Also, while pain frequently triggers distress, “the duration, intensity and stimulus contour of pain can trigger any of the negative affects as an accompaniment” (Nathanson,1994:415). However, all the negative affects are experienced as intrinsically painful, even though the discomforts of fear, anguish, disgust, anger, distress and shame are qualitatively different both from each other, and from the type of sensation experienced when one of the pain receptors is stimulated (Nathanson, 1994).

By their effects on bodily structures that evolved for other reasons (voice, heart rate, sweat, facial musculature, etc.), these nine innate affects call attention to their triggering source in nine quite different ways. These sites of action for innate affect are ordinary biological mechanisms set off by well-known groups of neurotransmitters. As these sites of action can be set off under the control of affect programs, it is inferred that one of the properties of the affect system is to control the release of neurotransmitters. If any aberration of neurotransmitter metabolism causes something to happen at the sites of action normally associated with one or another innate affect, individuals are likely to mistake any pattern of actions so released as the gestalt normally associated with that particular normal affect. One of the criticisms of this theory is that while it puts emphasis on an often-ignored affective dimension of pain, it was not successful at furnishing a systematic description and explanation of how it achieved the conclusion that pain is an emotion (Flor and Turk, 2012, 2015; DiMatteo, and Martin, 2001).

Specificity Theory

The underlying premise of Specificity Theory is that pain is the direct result of a noxious stimulus that triggers specific pain receptors in the body tissue to produce signals. These are carried through a special system of nerves to a pain centre in the brain, and then to a mechanical behavioral response (Melzack and Katz, 2003, Melzack and Wall, 1965). Calling a nerve receptor a “pain receptor” implies that stimulation of one type of receptor elicits a single psychological or physiological response. This has not been borne out clinically, physiologically, or psychologically (Moayedi and Davis, 2013). While specificity theory identified a basic physiological mechanism, constituted of highly specialized function receptors of the skin sensory system, for different sensations like heat and touch, it actually appears to have oversimplified this, as it assumes that fibres would cause pain alone and no other sensations. There are different types of neurons connected to pain discrimination: large, heavily myelinated fast conducing A-beta fibres, more thinly myelinated slower A-delta fibres and unmyelinated C fibres. Each one of these fibres responds to differing features of the pain experience and in diverse ways, depending on the different types of stimulation (Skevington, 1995). Also, “this theory does not explain the inhibition or exaggeration of pain by emotion or the continued presence of pain after surgical removal of a body part with its receptors” (Gilbert and Mahon, 1982:147). Patrick Wall pointed out that specificity theory not only failed to provide any explanation for clinical pain but also led to ineffective, and frequently counterproductive, surgical attempts to destroy the cells or their axons (Wall, 1996).

Pattern Theory

Goldscheider, in 1894, proposed that stimulus intensity together with central summation are the critical determinants of pain (Goldscheider in Melzack and Wall, 1965). Pattern theories derived from Goldscheider’s framework posit that afferent fibers respond to a host of stimulus modalities and that the ultimate perception depends on the brain’s deciphering and interpretation of the patterns of activity across the different nerve fibers (Wall, 1996). Pattern theories can be divided into two categories, both recognizing the concept of patterning of the input. Those such as Weddell’s and Sinclair’s[3] clearly emphasized the stimulation spatially or temporally of non-specific receptors, with a focus on intense peripheral stimulation, while ignoring physiological specialization. Other theories based on Goldscheider’s framework, such as Livingston’s[4], Hebb and Gerard’s and Noordenbos’ stressed central summation[5] (Melzack and Wall, 1975). Melzack and Wall state that the concepts of central summation and input control have shown remarkable power in their ability to explain various clinical phenomena of pain, but lack unity as they failed to propose a single theory capable of integrating the diverse theoretical mechanisms proposed within this framework (1975).

Gate Theory

Expanding on the accepted occurrence of which gentle stimulation inhibited pain sensation, Melzack and Wall (1965) developed the gate control theory of pain that expounds on the

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[3] Sinclair, D.C. *Brain*, **78**, 584, 1955

[4] Livingston, W.K., Sci. Amer. 88, 59 (1953);

[5] Noordenbos, W. *Pain* (Elsevier, Amsterdam, 1959)

psychological aspects of pain, the physiology of pain transmission and the modulating influences of pain. They provide a theoretical framework that acknowledges and underscores the body's in-built pain control mechanisms, and offer a feasible account for the non-intervention or low-tech approaches to pain control, comprising psychological methods, back-rubbing, acupuncture, and transcutaneous electrical nerve stimulation (Coffey and Mahon, 1982; Mander, 2011).

According to this theory, there is a 'gate' or, more precisely, a gating mechanism in the nervous system. This opens and closes in response to various factors. Opening the gate allows pain messages to travel to the brain. Closing the gate stops messages travelling to the brain. Activities in the pain fibers cause transmission cells (T-cells) to send pain signals to the brain and open the gate. Activity in sensory nerves not directly linked to pain causes larger-diameter nerves to carry information about harmless sensations (e.g., touching, rubbing or scratching). These activities close the gate and decrease the likelihood of the pain experience. In addition, messages from the brain can also open or close the gate. Anxiety, calmness, and excitement can have different effects on the gating mechanism. Relaxing and distracting an individual in pain can potentially close the gate. This model posits that pain is a two-way flow of information to and from the brain. It suggests that the brain not only processes this information but also directly affects the gating mechanism (Melzack 1965, Curtis, 2000).[6]

Engel, in 1977, notes that the Melzack and Wall theory integrated the medical approach of the previous theories with the biopsycho-social model of health proposing an interaction of biological, psychological and social factors in pain, and not just medical factors alone (Curtis, 2000). Their framework dealt with some of the apparent contradictions and inconsistencies in understanding pain, such as: the inconsistent relationship between injury and pain; that mild

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[6] Gate theory postulates that three spinal cord constituents are integral to sensory recognition and modulation: substantia gelatinosa (SG) cells in the dorsal horn, the central transmission (T) cells in the dorsal horn, and dorsal column fibers projecting to the brain. The SG cells act as presynaptic modulators of afferent patterns before they influence the T cells. These afferent patterns in the dorsal column act as a central control trigger which activates selective brain processes influencing the modulating properties of the gate control system. This results in activation of neural mechanisms by the branching T cell which comprises action responsible for perception and response. Gate control theory expressed in simplified form proposes that when pain (C and A-delta) fibers are stimulated, pain impulses are passed pre-synaptically in the SG and are then transmitted to the brain, where they will be perceived and will continue to be felt as pain so long as the stimulus persists. Relief of pain is dependent on stimulation of the large myelinated A-beta fibers which normally transmit the perceptions of touch and pressure. A-beta fiber stimulation results in an inhibitory effect setup in the same area of the SG where pain fibers synapse with a decrease in transmission or closing the gate to pain. Cessation of large fiber stimulation would remove the inhibition of pain in the SG and open the gate to the transmission and perception of pain. This theory seems to explain relief of pain by electrical stimulation of large nerve fibers but does not rule out the possibility of undetected postsynaptic control mechanisms (Coffey and Mahon, 2982, p. 148).

stimuli may elicit pain; the location of pain separate and distinct from the site of damage; pain in the absence of injury, or after healing; variations in the nature of pain over time and chronic pain with or without obvious cause (Wall and Jones, 1991).

Factors Affecting the Gating Mechanism		
	Conditions that open the gate	Conditions that close the gate
Physical	Extent of Injury/Tissue Damage Nature of Injury Lack of Exercise/Fitness	Massage Exercise, Fitness Counter-stimulation (heat, acupuncture)
Emotional	Anxiety Worry Tension Depression	Relaxation Meditation Positive Emotions (e.g., happiness, optimism)
Mental	Focusing on Pain Fear of Disability Catastrophizing	Distraction from Pain Trusting Capacity to Deal with Condition Intense Concentration Involvement and Interest in Activities

Curtis (2000, Pg. 45)

While Gate Theory has been widely accepted and can explain why drugs (pain suppressants such as aspirin), competing stimuli (like acupuncture) and the expectation of treatment effects (placebos) can sometimes block pain, it has failed to explain chronic pain issues, sex-based differences, and the effects of previous pain experiences.

The Neuromatrix Theory

In 1999, Melzack and Wall formulated the Neuromatrix Theory - an improved theory of pain, consistent with the idea of gate control, but addressing some of those unanswered questions. This framework proposes that pain is a multidimensional experience and that every individual has a genetically built-in network of neurons known as the "body-self neuromatrix". Just as each individual is unique in physical appearance, each individual's matrix of neurons is also unique and is affected by all facets of an individual's physical, psychological, and cognitive makeup, and also their experience. Thus, this neuromatrix, which is genetically determined and modified by sensory experience, acts as the primary mechanism generating the neural pattern that produces pain. Its output pattern is determined by multiple influences, of which the somatic sensory input is merely a part, which converge on the neuromatrix (Melzack, 2001).

While chronic pain still remains a mystery and the often attendant chronic psychological and physical stress relationship is poorly understood, the neuromatrix theory of pain affords a new conceptual framework to study these problems. Accordingly, pain is simply a part of a multi-system response to a perceived threat. There exist numerous other inputs to the brain that can trigger the pain neuromatrix and these include movement, thoughts, emotions, touch, memories, fear and visual stimuli amongst a plethora of inputs. The reason that these stimuli can trigger a pain response is in essence due to a perceived threat but also because the widespread neurons that make up the pain matrix are involved in all of the aforementioned activities while also being part of the pain neuromatrix (Melzack, 2005).

The neuromatrix framework furnishes a prime explanation for higher level parallel processing of information and the output that ensues as a smooth mechanism creating our conscious experience. The incredible neuroplasticity of the nervous system, as Melzack indicates, is evidenced in this genetically determined matrix and molded by sensory input (Doidge, 2007).

Each of the pain theory models furnished above is biologically complex and multi-faceted, and the description of the nervous system models and pathways involved is well beyond the scope of this dissertation, and therefore not further expanded. These theories inform current the medical practices, policies and strategies to treat chronic pain. Exposure to these theory models serves to illustrate the many intricacies and connections between biology and emotions. As the understanding of pain mechanisms improves, so does the emphasis on the importance of sensory input, and an individual’s sense of control and relational states. As drivers of therapeutic modalities used to facilitate pain management, the significance of these theories lies in their emphasis on the impact of social context on the individual’s responses to pain, and as such, they call for empowerment and self-determined regulation.

Prevalence of Chronic Pain

Estimates of the prevalence of chronic pain worldwide and in Canada are inconsistent (Reitsma et al., 2011), ranging from 10.5 percent to 55 percent (weighted mean: 35.5 percent) (Harstall, 2003 IASP) in the general population (Johannes et al. 2010), due to differences in methodologies employed in determining prevalence rates and the different populations studied (Boulanger et al., 2007). In 2002, the prevalence of pain in Canada was estimated through a survey of 2,012 adults (mean age 43.9 yrs.). Twenty-nine percent of the respondents reported chronic non-cancer pain, with increased frequency in women and older age individuals. The average duration of pain was 10.7 years, and the average intensity was 6.3 (on a scale of 1-10), with 80 percent reporting moderate or severe pain (Moulin et al., 2002). In older adults, the prevalence of pain is estimated to be between a quarter and three-quarters (25 - 75 percent) of this population, with a high impact on their mobility and dexterity (Reyes-Gibby et al., 2004; Jakobsson et al, 2004). This range increases even more for those residing in health care institutions (PHAC, 2011; Ferrell, 2003; Ferrell et al., 1995; Ferrel et al., 1990; Fox et al., 1999).

Burden of Chronic Pain

Currently, the burden of chronic pain to the public healthcare services and society in general, is staggering, due to its prevalence, its impact on the quality of life of those with this condition, the often-negative consequences to their personal relations and social supports, including caregivers and families, as well as the social and economic impact of this disease in general. This is true even when one does not take into account that pain will reach rampant proportions in the next two decades as a result of an aging population (Public Health Agency of Canada, 2011). The estimated proportion of seniors 65 and older is to increase from 14 percent in 2009 to nearly 25 percent of the population in 2036 (Statistics Canada, 2010). In Ontario, the number of seniors aged 65 and over is projected to more than double from 1.9 million, or 14.2 percent of the population in 2012, to 4.2 million or 23.6 percent by 2036 (Ontario Population Projections, 2012).

In a 2004 media release, the World Health Organization indicated that “Chronic pain is one of the most underestimated health care problems in the world today, causing major consequences for the quality of life of the sufferer and a major burden on the health care system in the Western world,” urging governments around the world to treat chronic pain as a disease in its own right (Breivik, 2004).

People with a chronic pain condition report the lowest health related quality of life when compared to those with any other chronic health conditions (Mäntyselkä et al, 2003). Currently, pain treatments and services in Canada fail to properly meet the needs of people with chronic pain, and often are not aligned with or do not meet the standards of current evidence-based literature (Phillips and Schopflocher, 2008; Lynch, 2011).

Chronic pain costs society – both governments and individuals, more than cancer, health disease and HIV combined (Schopflocher, 2008). The annual direct cost to Canada's health care system is estimated to be more than $6 billion, and costs to productivity due to job loss or sick days are appraised at $37 billion (Phillips and Schopflocher, 2008; Jovey et al., 2010).

In Ontario, primary physicians are the first point of contact with the health care system for most people with pain. Pain-related conditions account for up to 80 percent of visits to clinicians (Schmitt, 1985), and about half of all family practitioner visits. Seven million Canadians take pain medication at any given time. However, the treatments and services to control pain and obtain relief are inadequate (Moulin et al., 2006; Mason et al., 2004).

The epidemiological significance of chronic pain following surgery is enormous (Schmitt, 1985; Canadian Pain Coalition, 2011; Kehlet and Dahl, 2011). Lack of adequate pain management after surgery results in a chronic pain condition in 19 to 50 percent of post-surgery adults (Kehlet and Dahl, 2011).

In addition, the annual economic burden shouldered by patients dealing with a pain condition while waiting to access a pain clinic is estimated at $17,544, with the majority of expenses being indirectly incurred through reduced or lost work time and the purchase of private health care treatments (Gilron and Johnson, 2010).

2.3 Understanding Osteoarthritis and its Impact on Canadian population

The word arthritis means inflammation of the joint ("arthro" meaning joint and "itis" meaning inflammation). Inflammation is a medical term used to describe pain, stiffness, redness, and swelling. Arthritis is a disease that can involve any of the joints in the body, often occurring in the hip, knee, spine or other weight-bearing joints, but can also affect the fingers and other non-weight-bearing joints (The Arthritis Society, 2010:6). Joint pain, stiffness, and fatigue are common arthritis symptoms. Other symptoms include redness, warmth, inflammation, and decreased range of motion of the affected joints (PHAC, 2010). In some types of arthritis, the body’s internal organs are also affected (The Arthritis Society, 2014). There are more than 100 different arthritic conditions, ranging from relatively mild types of tendinitis and bursitis to crippling systemic types as in the case of rheumatoid arthritis. They include pain syndromes such as fibromyalgia and arthritis-related disorders like systemic lupus erythematosus, which involve every part of the body.

Joint and musculoskeletal pain is the common denominator in all of these conditions, which is why they are grouped together as ‘arthritis'' (Public Health, 2010). Arthritis onset can be either gradual or sudden (CDC, 2014). Osteoarthritis (OA) is the most common type of arthritis, affecting 4.4 million Canadians and is the most common cause of disability amongst older adults (Suri el al., 2013; (Murphy and Helmick, 2012; AAC, 2011). OA is a degenerative joint disease involving the cartilage and many of its surrounding tissues, a condition that leads to the breakdown of cartilage (the tough elastic material that covers and protects the ends of bones), and the underlying bone. Disease progression is usually slow but can ultimately lead to a bone-on-bone reduction in range of movement in the affected joints and joint failure, with pain and disability (CAA, 2011, PFAC, 2010, Litwic et al., 2013).

OA is associated with an excessively high economic burden, largely attributable to the effects of disability, comorbid disease, and the expense of treatment (Bitton, 2009). Research shows that OA was the fourth most common cause of hospitalization and the leading indication for joint replacement surgery in 2009 at a cost of $42.3 billion in North America alone (Murphy and Helmick, 2012). OA is not always developed due to abnormal stresses or injury; it is also related to the aging process.

Currently, there is no cure for OA, though protective behaviours to preserve joint health, exercise, self-management, the avoidance of repetitive stress on joints, physical therapy, weight management, medication and sometimes for severe OA, total joint replacement, OA continues to have a devastating and debilitating effect on millions of Canadians. Pain and disability are the effects that those with this chronic disease must face on a daily basis. Joint pain, stiffness, and swelling bring significant losses in functionality, disability and poor quality of life.

Economically, OA not only affects the life of individuals who live with it, mainly because it results in workplace limitations, the loss of income, and the capacity to financially take care of themselves, but this disease also affects society by impacting both the public health care system and the economy (Bitton, 2009; The Arthritis Society, 2015). Unquestionably OA's fiercest impingement is on the lives of individuals living with it; however, their families and community are also significantly affected by it.

Adequate pain management strategies for OA would by some estimates lead to savings of $488 billion over the next 30 years. This would represent a saving of $41 billion in direct costs and $447 billion in indirect costs. Unfortunately, Canada does not yet have a strategy to deal with chronic pain (Health Canada, 2011:13).

The long-term impact (2010-2040) of interventions and strategies that have the potential to reduce the burden of arthritis include: enhanced access to 'total joint replacement (TJR) which would decrease expenses by $17 billion to Canadians ($3 billion in direct health care costs and $14 billion in wage-related lost productivity costs); reducing obesity would result in the prevention of 200,000 new cases of OA, and savings of $212 billion to Canadian society – $48 billion in direct costs and $164 billion in indirect costs; and, early diagnosis,treatment and access to 'disease modifying anti-rheumatic drugs' (DMARDs) for RA, as well as access to Biologic therapy for individuals who do not respond to traditional DMARDs, and non-prescription drugs.

Finally, implementing an effective pain management strategy is clearly required in order to positively impact the quality of life for people with arthritis and reduce the cost burden on society. In Canada, about 48 percent of all new cases of OA took place among people older than 60 years of age in 2010. An increase of 53 percent is estimated by the year 2040 (AAC, 2011:30). An aging population will drive the prevalence of symptomatic OA among people over the age of 70 from 49 percent in 2010 to 71 percent by 2040. For people with OA, uncontrolled pain alone drives changes in health care utilization. Estimates of the impact of effectively reducing pain among people with symptomatic OA by 33 percent would result in savings of $11.7 billion in cumulative direct health care costs and $173billion in cumulative productivity losses over 10 years; and $40.8 billion and $447.2 billion respectively over a period of 30 years (AAC, 2011).

2.4 Arthritis Related Chronic Pain in the Ontario Healthcare System

Arthritic chronic pain is a long-term disease and its care and treatment are mainly managed in primary care, with or without the intervention of specialists (Breivik et al., 2006). Though pain specialists, rheumatologists, orthopaedics and other specialized health care providers play an important role in pain management (Marcus, 2008; Hanna, 2009), currently, in Ontario there are no clear protocols for referrals to these specialists, and there often are long waiting lists and limited access to needed services and supports for pain management (Hofmarcher et al., 2007; OMA[7], 2010). In part, this is due to a shortage of physicians. "Per capita, Canada has one third fewer active physicians than the United States, 15 percent more primary care physicians, and half as many specialists" (Rosser, 2010). Consequently, the heavy responsibilities of Canadian specialists result in shared care with family physicians, with specialists rarely seeing patients without a referral. Canada's physician mix has contributed to containing costs, though the government recognizes that it faces shortages of both primary care and specialist physicians (Rosser, 2010; Berwik, 2009). Moreover, few family physicians have proper training to treat pain (Canadian Pain Coalition (CPC), 2014; LHIN, 2016; OMA, 2015) and they struggle with the lack of adequately defined policies and guidelines for the treatment of non-cancer pain and for the management of chronic pain in general (Fischer et al., 2016).

Concurrently, Ontario is grappling with an epidemic non-medical/illicit use of prescription opioids which has resulted in an increasingly troubling rate of deaths in the last few years. Statistics show that over a five-year period, fatalities from fentanyl alone have nearly doubled in Ontario. When mixed with alcohol, fentanyl killed about seven times the number of people who died from this combination five years earlier (The Office of the Chief Coroner, 2015). Another study released by the Ontario Drug Policy Research Network noted that 638 people died from opioid overdoses in 2013 – a rate of about one death per every 20,000 residents in the province. Thirteen per cent of those fatal overdoses were suicides. Between 2009 and 2013, statistics show

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[7] Ontario Medical Association (OMA)

that in Ontario, there were 2,879 deaths from opioid overdoses. In 2014, hospital records indicate about 3,200 opioid-related emergency department visits in Ontario, which resulted in 1,620 patients being admitted to hospitals (Finestone et al., 2016). Ontario is not alone in this crisis. Opioid related deaths as a result of inappropriate or illegal drug use, both for street drugs and for prescribed drugs that are misappropriated and/or misused, have become a Canada-wide 'disaster' (Sud, 2016).

Meanwhile, there is a political quagmire and polarizations between medical experts, scientists and government officials about the causes for the spike of misuse of prescription and illegal drugs, with many pointing to over-prescribing by doctors as the main driver of people using and becoming addicted (Gome and Juurlink, 2016; Fernandes et al., 2017). Others link over-prescribing to inadequate pain management resources (Finestone et al., 2016). Another school of thought argues that the under-treatment of pain itself might be linked to people seeking to self-medicate by turning to the black market, thereby taking pain management outside the medical purview altogether (CPC, 2011; Malleck, 2015 & 2016) and denounce the apparent reluctance to investigate and address this matter. While concern about addictive painkillers is high and growing, and there is a clear effort to address it, concern about the broader social causes of pain does not appear to be a priority. Failure to investigate and address the causes of pain, both social and biological, and to provide timely and effective pain management is at the root of the present use of illicit opioids (Moore, 2015; Mallek, 2015).

Chronic pain remains a non-priority health issue at the national level (Chipman, 2014; CPC, 2014, 2015), and there is no specific framework for its management either at the national or the provincial level (Palmer, 2016). Instead, chronic pain falls vaguely within the Ontario strategy for the prevention and management of chronic diseases, which unfortunately makes disappointingly few references to pain. Lack of a fitting strategy for the effective provision of care for chronic pain is confounded by additional barriers created by a health care system built mainly for acute care (OMA, 2015). In addition to poor patient access, inappropriate referrals, and the lack of integration and coordination between the various levels of care (Chipman, 2017), further barriers stem from a dearth of research around actual patient health outcomes in pain care, the effectiveness of specific existing pain treatments, and their impact on the patient's health status and quality of life. These can be added to the inadequate systemic capacity to increase availability and access to non-narcotic pain management treatments and supports to people dealing with this condition (CPC, 2015; 2016, Mallek, 2016). Of import is that, at the federal and provincial levels, medical and government bodies have yet to formally designate chronic pain as a medical condition in its own right, despite the national and international efforts of advocacy groups, pain experts, and scientists to ensure that pain be recognized as a stand-alone disease (Cooper, 2016).

The Burden of Chronic Disease

Globally, chronic diseases have surpassed infectious diseases as the primary cause of death and disability. Non-communicable diseases are now the primary factor for 59 percent of the world's 57 million annual deaths, and 46 percent of the world's burden of disease. The proportion of the burden of Non-Cancer Chronic disease is expected to increase to 57 percent by 2020 (WHO, 2016). Similarly, in Ontario, chronic diseases are the leading cause for death (with myocardial infarction and heart disease at the lead, followed by cancers, stroke, and chronic obstructive pulmonary diseases).

"By 2003, almost 80% of those over the age of 45 (CCHS, 2003) or 3.7 million people were living with a chronic condition, including 34% with arthritis, 9% with diabetes, 30% with high blood pressure, and 12% with osteoporosis" in Ontario (MOHLTC, 2007:3). This constitutes a situation that has increasingly worsened with population aging (Hanna, 2009, 2010). Moreover, Ontarians with a chronic disease are likely to have more than one chronic condition, with 56 percent of those over the age of 45 presenting two or more chronic conditions (Statistic Canada 2003, 2009; Hanna, 2010; OMA, 2014). The rising number of co-morbidity is often due to untreated serious chronic conditions leading to additional conditions and other health problems (ICES[8], 2002). According to Statistics Canada[9] serious chronic diseases and related injuries account for over 33 percent of direct health care costs Canada wide, and 55 percent of direct and indirect health costs in Ontario alone (CCHS, 2003).

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[8] Institute for Clinical Evaluative Sciences (ICES)
[9] Canadian Community Health Survey (CCHS)

Furthermore, in Ontario, those with multiple serious chronic conditions consume disproportionately more health care than those with a single chronic condition. To address chronic care, in 2007 the Ministry of Health and Long-Term Care (MOHLTC) developed a policy framework (see Figure 1 Ontario CDPM Framework) to steer the redesign of health care practices and systems to improve chronic disease prevention and management in Ontario: The Ontario Chronic Disease Prevention and Management Logic Model[10] (see page 30) (MOHLTC[11], 2007).

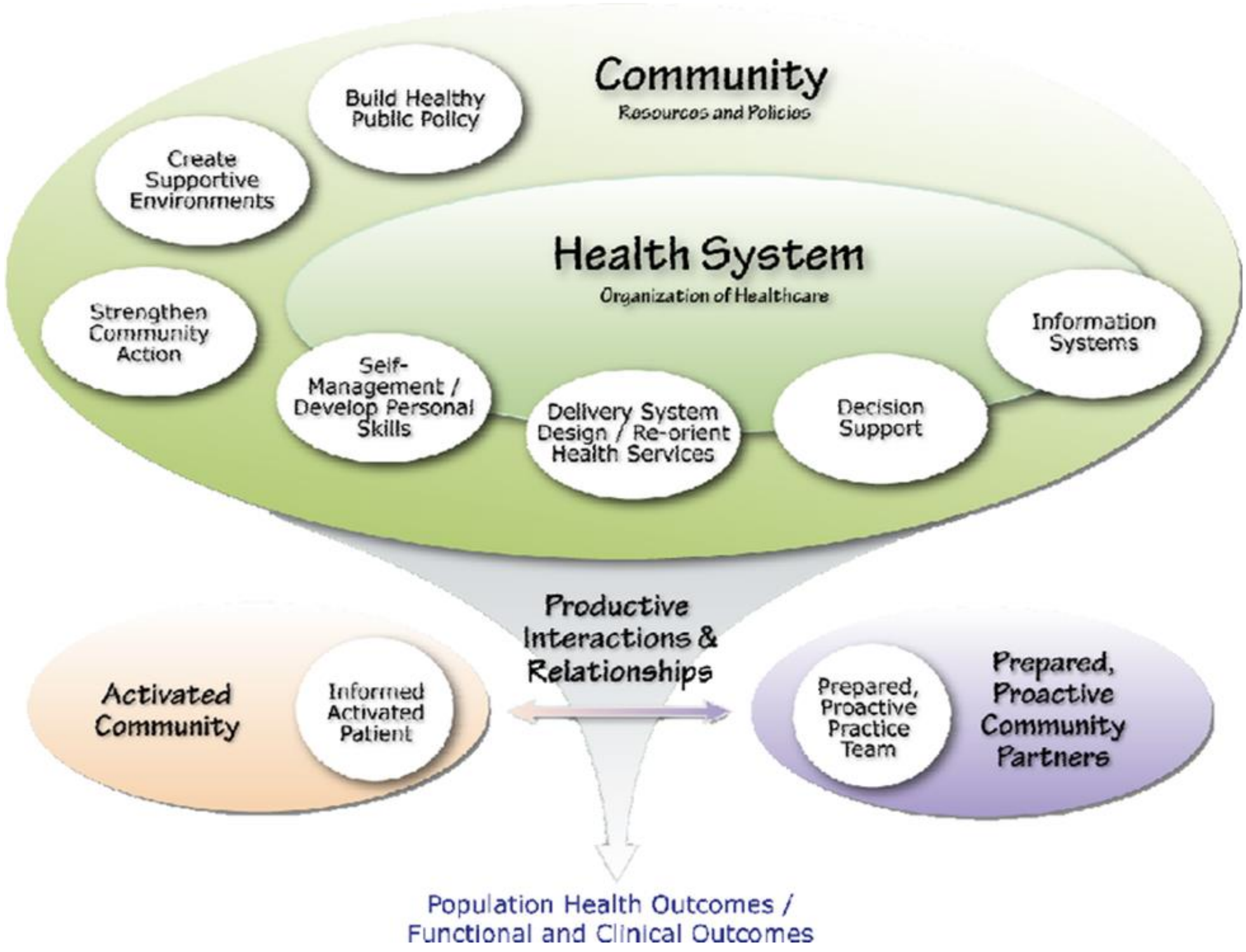

Figure 1 Ontario Chronic Disease & Prevention Management Framework (MOHLTC, 2007)

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[10] In addition to the Framework, the ministry has developed a CDPM (chronic disease prevention and management) Logic Model. The CDPM Logic Model is a visual representation of the CDPM Framework, showing how specific activities contribute to better health and system outcomes and, can be used to develop performance indicators. This tool, in conjunction with the Framework, has been used for the almost a decade for chronic disease planning and evaluation by the Ministry of Health and Long-Term Care, the Ministry of Health Promotion, LHINs, health organizations and providers

[11] Ministry of Health and Long-Term Care (MOHLTC)

As such, the CDPM model presented a new approach to the provision of care for chronic conditions that is evidence-based, population-based, and client-centered. It identified a few interconnected and mutually dependent practice and system changes as essential for the provision of quality care and the effective prevention and management of chronic disease. Among these are a call for improved access; continuity of care and flow through the system; the integration of evidence-based guidelines into daily practice; more information and assistance for individuals to manage their disease; the integration of services across the system, and the provision of supportive living and working environments by addressing inequities through policies and by removing barriers to healthy living (MOHLTC, 2007).

This framework also requires increased community control over issues affecting the health of their residents, the provision of self-management supports, and the stratification of the care of patients based on the severity of their conditions, particularly for those with complex conditions and the elderly. Furthermore, to be effective, this approach necessitates an engaged patient and involves interventions with family physicians working alongside a service coordinator, operating within a patient-defined problem and goals approach to advance patient self-management, and utilizing a structured, evidence-based care plan developed by patients together with their service coordinators and GPs (OMA[12], 2010).

2.5 Patient-Centred Care Model at the Core of Chronic Disease Management

In theory, the 2006 CDPM framework presented Ontario with a roadmap for effective care, better outcomes, and chronic disease management that could "be applied to both specific and generic chronic disease practice and to different types of health care organizations" (CDPM, 2007:9). The CDPM model represented an outright and total provincial endorsement of a full patient-centric model of care that called for the distinct needs of clients with chronic conditions to be addressed through the provision of multifaceted, planned, proactive, and seamless care in which

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[12] OMA Ontario Medical Association (OMA)

Logic Model for Ontario's Chronic Disease Prevention and Management Framework

Vision	An integrated, coordinated system for the prevention and management of chronic diseases, with productive interactions and relationships among individuals/families, communities, and health care organizations/providers, that are proactive, individual and family-centred, and that provides access to quality care by the right provider at the right time in the right place		
Inputs	Policy, Legislation/Regulations, Guidelines, Fiscal and Human Resources, Information Systems		
Components	Activated Communities and Prepared, Proactive Partners	Informed, engaged individuals and families	Prepared, proactive practice teams
Outputs	▪ Communities collaborating with HCOs to identify and prioritize issues affecting the health of the population. ▪ Communities championing activities for healthy public policy, and supportive environments. ▪ Community collaboration with HCOs to develop, link and coordinate services and information for individuals and families. ▪ Community information and programs integrated with health care services.	▪ Education, counselling, behaviour modification programs, and information for individuals and families to build skills for healthy living and coping with disease. ▪ Tools for individuals and families to become daily self-managers and communicate with providers. ▪ Care teams with individuals and families at the centre, and engaged in decision making and care planning. ▪ Self-management information and resources accessible and tailored to meet the needs of individuals and families. ▪ Community programs and resources integrated into care.	▪ Health promotion, primary, secondary, and tertiary prevention incorporated into care. ▪ Visible leadership, aligned incentives, policies, resources, measurement, and accountability for CDPM system changes. ▪ Interdisciplinary team practices, with links to specialists, where health care providers collaboratively provide patient-centred care in a seamless and coordinated manner. ▪ Integrated electronic information systems with comprehensive, accurate information for providers and individuals to share information & make the best decisions. ▪ Evidence-based tools for prevention, assessment and management incorporating planned interactions, and prompts for follow-up.
Short-term outcomes	▪ Increased community collaboration with HCOs to identify and prioritize issues affecting health. ▪ Increased community action for healthy public policy, supportive environments to meet the needs of their population. ▪ Increased awareness, linkages and referral to community programs, information, and resources.	▪ Individuals and families have increased skills and knowledge for healthy behaviours. ▪ Individuals, families and providers have improved understanding of their roles as partners on care teams, and consumers are involved in care planning. ▪ More individuals and families have increased knowledge of their disease processes and role as daily self-manager. ▪ Increased knowledge and skills of consumers in self-management. ▪ More individuals and families are aware of and linked to community programs and resources.	▪ Providers have increased knowledge, skills and tools to incorporate prevention into their practices. ▪ More HCOs promote system change and provide incentives, align policies, resources, measurement, and accountability. ▪ Increased number of interdisciplinary teams, with links to specialists working collaboratively and providing coordinated, patient-centred care. ▪ More providers using electronic information systems and sharing information among team members, their clients, other health providers and settings. ▪ More providers using evidence-based tools, and quality improvement approaches for prevention, assessment and management.
Intermediate outcomes	▪ Improved healthy public policies and supportive environments. ▪ More community information and programs integrated with health care services.	▪ More people exhibiting healthy behaviours ▪ Individuals and families at the centre of the care team, actively engaged in decision-making, and daily managers of their health. ▪ More individuals and families gaining benefits through involvement in self-management ▪ Increased participation in community programs and resources ▪ Increased overall satisfaction of individuals and families with the responsiveness of the health care system to meet their needs	▪ Health promotion and prevention integrated across continuum of care. ▪ Health care coordinated across the continuum of care, providers and settings. ▪ The appropriate type and number of health care providers working in collaboration to meet the needs of the individual and family. ▪ Care is evidence based and meets the diverse needs of consumers. ▪ Care is proactive, and provides for complex and continuing care, with follow-up and ease of navigation. ▪ Integrated information systems with consumer, decision support and community information.
Long-term outcomes	Improved Clinical Outcomes	Reduced burden of Chronic Disease	Improved sustainability of the health system

clients are full participants in managing their care and are supported to do this at all points by the system (MOHLTC, CDPM 2007:9)." The framework is based on the best research evidence available at that time which showed that this approach to CDPM would result in improved health and functioning of chronically ill Ontarians. To make this possible, Ontarians were promised the following:

> "Ontarians with chronic conditions will experience a change both in their care and their disease management. They will become equal partners in their own health and full collaborators in managing their conditions, and they will be supported in this. Their care will be organized and delivered to give the expert care they need when and where they need it, without their having to struggle through the system on their own, bounced from provider to provider. Their care will be planned and based on the best evidence, and both providers and clients will be supported in following through with the plan (2007:10)."

A subsequent step in rebuilding Ontario's health care system was to focus on the quality of care available to Ontarians. To ensure that patient-centred, driven by outcomes and evidence-based care was being provided, the Province passed in 2010 the *Excellent Care for All Act* (ECFA) (Ontario, 2010). This legislation mandated annual public quality improvement plans for every hospital, and required hospitals to publicly report on nine key patient safety indicators, prescribed patient and employee satisfaction surveys and a patient complaints process in all hospitals, and created Health Quality Ontario (HQO) – an agency responsible for promoting evidence-based standards of care, recommending best practices, monitoring, and reporting on and supporting quality of care (Kutty et al., 2012).

A further emphasis of the Province's commitment to patient-centred care is re-stated in the 2012 Ontario's 'Action Plan for Health Care' declaration to be 'obsessively patient-centred', by setting its priorities around patient needs, and echoing of earlier promises that Ontarians could expect increased support to become healthier, with more timely access to services and stronger links to primary health care, while receiving the right care, at the right time, in the right place. In the 2012 Plan, the Government of Ontario also indicated its resolve to change the provincial health care system, transforming it into a more sustainable system to meet these goals for patients (MOHLTC 2012).

This Action Plan not only reiterated that the province's major goal of keeping Ontario healthy can only be implemented through a partnership between the health care system as a whole and the patient, but also restated the government's 2007 pledge to increase efforts to promote healthy habits and behaviours by providing the supports needed for people to embrace lifestyle changes and to better manage their chronic condition. Simultaneously, this plan cautioned Ontarians that for it to succeed, they are expected to take an active role in their own health care by embracing healthy living and wellness practices (i.e., avoid smoking, alcohol and substance abuse, prevent obesity through healthy diet and exercise, stress reduction through meditation, yoga, etc.), as well as by following recommended screenings and vaccination programs (MOHLTC, 2012). A further move towards a more patient-centric model takes place in 2015 when the Ontario Government released two documents: '*Patients' First: An Action Plan to Strengthen Patient Centred Health Care in Ontario*' (January 2015), closely followed by '*Patient First: Proposal to Strengthen Patient-centred Health Care in Ontario*' in December 2015.

Patients First: An Action Plan represents the next phase of Ontario's plan to improve Ontario's health care system, building on the progress that has been made since 2012 as a result of the original *Action Plan for Health Care*. *The Patients First: Action Plan* builds on the 2012 commitment to transform Ontario's health care structure into a patient-centred system and is "designed to deliver on one clear health promise – to put people and patients first by improving their health care experience and their health outcomes" (MOHLTC, 2015). As such, it set clear and ambitious goals for Ontario's health care system, geared to improve access, deliver better coordinated and integrated care closer to home, provide education, information and transparency to help Ontarians make the right decisions about their health, and make the Ontario health care system more sustainable. Later, the 2015 '*Patient First Proposal*' outlined the Ministry's future steps for further transformation of the health care system. This document focused on four interconnected and overarching themes that are intended to inform the Ministry policy and program decisions moving forward, including:

- More effective integration of services and greater equity
- Timely access to primary care, and seamless links between primary care and other services
- More consistent and accessible home and community care

- Stronger links between population and public health, and other health services (MOHLTC, 2015)

What Constitutes Patient-Centred Care?

The Ontario Medical Association (OMA) defines patient-centred care as follows: “A patient-centred care system is one where patients can move freely along a care pathway without regard to which physician, other health-care provider, institution or community resource they need at that moment in time. The system is one that considers the individual needs of patients and treats them with respect and dignity” (Hanna, 2010). Similarly, the Institute of Medicine (IOM) defines patient-centred care as “providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions” (Cook, 2005:48-50). Ultimately, patient-centred care can be defined as ‘the experience’ (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity and choice in all matters, without exception, related to one’s person, circumstances, and relationships in health care” (Berwick 2009). Patient experience is “the sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care” (The Beryl Institute, 2010).

Patient-centered care, particularly when applied to chronic conditions, is multifaceted; requires adequate infrastructure and resources; occurs across various contexts (including mandated treatment, psychotherapy, medication management, supported employment, caregivers and family education, supportive care, rehabilitative services and so on (William et al., 1998, 2004 and 2007; RNAO, 2006); entails coordination and integration of services, ensuring continuity from one setting to another, and the provision of information in a timely and accurate manner (OMA, 2010; Cook, 2005).

However, for care to be genuinely patient-centered, it must include both effective communication between the heath care practitioner and the patient, and a shared decision-making process. Effective communication must take place in the presence of healing relationships, shared understanding, trust, emotional connection, informed choices (Epstein and Street, 2007), autonomy-supportive behaviours (William et al., 2007; Ryan and Deci, 2008), and patient enablement and activation (Epstein and Street, 2007; RNAO[13], 2006). Accomplishing these tasks necessitates much more than the perfunctory use of clinical skills. More precisely, it demands genuine personal engagement and "emotional labour (i.e., management of experienced and displayed emotions to present a certain image" (Larson and Yao, 2005: 1100) as necessary elements of a physician's job and responsibility and crucial to creating healing interactions, strong bonds and increased trust with the patient, all of which "remain essential to quality care" (Larson and Yao, 2005:1100).

Effective communication also requires a comprehensive understanding of the patient's life, and the way it affects their health, and a simple and easy to understand explanation to the patient of the issues. For instance, providing information, such as communicating risk, can be challenging, and particularly exacerbated by poor health literature (Hanna 2007, 2009 and 2010). Physicians need to know how to assess a patient's capacity to grasp disease concepts and participate in decisions about treatment. Ensuring patient comprehension can positively affect patient compliance (Corrigan, 2015). Further, patient comprehension is problematic with patients with mental health or substance abuse issues. However, it is important to involve patients in decision making though this can be difficult for both the physician and the psychiatrist. Those with substance abuse and mental health issues face discrimination and bias, and are frequently marginalized and disenfranchised from society. These patients may also present marked disparities in their abilities and capacities to comprehend concepts or in decision-making ability. It is important for physicians to take appropriate steps to provide their patients the necessary assistance to ensure they are dispensed patient-centred care, and that communication and decision making participation opportunities are consistent with their individual capabilities (Hanna, 2009; OMA, 2010).

A crucial element of effective communication is showing respect for the patient. Communication in patient-centred care requires physicians to ensure that clients feel respected. Patients that feel disrespected are less likely to follow doctor's advice and tend to delay needed care. Another key dimension of effective communication and patient-centred care is ensuring that

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[13] Registered Nurses' Association of Ontario (RNAO)

patients are not depersonalized. Depersonalizing patients is a risk across the system[14] (OMA, 2010).

Physician communication skills are thus key to patient-centered care and current data shows that this approach has positively impacted health outcomes (Jahng, 2005; Levinson et al., 2010; Pincus et al., 2013; Gill, 2013; Jackson, 2005), in addition to increasing patient satisfaction (Mallinger, 2005; Pincus et al., 2013), adherence to prescribed treatment (Robinson et al, 2008; Stewart et al., 2000), adoption of healthier lifestyles (Doyle, 2013) and self-management of chronic disease (Levinson et al., 2010, Epstein and Street, 2011; Epstein et al., 2010; Hudon et al. 2012; Gill, 2013).

Furthermore, a fundamental tenet of patient-centred care is the requirement that patients be provided with opportunities to participate in the decision-making process regarding their treatment options, to the extent they are willing to do so. The OMA states that, "The process may be shared; the decision resides with the patient. Informed consent is a basic premise in law" (Hanna, 2010:39). The engagement of patients in the decision-making process presupposes that physicians are knowledgeable about how patients make decisions and the type of influences that factor into their decision-making processes. In addition, both physicians' and patients' decision-making processes will be influenced by the type of decision being made (Hanna, 2010).

The capable patient's right to make autonomous decisions is recognized in law (OMA, 2010). Further, the patient autonomy concept is a fundamental component of Canada's common law on consent, as well as the legislative framework under the *Health Care Consent Act* (1996); *Substitute Decisions Act* (1992); and the *Mental Health Care Act* (1990) (Hanna, 2010, OMA 2010:39; CNO[15], 2009).

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[14] At all stages of the system, the capacity of physicians and other health care providers to respond to patients as individuals is at risk. This is due to "an inherent conflict between the ability to cope daily with strangers who are partly depressed, sick, suffering, in pain, or dying, and the ability to remain sensitive to these individuals as people." A common defense mechanism to deal with these situations is to depersonalize the patient in distress in a manner that facilitates the heath care professional on-going coping capacity. This creates practices which protect health care practitioners but that can often be insensitive to patients. Patients thus feel that "events that are unique, profoundly important, and personal are transformed into matters of routine, and patients become one of "this group of patients", "this type of problem" or "this procedure" (Hanna, OMA, 2010, Page 38).

[15] College of Nurses of Ontario (CNO)

Moreover, there is a growing body of evidence that patient-centered care leads to increased patient engagement, an essential element of self-management (Doyle, 2013; CCO, 2014, 2015, Baker 2014). Indeed, self-management is critical to establishing patient-centred care. Self-management requires the planned and systematized delivery of information, training and supportive services to enhance patient self-competence and self-confidence by building their knowledge, access to resources and necessary skills to manage their condition. Self-management must also include provider autonomy support behaviours such as the reinforcement of the patient's primary and active role in this endeavor; the adoption of evidence-based practices in care delivery; and customized care plans developed through a collaborative partnership between care providers and patients focused on patient-centered problem solving (Glasgow et al., 2002; MOHLTC, 2007).

2.6 Self Determination Theory and Patient-Centred Care

Patient-centred care is better conceptualized in relation to the notion of self-determination. According to self-determination theory (SDT), autonomy, self-perceived competence, and relatedness are the three key psychological needs that must be met in order for human behavior to be volitional, that is for individuals to perceive that they engaged in their own actions with a full sense of choice, (Deci and Ryan 1985, 2000, 2003). SDT suggests that individuals must perceive themselves as competent and experience their own actions as volitional for intrinsic motivation to be present. Research indicates that perceived self-determination is highly correlated with satisfaction, increased quality of life and positive health outcomes in chronic conditions. Patient empowerment, decision-making capacity, informed choices, social connection, health literacy and perceived self-competence are basic elements of SDT, key components of the Ontario Chronic Disease Management Strategy (2007) and crucial to patient self-management of long-term conditions. Ultimately, the successful management of chronic illness is closely related to the quality of the relationship between health care provider and the patient and the degree to which individuals feel they had choice in their care and that their unique needs, preferences, and values are taken into account and supported by health care providers, and are fully reflected in the type of care they receive (Ryan and Deci, 2008). As restoration of health is not always possible, people with chronic disorders take control of their conditions by:

a) Accepting responsibility for adjusting to the changing phases of their health status, with the varying, and sometimes progressive degrees, of partial or full disability, impairments and other limitations;
b) Increasing their competence to manage their conditions; and,
c) Developing social relationships that give their lives meaning.

These outcomes propose patient-centred care, and are distinctly consistent with the SDT tenets of "contexts supportive of autonomy, competence, and relatedness" (Deci and Ryan, 2002; Podlog and Brown, 2016; Zubialde, 2009).

SDT represents a framework for the study of human motivation and personality that has been used in medical sociology and psychology to help understand how health care providers, researchers, and policymakers can improve patients' biological and psychosocial outcomes (Deci and Ryan 2004; Patrick and Williams, 2012). SDT is based on the assumption that humans are active organisms, who are innately oriented toward growth and health, managing challenges in their environment and integrating new knowledge or skills into a sense of self. Such innate tendencies or orientations do not function in isolation and necessitate ongoing social nourishment and support. Individuals are more motivated when their needs for autonomy, competence, and relatedness are met (Ryan and Deci, 2000; Deci and Ryan 2002). It is this particular social context and its dialectic to the human being that is the basis for SDT's predictions about behaviour, experience and development (Patrick and Williams, 2012).

Self-Determination Theory and Health Research

Concepts related to self-determination first emerged as an influential construct in personality, humanistic, and social psychology in the 1960s (Rotter, 1966; Sheldon et al., 2003, Joiner et al., 2003) and were espoused by the physical and developmental disabilities fields to increase the effectiveness and appropriateness of treatments (Wehmeyer and Bolding, 2011; Smart, 2016). Self-determination has recently been introduced as a goal for persons with mental health challenges (Nota et al., 2007; Mancini, 2008; Lachapelle, 2005; Curryer 2015). Currently, SDT is used extensively in medical sociology, social work and nursing practice, particularly when studying issues related to chronic illness (Edozien, 2015; McDougall, 2015; Nielsen and Bark, 2014, Johnson, 2007). Since SDT principles have been found to be associated with treatment engagement and outcome in a wide variety of health-related behaviours (Ryan and Deci, 2000, 2002; Johnson, 2007), recent and current research applying SDT to medical treatments has significantly focused on patients' preference to be autonomous or controlled, that is 'autonomous orientation'; their perceptions of physician support for their autonomy, namely, 'autonomy support', and their autonomous motivation for, and perceived competence about, engaging in intended behaviours, as well as the impact of patients' sense of connection, belonging, personal safety and security on autonomy and competence (Ryan et al, 2008). Such research suggests that an autonomous orientation and clinicians' support for patients' autonomy boosts patients' autonomous motivation (Williams et al., 1996, 1998, 2006, 2009; Zeldman et al., 2004, Ryan et al, 2008), which in turn advances their perceived competence (Kennedy et al., 2004; Pelletier et al., 2001, William et al., 2009).

Autonomous motivation and perceived competence are known to increase treatment engagement, which in turn improves treatment outcome (Sheldom 2003; Kennedy et al., 2004; Zeldman et al., 2004). Further support for these processes is provided by in-depth research studies in treatments or interventions for tobacco dependence (Williams et al. 2009, 2015); obesity (Sweet et al., 2014; Santos et al., 2015; Texeira et al., 2015; Guertin et al., 2015); physical activity (Santos et al., 2016; Murray et al., 2015); diabetes (Zoffmann and Lauritzen 2006; Williams et al., 2005, 2009; Husted et al., 2014); dieting and healthy eating (Mcspadden, 2016; Lopez, 2016); and adopting healthy behaviours (Hagger et al., 2014).

Furthermore, research into relatedness and its value in increasing competence and autonomy provide strong support for its importance to care. As well, recent research indicates that there is a strong correlation between relatedness and adherence to treatments, engagement in therapeutic action plans necessary for the effective management of chronic conditions, and a patient's sense of empowerment and well being, with the therapeutic alliance being a key predictor of treatment outcomes (Levenstain, 1986; Brody, 1999; Williams et al. 2000; Martin et al., 2000; Olesen, 2003; Krupnick, 2006, Sussman et al., 2010).

Self-determination pertains to individuals making life choices based on personal preferences (Deci and Ryan, 2000; Cook and Jonikas, 2002; Paulson et al., 2002). Decisions about personal or professional life circumstances and interpersonal relationships, including the social roles attached to these domains, whenever based on low-levels of self-determination among individuals with developmental disabilities, and chronic physical and/or mental illnesses, are commonly related to poor quality of life and limited social participation (Nota el al., 2007; Larsen and Lubkin, 2013; McDougall, 2016). This holds particularly true in the field of health and medicine, especially when dealing with chronic pain (Schatman and Cambell, 2007; Larsen and Lubkin, 2013; Deer et al., 2013; Gardner, 2016). The need to explore, analyze and fully comprehend self-determination as a construct, as well as the situational context that either supports and furthers, or thwarts and diminishes, individual capacity to self-determine his/her behaviour, strongly derives from the theorized impact of this construct on individual quality of life.

Extrinsic and Intrinsic Regulated Behaviour Motivation

Self-determination theory posits that different motivational regulations exist, each reflecting varying levels of self-determination (Ryan and Deci, 1985, 2002). At one end, and arranged from highest to lowest degree of self-determination, intrinsic motivation entails pursuing an activity because of interest and enjoyment and without the influence of external contingencies (Ryan and Deci, 2002). Extrinsic motivation pertains to engaging in a behaviour or activity to attain an outcome apart and distinct from the activity itself. Extrinsic motivation is externally regulated through external contingencies, for instance, punishments and rewards (Ryan and Deci, 2000, 2002).

Extrinsic motivation can be additionally categorized, in descending order of self-determination, into: i) integrated, which refers to a motivation for a particular goal, as when engaging in an activity because it is consistent with the individual’s core values and beliefs; ii) identified, which entails setting about an activity because one accepts the value of the activity; iii) introjected, which refers to pursuing an activity because of internal pressures, namely guilt or shame; iv) external, as when engaging in a behaviour or an activity owing to external pressures or incentives such as social pressure, rewards and regulations; and last, v) amotivation, pertains to a perception that there is no valuable or useful basis for partaking in an activity and consequently a complete absence of self-determination (Ryan and Deci, 2002). When health care providers are more autonomy-supportive, patients perceive themselves as responsible for their behaviour and are hypothesized to become more invested in those treatments that lead to better outcomes (Ryan and Connell, 1989; DiMatteo et al., 2007; Ryan and Deci, 2012).

Intrinsic motivation is associated with enhanced mental health and well-being (Ryan and Deci, 2000). However, not all beneficial behaviour is intrinsically motivated (Deci and Ryan, 1985). Extrinsic motivation is commonly required to encourage the adoption of behaviours perceived as unimportant or unpleasant, although necessary for the socialization of individuals and vital to functioning in society (Deci and Ryan, 1985, 2000). Given that many of the behaviours and activities that therapeutic interventions require are frequently unpleasant, problematic or inconvenient, such as healthy eating, exercising, or dealing with the unintended effects of drug therapies, they are commonly regarded as being extrinsically motivated (Williams et al., 1996; Ryan et al, 2008). However, SDT argues that the internalization and integration of these health-related activities are mediated through enhanced relatedness. Individuals tend to take on values and adopt behaviours advanced and encouraged by those they trust and to whom they feel connected (Ryan et al, 2008). The magnitude of the impact of relatedness on a patient`s health-related behaviours, and on their perceptions of self-determination, emphasizes the value of quality of relationships between patients and health care and health support providers, as well as between patients and their loved ones and society at large (DiMatteo et al., 2007; Schatell and Stec Alt, 2008).

SDT argues that the development of a sense of autonomy and competence about these new behaviours is critical to the processes of internalization and integration, through which a person comes to self-regulate and sustain behaviours that are conducive to health and well-being (Ryan et al., 2008). As such, treatment environments that afford autonomy and support confidence are likely to enhance adherence (Ryan and Deci, 2012), and the adoption of healthier lifestyles that include more exercise, which can help them achieve better health outcomes, wellness and quality of life (Ryan et al., 2008; Ng et al., 2012; Flannery, 2017). Furthermore, SDT suggests that some beneficial activities require extrinsic motivation in the form of direction, structure, expertise, information, and the communication of expectations and easy, timely access to health-supportive educational and training programs (Ryan and Deci, 2008, and 2012). Paramount to the treatment and management of chronic diseases, a self-determination approach also contributes to increasing "clients' internalization of extrinsic motivation by providing as much support for their autonomy, competence, and relatedness as is possible"(Britton et al., 2008).

In conclusion, an SDT-based approach is client-centred and posits that people innately value activities that add to their health and growth (Hugger et al., 2014, Texeira, 2015, Williams et al., 2009). Through the support of a patient's autonomy, competence, and relatedness, practitioners may help activate a patient's intrinsic motivation, which in turn will boost and enhance treatment engagement and improve treatment outcome.

Self-determination Theory and Chronic Disease Medical Praxis

The constructs of autonomous self-regulation and perceived competence are pivotal to the application of the SDT to chronic disease. Through the application of the principles of SDT to the services, treatment and care of clients with chronic conditions and the use of interventions that are consistent with SDT, such as motivational interviewing (Miller and Rollnick, 2012; Miller and Gramzow, 2016; Friederichs, 2016; Patrick and Williams, 2012; Miller and Rose, 2009; Teixeira et al., 2012; Deci and Ryan, 2012), health care providers may increase clients' motivation for treatment and improve treatment outcomes (Zubialde et al., 2009, Flannery, 2017). Patients are autonomously motivated to the extent that they have volition and choice. Relatedness moderates autonomy and self-competence, facilitating the balance of individuals' own first-person viewpoint and the acceptance of responsibility. Consequently, autonomy, perceived personal competence and relatedness combine and encourage individuals to engage in behaviours that reflect their willingness to take responsibility for their own wellnesss and well-being, and those of others (Deci and Ryan, 2000 and 2013; Ng., et al., 2012).

Autonomy

Autonomy relates to the degree of volition one feels in pursuing an activity and the need to feel congruence between that activity and one's values (Deci and Ryan, 2000, 2008, 2013). Autonomy on a particular health behaviour denotes that an individual feels that his/her actions are the result of their own choosing and not the pressure to do so by others (Deci and Ryan 1989, 2000). Clinicians that encourage patients to make a choice to follow a treatment plan can increase patients' feelings of autonomy, dignity, and self-esteem. Health care teams that rely on controlling methods such as behavioural contracts, orders, or demands may invoke resistance, rebellion, and contrary behaviour instead (Schatell and Stec Alt, 2008; Deci and Ryan 2008, and 2013).

To help increase patients' sense of autonomy clinicians should engage in behaviours such as: asking for and acknowledging patients' perspectives and preferences; answering questions and addressing concerns; supporting patient initiatives; providing timely referrals to pertinent specialized care and necessary resources; offering choices and clear advice about effective treatment options; minimizing overt pressure and control; encouraging dialogue and participation in decision making; engaging patients in collaborative therapeutic action plans that include their input; promoting and providing essential information about treatments and expected outcomes; providing patients with a meaningful rationale for the care and therapeutic interventions they are afforded and the importance of adhering to prescribed treatment; and, encouraging and supporting the undertaking of activities that may lead to effective self-management of their conditions (Ryan and Deci, 2008, 2012, 2013).

Competence

Competence relates to the need to feel capable of achieving intended goals (Deci, 1975). Perceived competence increases intrinsic motivation when it co-occurs with perceived autonomy (Deci and Moller, 2005; Ryan and Deci, 2000; Fisher, 1978). People who feel personally responsible for engaging in an activity are more likely to care about and feel invested in their performance. Perceived competence is based on the assumption that there is a link or dependency between behaviour and outcome. Hence, individuals are more likely to believe that if they engage in specific behaviours (i.e., maintaining an active and healthy lifestyle, taking daily medications), they will eventually reach the desired health outcome – being pain-free or reducing pain levels, increased mobility and functionality, etc. Consequently, perceived competence is about an individual's personal belief in his/her capacity/competence or ability to carry out the behaviours required to reach a better health outcome. Research in the domain of perceived control suggests that providing instrumental support to increase a patient's own perception of competence increases the likelihood of successful health-related outcomes (Deci and Moller, 2005, Deci and Ryan, 2012; Flannery, 2017).

Patients are much more prone to engage in certain behaviours when they feel confident and perceive themselves as capable of mastering required and relevant knowledge and skills to successfully adjust to new situations, achieve proposed health outcomes, and effectively manage their health condition. SDT predicts that clinicians who support patients' competence with access to relevant health information and through facilitating the transformation of that information into knowledge, necessary skills and training, and furnish the supportive structures and services to help patients to successfully deal and cope with challenges created by their condition, will increase patients' active engagement in health care plans (i.e., participating in target behaviours), which will in turn enhance the attainment of health outcomes (Deci and Ryan, 2008, 2012; Flannery, 2017).

To develop and increase competence, clinicians should ensure that patients get relevant education and training, promote and support participation in self-care activities, encourage and provide resources and supports for patients to acquire and use needed and relevant skills, and offer constructive performance feedback while avoiding negative or humiliating evaluations of performance, all with the intent to empower patients to help themselves to the best of their abilities (Deci and Ryan, 2000 and 2008; Williams et al., 2004).

Relatedness

Relatedness refers to a need to feel supported, connected and have access to important others, as well as vital networks and resources [Ryan and Deci, 2000). Relatedness is linked to the need for interpersonal involvement, emotional involvement with others and the feeling of belonging to a larger community. It is also about the personal human need to sincerely care about others and have others care about them. Safety and security are a crucial and necessary requirement for people to be able to explore their own environment and experiment with new behaviours (Baumeister and Leary, 1995; Ryan et al., 1995; Moller et al., 2010). Relatedness also refers to the need for regular, frequent and continuous caring (Baumeister and Leary, 1995, Moller et al., 2010). SDT suggests that relatedness pertains to the willingness of individuals holding positions of authority, such as health care providers, and in the case of this research, primary health care practitioners (i.e., family physicians, nurses) to bestow psychological resources (i.e., time, energy, and affection) on those with whom they interact (Deci and Ryan, 1991, 2002; Moller et al., 2010). SDT also implies that relatedness would be further enhanced by providing access to medical knowledge, health and community-based supports and resources, and the provision of quality health care and allied health services, in a timely, effective, coordinated and appropriate manner to the meet the needs of patients.

Nevertheless, and as will be discussed later, the social environment can also be maladaptive. Notably, SDT posits that social contexts can be controlling by being coercive and by using monitoring, surveillance, and task-contingent rewards (Ryan and Deci, 2008).

The importance of relatedness in the health care field is underscored by its impact on the patient's adherence to treatment and therapeutic action plans, which in turn improves health outcomes, especially in chronic diseases (Horvath and Symonds, 1991; Martin et al., 2000). Patients are more inclined to engage in successful self-management practices if the behaviours are urged, encouraged, modeled, or valued by people with whom they have a significant bond, or to whom they feel or want to feel attached or related (Schatell and Stec-Alt, 2008).

Clinicians that support relatedness foster the building of strong bonds by trying to increase their understanding of the patient's life, experience of the illness and also their emotional reaction to this experience. Clinicians should also attempt to convey respect, a sense of caring and concern for the patient and that they are as invested as the patient in managing the patient's health condition and minimizing its negative impact on the patient's quality of life. Recognizing the importance of social networks, family members and community-based supports in helping patients in their self-care and facilitating the patient's access to some of these supports, as well as services that will increase the supportive roles of patients' family members and social networks, reinforces the patient's sense of relatedness. Furthermore, to increase the sense of security and safety, it is important that the patient be provided with seamless care and access to appropriate services to decrease the sense of loss, confusion and lack of control (Schatell and Stec Alt, 2008; Ryan et al., 2008).

In view of the importance of these basic psychological needs satisfaction for health, well-being, optimal functioning and increased quality of life, the SDT model will be applied in this study to identify the contextual and personal factors that optimize or hinder patient self-determination and their impact on the patient capacity to successfully manage pain.

This chapter provided available literature on etiology, concepts and burden of chronic pain and arthritis, and Ontario's current stance on patient-centered care and its chronic disease strategy. The background of the Self-Determination theoretical framework underlying current Ontario health care policy was presented alongside its theoretical fit for research into the contingencies that affect patient motivation, choices and behaviour in the domain of health and well-being, and their impact on patient control and decision making in their interaction with the Ontario health care system.

3. Chapter Three: Methodology

Chapter Purpose and Organization

Chapter three presents a description of grounded theory as a methodology to gather information, and the symbolic interactive perspective that is a part of the approach to grounded theory used in this study. It is a detailed description of the procedure used to recruit and select subjects, including how the interviews were conducted and the resulting data collected. It elaborates on the ethical requirements, including unanticipated concerns experienced, the methodological strategies and measures used to organize and analyze experiential texts, and finally, the steps taken to shift from 'perceived experience' to more nuanced insights into the needs and understandings of CP patients in their interactions with the health care system.

3.1 Procedures of the Study

Description of the approach to grounded theory method

Given the inductive nature of this research, a qualitative methodology *(i.e., hypothesis deriving instead of hypothesis testing),* the Glaser and Strauss grounded theory (GT) method, as expounded in *The Discovery of Grounded Theory* (1967), was applied in this study. This methodology offers a meticulous inductive approach to data analysis and knowledge development, which is deeply rooted in symbolic interactionism.

Grounded theory, as a method of data collection, allows us to examine and better understand how situations are perceived, and the behaviours that ensue as a consequence of ascribed meanings (Glaser, 1992). This methodology made possible a deeper analysis and exploration of the complexities of structure, agency, and the cultural, social and economic influences impacting the capacity for self-determination and choice in individuals with chronic pain. Such an approach is highly appropriate for nursing research (Nathaniel and Andrews, 2007; Schreiber and Stern, 2001; and Artinian et al., 2009), public health studies (Bryant and Charmaz, 2010; Green et al., 1996), medical sociology (Charmaz, 2005; Cockerham, 2013), but especially for studies in chronic illness (Charmaz, 2001 and 1999; Orona, 1997), chronic pain (Miles et al., 2005), and pain medicine (Baszanger, 1998; Smith and Parkles, 2008). It is also ideally suited for furthering our knowledge of the behaviour of groups where there has been little exploration of contextual factors that affect people's lives (Crook 2001), and understanding the underlying processes of what is going on, so that interventions can be confidently developed to help resolve participants' main concerns (Glaser, 1978).

Indeed, the development of grounded theory emerged from a perceived research need within the medical sociology and nursing fields (Glaser and Strauss, 1964, 1968). A theoretical stance in the study of health-related issues that balanced the dualism of structure and agency was urgently required. It had become clear that a framework that engaged individual and social influences impinging on health and human behaviour, while correctly integrating contexts, had been undervalued in health methodologies (Poland, 1992). Thus, grounded theory responds to this need to temper sociological determinism with the notion of human agency. "Although it is true that the larger structural (economic, political, cultural, organizational) forces (the macro level) in any society shape the everyday lives of individuals (the micro level), it is also true that the everyday practices of individuals shape those same larger structural forces" (Robertson and Minkler, 1994, p. 297).

Symbolic Interactionism

The early roots of Symbolic Interactionism (SI) can be traced back to 18thcentury Scottish moral philosophers such as Adam Smith, Adam Ferguson, David Hume, and Francis Hutcheson (Stryker, 1980). Yet SI, influenced by the work of George Herbert Mead and Herbert Blumer (Cockerman, 2010), only arises as a serious theoretical perspective to challenge Parsons and structural-functionalist theory in medical sociology.

Relevant to this thesis are Blumer's (1969) conceptual approach and the main assumptions of SI, and the extent to which they can be meaningfully applied to the study of chronic health conditions (i.e., chronic pain), and the understanding of how situations are perceived, and the behaviours that ensue as a consequence of ascribed meanings.

Symbolic interactionism as a sociological perspective posits that meanings are "social products, creations that are formed in and through the defining activities of people as they interact"

(Blumer, 1969, p. 5). Thus, conceptualizations of reality, selves and society are socially created through the process of social interaction.

Symbolic interactionism hinges on the following premises: a) human beings act toward things on the basis of the meanings those things have for them; b) the meaning of such things arises from the social interaction individuals have with each other and society; c) it is through such interactions that symbols are created; and, d) these meanings are handled in, and shaped through an interpretive process used by each individual when dealing with things, others and particular situations they encounter (Blumer,1969). As such, a basic assumption of SI is that individuals do not act instinctively, but rather manipulate symbols and use 'minded behaviour', or creative thinking to interpret, define and attach meanings to those symbols in their environment (Stryker, 1980; 1982). It is precisely this key principle of reciprocal effect between self and social interaction in SI, and as it is embedded in GT accounts, that can assist this study in understanding the manner in which the perception of being disbelieved, the stigma attached to invisible disabilities, biomedical approaches, and gaps in the Ontario health care system, are all linked to the CP patient's capacity for self-determination and decision-making power with respect to their treatments, care, and interactions with the health care system.

For example, it cannot be safely concluded that treatment of the CP patient by a multidisciplinary team constitutes a more effectual level of care, since interactions may be lacking in effective communication (both among team members and between team members and the patient) and in an adequate focus on the particular needs of that patient. This may ultimately prove to be detrimental to the patient's capacity for self-determination and the needed empowerment to comply with therapies or actively engage in the management of their condition. Thus, the meaning/s that individuals attach to each interaction are of great import, since, as posited by Thoits (1982), interactions can only be considered as support to the extent to which they meet individuals' basic needs. Namely, that the value and consequently the benefit of any interaction are dependent on the definition of a particular situation as well as on subjective meanings ascribed to it.

Also, seemingly supportive practices and 'choices' offered may not be considered as empowering, supportive or enhancing of patient capacity for self-determination when they lack the attributes required by patients to make their own decisions. An instance of this is the case of physicians using 'collaborative' or engaging language when providing an array of optional pain relief treatments but lacking in the actions that will turn that interaction into empowerment and make collaboration possible. In this regard, physicians may not provide enough information for a client to make informed decisions, or ensure treatments are truly accessible, or account for how a particular treatment may affect the capacity of the patient to continue working or engaging in daily activities, and so on. The absence of such attributes could result in non-compliance, lack of cooperation and patient disengagement. In theory, this is empowering, but not from a patient's point of view.

3.2 The Methodology of Grounded Theory

In an attempt to reduce the split between the "theoretically uninformed" empirical research and empirically "uninformed" research, grounded theory proposes the induction of theory from data (Goulding, 1999, p.6; 1998, p.54)." In *The Discovery of Grounded Theory* (1967), Glaser and Strauss put forward an inductive process for the generation of knowledge from observations of phenomena as they occur within social contexts. Knowledge, they argued, is discovered within the data. Since Glaser and Strauss (1967) presented their stance, approaches to grounded theory have varied, yet the intended goal is much the same, as articulated by GT experts: to gather insights about lived experiences (Piantanida et al., 2004), to gain insight and broaden/develop understanding (Strauss and Corbin, 1994), to study experience (Rennie, 2006), to describe the world of the population under study (Stern, 1994), and to understand how subjects in a study socially construct their own reality (Charmaz, 2000, 2008).

Actually, grounded theory arises from an effort to harness the logic and rigor of quantitative methods to the rich, interpretive insights of symbolic interactionism and thus it has emerged and is closely tied to it (Dey, 1999; Schreiber and Stern 2001). Grounded theory, as a meticulous approach to data analysis, is indeed grounded through the essential theoretical structures of symbolic interactionism (Melia, 1996; Stern, 1994). The analyses and understanding of human behaviour require studying actors' overt and covert behaviour. This, in fact, constitutes the primary methodological implication of SI as directly addressed through the use of GT (Milliken and Schreiber, 2001).

Grounded theory methodology is not concerned with the ‘truth’, but the conceptualization of what is happening through the use of empirical research. The GT method does not require the formulation of hypotheses in advance; on the contrary, such preconceived hypotheses are regarded as not grounded in the data (Glaser and Strauss 1967). Grounded theory aims at creating concepts that can accurately explain the manner in which people resolve their concerns irrespective of time and place. Description within this methodology only applies to concepts (Glaser 1998, 2001).

Unlike most behavioral research undertakings, the units of analysis in grounded theory are not the individuals or patients but the incidents. Consequently, hundreds of incidents are analyzed in any particular GT based study, as each participant typically reports several events (Glaser and Strauss, 1967).

Researchers using grounded theory start inductively gathering data and formulating hypotheses, which are later confirmed or modified when disconfirmed through the subsequent and continuous collection of data (Glaser, 1992; Silva et al., 2014). This constant comparison of the many incidents/data in a particular area leads to emerging concepts, and their relationships represent probability statements. Thus, grounded theory has the potential to use any type of data, although it is commonly used with qualitative data (Glaser, 2001, 2003).

Notwithstanding the fact that GT only deals with probabilities, it is commonly regarded as qualitative in nature as statistical methods are not employed, and figures are not presented. GT studies do not report statistically significant probabilities but sets of probability statements on the relationship between concepts, or an integrated set of conceptual hypotheses arising from empirical data (Glaser 1998). Glaser and Strauss suggest GT should be evaluated not on validity in its traditional sense since this is inconsequential to this type of study, but rather by their fit, relevance, workability, and modifiability (Glaser and Strauss 1967).

3.3 Research Design

Grounded theory informs this research study. This qualitative and inductive methodology requires the researcher to follow a rigorous process of scientific research (Glaser and Strauss 1967;

Glasser, 1992), and to identify personal assumptions and biases that may interfere with the interpretation of data. Further, GT demands the generation of a sound explanatory substantive knowledge, grounded on the experience of participants and which accurately reflects the reality it seeks to represent (Glaser and Strauss 1967).

Interviews are frequently used as an inquiring device by GT researchers intending to advance their knowledge and understanding of others' experiences (Holstein and Gubrium, 2003). Weiss suggests that, "It is impossible to observe the internal events of thoughts and feelings except to whom they occur" and that, "the significant events of people's lives can become known to others only through interview" (Weiss, 1995, p. 2).

Accordingly, to further understanding and acquire a deeper insight into the meanings patients create about their own participation and self-determination in interactions with the health care system, in this study individuals with severe chronic pain were selected and interviewed to collect the data needed to create a grounded theory.

Criteria

To further participant diversity, the set of criteria for selection was fairly broad. It included any individual who: a) is 21 or older, b) has received care by a family physician practicing in Ontario during the last three years, c) has osteoarthritis and has had permanent pain for at least a period of two years, and, e) rated the average intensity of their pain at a level of 8 to 10 on a scale of 1 to 10, (where 1 represents no pain at all, and 10 represents the most extreme pain they could experience). At first contact, it was ascertained whether the potential candidate for participation met the selection criteria. If so, then they were invited to participate in an interview.

Even though the criteria consisted of any person with pain for at least two years, all of the interviewees included in this study have had pain for several years at least – ranging from three and a half years and up to two decades, with over 90 percent of them experiencing over five years of chronic pain.

Additional criteria were that participants were to be dealing with the Ontario health care system, be mentally sound, spoke English, and be willing to talk about their experiences while being recorded.

Recruitment process

The process of recruiting participants started with the presentation of the study's purpose, significance, and scope. This was done in person at a chronic pain peer support group and a chronic disease self-management peer support group. It soon became evident that individuals accessing differing primary care settings could offer different perspectives concerning the models and delivery of care, services, medical and supportive treatments which varied from one setting to another.

In line with theoretical sampling requirements to increase representation of participants whose experiences differed from the rest, a new intake of participants was later sought. Leaflets were posted on bulletin boards at community agencies and health care centres across Toronto, and referrals were also provided by participants themselves, as well community workers and care providers. Interested potential candidates were encouraged to contact the researcher by phone, e-mail, or in person through the peer support groups. Every effort was made to include people who had access to differing primary care settings such as Family Health Teams (FHTs), Community Health Centres (CHCs), and private practice (i.e., a single doctor working from a particular office) and walk-in clinics.

Also, interviews with individuals who were accessing secondary and tertiary levels of care (i.e., specialists at hospitals, pain management centers and rehabilitation institutes) or private care (i.e., AIM Health Group) through private insurance (i.e., automobile insurance and extended health care insurance) and through workplace insurance such as the Workplace Safety and Insurance Board (WSIB), resulted in a diverse set of themes. For that reason, additional participants that dealt with such insurance providers were sought so as to increase the comprehension of a different but closely related perspective on the issue of care delivered to individuals who suffered CP, and their own role, and self-determination within the context of such care.

Data collection

A form of purposive, non-probabilistic sampling technique, known as theoretical sampling, was used in the selection of these participants.

A central tenet of Glaser's approach to grounded theory is that the emerging knowledge itself dictates who should be included next in the sample and how to find new sources of information. Consequently, the data will also guide the questions that will be posed. Such technique of selection for a suitable sample for study is termed 'theoretical sampling' (Glaser and Strauss, 1967). "What groups or subgroups does one turn to next – and for what purpose" are the fundamental concerns guiding this type of sampling (Glaser and Strauss, 1967:47).

In fact, theoretical sampling was defined as a process that maximizes opportunities to discover variations among concepts and to refine categories in terms of their properties and dimensions (Strauss and Corbin, 1998). Since the use of theoretical sampling prevents a researcher from knowing in advance what to sample or where the data will lead (Coyle, 1997), it is the analysis of data at early stages that points to issues that need further examination, and as such the sampling process directs the on-going theory development (Glaser and Strauss, 1967).

Accordingly, in this study, initial decisions about the type of data to be collected were based on the research topic or problem under investigation. However, it was the emerging knowledge itself that governed and regulated the process of data collection (Glaser, 1992). Following Glaser's approach, further samples were carefully selected as and when considered necessary or required and not prior to research.

Initially, the researcher set out to find candidates that 'were knowledgeable and informative about the phenomena' under investigation (McMillan and Schumacker, 1993, p.378) and that also met the theoretical needs and focus of the research study. Candidates were purposely selected based on having CP and their willingness to share their experiences to contribute to the generation of substantive knowledge related to choice and self-determination within the Ontario health care system for people with this chronic condition.

Participants

Recruited participants constituted a diverse group with regard to their social and cultural background, the range of change between past and present socio-economic status[16] (economic status can change a great deal due to chronic pain and the consequent loss of functionality and increased disabilities), the type of primary health care setting of their family physicians, the quality of their interactions with health care providers, access to treatments, insurance coverage and perceived quality of life. Overall, a total of 23 participants were interviewed through the two intakes.

Study setting: recruitment sites and selection of participants

To establish how to better gain access to a substantive number of people with severe CP, the Canadian Pain Society and the Canadian Pain Coalition were contacted. Based on information provided about several sources that could be mined for participants, a decision was taken to interview members of two groups: The Bridgepoint chronic pain peer support group, and a chronic disease self-management peer support group in a Community Health Centre (CHC).

Several factors led to considering chronic pain peer support groups and chronic disease self- management peer support groups as the most fertile settings to recruit the type of population that best suited the purpose of this study. These groups cater primarily to people with chronic pain and chronic disease who need support (i.e., the most likely people to experience ‘high levels’ of pain). Many are people with OA. These participants were the main focus of this research.

Secondly, these individuals are actively engaged in searching for knowledge, support and the means to deal with the management of their disease through participation in a peer group. This means that the range of experience and awareness about their condition and those factors that assisted them in addressing issues around pain management would, in all likelihood, be

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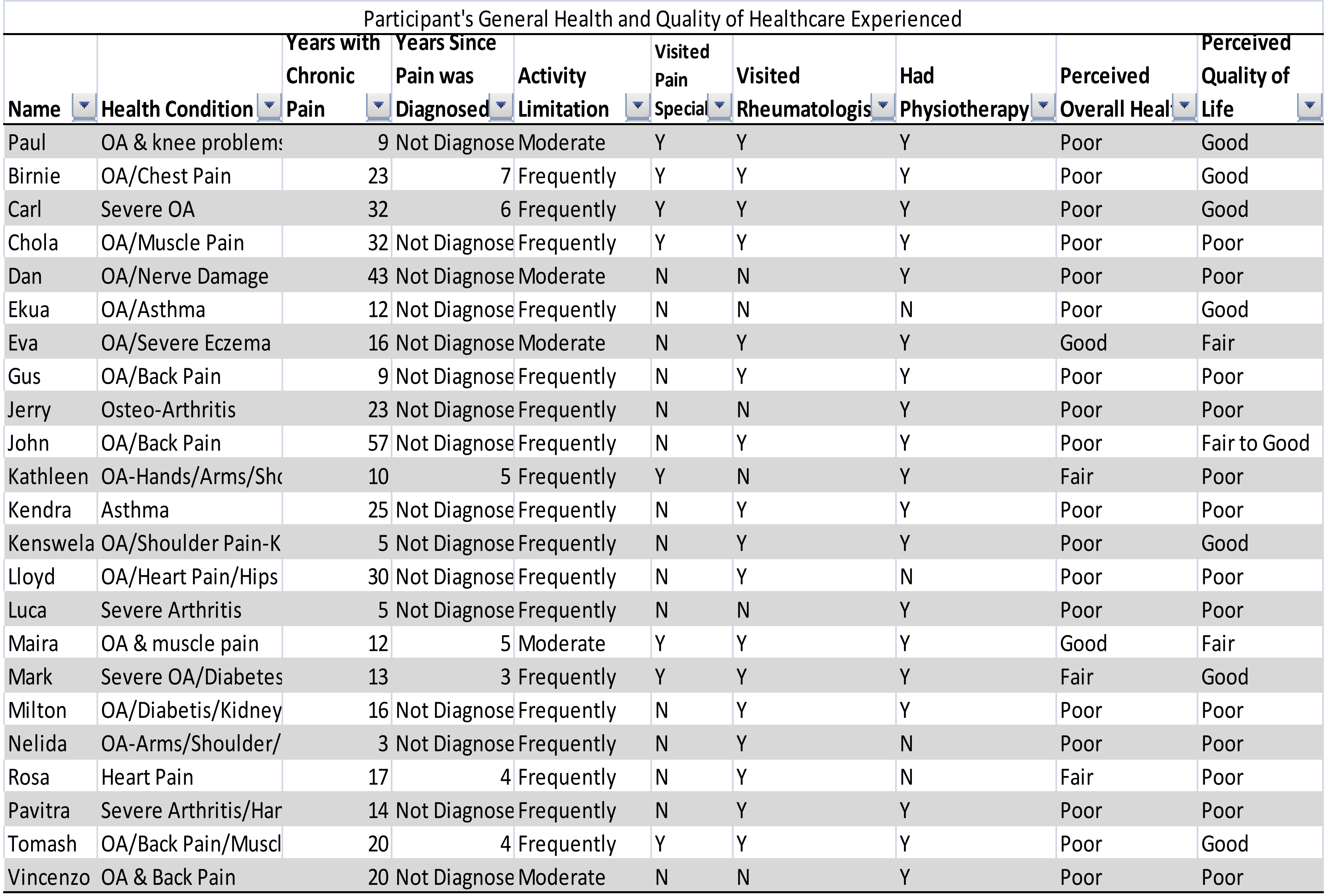
[16] See Table 2 and 3, which provide background information on all of the participants. Please note that the severity of pain and disability classifications are based on the information provided by the participants themselves, and not by their respective health care providers. In other words, patients were not required to provide documentation as to their diagnoses, prognoses and treatments as prescribed/stated by their GP, a rheumatologist or another health care professional qualified to do so.

3.3 Table 2: Participants Demographic Characteristics

Participant's Demographics

Name	Ag	Se	Ethnicity	Education	Region (Urban / Rural)	Marital Status Before Chronic Pai	Current Marital Status	Employment Status prior to Chronic Pain	Current Employment Sta	Income Sou	Received WSIB Support
Jerry	58	M	White-Danish	High school	Urban	Married	Divorced	Self-Employed	Unemployed	ODSP	N
Birnie	57	M	White-Polish	College diploma	Rural	Widowed	Widowed	Employed	Fired - Unemploye	CPP-Old Age Se	y
Carl	63	M	White/African	High school	Urban	Married	Diveorced	Employed	Unemployed	Insurance	Y
Chola	45	F	Latino	High school	Rural	Married	Separated	Employed	Unemployed	ODSP	N
Dan	45	M	White-English	Apprenticeship	Urban	Married	Separated	Employed	Unemployed	ODSP	Y
Ekua	63	F	Black-Jamaica	High school	Rural	Married	Widowed	Employed	Unemployed	ODSP	N
Eva	71	F	White/Ukrani	High school	Urban	Married	Widowed	Employed	Retired	CPP-Old Age Se	Y
Gus	41	M	Black-Ethiopi	Masters	Urban	Married	Divorced	Employed	Unemployed	Insurance	N
John	57	M	White-Can	High school	Urban	Married?	Divorced	Employed	Unemployeed/Qui	ODSP	Yes
Kathleen	38	F	White-English	Bachelor degree	Urban	Married	Married	Employed	Unemployed	Family	Y
Kendra	57	F	White-Irish	Masters	Urban	Married	Divorced	Employed	Unemployed	Insurance	N
Lloyd	63	M	Black-Jamaica	High school	Rural	Married	Married	Employed	Unemployed	Family	N
Luca	56	M	German	Bachelor degree	Urban	Married	Divorced	Employed	Unemployed	ODSP	N
Maira	43	F	Jewish-Hunga	bachelor degree	Rural	Married	Divorced	Employed	On & Off Part Time	ODSP	N
Mark	43	M	White-Croatia	University Degree	Urban	Married	Divorced	Employed	Self-employed	Self	Y
Milton	53	M	Black/Nigeria	bachelor degree	Urban	Married	Married	Employed	Unemployed	Family	N
Nelida	70	F	Latino	High school	Urban	Married	Widowed	Self-Employed	Retired	CPP-Old Age Se	Y
Pavitra	51	F	South Asian	University Degree	Urban	Married	Married	Employed	Unemployed	Family	N
Rose	44	F	White-French	none	Urban	Married	Married	Employed	Unemployed	Family	N
Tomash	51	M	White/Irisch	bachelor degree	Urban	Married	Separated	Employed	Unemployed	ODSP	Y
Vincenzo	54	M	White/Italian	High school	Urban	Married	Married	Self-Employed	Self-Employed	Self	N
Kenswela	47	F	Latino	Masters degree	Urban	Married	Divorced	Employed	Unemployed	Insurance	Y
Paul	49	M	White/English	High school	Urban	Married	Separated	Employed	Unemployed	ODSP	.

3.3 Table 3: Participants; General Health and Quality of Healthcare Experienced



Participant's General Health and Quality of Healthcare Experienced

Name	Health Condition	Years with Chronic Pain	Years Since Pain was Diagnosed	Activity Limitation	Visited Pain Special	Visited Rheumatologis	Had Physiotherapy	Perceived Overall Heal	Perceived Quality of Life
Paul	OA & knee problem	9	Not Diagnose	Moderate	Y	Y	Y	Poor	Good
Birnie	OA/Chest Pain	23	7	Frequently	Y	Y	Y	Poor	Good
Carl	Severe OA	32	6	Frequently	Y	Y	Y	Poor	Good
Chola	OA/Muscle Pain	32	Not Diagnose	Frequently	Y	Y	Y	Poor	Poor
Dan	OA/Nerve Damage	43	Not Diagnose	Moderate	N	N	Y	Poor	Poor
Ekua	OA/Asthma	12	Not Diagnose	Frequently	N	N	N	Poor	Good
Eva	OA/Severe Eczema	16	Not Diagnose	Moderate	N	Y	Y	Good	Fair
Gus	OA/Back Pain	9	Not Diagnose	Frequently	N	Y	Y	Poor	Poor
Jerry	Osteo-Arthritis	23	Not Diagnose	Frequently	N	N	Y	Poor	Poor
John	OA/Back Pain	57	Not Diagnose	Frequently	N	Y	Y	Poor	Fair to Good
Kathleen	OA-Hands/Arms/Sh	10	5	Frequently	Y	N	Y	Fair	Poor
Kendra	Asthma	25	Not Diagnose	Frequently	N	Y	Y	Poor	Poor
Kenswela	OA/Shoulder Pain-K	5	Not Diagnose	Frequently	N	Y	Y	Poor	Good
Lloyd	OA/Heart Pain/Hips	30	Not Diagnose	Frequently	N	Y	N	Poor	Poor
Luca	Severe Arthritis	5	Not Diagnose	Frequently	N	N	Y	Poor	Poor
Maira	OA & muscle pain	12	5	Moderate	Y	Y	Y	Good	Fair
Mark	Severe OA/Diabetes	13	3	Frequently	Y	Y	Y	Fair	Good
Milton	OA/Diabetis/Kidney	16	Not Diagnose	Frequently	N	Y	Y	Poor	Poor
Nelida	OA-Arms/Shoulder/	3	Not Diagnose	Frequently	N	Y	N	Poor	Poor
Rosa	Heart Pain	17	4	Frequently	N	Y	N	Fair	Poor
Pavitra	Severe Arthritis/Har	14	Not Diagnose	Frequently	N	Y	Y	Poor	Poor
Tomash	OA/Back Pain/Muscl	20	4	Frequently	Y	Y	Y	Poor	Good
Vincenzo	OA & Back Pain	20	Not Diagnose	Moderate	N	N	Y	Poor	Poor

broad. Thirdly, since the researcher would be able to meet them in person during some of their support sessions and explain what this study was about, it was anticipated that in all probability they would participate in this research. Fourthly, the diversity of people participating in pain and chronic disease peer support groups is usually high (i.e., pain support group members varied in terms of ethnic backgrounds, socio-economic backgrounds, scope of disability, accessibility to services, and included people whose attending general practitioners were working out of various primary health care settings, ranging from private offices to community health centres). Moreover, these groups were populated with rural as well as urban dwellers.

Out of the 48 people who attended these research presentations at the Bridgepoint pain support group and at the chronic disease self-management peer support group at a CHC, 22 showed interest in participating in this study. Of those, only 12 met the eligibility criteria.

Later in the recruiting process, in search of as much diversity in participants as possible so as to ensure that all themes were saturated, leaflets about this research were posted in doctors' offices, and also in health and community agencies across Toronto. This effort yielded 17 potential candidates. Of these, 10 were found eligible but only 8 participated in this study. The remaining three interviewees were recruited through word of mouth.

This selection process made possible the recruitment of participants with as many different backgrounds as possible. This was key to examining various diverging experiences in order to cover a broad range of circumstances and situations, so as to meet an essential feature of GT theoretical samplings as stated by Glaser and Strauss (1967). Criteria for selection were identical regardless of the recruiting means.

Saturation and the Process of Data Collection

Stipulating the number of participants required in a qualitative study *a priori* is not always feasible (Brantlinger et al, 2005). Within GT methodology, data is collected until theoretical saturation is achieved (Glaser and Strauss, 1967), even though the concept of theoretical saturation itself has often been challenged. Charmaz suggests that categories are saturated when "gathering fresh data no longer sparks conceptual insights" (2006, p.113), while other definitions of saturation imply that saturation is only achieved when the researcher is not hearing any new themes or data.

Dey regards the term saturation as "an unfortunate metaphor" (1999, p.257), and holds that given the uniqueness of each personal experience and every individual experience, it follows that theoretically new information could always be gathered (1999) and researchers using GT should aim for conceptual sufficiency instead, naming categories through partial rather than exhaustive coding (Charmaz, 2006; Dey, 1999). Further, Charmaz speculates that it may never be appropriate to claim true saturation and adds that for data to be regarded as sufficient it must "fit the task and give as full a picture of the topic as possible within the parameters of the task" (2006, p.18).

For the purpose of this study it was initially anticipated that conversational interviews with 10 to 12 participants would furnish enough raw data to start theorizing and to create a coherent depiction and representation of how patients create meaning about their own degree of control and capacity for self-determination in their interactions with the health care system.

Once the interviews were carried out, all but one of the initial 12 participants felt that they failed to manage pain successfully, and that their quality of life was very poor. Since only one participant stated that his quality of life and level of empowerment were relatively good despite having severe pain, there was a clear need to continue the recruiting process. This was done in hopes that it would eventually furnish more participants who experienced a relatively good quality of life, and a sense of empowerment and control over decisions regarding treatments and regimens followed to manage their pain condition. They would assist in better ascertaining factors that helped them to achieve such a favourable position. This realization led the researcher to the recruitment of another 11 participants.

At this stage, and following the Charmaz concept of sufficient data, it was concluded that for this research, under these circumstances, and within the parameters of this study, data saturation had been attained.

From this standpoint, the findings, understandings, knowledge and conclusions identified in this research embody the researcher’s efforts to develop a deeper understanding about the particular group of individuals interviewed. To this effect, theoretical saturation or sufficiency represents the researcher's undertaking to mine gathered data as much as possible. Furthermore, conclusions and recommendations were then the result of the attempt to analyse and categorise the experiences, perceptions and information collected through 23 interviews into a conceptual framework that may provide other researchers, chronic pain experts, health care providers, policy makers and people with chronic pain with deeper, richer insights into the lived experiences of CP patients.

The existing literature was also used for additional knowledge, pertinent to the experiences of people with CP, which supported or provided greater insight about ideas, situations and concepts that informed the categories that were found to be of particular relevance to this study.

Limitation

The diversity of the recruited participants was not wide enough to include various rural and urban communities across Ontario. Most of the participants in this study live in Toronto, and nearby urban and rural settings covering a radius of 150 kms. This limitation was mostly created by the nature of this research (i.e., to meet the requirements of a PhD dissertation and the lack of resources such as money and time). Though this will not affect the strength of the research results in that the issues encountered in different communities across Ontario may differ in degrees as opposed to the nature of the situation (i.e., access may be more limited in smaller communities, especially those not in close proximity to a large centre such as Toronto, but the issue of access itself remains a constant).

Another limitation related to this research design involves the volunteer nature of the sample. According to Sandelowski, researchers should be aware that those who volunteer tend to be some of the most articulate, accessible or high-status individuals of their groups (1986, p. 32). Participants in this research were quite articulate, had above average knowledge about the health care system, are actively engaged in at least one self-management peer support group and were very vocal about their needs and the challenges they encountered in dealing with the health care system. It is possible that other people with chronic pain may not be that self-reflective, or aware of the dynamics between health care professionals and patients, or may not have a relatively thorough understanding of the different components of the health care system.

Gathering of Interview Texts through Guided Conversations

Interview setting

Once eligibility was ascertained and candidates who met the criteria to qualify as participants were identified, interview times and locations were arranged.

To uphold a participant-centred approach, participants were interviewed in locations that they felt best fit their personal needs. Thus, the majority of interviews took place in the homes of participants to make the interview easy and accessible for participants, as so often physical impairment made it difficult to meet elsewhere. On three occasions interviews took place in public locations: two in local coffee shops (close to the homes of the respective participants), and one at a local public library. These venues were chosen exclusively for their capacity to allow for a private area for the interview to take place away from prying eyes, and without interruptions of any kind. In addition, two other interviews took place by phone – as one participant lived far away from the city and the other has a fairly high degree of disability, did not feel comfortable meeting at his home, and was unable to go out to meet in a public place as it would trigger more pain. In both of these cases, the researcher had already met in person with the interviewees (one through the CPC and the other through a pain support group), and sufficient rapport had been established so that the participant and the researcher felt comfortable enough with the process of a phone interview.

All participants consented to face to face interviews or phone interviews. Whenever deemed appropriate, participants were contacted with follow-up questions by phone. Interviews on average lasted 90 minutes. On a few occasions (3) interviews lasted less than an hour. In one case, the participant was overcome with sadness. She explained that talking about her pain with someone ‘that would listen’ made her realize how alone she was with her plight. Total time of the interview was 25 minutes. As the participant appeared very emotional about this and cried, the researcher decided that it was appropriate to stop the interview and remained for another half an hour with participant talking about unrelated topics that brought about some comfort. The intention was to bring emotional containment to the participant so as to ameliorate the effects of the interview (i.e., feelings of sadness and grief). Later, a second interview was set up.

In the remaining two cases, the researcher had already agreed to meet the participants for two 45 minutes periods of time so as to avoid overwhelming the interviewees given that they both anticipated that a longer interview would tax their health condition.

All participants signed a consent form prior to being interviewed and were provided with a copy of the signed consent form for this research study. The researcher also kept field notes of observations during each interview, describing the physical appearance, demeanour, and disposition of participants, their home environment (whenever applicable) and also impressions about the entire interview and interaction. A good example is the documentation of how the researcher felt when an interviewee started crying over her broken relationship with her children, her sense of isolation, and the despair she felt in dealing with her disability and the attached stigma.

Every single interview was carried out by the same researcher. The majority of interviews (19 of 23) were recorded and later transcribed.

Data Collection Through Conversational Interviews

To more deeply comprehend the participant's social reality, the best methodology is one that enables the researcher to gain insights into the participant's world by way of their own perceptions, perspectives and in their own terms (Denzin, 1989). The choice of conversational unstructured interviews for this study was based on the fact that the purpose of the study was to make sense of the participants' social reality. Such approach more accurately conforms to the requirements of a study where the purpose of inquiry is the development of substantive knowledge within an interpretive research paradigm (Denzin, 1989; Robertson and Boyle, 1984).

Another reason to use a conversational approach originated in the researcher's desire to de-emphasize the idea of participants as 'being studied', and instead to engage them as 'producers of knowledge' in the process of finding information that would contribute to an improved understanding of the issue under study (Rubin and Rubin, 1995).

Unstructured interviews allow for no predetermined theoretical framework (Patton, 2002). Question and answer categories in informal conversation interviews are also not predetermined (Minichiello, 1990), hence not only do they rely heavily on social interaction between interviewer and the interviewee, but they also provide the flexibility needed to enable a more productive means to collect text often absent in standardized interview protocols (Brantlinger et al., 2005; Ferguson et al., 1992). Since interviews are unstructured, they help understand complex human behaviour devoid of the constraints of (any) *a priori* categorization(s) (Punch 1998).

Unstructured interviews thus furnish researchers with a wider range of opportunities to uncover unforeseen or unexpected themes and further advance understanding of the participants' social realities as perceived and experienced by the participants themselves (Patton, 2002). Thus, every single interview can then lead to new overarching topics.

However, interviews were not random and non-directive. The purpose of this study and the general scope of the issues guided the discussions (Fife, 2005) of all 23 interviews, ensuring that lack of structure did not translate into an unrestrained conversation. As Minichiello indicated, unstructured interviews are "always a controlled conversation, which is geared to the interviewer's research interests" (Minichiello et al., 1990, p.93). Ten questions, loosely based on the survey questions were used to guide the interviews.

The intended result was that gathering data followed a thematic inquiry – that of the choice, control and self-determination experienced, which is about the meaning participants created about their personal power and self-determination with regard to the treatment and care received within the Ontario care health system.

The conversational nature of these interviews allowed the researcher to easily respond to individual differences and situational changes (Patton, 2002) and to rapidly formulate questions generated upon reflection on those narratives (Briggs, 1999).

Probing questions or comments would almost always revolve around a participant's perceptions, responses, coping strategies and solutions to issues encountered, as well as the reasons why a certain course of action ensued or was followed.

However, abiding by a conventional and accepted practice of loosely guiding the structure of the interview through a list of questions, referred to as an *aide memoire* or agenda (Minichiello et al., 1990; Briggs, 1999; McCann and Clark, 2005), the researcher used a series of questions around a broad guide of topics (Burgess, 1985) to be covered within the interview, but with the intention of creating a certain degree of consistency across the various interview sessions, and without compromising any flexibility.

Theoretical Sensibility

In grounded theory, particularly when coding and analyzing data, and during the process of constructing new knowledge, the researcher's theoretical sensitivity plays a key role. According to Glaser and Strauss, theoretical sensibility refers to the researcher's ability to gain insight into people's interactions as well as to interpret their meaning from relevant data (Glaser and Strauss 1967). This concept, as presented in Glaser and Strauss in 1967, not only entails a level of insight into both themselves and the area of study, but also reflects the intellectual history of the researcher. The concept of theoretical sensitivity acknowledges the fact that researchers are the sum of all their experiences, and accounts for it in the research process (Birks and Mills, 2010).

Even during the interviewing process, theoretical sensitivity guides the researcher in what to listen for and how to follow important cues throughout the conversation. According to Charmaz, theoretical sensitivity is the act of examining life from various standpoints so as to make comparisons, ponder ideas and follow leads. Further, she posits that theoretical sensitivity is developed through theorizing, that is by pausing to take the time to reconsider, assess, examine, compare, weigh up, mull over and think anew (2006).

Issues in Ethics

In many cases the participants were teary, cried or were simply emotionally overwhelmed during the interview. This was difficult. However, the participants clearly welcomed an opportunity to talk about their condition. It seemed though, that as they were explaining the many challenges and changes experienced since they started dealing with pain, the reality of their plight just sunk in.

To strike a balance between the need to seek knowledge and the need to ensure that a respondent's emotional health would be kept intact, whenever a participant was visibly (perceptibly... even if slightly) overwhelmed or emotional (i.e., a shaky voice, tense tone of voice, teary, crying, etc.), no attempt was made to probe into the subject at hand, and the participant was encouraged to either keep talking or shift to another subject at will. Any effort to push for more information felt clearly unethical. Regardless (or in spite of this), the information, the knowledge, and the data offered in each interview was rich, detailed and complex. Efforts were made at all times to avoid broaching sensitive subjects that would have meant that participants would then be left on their own to deal with the repercussions.

While perhaps probing deeper or finding a way to open the participant to a safe discussion of the subject could have been an option, the researcher felt that the lack of formal training in counselling and behavioural interviewing was enough reason to not further explore a situation. The researcher brought a list of social, community and mental health care contacts to be used in case a participant felt emotionally distressed. There was no need to use any of these contacts. Regardless, all participants were handed a list of these contacts in case they wanted to make use of them.

3.4 Analysis

Grounded theory affords researchers in the healthcare field a systematic and interpretive mechanism and a process to be used in order to generate data which has the potential to expound, interpret and guide practice which can be widely embraced by the health professions. Indeed, Glaser and Strauss posited that GT would allow for substantive knowledge to develop in direct response to immediate issues under investigation and unambiguously be more pertinent to the studied area than all other pre-existent knowledge (1967).

Glaser and Strauss specify the four-stepped process involved in the grounded theory methodology to analyse data. As the theoretical sampling starts with inceptive data collection and analysis, Glaser (1978) indicated that open coding becomes the first step of such analysis, leading to the discovery of categories and their properties. This process underscores data that the researcher believes may be of relevance beyond the plain description of the data context (Lowe, 1996). By constantly comparing code-to-code and incident-to-incident and sampling for similarities and differences, while querying the data through basic questions such as 'what is this data a study of?' (Glaser 1978), 'what category or property does the incident indicate?' (Glaser, 1978:57; Glaser and Strauss, 1967), and 'what theoretical category does this datum indicate? (Glaser, 1978), Glaser suggests that the research thus 'moves from description to conceptualization' (Glaser, 1992:51).

As codes are elicited, certain theoretical propositions occur concerning links between categories, categories and their properties, or a core category. At this point, through memo writing, those theoretical links are captured. Memo writing assists the researcher in conceptualizing the boundaries and properties of every single category and elucidating gaps in the emergent concepts and information which will guide the decisions about where to sample next and for what theoretical purpose (Glaser 1978). Alongside data collection and comparison, theoretical sampling and memo-writing are a joint process through whereby codes can be adjusted, trimmed and continually fitted to the data (Glaser 1978).

Grounded theory methodology proposes that knowledge is concealed in the data and must be discovered. While coding makes visible some of its components, memos supplement the relationships which link the categories to each other, acting as the building blocks of knowledge development within the GT methodology (Haslam, 2014). As such, memos stand as written notes of analysis concerning the development of knowledge (Chenitz and Swanson, 1986) and are used as a part of the process of abstraction, and must, therefore, be expressed in conceptual terms (Goulding 2002).

Only when this 'analytical framework' shapes into a systematic understanding that could be regarded as a reasonably accurate reflection of the issue studied, and can be couched into a form which can be used by others in that same field (Glaser and Strauss, 1967, p 113), then a final version of such knowledge as it emerges from coded data and the research notes can be rendered.

Coding is the first stage in knowledge development (Glaser and Strauss, 1967; Charmaz, 2006). In this study, the coding process started as soon as the first interview was concluded and transcribed. Words, phrases or passages relating to issues of personal control, choice, input, empowerment and self-determination were identified. In addition, any text that indicated situations and elements that afforded support for, or a barrier to these passages were flagged. Also, any themes that appeared to carry some significance or pertinence to the subject of study were also identified and marked with a code. Constant comparison started immediately, by comparing code-to-code, incident-to-incident and by searching for similarities and differences, and documenting any significant ideas that emerged.

Soon categories were discovered that made sense of what participants had related to the researcher. For example, while some participants talked about 'doctors dismissing or ignoring their frequent complaints about constant pain'; others complained that 'doctors treated them with rudeness and disapproval'. These two instances became a property: a subcategory of 'Relationship with Primary Physicians'. Eventually, a core category emerged with high frequency of mention and was connected to many other categories. After much iteration, codes were finally collapsed into nine subcategories: 1) All-Encompassing Impact of Chronic Pain on Individuals; 2) Access to Services; 3) Etiology of Pain; 4) Treatment; 5) Family Physician Relationship with Patients; 6) Issues with Ontario's Health Care System; 7) Stigma; 8) Lack of Negotiating Power; and 9) Empowerment. These nine subcategories, were then collapsed into a broader core category 'Structural Alienation'.

Trustworthiness and Validity in Qualitative Research

Rigour, as applied to qualitative research, refers to 'the evaluation of good research and the unspoken standard by which all research is measured' (Davies and Dodd, 2002), which is reached through trustworthiness. The concept of trustworthiness relates to the ability of the researcher to persuade others that the study or enquiry in question is worthy of attention, and they can have confidence in its validity (Lincoln and Guba, 1985).

The criteria applied to ensure the trustworthiness and scientific rigour of this research arises from the operationalizing of its credibility, transferability, dependability, and confirmability. These alternate criteria are seen as appropriate for qualitative research (Lincoln and Guba, 1985) instead of the conventional approaches applied to quantitative and quasi-experimental methods relating to internal and external validity, reliability, and objectivity, with the view of ensuring generalizability of results (Cook and Campbell, 1979).

Credibility was determined through three major techniques. The first technique refers to activities that increase the likelihood of producing credible interpretations and findings through prolonged engagement and persistent observation. A second technique involves external checking of the inquiry by peer reviews. Another technique advanced by Guba is the process of refining working hypotheses through new data and information, for instance through negative case analysis**.**

Prolonged engagement was attained through the researcher's professional activities. These included being a board member of the Canadian Pain Coalition, and engaging with other academics and medical scientists in research and advocacy for people with chronic pain. Throughout this period the researcher started working on the conceptualization and background review of relevant theories and literature. These engagements also allowed for the refinement of the line of inquiry, the focus of the research (i.e., focus shifted from care provided at all levels – primary, secondary (hospitals), tertiary (rehabilitation centres and specialized care) to only primary health care), and the interview tools (which moved from structured questionnaires to conversational interviews).

At the same time, the researcher was working as a clinical director at a community health centre, and as a director of a centre for people with disabilities, and became a member of the Local Health Integration Network's (LHIN) newly created Health Links. All of these undertakings increased exposure to the health care system itself, the field of chronic pain, and to medical scientists, policy makers and academics. This facilitated learning about the culture and the field of CP, enhancing the opportunity to produce better insights into the plight of people with complex and chronic diseases. It made possible more credible findings through discussions and case presentations with experts in the field and other health care professionals. These same work situations afforded the space for persistent observation and peer debriefing, and the chance to undertake negative case analysis and referential adequacy**.**

A fourth technique employed in this study is theory triangulation. Grounded theory, self-determination theory and critical theory afford differing perspectives for the interpretation of data and serve to strengthen the study.

Lastly, the fifth technique used in the establishment of credibility was the direct testing of findings and their interpretation by two of the participants in this study, who were further encouraged to critique and check the accuracy of the emergent theory.

Dependability and Confirmability

This study constitutes a doctoral research project. Thus, supervisors and peers ensure dependability and confirmability of the data, processes and findings. According to Lincoln and Guba (1989), both these criteria are attained through an audit trail. Both the process and product of the inquiry are examined by the audit trail. This entails a thorough review encompassing all facets of the inquiry, from its acceptability to the findings, interpretations, and recommendations. This includes both the acceptability of the inquiry to establish dependability through support of the data and the confirmability through internal coherence. In order to ensure auditability, the researcher has kept raw data, field notes, the iterations that were developed when working and reworking the data into various categories, data reconstruction and synthesis, and any materials and notes that related to intention and disposition informing instrument development, which may be of significance in confirming findings.

Transferability

Lincoln and Guba note that transferability in naturalistic inquiry is indeed impossible, suggesting that the concept of external validity in its conventional meaning cannot be applied to qualitative methods (1989). For this reason, researchers are encouraged to provide detailed, and exhaustive descriptions of their research, containing comprehensive information about informants' backgrounds, context of inquiry, including reasons for the use of purposive sampling, and any procedures followed. As such, the researcher is charged with providing a data base leaving the burden of judgment as to the transferability of data and findings to the reader. Consequently, each step of this research has been thoroughly detailed in each chapter; from the conceptualization of this study to its qualitative approach theoretical framework and methodology.

3.5 Ethical Considerations

To adhere to relevant university guidelines for ethical approval, an application was made to the York University Ethics board and approval was obtained prior to undertaking this study. Detailed information about the study purpose, scope and significance was given to all participants, including details about the interviews and any aspect that might have affected their willingness to participate.

Consent forms explaining benefits and risks and including assurances of confidentiality and anonymity were signed by all participants prior to the interview process. Participants were advised that their conversations would be recorded. Participants who did not wish to be recorded were asked if they would agree to notes being taken during the interview process. Pseudonyms were used throughout the process to ensure anonymity. Participants were informed that they could withdraw from this study at any time. Contact details of the researcher and her study supervisor were made available prior to starting the interview. Consent forms and data for this study are maintained in a locked cabinet in a designated location. At the conclusion of this study, all identifying information shall be destroyed.

Chapter Four

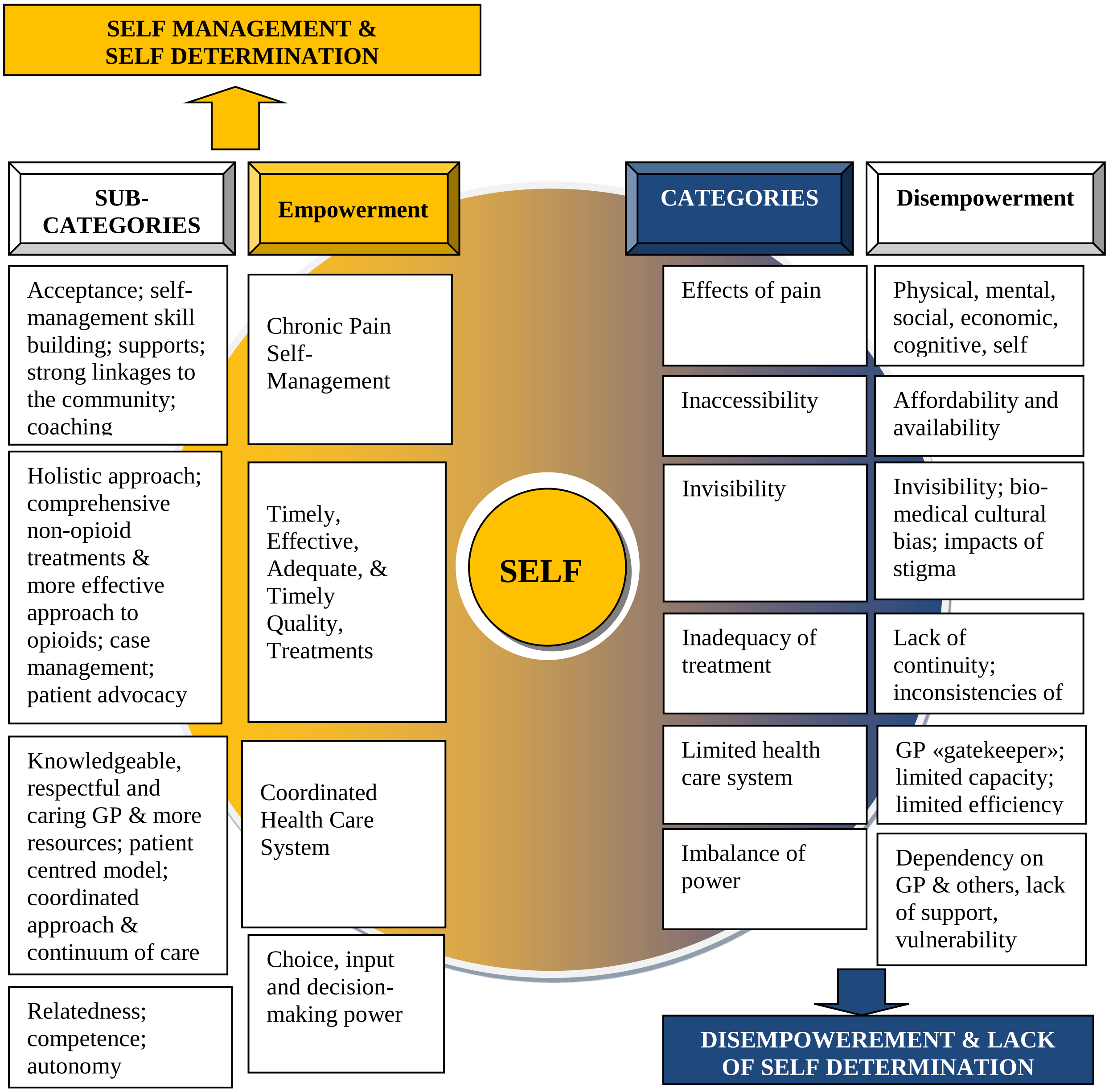
4. Data Analysis

The analysis of the data as presented here elucidates the social constructs of individuals with chronic pain which can lead us to a deeper understanding of the outcomes for individuals with chronic pain within the Ontario health care system.

There are nine (9) categories that are supported by the narratives, stories and bio-data of 23 participants, namely: All-Encompassing Impact of Chronic Pain on Individuals; Access to Services; Etiology of Pain; Treatment; Family Physician Relationship with Patients; Issues with Ontario's Health Care System; Stigma; Lack of Negotiating Power; and Empowerment. These categories and properties within those categories, as well as their mediating relation to the core category 'alienation as the loss of autonomy and the preclusion of self-determination' as perceived by individuals within the Ontario health care system and the impact on their perceived quality of life are presented below.

The following chart represents a framework which articulates the thematic concepts within these categories along a spectrum ranging from disempowerment and non-self-determined regulation (a disempowering process, leading to the increasing loss of self-determination of the patient, who feels trapped by both his body and the system, with no way of escaping the pain and the ensuing suffering) on the one hand, to self determination and self management (all the positive elements and contextual conditions in the interaction of patient and heath care system, measured in terms of control, self-esteem, autonomy, support, knowledge, and, ultimately, empowerment and self-determined regulation) on the other hand. At the centre of this framework is the patient; the circle of chronic pain represents the omnipresence of this pain, which affects every single aspect of the person's life.

FIGURE 2: CAPACITY FOR CONTROL AND SELF_DETERMINED REGULATION FRAMEWORK



SUB-CATEGORIES	Empowerment
Acceptance; self-management skill building; supports; strong linkages to the community; coaching	Chronic Pain Self-Management
Holistic approach; comprehensive non-opioid treatments & more effective approach to opioids; case management; patient advocacy	Timely, Effective, Adequate, & Timely Quality, Treatments
Knowledgeable, respectful and caring GP & more resources; patient centred model; coordinated approach & continuum of care	Coordinated Health Care System
Relatedness; competence; autonomy	Choice, input and decision-making power

CATEGORIES	Disempowerment
Effects of pain	Physical, mental, social, economic, cognitive, self
Inaccessibility	Affordability and availability
Invisibility	Invisibility; bio-medical cultural bias; impacts of stigma
Inadequacy of treatment	Lack of continuity; inconsistencies of
Limited health care system	GP «gatekeeper»; limited capacity; limited efficiency
Imbalance of power	Dependency on GP & others, lack of support, vulnerability

4.1 Category One: All-Encompassing Impact of Chronic Pain on Individuals

The impact of arthritis and chronic pain on individuals is pervasive and often debilitating. Over time, all aspects of the person's life can become consumed with the pain. This ubiquitous aspect of pain is reflected in a number of subcategories, ranging from the physical to the mental, and from the private to the social spheres of participants' lives.

4.1.1 Physical impact

All the interviewees related their physical changes and the experience of pain as devastating and overwhelming.

> the pain comes—just like that, and it doesn't go away. It usually comes at night. I have throbbing pain, in the middle of the night. I cannot lie down. I cannot open my eyes. I cannot stand up. I change positions. I sit. I stand. I sit. I go to bed. I move to the couch. I sit again. I stand again. I cry. Pain becomes worse if I stand still and any movement makes it worse. (Pavitra)

In most cases (22), increasing levels of pain are accompanied by higher levels of disability and declining capacity to function and carry out the most basic activities of daily living or even perform a hobby. This disability is represented as loss of mobility:

> I will be in pain so bad that it paralyses me. I cry sometimes. (Kathleen)

> When [the pain] is bad I can't put my socks or my underwear on, and it gets bad with the change of weather. Winter is the worst. (Vicenzo)

Many participants (12) relate to pain as more than a disability, in that it does not just create impairments, limited or restricted movement, and lack of functionality (mental and physical); it also carries with it an overwhelming amount of suffering that is perceived as taking away any ability to manage their lives with a modicum of control, satisfaction, dignity, and quality. This they attribute to the pervasive presence of sorrow, hurt, misery, agony, and vexation brought about by persistent and intractable pain.

> It's different from any other sickness. Anyone can be disabled. Hurting all the time is more than being disabled. I suffer and suffer and suffer with no breaks to feel slightly happy. Being blind will not let you do many things. You can't read or watch a movie. But you can learn other ways of reading [by] going to blind people schools. People without legs can't run, but they can sit down and use a wheelchair to move around. They can be happy and enjoy a party. When I hurt, I can't walk, I can't sit and enjoy

> a movie, I can't read because my mind doesn't work. I hurt and then I hurt more. (Lloyd)

Participants spoke about the most common health issues they experienced beyond decreased mobility, disabilities, and functional impairments, such as chronic constipation, diarrhoea, anal fissures, bloating, gas, grogginess, cognitive dysfunction, weight loss (due to the inability to keep food in the stomach), weight gain, inability to think clearly, inflammatory bowel syndrome, ulcers, kidney problems, high blood pressure, and cardiovascular disorders. These health issues, they claim, are largely related to unwelcome after-effects of treatments (i.e., NSAIDs, morphine) used to manage the arthritic pain condition.

> I am nauseous. Morphine does it to me, always constipated. My doctor, she gives me laxatives, and they stop working after some time... I have hemorrhoids... (Nelida)
>
> The worst was with some types of antidepressants. I could not stand the dry mouth. (Rose)

4.1.2 Mental impact

Participants state that their cognitive and physical abilities are continuously drained by the constant and often crippling intensity of pain. They argue that subsequently their intellectual competence and capacity to perform tasks that require concentration and use of reasoning skills are reduced.

> I don't think straight when the pain is high. It sucks my brain like a leech. (Maira)

According to most participants (20), cognitive abilities have also been affected by side effects of drugs used in treatments received. They claim that pain suppressants, antidepressants, and other drugs affect their ability to think and reason or make decisions. Here are comments on this particular phenomenon:

> I take drugs for depression. I feel like I am never fully awake. I can't think straight. I can't focus and I still feel depressed. (Kenswella)
>
> To apply for disability and all the insurance is difficult... I cannot think clearly. I lost most of my memory. I cannot focus as I used to. The antidepressants and no sleeping have hurt my mind. I noticed I can't figure things out; it is more difficult now. (John)

All participants cite chronic insomnia as a most challenging effect of severe chronic pain and commonly a catalyst that sets off a chain of equally injurious consequences, such as mental, emotional, and physical exhaustion; diminished cognitive abilities; stress and nervous tension; loss of balance, muscle tension, and more pain, and most important, a sense of doom due to lack of rest.

> I only sleep two hours at a time and I wake up and… get up because the legs and arms are numb or something hurts and I need to move around, or I go to pee. I[‘ve] turned into a zombie. Never sleeping. Never feeling completely awake. It’s devastating. (Carl)
>
> Terrible. Sleep deprivation is the worst side effect of pain and the drugs. When I get so bummed out and wired because I’m not sleeping enough and then the stress makes tense muscles, and then I have chest pain and all the body starts hurting. (Gus)

Emotional health

Mental health disorders such as depression, stress, anxiety, and mood swings are widespread among participants, with 23 out of 23 cases reporting currently experiencing, or experiencing in the past, one or more of these effects:

> I cry all the time… I am stressed and can feel edgy, upset, angry, and irritated all within one hour. Pain does me in. I am losing it. (Marc)

Participants often express their fear that pain will never stop and that it will lead to total disability. This fear, according to their accounts, is generally exacerbated by a sense of being shunned by those who matter most at a time of deep vulnerability and largely the concern that they may not have anyone around to care for them in the future.

> I’m scared. I have been abandoned by my wife; my children are not talking to me, and I am getting worse. I don’t want to think about the future, but I think about it all the time. I see nothing but more pain and more stiffness. (Jerry)

Feelings of uncertainty, powerlessness, and loss of control are widespread among participants.

> I can’t do anything—absolutely nothing. I mean, I can barely walk, sit or stand, and I can’t do anything with my arms unsupported, so there is not a lot left to do. I feel powerless. I feel impotent—yeah, that’s what I feel. (Kathleen)

Most interviewees (17) talked about frequent suicidal thoughts, oftentimes precipitated by bouts of prolonged severe pain. Suicide appears to be usually regarded as a potential exit from an already unbearable situation that may become even more intolerable.

> It is cruel. It is not a good thing. I get exasperated when it peaks. I often think that it would be better for me and for my family that I die. I used to think often about suicide, but I never tried anything strange. I am a pastor. I am a man of God. But I think about it. (Milton)

4.1.3 Social impact

All participants in this study report that their social supports and networks have been negatively affected by their chronic pain condition. Indeed, shrinking social networks and social isolation are cited as common occurrences, mainly caused, they claim, by factors such as family dynamics, which transform as a result of the changes in levels of functionality and disability, and accompanying shifts in roles and identities in private and public life caused by CP.

> I can spend weeks without talking unless I count the cashier and the pharmacist. (Luca)

Increasing levels of pain can be accompanied by or associated with higher levels of disability and declining capacity to function socially, both at home and in the community as a whole. Disability and lack of independence have had a great impact on relationships with family members. Interviewees reported feelings of humiliation, ineptitude, uselessness, depression, and low self-esteem. These feelings are not only the result of experiencing pain and increased disability, but frequently because they perceive that those around them become increasingly less understanding and supportive and are more likely to respond to them with aloofness, contempt, or even condescension.

> My husband could not understand pain. I looked terrible. I was feeling depressed and angry. I was an equal partner before this problem and I am not an equal partner now. He felt left out of my life. I could not pay much attention to him, and he started drinking a lot. He knew something was wrong. He withdrew emotionally. Before the pain, my relationship with my husband was very good. (Rose)

In fact, interviewees report that often these changes (increased disability and dependence) cause stress and resentments among family members, which commonly lead to relationship breakdowns, family breakups, and most importantly shifting family dynamics.

> I was the head of this house; now they lost respect for me. My wife and my children had to learn to manage without me. They don't need me, and they certainly haven't embraced the burden I have become… They avoid talking to me as much as they can without being outright rude. (Paul)

In many cases, marital and spousal relationships take a turn for the worse, mostly because their sexual lives become casualties. Chronic pain undermines physical and emotional intimacy with partners and spouses.

> I don’t feel romantic when I know that having sex will hurt… having sex means pain… there’s no fun. I don’t care anymore if my husband wants to see somebody else. I love him, but I am resigned. (Kathleen)

All interviewees feel the negative effects of pain within their family relationships. Of the 23 cases studied, the following occurred: (a) In 13 cases, relationships ended in separation or divorce; (b) With the exception of two cases involving individuals who are widowed, the rest feel that their spouse/partner relationships have taken a turn for the worse; and (c) Despite reporting that family relationships have deteriorated since they became ill, five out of 23 interviewees report that they feel supported by their spouses, and in four cases the individuals have moderately satisfying relationships with partners and/or children.

Relationships with children seem to take a toll, mostly when children are young and/or living in the same household. This is due to changes in family roles (provider, parent, caregiver), and the stresses and tensions created by changing levels of functionality in the CP patient.

> I stopped being a mother. I was the caregiver; now they were. It was hard on them. They were young. It was hard on me too. Soon they stopped treating me as their mother. They started to order me around and did not share anything about their lives with me. (Kathleen)

In all the eight cases involving adult children who have already left home, interviewees report not seeing them as often as before they became ill. The offspring are not visiting as often as a result of their relationships being negatively impacted by the disease and/or the interviewee cannot visit the adult child due to impairments and disabilities, which include their own need to withdraw from everyone due to the intensity of pain and/or depression.

> I am a widow. I was close to my children until I started having pain. They think I am obsessed with my pain. I can’t help it. I cry all the time and I hurt. They don’t want to be around me anymore. I am a burden now. (Nelida)

In all cases, interviewees report that CP has negatively impacted friendships and other social involvement as well. CP affects socializing because depression, feeling worthless, loss of functionality, increasing disability and pain itself reduce the desire and ability to socialize. Activities such as going out, visiting relatives or friends, using the public transport system, and travelling can simply be too daunting. Visiting or even being visited becomes complicated by the illness itself.

> I avoid going out. Everybody has a life, something they do, stories to tell, like about their jobs and the movies they watched. I am increasingly boring. Nothing I've done, no places I went, and no job to talk about. (John)

Social support breakdown and increasing isolation are sometimes caused by the interviewees' sense that pain must be hidden. For example, regular social activity often decreases or disappears entirely as chronic pain begins to impact physical capacity, and the pain sufferer feels compelled to hide their pain to avoid rejection or negative judgment.

> I don't initiate friendships because it is hard to maintain them when you are always ill, so you try to hide it as much as possible. In the past I tried. Now I don't. I know I will not be able to keep up. I don't like telling them that I can't do something because I am in pain. The rare times I did, I noticed that others felt turned off. (Chola)

> Never talk about pain with friends. If you do they don't get it… You pretend everything is OK, but you can only pretend so much. They see you tired or quiet. They think you are not interested in what you are doing. It's not so. (Vicenzo)

4.1.4 Economic impact

According to participants, their livelihood and sources of income have been compromised by the challenges of living with CP. Most interviewees (22) found themselves sooner or later grappling with their ability to maintain the source(s) of their livelihood, often leaving them in a fragile economic state.

> First worked part-time—three half-days. Then I worked two hours twice a week until I could not work at all. (Carl)

Twenty out of 23 participants affirm that their capacity to be gainfully employed has been compromised by arthritic chronic pain. The three exceptions are two participants who have never held a job for pay and a third who is self-employed. One is a widow and was never gainfully employed; the second identifies herself as a house engineer and, though her capacity to run her household has been severely mired, she has not wrestled with an economic downturn due to chronic pain because her husband has always been the sole breadwinner. All participants but one report lower economic solvency, including those who depend on their spouses or pensions for income since they have to pay for household care, child help, etc. The exception is a case where the participant is self-employed and enjoys a privileged economic position that allows him to secure support that enables him to continue successfully with his enterprise.

> I didn’t have money for the mortgage. I had no income. I applied for disability, but the money was not enough to save my house. My home is gone. I live in a rooming house. I have to be careful about food so I don’t go over budget. (Gus)

Oftentimes the pain itself is identified as the primary impairment preventing employment.

> It’s difficult to be a roofer if you can’t go up to that roof because your knees give out in pain. (Paul)

Interviewees reported that resultant physical symptoms such as exhaustion, lack of energy and insomnia lead to stress, anxiety, depression, and decreased cognitive capacity, which makes it difficult for them to maintain employment.

> I was exhausted. I barely slept. I could not deal with meetings anymore. I was so anxious because I knew I was failing everybody. I got two PIPs (performance improvement plans), and I was fired when I forgot that I had a presentation. (Luca)

Also, side effects of drugs taken to deal with chronic pain conditions often play a role in interviewees’ inability to maintain adequate employment.

> I started getting very sick. The pain had spread to my hips and knees. During some periods I could cope with [my job] a lot better because I could work from home at times. Many times I would be sitting in my office gagging on the desk, needing to run to the bathroom and not being able to even walk slowly, or hardly making it to the washroom or vomiting on myself. Fentanyl [patch] did not agree with me, and I got permanent diarrhoea. (Maira)

According to some interviewees’ accounts, inadequate medical care is common. Doctors frequently fail to monitor and alternate opioid-based therapies and other mood-altering drugs, or readjust drug doses used to help prevent or diminish unwanted side effects that influence the capacity to work:

> I was on Fentanyl since 1999—more than 15 years and with same dose. Same dose of fluoxetine too, for the last 10 years at least. The pharmacy has to have records… the same doses for years on end. I quit the patch in 2014 I believe because it did nothing but make me sick... I cannot work when I am in pain. How can my doctor expect to make me better when he doesn’t follow the guidelines? (Chola)

> The pain will not stop when I take the same pain killer time after time…we become used to it. We all know that. Doctors know it. Nurses know it. Nobody cares. I can’t work, I feel miserable, and I am poor because my doctor is careless. (Jerry)

Eligibility criteria used by private health insurance, Ontario Health Insurance Program (OHIP), and the Assistive Device Program (OMHLTC), also affects working life. According to some participants, insurance plans and workplaces are often unable to provide an ergonomic work environment, assistive devices, or occupational therapy to allow CP sufferers to continue to work as pain is highly subjective, and the medical understanding of the origins, progress, and treatment of this condition is evolving. Chronic pain is often not considered a disabling disorder unless tissue damage or some other biological marker accompanies it. Assessing chronic pain claims appropriately is one of the most difficult tasks for disability claims adjusters. In addition, there are specific eligibility criteria that apply to "each assistive device" category.

> You do not qualify for coverage if there is no proof of tissue damage, and if there is no tissue damage, then no devices will be provided. You don't get any supports to keep working. No! You must apply and qualify for each one of them individually. I have no energy to do this. I loved my job. Why would I like to sit or be in bed all day, every day? As if one day I woke up and said, "OK, I will not exercise anymore, I will not work anymore, I will lose my home, live in this cheap apartment. (Dan)

Economic hardship is made worse as a result of difficulties securing insurance coverage for treatments and drugs commonly available to people dealing with other health conditions and/or with limited incomes.

> I've got no drug coverage. They need to know that it's legitimate pain. My type of pain isn't legit because it's from arthritis, and unless I have big changes to my joints, I cannot prove it hurts and it's real. (Lloyd)

Moreover, participants reported being unable to meet the eligibility criteria of private disability insurance plans, employment insurance (EI), and Ontario Disability Support Program (ODSP) for income support coverage since such payments are usually triggered when the insurer can establish a specific disorder or cause for disability. Pain is highly subjective and, therefore, difficult to corroborate.

> I was sick. They rejected my application for disability because they could not prove it was for real. Having pain was not a disability. So, I got workfare, but was constantly harassed. They wanted me to work because I was healthy, but I was sick. I could not prove it, and I could not work. I lost everything… Different insurances have different ways of looking at pain. Usually here in Ontario, if there is not enough evidence of damage of tissue, they make you wait for a long, long time before you qualify. After you qualify, it's still difficult to get the same kind of backup a person with a visible disability gets. It took five years to get coverage. (Luca)

The capacity to be gainfully employed and the ability to support oneself and one's family financially and to create economic independence are regarded as fundamental aspects of quality of life. In many instances, interviewees report great frustration, distress, loss, and aggravation due to loss of economic independence.

> I didn’t only lose my health. I lost my job and with it my lifestyle, my friends… it all vanished into thin air. I feel miserable. (Luca)

Some interviewees attempt normalizing or hiding disability to be able to continue working, to avoid stigma, or to avoid being further disenfranchised by negative attitudes of coworkers.

> I am lucky. I am a financial manager. I don’t let people know that I am in pain. Everybody knows that people with pain need drugs. Nobody wants people to manage their money when they are taking painkillers. (Marc)

Loss of self-sufficiency and financial autonomy often lead to family breakdown.

> I felt out of sorts once I lost my job. Not knowing what to do with my time, I felt uneasy. I made life miserable for my wife. I started feeling anger and jealousy. Any guy with a job was competition. Of course, she left. (Dan)

> Both of us changed. I resented him. I was used to my money… He was so abrupt with me. I lost value since I was bringing nothing to the relationship… I haven’t been much fun to be around since I got ill… and I wasn’t bringing money to the household… his love was gone together with my income… I had to leave so that I could get healthier. I started to hate myself as much as he did. (Maira)

4.1.5 Self

Continuously being ill and the agony of intractable chronic pain can be taxing on self-image, self-esteem, and identity. Indeed, losses, changes, chaos, and the challenges of adjusting to rapidly shifting situations often lead to emotional responses such as anger, despair, and worthlessness. These negative emotions, in turn, directly affect the way participants perceive themselves, impacting their identity, self-esteem, self-image, and relationships.

Interviewees often reported struggling with their very sense of self, which often leads to confusion, disrupted identities, and lack of direction.

> My shop went bankrupt… My car was repossessed. My partner left. I was depressed and I didn’t know what happened to my life. I was not the same person anymore. Everybody is gone. I don’t belong in the shop. I don’t belong with my partner. I don’t belong with my friends. They have lives, big lives. I fit nowhere. I am only a sick person… crippled and without money. (Lucas)

According to most participants (22), the constant presence of pain adds to their perception of themselves as powerless and lacking control over their lives.

> A thousand sleepless nights, endless suffering, constantly trying to find a position to take pain away, and never finding the right one, but moving and moving to find relief. And there is no relief, but you can't keep still because you are in too much pain. It's a hopeless game. I'm not in control and I can do nothing to stop this. (Paul)

Participants reported a feeling of discomfort and estrangement with new body images.

> I don't know how to dress my new body. You change when you grow up and when you get old. But you never change this much in just a few months. (Dan)

A diminished sense of purpose and value, connected to feelings of leading a less meaningful and productive life, is reported by some.

> I am just here, aimless and wasting away. Crawling like a worm… a nasty bug. Just around the house, lost in my pain. The days come and go. (Milton)

Guilt, shame, and humiliation—related mostly to loss of ability to perform their roles as parents, spouses, and as creators of economic self-sufficiency—are commonly expressed.

> It's not easy to lie in bed in the morning when my husband gets up and goes to work. Psychologically it hurts, yeah, it hurts my self-esteem. (Chola)

Disrupted identities, in turn, create a sense of reduced self-worth.

> I am a man of God. I have been a pastor all my life. People came to me for help. Now I am here. I can't go out there and help anymore. I went from being a pastor to being the one that needs the help. I can't respect myself. I'm unworthy of God, of being a man of God and of my people. I failed. (Milton)

4.2 Category Two: Access to Services

Ironically, the various forms of helplessness experienced by participants can also negatively impact their abilities and efforts to achieve so much as a minimum standard of wellness. Just as all aspects of the lives of participants become consumed with pain, efforts by them to access necessary medical, social, and health-supporting services become compromised. Access to needed treatments and services may be partially or entirely unavailable due to several factors.

4.2.1 Affordability/Access Failures

For most participants, the first and most obvious barrier is the financial cost associated with many treatments and lifestyle adjustments that could help them overcome at least some of the effects of CP on their lives. All but one participant report that the cost of necessary services, treatments, and ergonomic equipment and accessories to help manage their chronic condition had a serious impact on service accessibility. Important therapeutic modes of treatment and management of arthritis and chronic pain, such as access to rehabilitation therapies, fitness and fall prevention classes, yoga, walking devices, or just following a healthy diet (which may entail buying organic produce) are not affordable for many participants.

> I get $1,200 from CPP. When you are disabled, your expenses and special needs go high. But they do not think about this. My financial situation affects the treatments I can choose… and healthy food can be expensive too. (John)

One interviewee described her frustration with knowing that good treatment options existed but are not affordable to her:

> I want more treatment of many kinds. While my doctor tells me we can't do anything about it and fills my prescription for pills, we all know that the rich and the lucky ones who have insurance go to private clinics and get therapy and support that truly helps them keep on top of pain. Some (private clinics) even offer meditation and mindfulness, but it's expensive… I can get that for free four bus rides away from home and after a year-long waiting list. OHIP has money for antidepressants, but not for massage and physio. (Rose)

Also, private and public insurance plans do not often recognize chronic pain as a cause for disability. Chronic soft tissue pain is highly subjective and difficult to corroborate. Consequences to interviewees are twofold. Firstly, they are often not eligible for insurance coverage for income loss, and to qualify, they have many hurdles to overcome; commonly this involves a lengthy process that will, in some cases, entail years. Second, interviewees have difficulty accessing treatments available to others because insurers are reluctant to cover therapeutic procedures for disabilities or diseases they do not recognize as such. Even after qualifying for insurance coverage, hurdles continue as insurance plans request a series of qualifying requirements for specific treatments, procedures, and coverage for assistive devices. This, in turn, creates more aggravation and frustration for those in such a predicament.

> You can't apply for disability. You have no income then, so you lose your house, or you get kicked out for not paying rent. Your insurance does not cover you because they do not believe you… Your doctor makes it difficult for you because he does not believe you, and there is no proof you are sick or have pain. If the doctor cares to refer you to a specialist or send you to physiotherapy or rehab, your insurance does not agree that you need the treatment because according to them you aren't sick. Enough to drive you nuts. (Pavitra)

Access is often limited to treatments and services covered by the OHIP, private insurance, or extended health benefits.

> I worked for the government, and we had great insurance coverage, so I had more services than most people in my pain management group. I even had massages paid for. Now, I can't get basic physio. It's not covered in my case, unless I have a GP that works at a CHC [community health centre] or I'm old enough. (Carl)

For instance, Rose reported feeling as though appropriate treatment options and continuity of care are only available if covered by OHIP and that the GP does not consider other options. She explained:

> The injections were covered by OHIP, so he will give you that. His focus was that narrow… He said it just was this way—whatever that means… Same with my private insurance. It only covers a few visits to the physiotherapist; that is the exact number of visits you are prescribed. If you need more physio they tell you, "Well you already had physio; it obviously didn't work. Why would you want more?" Now we have less access to physio than ever, so we should get better with fewer sessions. Our illnesses must adjust to the system, not the other way around.

A third interviewee stated that inadequate access to beneficial treatments in the private sector for those who can't afford to pay for them often compounds the problem:

> There are many things that can help—like yoga, specialized fitness classes for people with arthritis, art classes and mindfulness, but if you don't have money, you cannot have it… You can go on a waiting list, but will take months to get in, if not a year—literally, I am not exaggerating. And then after a couple of months, you will be bumped out so that somebody else on the waiting list has a chance. Nothing helps when done intermittently… They do not have enough money to offer classes or yoga for all people with arthritis… it's like having enough food to save 10 starving children in Africa. But since there are 100 that need food, they make sure they feed the hundred, but only a bit. In a couple of months, they'll have 100 children that died of hunger and none alive. We are all sick. None gets better. We all get a bit of physio, a bit of yoga. OHIP covers 12 sessions of physio. All of us get 12 sessions and nothing more. That's the magic number. (Carl)

Alternative/complementary medicine is not covered by OHIP and is therefore often unavailable to participants with no private insurance coverage or other funds. Moreover, not all alternative treatments (for example, massage) are available under private insurance plans that are normally capped at a specific amount, thus limiting access. The cost of such potentially beneficial and non-invasive treatments is, therefore, a major hurdle for CP sufferers, as many interviewees report.

4.2.2 Availability

Some interviewees found that many of the medical interventions required to effectively manage untoward symptoms and prevent progression of arthritis-related pain conditions are either not available, or, if available, they are frequently deficient or inadequate. In such cases, available services are not suitable in either their quality or quantity and, therefore, often do not meet the therapeutic needs of the client to manage medical conditions related to arthritis and chronic pain.

> We are told to exercise. I cannot exercise on my own. I don't know what kind of exercise I could do. In Downsview, there isn't a single place that teaches yoga for people in my situation. Nobody teaches mindfulness in my neighbourhood… and certainly not for free. I'm yet to find a pain support group around here. I have to take two buses and the streetcar to get to Bridgepoint… almost an hour-and-a-half. My doctor tells me there is no cure; I must just manage the disease doing yoga and mindfulness. But where? (Maira)

Accessibility to services is even more limited in smaller communities and rural areas of Ontario, especially if those that do not have a local GP. In some cases (5), interviewees reported having to move to a large urban center like Barrie or Toronto in order to get services on a regular basis. In other cases (2), lack of access to services prevented them from moving to smaller communities where they could be closer to family, friends, or social supports that are badly needed by those facing high levels of disability.

> My doctor told me that I needed physical and occupational therapy. He told me I have to learn how to reduce strain on my joints during daily activities. There was no physical therapist in my town and no occupational therapist and no nurses and no doctor. I had to choose to go without treatment or to move away from my children and my friends…, I came to Toronto. (Paul)

Other interviewees found that even where they have some access to services (such as exercise classes), those services are often not appropriate or effective because they do not address their level of disability and are not tailored to their needs.

> I only saw a physiotherapist for six weeks in the last three years. That is all that the insurance paid for… not enough. It was very good. But I need more of that. Now that I go to a community health centre, I can get physio for free. But there is only one physiotherapist working there, and there are hundreds of patients. We can't all get physio—just the blessed ones. Sometimes I get physio for a month-and-a-half then you must wait for another year or more. (Rose)

Sometimes services accessed failed to address the needs of CP sufferers due to lack of cultural sensitivity. For instance, not taking into account cultural differences made the information and education imparted by a dietician irrelevant and inefficient for one participant.

> The nutritionist gave me a diet of fruits, cheese, nuts, and lean meats. I don't cook like white people; we don't eat rice alone or meat alone. When I get home, if my wife cooked oxtail and butter beans, we all eat oxtail and butter beans. It doesn't work. It is like that. We live in a different world. Linda [the dietician] is great. She should meet my family. We are a big family. We meet every day. We are always together. Food is for us like beer for you Canadians. We eat pork belly, head, and feet… chicken feet… We eat things that cost nothing. We like it tasty and greasy. We don't buy lean meat. Chicken is the best I can do. I try. (Lloyd)

4.2.3 Referrals (or lack thereof)

Many interviewees described being denied access to services that might prove beneficial to them because they were never referred to such services by their family doctors (collectively, GPs). (This is discussed more extensively in sections 5.2 Variations in GPs' training, experience, and behaviour around chronic pain, and 5.2.2 GPs fail to make appropriate referrals).

4.2.4 Lack of Knowledge/Education About Chronic Pain Resources Limits Access

Information about available treatments, resources, and support services provided by allied health practitioners, community-based organizations, and other wellness and social programs to better manage pain and increase personal independence is not easily accessible and often not offered to patients by primary health care providers. Interviewees often indicate they were unaware of existing programs, such as self-management workshops for chronic diseases and pain management support groups.

> It pays knowing what's out there to help us manage pain. It would have been helpful to know earlier. (Milton)

Most interviewees (15) reported that their GPs failed to let them know about pain support groups in their area.

> One would expect more from a family doctor. It's so good to get access to a pain support group but my GP never mentioned it. Shouldn't they have this info ready so that patients know? (John)

> A good thing is that at the hospital they told me about the pain support group at Bridgepoint. I only started going to this group not long ago. They give a lot of

> information about where you can go for classes and how to ask your doctor for help… or get this or that treatment, or get a letter to help us get faster to a yoga class. (Ekua)

Moreover, according to most interviewees, GPs also fail to refer them to social and community resources that can provide support, advice, and critical help needed to better manage chronic illnesses such as self-management clinics/workshops for chronic diseases, transportation services for people with disabilities, meals on wheels, art therapy, healthy eating programs, food banks, and socializing events.

> I heard about this [Bridgepoint] self-management program for people with chronic diseases while casually talking to a lady at a McDonald's. If she knows about it then I would assume my doctor would have known about this program too. I had no idea they had these types of programs. How could I look for something I didn't know was there? (Paul)

In general, GPs are often perceived as not knowing how to help their patients properly.

> My doctor under no circumstances referred me to a pain specialist or to a pain clinic. Maybe he does not believe in these things. Once he told me he did not believe in massages and water therapy. Besides, he is against drugs though he has me on Fentanyl. He believes pain is in the head—so how is he supposed to advise me to go to a pain specialist? (Jerry)

> Doctors go to college, but then you must go and learn at your pain support group yourself so that you can remind your doctor how to cure you… and tell him about those treatments that you read about that help other people… But they get paid. They get paid well, and the job is not done. They don't like being reminded either. So you are screwed whatever you do. (John)

Issues with GPs are further discussed under category Five: Family Physician Relationship with Patients, below.

4.2.5 Mental and Physical Exhaustion of CP patients

Participants claim that often crippling pain, mental exhaustion, and isolation impair their cognitive and intellectual abilities, thus impacting the ability to avail themselves of services.

> When I see my doctor, there are a few minutes for her to see me, and I am too slow to ask for questions or how to get more help because I am in pain. (Kendra)

> I would like to go for counseling and self-management workshops, but each class lasts three hours; when I'm in pain and haven't slept for days I can't go. (Chola)

4.2.6 Shortage of GPs or Shortage of Available GPs

Access to services requires having a family doctor or GP. However, there is currently limited access to GPs in Ontario. In some regions this translates into a shortage of GPs; in others this is about available GPs. This shortage and the consequent lack of access to a family doctor often prevents or delays access to timely and necessary treatments and services.

Several interviewees made clear that access to appropriate services is delayed or thwarted because they do not have a family doctor and have to rely on walk-in clinics.

> It's not that I did not want to have a family doctor. Once I moved to Toronto in 2004 I tried a few doctors' offices in my area, but they were not accepting new clients. Then I called the community health centre where they told me the same thing. So, if I felt very sick and the pain was unbearable, I went to the [walk-in] clinic during the daytime. If it was too late or the clinic was closed, I went to emergency at St. Joe's or Western [hospitals]. (Luca)
>
> I heard this too many times: they can't take new patients. Not having a family doctor made things difficult. I live in Mount Dennis. We still have a shortage of doctors. It took me years to get one and meanwhile I had to do without treatments. (Birnie)

Problems connected to the shortage of GPs or limited access to GPs in Ontario will be discussed more extensively in Category Six: Issues with Ontario's Health Care System

4.3 Category Three: Etiology of Pain

Both the nature and etiology of pain are poorly understood. All participants share a feeling of deep vulnerability that they relate to chronic pain being complicated to diagnose, assess and manage, likely incurable, and serious and taxing (though generally non-life-threatening). This, in turn, compounds their feelings of negative self-worth (see 1.5 Self -Effects of Pain).

4.3.1 Chronic Pain and lack of Biological Markers

Perhaps the most problematic feature of arthritis and chronic pain is that they are both non-life-threatening, slow-moving, progressive diseases which cannot be easily measured by external factors, and therefore do not command immediate and appropriate care from the health care system. As participants explained:

> When people with other chronic illness, the "right" ones … as having cancer... at least they have authentic pain—not make-believe pain… Most of us don't get (pain) treatments, or we get treated for mental issues. (Pavitra)

> We are not dying—just in pain. When one doesn't get relief, one won't die. A person with high blood pressure can die unless he's treated immediately. Doctors don't want to be sued, so they take care of those issues. But with pain, this is not a problem. One can suffer for months or years and still make it—same with arthritis, same problem. When a doctor decides he won't treat you, there is nothing you can do. (John)

The fact that individuals with similar degrees of arthritic deterioration in bones, joints, and soft tissue may not present the same levels of pain can confound establishing credibility as well. Participants relay that it has often been problematic for them, particularly when seeking pain medication, that pain intensity reported does not necessarily correlate to the level of tissue damage.

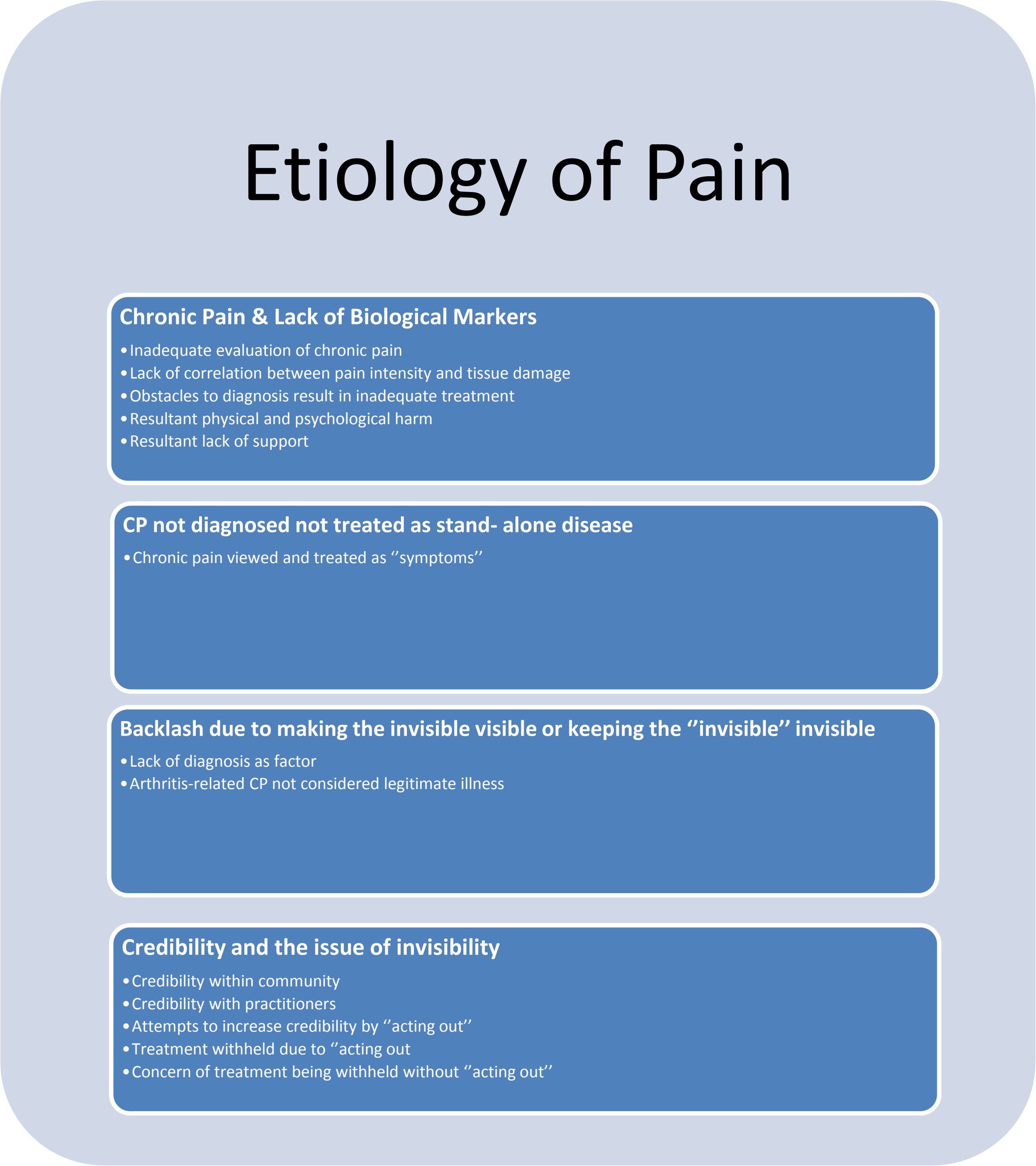
> You suffer because you are in pain. You suffer because nothing explains it. There is no reason for the pain, at least not according to my doctor. Others are much worse and they are still working. This is why he [GP] is not interested in helping me. I'm not making this up. I'm so depressed. (Milton)

> I'm not believed because some people have bigger problems with their knees, and they don't have the same pain I do. (Jerry)

Finally, the incapacity to measure pain, other than by asking clients how much pain they feel, often interferes with participants receiving the diagnosis needed to obtain adequate treatment.

> [Pain] can't be measured. Doctors depend on you to tell them, but when you tell them they doubt you. You don't get painkillers. You aren't sent to a pain clinic, and you will be left to deal with it on your own. I'm frustrated. Pain is brutal. (Nelida)

Most interviewees (18) feel that inadequate diagnosis and treatment frequently cause them serious physical and psychological damage, such as increased stress, depression, loss of function, and incapacity to work. (This was more fully discussed in Category One: Impact of Chronic Pain on Individual).



Etiology of Pain

Chronic Pain & Lack of Biological Markers

- Inadequate evaluation of chronic pain
- Lack of correlation between pain intensity and tissue damage
- Obstacles to diagnosis result in inadequate treatment
- Resultant physical and psychological harm
- Resultant lack of support

CP not diagnosed not treated as stand- alone disease

- Chronic pain viewed and treated as ‘‘symptoms’’

Backlash due to making the invisible visible or keeping the ‘‘invisible’’ invisible

- Lack of diagnosis as factor
- Arthritis-related CP not considered legitimate illness

Credibility and the issue of invisibility

- Credibility within community
- Credibility with practitioners
- Attempts to increase credibility by ‘‘acting out’’
- Treatment withheld due to ‘‘acting out
- Concern of treatment being withheld without ‘‘acting out’’

Figure 3. Etiology of Pain

According to many participant accounts, the legitimacy brought about by a diagnosis appears only to apply to the so-called “serious diseases” such as cancer. For example, the lack of biophysical damage or insufficient physical proof of biophysical damage to support the level of pain reported is problematic, particularly with practitioners who firmly adhere to the biomedical model.

> Being diagnosed… it's a tool…it opens doors to pain centres and to programs, but it's no panacea. One will always be better off if the illness can be life-threatening, like congested heart failure or diabetes. (John)

Participants (20) feel ambivalent about the need to be diagnosed. It is not uncommon for them to point out that diagnoses are not as helpful when the disease at issue is arthritis or chronic pain, in that diagnoses do not command aggressive care from health practitioners, or at least the "understanding" from family and society at large. However, participants are also of the opinion that a diagnosis of chronic pain is helpful when seeking referrals to pain clinics and pain management programs and insurance coverage (as discussed under 4.2. Access to Services and 6. Issues with Ontario's HealthCare System categories). Moreover, some (8) felt that it does bring some legitimacy to their situation by making pain (and arthritis) more visible and helps to stave off stigma. Also see Category Seven: 7. Stigma, 7.4 When Pain is Invisible; a diagnosis helps protect an individual from stigma, prejudice.

4.3.2 CP neither Diagnosed nor Treated as Stand-alone Disease

In part because of the difficulty associated with CP not having a biological marker and the fact that pain cannot be objectively measured, CP is not commonly diagnosed or treated as a disease in and of itself. Only four of the 23 interviewees were diagnosed specifically with chronic pain. Three of these cases involved the WSIB, and the fourth involved another private insurer. In all four of these cases, the individuals report that their insurance carrier requires the formal CP diagnosis, and this is a necessary part for processing their insurance claims.

> No one ever mentioned chronic pain. I always believed it was my arthritis that hurt, as one would think cancer hurts or falling down hurts. My doctor gave me Tylenol for arthritis. I guess it was for the pain. An insurance doctor wrote that I have chronic pain. It was needed for the [insurance] claim. (Marc)

Moreover, interviewees claim that their GPs view and treat CP merely as "symptoms" of other disorders, such as arthritis. In other cases, CP is also considered by GPs as a by-product of depression or as some type of somatization or psychosomatic disorder. This is connected to the insinuation (by health professionals) that the pain is of an imaginary nature; a manifestation of stress or some other variable, such as conflict or fear; or that the patient needs or wants attention and is simply malingering. Rarely, based on participants' accounts, is CP regarded as a medical condition or disease in and of itself.

> Oh, so what? I may be stressed, but I am certainly not lost. I can understand that stress can make pain worse. But I also understand the difference between being treated like I am bullshitting about the pain I feel. I understand that we can treat mental depression and stress, but I want to treat the pain as well. (Dan)

> Neurotic or not, I need painkillers. It's not about calling attention. I feel insulted. Stop asking me to calm down. If the pain is there, I can't calm down because I don't sleep. I need to sleep, and this will not happen without something to stop the pain. What part do they not get? (Vicenzo)

4.3.3 Backlash Due to Making the Invisible Visible or Keeping the "Invisible" Invisible

Chronic pain is an invisible disability that causes backlash from society, family, and health practitioners alike. Most interviewees (18) reported that they struggle with backlash in reaction to revealing a disability that is invisible—a disability incapable of being perceived by the mind or senses.

> I lost count of the times I've got criticized for saying that I'm in pain. They see nothing, and I look well. To them I am crazy. (Paul)

Lack of diagnosis helps keep chronic pain invisible. Many diseases or disabilities, interviewees argue, are not necessarily perceptible. For instance, cancer may not be visible in its early stages, but a clear diagnosis makes it visible to family members and society as a whole. This is not the case with CP.

> More than 20 years in pain and I'm yet to be diagnosed with chronic pain. If my GP sees nothing wrong with me, who will believe that I'm in pain? (Jerry)

Most participants hold that arthritis-related CP is seldom acknowledged as a legitimate illness. This, they claim, is due to CP being mostly an invisible disability, along with the fact that arthritis is not generally regarded as a severe disease.

> What a combo… arthritis and chronic pain. We are at the bottom of the pot. Every bit helps: a doctor that trusts you and a diagnosis—one for arthritis and one for chronic pain. Because not all people with arthritis hurt all the time… some manage well… so you need all the help you can get because it is not an acceptable illness. (Birnie)

In summary, all interviewees reported that the most common stereotypes they face include being judged as mentally unstable and/or having a mental illness, malingering and being manipulative to gain access to drugs because of addictions, or only suffering from a penchant for calling attention to themselves. These assumed or perceived causes of chronic pain are themselves strongly stigmatized (See below under Category Seven: Stigma).

> It took almost four years and literally four doctors to get some answers. Meanwhile, my family kept acting like I was somehow bored and created these stories. I looked healthy. That did not help. Nobody believed me. I also questioned my sanity. (Rose)

> My doctor kept insisting that I did not need painkillers. Kept giving me Prozac [fluoxetine]. (Chola)

4.3.4 Credibility and the Issue of Invisibility

All interviewees' encountered issues of credibility to varying degrees. These are strongly connected to the issue of invisibility and staunchly held stereotypes and prejudices attached to illnesses that do not present a strong etiology.

> I want to show how much I hurt, like through a cut, or bruise, some gross growth. Anything is more welcome than being robbed of your credibility, being called crazy or a lazy crook. (Gus)

Stereotypes of people with chronic pain as mentally ill, addicted, or simply malingering contribute to individuals' added distress, sense of vulnerability, anxiety, and humiliation, robbing them of their sanity, social supports, and quality of life.

> The whole [health/social] system tells you how important is wellness. How can you talk about wellness when everybody thinks you are insane and you yourself ponder if this is not the case? (Paul)

The invisibility of pain negatively impacts participants' credibility with health practitioners and treatments offered.

> Doctors think that I am lazy. They cannot accept a bad back, a sore arm, if they don't physically see a defect. They cannot accept it if you say you have a sore neck. They think you are trying to get away with it, using it for self-need and to gain attention, get somebody to do work for you, for ego, even drugs, or whatever you have, maybe like taking advantage. (Vicenzo)

Some interviewees (9) reported that this invisibility can cause them to "act out" or feel compelled to describe their pain in great detail, or even exaggerate its impact in hopes that doing so will increase their credibility, which in turn leads to a feeling of debasement and humiliation.

> So one eventually learns that if one is to be believed one has to mention many times—once is not enough—that "I'm in a lot of pain." You have to look in pain, talk about your disability. Make sure that you let them know that you are "doing [your] best today" and "feeling better than most days," but make sure to act your worst. To be taken seriously, look really bad... when it comes down to insurance companies, and doctors and specialists, they don't believe you. They will discount my condition, so it's like you must humiliate yourself by becoming someone else and exaggerate your pain so they believe you. It hurts your heart. (Carl)
>
> Repeat again and again that you are in pain and hope they will listen. Tell them all the horrible hours you spend in pain. Don't keep anything to yourself. While you are doing this, you want to cry that you got this low. (Eva)

Some interviewees sensed that sometimes "acting out" or simply complaining repeatedly about the pain they experience might backfire and result in them seeming "unlikeable" and "untrustworthy" and thus not worthy of treatment.

> It's a catch-22. You complain and exaggerate and hopefully, it works. Sometimes it's worse. You do not complain and try being nice, and it might go against you. You only know after you tried, and it may be too late. But it didn't start with us. It's [health care practitioners] that have their shallow definitions of what a person with pain is supposed to act or look like. (Paul)

Other participants worried that GPs may withhold treatment if they do not 'act out' and appear to not be in pain.

> Look your worst and act like you are cool about feeling so sick… or they think you are depressed and the pain is in your head. (Vicenzo)
>
> You soon learn that if you want people to believe that you have chronic pain, you have to show signs. (Gus)

Keeping the invisible "invisible" requires concealing or minimizing pain and its effect on their lives so that GPs perceive patients as credible. Paradoxically, the same conditions that caused some interviewees to describe or act out their pain in ways that "exaggerate" symptoms and the effect of pain on their lives to ensure its visibility and credibility in the face of stigma and prejudice, also caused some of them to engage in behaviours to conceal their disorder in order to protect their credibility to avoid stigmatization and discrimination. Some interviewees fear that merely stating how affected they are by CP could be perceived as exaggerating. They feel that their physicians are more likely to offer the right type of care and the most effective procedures when they play down the effects of pain. This, they claim, will help them be perceived as credible.

> Mention casually that the pain is unbearable, but minimize the impact on your life… do not mention how sad or angry you feel, or how hurtful it is that your energy is sucked out of you, that you had to stop working and are worried about your finances, or that your family does not believe or support you. Doctors are taught to not tolerate complains about pain. Must be the only illness that gets cured by pretending in front of others that it doesn't exist or that it has no impact on the quality of your life (Dan)

4.4 Category Four: Treatment

This category identifies the etiology of pain, issues arising from poorly understood causes, difficulties inherent in the lack of ability to objectively measure pain and attendant issues of credibility, along with strongly held stereotypes and stigma often attached to those with chronic pain seeking treatment, presents its own complexity.

4.4.1 Treatment for Pain Relief as Optional

All interviewees reported being deprived at one stage or another of appropriate pain management treatments and relief by their physicians for various reasons. For these interviewees, actual treatment of the pain they suffered appeared to be viewed by their GPs as optional. The nature of the pain, lack of timely referrals, and doctors' often limited knowledge and training about pain, are just but a few of a plethora of factors influencing the treatments afforded to a client. This subject is extensively discussed under other categories. (Please see Category Five: GP Relationships with Patients.)

4.4.2 Opiates and Pain Management

According to most interviewees (19) their doctors often feel uneasy prescribing narcotics. This can prove quite difficult for those clients already undergoing a successful Opioid-based therapy. Benefits such as pain relief to allow sufficient functionality and mobility to engage in regular endeavours are soon lost. Activities such as holding a job, attending school, or participating in an exercise program to keep joints and muscles stronger and stave off early disability depend on pain relief.

> One has to shop around to get a doctor with the knowledge and willingness to prescribe narcotics. It's about biases, not trusting us, and many do not know enough about narcotics and do not want to get in trouble. It's easy to deny us treatment. (Dan)

Only six out of 23 interviewees reported that they were sent to pain specialists or pain management clinics. But after they were stabilized and started to function somewhat satisfactorily, or at least felt considerable relief to their pain, they were referred back to their family doctor. In five cases interviewees claimed that the continuity of Opioid-based treatment was affected while transitioning from specialists' care to GPs' care. Only in one case the family doctor continued treatment with narcotics other than Fentanyl. In all other cases the GPs did not follow through with the specific Opioid treatment that initially stabilized them.

> People want pain medication and do have pain… I found that the majority of physicians will not prescribe narcotics regardless of how much pain you have—most frustrating. When you are prescribed medication by pain clinics then, when they normalize you, and you are better, and the pain is manageable, they refer you back to your GP, but the medication prescribed by the specialist is not continued by your GP. There is nothing in the system to take care of this problem. It breaks down. (Rose)

One interviewee reported a troubling, painful, and expensive cycle in this regard:

> Pain clinics prescribe stronger narcotics and the GP will not do that, so you will start to deteriorate and get more and more pain. When you cannot move anymore because of the pain and you are not functioning, then they can refer you to the pain clinic again, but you must pay a fee, it used to be around $150, and wait six months to see the pain clinic specialist again. Some clinics require that the $150 fee gets paid out-of-pocket before they review your file. (Tomash)

Only one interviewee was referred more than once to a pain management clinic:

> I know I'm lucky. I visited three clinics in 19 years. I learned so much there. This is why I can feel I still have a good quality of life. (Carl)

Interviewees (17) also feel that the lack of appropriate and frequent assessments, monitoring, and rotation of opioids to minimize the risk of addiction is widespread.

> More monitoring could have helped. How many GPs rotate narcotics every few months? No kidding! Nobody wants to mention the unmentionable. Maybe docs are neglectful; maybe they are overworked, or maybe the system is rotten. We can prescribe fewer narcotics in the future. But when doctors continue to give people just a few painkillers as the only treatment for pain, I'm afraid that the deaths will continue. The soul breaks down with pain and people will do anything to feel less pain. (Maira)

> I have had the same prescription for the last nine years. No rotation of painkillers to avoid addiction. The only thing my doctor rotates is her insults towards me: “You are a drunk.” “You don’t care about your health.” “You don’t even try to exercise.” “You smoke.” “Stop smoking and that will help.” Not once did she try to think, just think, about what other drugs she could give me that could help. She knows I do not function with this treatment. I may be a drunk, but it doesn’t explain why I have been on Fentanyl—same dose, same strength—for nine years. Yes, I drink. But she is a lousy doctor. (Kendra)

Some interviewees (7) described a sense that when individuals with CP get addicted to pain medication or other substances, they themselves are blamed.

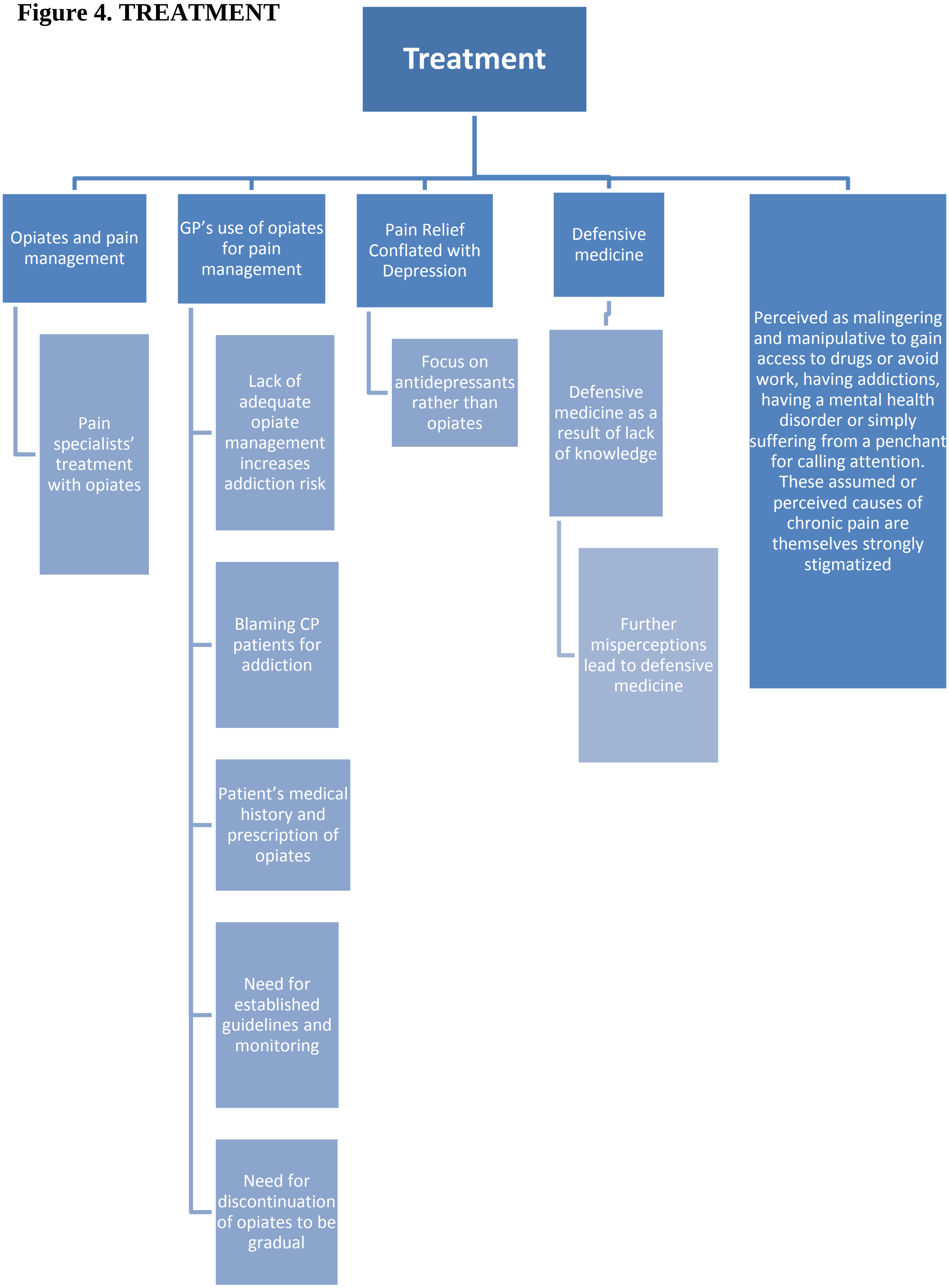
> Addiction will still happen. Where is the support system? The government and scientists are one-sided in this problem. I think that prejudice against people that need painkillers all the time makes them that way. (Rose)

A medical history that includes previous or present addictive behaviour results in no access to narcotics, even from doctors who would sometimes prescribe narcotics to other patients. According to some participants, such a medical history also influences GPs to take patients’ complaints about severe pain less seriously.

> I was stupid enough to tell my doctor that I used drugs when I was a teen. I’m 57 and have not done drugs since I was 22. It doesn’t make a change. Oh, I’ll never get narcotics… only Tylenol or antidepressants. (John)

Interviewees also express concern that ill-considered changes focused on curtailing the prescription of Opioid-based pain medication are on the horizon. Moreover, while urging the establishment of better guidelines for patient assessments, interviewees flag the critical need for GPs to be trained in the effective and appropriate use of Opioid-based pain medication, including monitoring and rotation of drugs.

Figure 4. TREATMENT



> ...we may need painkillers, and narcotics are necessary… there are consequences for the use of painkillers. We have many side effects that can get us sick, or [we] get used to them or become addicted. I still believe we need efficient painkillers when the pain becomes unbearable. What I object to is the way my doctor deals with painkillers. I've been on the patch for seven years. No monitoring, no rotation to another painkiller. Fentanyl [patch] stopped working years ago. How come nothing is done to help with this? (Milton)

A related issue to the lack of monitoring is that of failing to wean CP patients off Opioids properly.

> My doctor moved to another health centre, so they gave me another doctor. He cut off my treatment without explanation and didn't even care to wean me off the narcotics. I went from three pills every day for over a year, to two days on one pill, to no pills. I vomited every day and was beyond sick. (Kathleen)

Moreover, when GPs refused to prescribe Opioids to interviewees who were already receiving an Opioid-based therapy, interviewees report that they were not provided with a tapering schedule that effectively reduced opiate withdrawal symptoms. This circumstance, along with the absence of drug alternatives sufficiently powerful to block or lessen opiate withdrawal symptoms and make possible continued functioning resulted in great distress and life disruption, including job loss, dropping out of school, and disruption of parenting or other family roles.

> Weaning off OxyContin was lethal. It ruined my digestive system. I had diarrhea that lasted for three months. Uncontrollable diarrhea. It affected my sleep. I have suffered from insomnia since. I think it affected my brain forever. I don't tend to complain. But the treatment I received was the worst. No emotional support. No counselling. No help with my depression or with the pain. I was studying, and I stopped all the work because of how disabled I was. I feel like crying when I think about how much this cost me. (Rose)

> He called it tapering it off… but no… one day I was on Percocet; the next day I was not. I was sick, very sick… the straw that broke the camel's back. Vomiting and diarrhea for months on end also finished up my marriage. He left and never looked back. (Eva)

There is a need to ensure GPs adhere to established guidelines concerning Opioid treatments while also providing multi-faceted pain management approaches. Expanding the quantity, scope, and comprehensiveness of services geared to managing chronic pain with the ultimate goal of increasing the quality of life of people is what interviewees state they deserve and hope for.

> If you expect me to get better, make sure I can have treatments that are effective. Any concerns you have about drugs should be coupled with concerns about our wellbeing and how you will offer other ways of treating pain. (Marc)

> There is a difference between addiction and dependence. Good management for pain will help people not get addicted. Besides following protocols, they need to provide supports and programs for exercise and rehab for people to become more functional. That is their shortcoming. Action plans are not on the table or are not complemented with programs that help us follow through. It is not lack of knowledge; it is lack of resources most often than not. But still, shaming patients while they are being short-changed is not the answer. It's simply abuse. (Kenswella)

4.4.3 Antidepressants and Chronic Pain

According to some interviewees' accounts (12), a perhaps-related issue to the philosophical issues that some GPs seem to have with Opioid-based pain management therapies, is the choice to *focus on medicating for depression, anxiety, or other mental health issues rather than pain itself.* Participants claim that GPs responded to their constant complaints about relentless pain mostly by prescribing antidepressants and sleeping pills rather than pain medication or other treatments that can help relieve pain.

> Meanwhile, he gives me more antidepressants to deal with the pain. I am not depressed just because. I am depressed because I can't sleep because I am in pain. Give me a painkiller, and I sleep and won't be depressed. It's a chain process. But they treat the depression; they treat the symptom and leave me with the pain. (Luca)

> My doctor does not believe in OxyContin because I can become an addict. Mind you he is OK with me becoming an addict with Prozac and Lorazepam. (Chola)

While interviewees in all but one case feel that antidepressants and sleeping pills might be helpful, they are also bewildered by the fact that the more they complain about severe pain, the higher the dosage of antidepressants prescribed by their doctors. However, according to their accounts, rarely do doctors change the dosage of pain medication, rotate pain medication to avoid tolerance development, prescribe anti-inflammatory drugs and muscle relaxants, or provide the means to engage in a more active lifestyle in an effort to find an effective pain management regimen.

> My doctor says, 'you have to exercise.' I say sure. He must be out to lunch. I need a specialist or someone, some expert to teach me how to do it. And I cannot hurt and follow the exercise… I need to hurt less so I am not crippled by the pain. I am not sure that this simple matter is easy for my doctor to grasp. I can't just go to the YMCA and start a fitness class with all the 20-year-olds there. I can't put my pants on by myself, and I am asked to exercise but not told how to get there? But at the end of the day, I am the irresponsible one here… anti-inflammatory drugs can help with my swollen knees and I can move better, but I don't get them… Makes you feel like giving up and heading to the subway tracks to wait for the first train and jump. (Vicenzo)

> I can’t work or clean the house because I’m stoned out of my tree with anti-depressants, and my doctor wants me to increase the dose. I have taken the same anti-depressant for years. I have no ambition, I have no sex-drive. My mouth is dry. I have bad breath, and the pain isn’t going away. I never complained about depression… then there must be another way to deal with it. (John)

4.4.4 Defensive Medicine

As stated previously, participants claim that often GPs’ “feelings” and comfort level about prescribing Opioid-based therapies lead to restricted or denied access to such treatments.

This reluctance of some GPs to prescribe opiates to help with pain relief might be related to the practice of defensive medicine. That is, some GPs’ feelings, beliefs, and attitudes towards the use and prescription of narcotics are largely determined by their own lack of knowledge, training, and experience with Opioid-based therapies to treat CP.

> My GP assured me that pain can be treated in many other ways, and narcotics were notorious for creating addictions. Unfortunately, without narcotics I couldn’t exercise; I couldn’t work … (Marc)

Defensive medicine is a result of political environment/current legislation.

> The government checks if she prescribes narcotics to many of her patients… she would rather not be checked. It’s easier for doctors to just let you suffer. (Paul)

> I was told that narcotics do not work well after a while and are addictive, so it was better to prescribe me something else. But the something else was not a painkiller, just an anti-depressant. The anti-depressant is also addictive and does not work I believe he is afraid because they get flak from the government.. (Gus)

The failure of GPs to prescribe Opiates (in the absence of any other effective treatment for pain relief) can have devastating results, as one interviewee states:

> I was fit and proud of my achievements. Then, the new doctor told me she was uncomfortable prescribing Percocet. Despite the gruesome pain in my neck, I had to stop the Percocet… lost my work. I could not exercise. I could barely move. Not having a treatment that works enough to keep you going is disastrous. (Kendra)

Admittedly there is a current contentious policy debate around the use of narcotics for the alleviation of CP. However, participants claim that entrenched attitudes of many health care providers continue instead to be based on the misperception that individuals with CP are malingerers who are prone to addictions and continually seek access to mood-altering drugs for recreational purposes, to feed their cravings, or to engage in drug trafficking.

> My doctor bluntly told me that people that are always asking for narcotics have other addictions and they are after more drugs. He never said that this is what I was doing, just talked about what other patients were doing. Of course, I was the one doing the asking the day he made that comment. It's humiliating. (Tomash)

4.5 Category Five: Family Physician Relationship with Patients

As discussed in the previous section (4.4. Treatment), a significant factor for CP patients pursuing pain relief and relative wellness is the nature of the relationship with their general practitioner.

4.5.1 Importance of the quality of interaction

Participants' (all) experience with the health care system in this study suggests that patient-centred services, patient participation and collaboration with health care professionals, and a patient's capacity to influence their own care and treatment decisions are determined by the quality of the relationship between patients and the GPs. No matter how good the Ontario health care model and protocols are, the relationship between doctors and patients is paramount.

> A bad doctor is better than no doctor. I believe that is the main idea. I disagree, though. A bad doctor can destroy your life… And whether the doctor is good or bad won't matter if your relationship with them is bad. A bad relationship with a good doctor will be bad for you as well. (Kenswella)

4.5.2 Poor quality of interaction as a barrier to patient-centred care

All participants in this study identified the quality of interactions with general practitioners as one of the greatest barriers and stumbling blocks to adequate patient-centred care. The relationship with the GP— the "gatekeeper" of the health care system—is hugely significant in the life of interviewees. Sadly, most related feelings of dissatisfaction and frustration; in some cases, they express fear. These feelings are reflected in the comments below, the latter often being the echo of the former, with subtle variations summarizing many of these recurring themes. Many feel that their accounts of their own disease and their complaints and requests are dismissed or merely disregarded by physicians:

> It doesn’t matter that I keep saying that I am in pain. I am ignored. (Jerry)

Several interviewees feel rushed, not truly listened to, or both by their GPs.

> She looks at the door when I start talking, or at the wall… she’s not listening. Then she looks at the clock. She fills the prescription for fluoxetine and sends me on my way… I did not come in to talk about depression. Fluoxetine is all I will get for pain. (Chola)

They further express some of the following frustrations.

Having no input into their treatment:

> I don’t recall my GP ever asking for my input… or if I had a better idea or what can help me get started on a diet or exercise, they are not interested. They ask, but they won’t let you finish talking. It’s an invitation that you must refuse. You must understand their lingo. (Vicenzo)

Feeling helpless and patronized:

> I asked if there was anything else I can do to feel better, but his attitude is: “Sooorry, too bad so sad,” and [GP] does nothing. Whatever I say falls on deaf ears. (Paul)

Feeling confused:

> He will not give me an objective answer. His solutions are neither here nor there. I always leave his office more confused and depressed. I need help. I need to know [what to do]. (Jerry)

Feeling inferior:

> It is difficult to communicate with somebody that acts like what you are saying is not important. I guess they always try to err on the safe side, but this is not helping me. (Rose)

Feeling vulnerable:

> I’m afraid that if I talk too much, I’ll get myself in more trouble. They can take the little painkillers they give me away. (Dan)

Most participants (20) explained that some GPs often fail to communicate relevant information, lack professionalism and ostensibly deal with them as if there is no need to explain actions or decisions that affect their treatment and care. In some cases, decisions made by health care providers to increase, change, or decrease pain medication doses are not fully explained to the participant, or participants do not understand how the decision is reached.

> There is nothing that can quantify your pain and the amount of doses that you should have to deal with that specific pain level. Out of eight doses that I received, I mean

> the eight injections with the cortisone and pain killers, the first four doses I got in this clinic were stronger and I was feeling less pain, but they did not stop the pain. Then they gave me four lower doses. I said the four first doses were not enough, and his answer was to lower the next four doses. (Rose)

In other cases, the GP is perceived as inadequately informed regarding how to assist patients.

> Does he care? He knows how to help and does not want to help? I don't think so. Either he is busy and not paying attention—with his head in the clouds—or he just doesn't know. He did not take the time to find out or is too busy to find out… and he has no supervisor. He doesn't have to be a perfect doc. Give a few pills. Yeah, yeah, you'll be fine. Send you home. He gets paid. (Vicenzo)

Some interviewees report feeling they have not been dealt with in a clinically appropriate manner. There may be no assessment of pain levels, number of pain sites, progression of illness, or impact on quality of life. When an assessment of the aforementioned indicators takes place, the interviewees note that it is not clear to them how the assessment affects the treatment provided or why doctors make a particular decision on the treatment to follow.

> She'll ask how I am doing… and gives me the same treatment. More pain or less pain? Can walk or not walk? Sleep or can't sleep? At the end of the visit, it's of no importance. She gives me the same treatment. Good dog, good dog, please go home now. (Pavitra)

According to many interviewees, GPs do not engage them in developing goals and specific therapeutic plans of action or "contracts" to effectively manage their pain, which often results in aggravating effects on their health.

> It annoys me to read about doctors setting goals with patients and having plans to help manage pain with different things we can do to have relief. Where are those doctors? I never met one. (Eva)

In sum, in only eight of 23 cases interviewees did state that they had worked with professionals who helped them to adjust their perceptions and attitudes towards the disease itself, their capacity to manage it, and to adapt to shifting environments and changing levels of functionality and mobility. This was done through the use of therapeutic plans and referrals to pain clinics and to other health care professionals. Acquiring such knowledge and new skills increases the likelihood of successful and swift adaptation. Of these eight cases, five shopped for a doctor who would provide the care they felt was appropriate. Also, in all but one of these five cases, WSIB was involved. In the remaining 15 cases, however, the interviewees were mostly left to their own devices.

4.5.3 GP as the "Gatekeeper"

In many cases, the CP patient must rely on the GP for access to other services. Because the GP is effectively the "gatekeeper" to treatment and to specialists or other allied health care providers (i.e., chiropodist, medical orthotics, exercise, physiologist, behavioural therapist, dietician, etc.), those patients who are not referred lose out altogether. Many CP patients go without the help and treatments they need because they are not referred to appropriate services.

> It's difficult to be sent to a pain specialist if your doctor thinks there's no pain or can't find a good reason for the pain you say you have. He is the gatekeeper. If he doesn't like you, he doesn't trust you too. If there is no trust, then he'll think you have an addiction and you are after 'the pills.' This basically means no physio, no painkillers, and no therapy, and no counselling. (Paul)

To compound this situation, a "chronic pain" diagnosis is typically perceived as the key, not only to treatment and relief from the pain, but often also to social acceptance and legitimacy of "sick" status. Yet, in the absence of visible and objectively measurable symptoms, chronic pain falls into a gray zone of medicine, where diagnostics will vary significantly from doctor to doctor. In this context, to be listened to and believed by a doctor is so important that participants will go to great lengths to secure and preserve their relationship. Paul explains why the quality of interactions with general practitioners can be one of the most serious hurdles to positive patient-centred care that individuals identify in this study and comments that there is

> "no thermometer for chronic pain diagnoses … it's based on the doctor believing you. If you are not on good terms with them, then you are not going to get it. And it won't be any good for you. No diagnosis? Then you won't have pain treatment, nor pain specialist, or insurance [coverage], and your wife will give you crap for complaining when even the doc says you are not sick."

Access to appropriate care and effective treatments depends on ensuring a healthy therapeutic bond or strong relationship between doctor and patient.

> It takes much strength to develop a good and respectful relationship with your family doctor. This is most important because they manage your whole case. I would like to know who is knowledgeable and knows about chronic pain and is willing to treat you with respect and believe in you. I only had some choice, depending on the doctor. I changed a few so that I could get one that listened… Some of the people get epidurals

> for pain. When I was screaming all day and all night, I asked for one, but my doctor said he didn't do epidurals… so I had to change my family doctor to be heard. I needed to sleep. I spent days without sleeping. After the epidural, I slept and that helped my stress, and then I got some pain blocker shots and I got much better. (Dan)

Management of the "perfect patient" image for GPs' approval

Most interviewees (16) stated that since their GPs have unfettered power to improve access to treatments, specialists, and other necessary services, being "liked" is a major factor in getting treatment. Therefore, they often spend considerable time and effort attempting to present a "perfect client/patient" image.

> Being likable… learning to avoid talking about pain…being the perfect patient… knowing how to get through to the doctor…The problem is that different doctors like different things. Some doctors want to see that you are really helpless before they give you a hand. Others want you to have pain and still not mind it; you have to show that you are strong, not a cry-baby, so they will help you. (Birnie)

> This is the reason we are so focused on making sure that our doctors care for us or like us. When they do not like us, they are not going to believe us. You can have attitude and still get treated for diabetes… no such luck with pain. We are pariahs in the system. (Dan)

Power imbalance

In the opinion of some of the participants, snobbery coupled with the unfettered power of health practitioners over treatments rendered contributes to the sense of powerlessness, helplessness, and defeat. They note a discernible and marked power imbalance between GPs and their patients.

> It's only lip service to the health system that tells us about patient-centred services and whatnot. At my [pain management] support group we are told to be our own advocates and make our decisions. Yes, this may very well be truth, but I am not sure that it works in practice. It all depends on your state of mind. When I'm in too much pain, I'm not thinking straight. And when I'm afraid of offending my doctor and not getting what I need, I can't ask for anything. I lose my choice don't I? In reality, when I asked my GP, it did not work. He didn't answer. Not much choice I guess. (Tomash)

(For further discussion of power imbalance, see section 8: Lack of Negotiating Power.)

Some interviewees reported that GPs do not engage them in a therapeutic plan that provides clear actions, steps, and objectives to effectively manage their pain.

> What plan can I have? I hear about being a participant in my pain treatment. Hey, I am. I do my part. I feel the pain, and he gives me some pills (antidepressants) and the patch. Then I lie on the bed or the couch or in the car when taken to the next office visit, and he (GP) again does his part by being at the office and seeing me again. I participate by not complaining that it does not work, so he does not get upset. He participates by not getting upset and giving me more pills. I do not complain. I'm just saying what is. I need the pills and need the patch. That's my plan. (Luca)

Many interviewees have the sense that they have no choice or agency on how to manage their condition. They describe GPs telling them what to do in a high-handed fashion, even when the advice given has no chance of actually working, and not listening to their own suggestions as to what might actually help.

> My doctor tells me to try this and then try that for two to three weeks, and I have no choice but to do what he says. I am not the doctor. He is the boss. I say something, and he has a way of letting me he is the boss. You know he is getting upset. You stop asking for help so he feels OK, but I am not OK then. I doubt he ever heard any of my suggestions. It's his way or the highway. (Gus)

Consequently, persons with CP feel overpowered by those who should be providing care and feel utterly defeated by their CP condition.

> Where do I go for help when even my own doctor does not want to help me? It's a crapshoot. Some nights I lie in bed and sob in total despair. (John)

The sense of being scorned and disregarded is often compounded by GPs' attitudes about prescribing opiates (see additional discussion in 5.4.2. Opiates and Pain Management and 5.7. Stigma).

4.6 Category Six: Issues with Ontario's Health Care System

There is a great deal of circularity within the health care system that might impact GP behaviours. Just as the GP is the "gatekeeper" of the health care system, the health care system itself impacts the physician's decisions about care and treatments, including the type of pain medication (i.e., narcotic or non-narcotic) patients should receive.

Furthermore, the complex nature of the Ontario health care system itself—with sometimes ineffective, poorly coordinated and integrated processes and models of care—was identified as having negatively impacted participants. They, in their majority (20), reported feeling sometimes lost and confused and receiving little or no help in navigating or negotiating within the system.

This is more noticeable in cases where participants, as discussed previously (see section 3. Etiology of Pain), are already overwhelmed and exhausted by their disease.

Identified issues with current health care system in Ontario follow.

4.6.1 Shortage of GPs or Limited Access to GPs; Reliance on Walk-in Clinics

In addition to the issues discussed in Category Two: Access to Services, some interviewees flag problems with having to rely on walk-in clinic services because they do not have a family physician. Though only three participants reported having no family physician at the time of the interview, most claim to have fallen into this condition every so often when their doctors passed away or lost their license, either the physician or the patient relocated, or participants merely chose to shop for a new doctor because of an unfavourable relationship with a previous doctor. The reason for the reliance on walk-in clinics, according to interviewees' narratives, has to do with doctors not accepting patients with complex histories, especially patients with a history of opioid-based treatments.

Given the nature of walk-in clinic services, patients are not always able to see the same provider and have to make do with whoever is available at the time they need to see a physician.

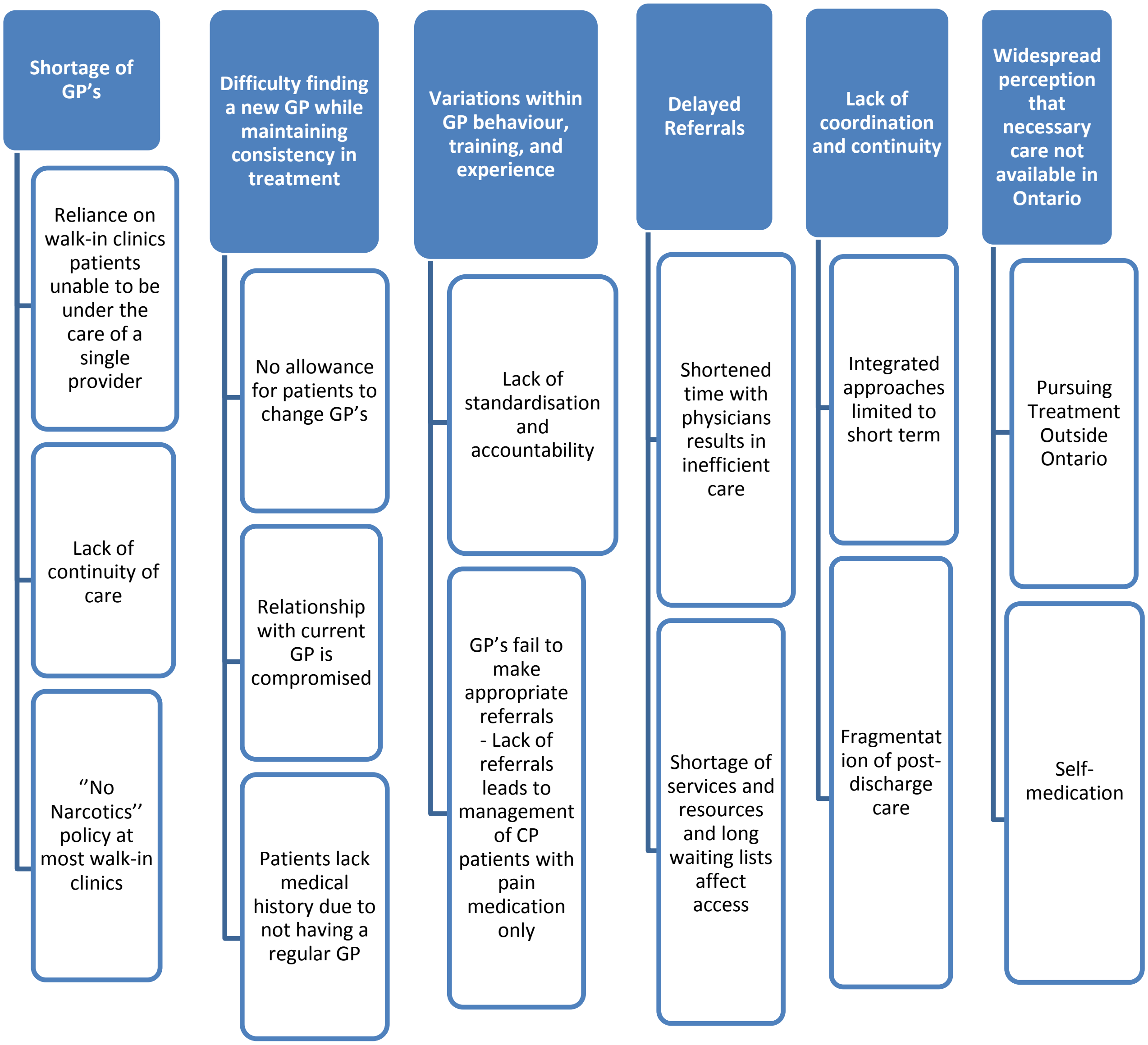
> They continued giving me appointments with different doctors at the walk-in clinic. It was frustrating. I begged them… asking to see the same one and was told that if I wanted to see the same doctor every time, then I would have to get myself a family doctor. (Gus)

Lack of credibility impacts provision of care

Another downside of relying on walk-in clinics is that a person without a regular GP likely does not have a medical history. Interviewees report that having a medical history and an established relationship with a GP is desirable and even recommended, since having a health provider that will attest to an individual's claims of severe and chronic pain increases credibility.

This is crucial, as there is no other reliable assessment of the severity of pain except for an individual's own report of the level of pain felt. Because the relief of chronic pain may necessitate aggressive treatments—timely referrals to specialists, multi-disciplinary care, medical and social

Figure 5. ISSUES IN ONTARIO’S HEALTHCARE SYSTEM



supports, and possibly the on-going prescribing of narcotics, which are highly addictive and often abused or misused—walk-in clinics can hardly provide the quality of care required, often affecting the continuity of care. For example, walk-in clinic physicians might not believe CP patients, as they do not have enough interaction to create a bond or establish themselves as credible patients or because they do not have their health history.

> I needed good care. I was in crazy pain and going insane. I kept seeing different doctors at my walk-in clinic and each kept giving me aspirin, ibuprofen, or Tylenol. I kept getting worse. Only when I got a [family] doctor and she took me seriously I got the help I needed. She worked with a nurse and a rheumatologist at Western. They've got me back on my feet. (Maira)

In addition, walk-in clinic doctors regularly adhere to a "no narcotics" policy. Many interviewees report frustration with the lack of access to effective pain medication when they rely on walk-in clinics for primary care due to lack of family doctors.

> Not only [walk-in clinic GPs] don't know you… even when they believe you are in pain and not lying, they can't offer you any narcotics because they don't prescribe narcotics to patients if they work in a walk-in clinic. (Luca)

Lack of continuity of care

Many participants report great difficulty finding a new GP when they lose their own due to illness, death, relocation, or worse because of suspension or loss of the GP's medical licence. In the latter case, finding a new physician willing to continue their treatment is awkward and virtually impossible.

> Nobody thinks about the patients in this system. They take the license away, and they give you no time to find another doctor and to make a transfer of the medical records. They should look into this first and already have another [GP] ready to take you on. (Birnie)

> I was on narcotics and my doctor retired… It's nigh impossible to get a doctor that is willing to continue narcotic therapy. This would never happen with other illnesses. (Kendra)

As discussed in section 5.3.4. Credibility and Treatment, this can be particularly problematic for people with CP given current attitudes held by many GPs about prescribing the medicines that help their pain.

Transition to a new GP is not properly managed. As noted above, interviewees cite that the Ontario health system does not presently provide support to patients when they need to find another GP unless the patient has lost a GP already. There is no allowance for people to change GPs because the current one is not meeting their needs.

> What they put in place is a system where somebody will try to match you to a new doctor. You must lose a physician to be matched with a new one. That is a requirement

> with Health Connect. You must stop your enrolment with your current one first. Then they will help get another physician when one becomes available… they say they give priority to people with serious issues but there is no time guarantee. When you are on narcotics, this makes changing doctors out of the question. It's absurd. (Rose)
>
> Health Connect looks good on paper. When you call the doctor's office they don't usually take you if you tell them that you are on narcotics. They cherry pick clients. By the time you find a doctor to take you on as a client, time passed by and you are already down the rabbit's hole... and that you get a new GP is not the end of the story—it has to be one that knows about pain and has experience with narcotics or other treatments, and this is not likely with this system. Doctors who are specialized and know what they are doing already have more clients than they want. So, you wait for your turn and meanwhile no treatment to help the wait. (Birnie)

The negotiating power participants have with their existing GPs might well also be compromised because of the known difficulty of finding a new GP under the current Ontario system. For example, if a CP patient knows that it will be taxing and vexatious to find another GP, the patient may feel that she cannot fully assert her needs with the current one for fear of destroying the relationship. (For a fuller discussion of this issue, see section 4.8 Lack of Negotiating Power).

Regrettably, in all the cases involved in this study, save those interviewees whose medical care involved WSIB and/or access to a CHC-based physician, participants reported the challenge of finding a doctor who is knowledgeable about chronic pain as an illness and is willing to deliver expanded health services by collaborating with other health professionals and social and community service providers. Indeed, shopping for a CP-patient-friendly GP is unimaginable to some of the interviewees, since they find themselves simply trying to find a family physician, any family physician, because they lack one. In other cases, because of disability participants stated they have no energy to look for a new physician and have given up any hope of doing so in the future.

> Can't bother anymore… getting up every day is difficult … I got three new names of doctors with good reviews … they are not taking new patients. They work with people with pain… like me. (Nelida)

This situation is made increasingly difficult by the shortage of doctors in Ontario. In addition, starting a new relationship with a new physician means that patients also need to spend more 'energy' in establishing credibility with the new provider.

> It’s best having a GP that you know has long experience with people who suffer chronic pain and knows a lot about it and can refer you to a specialist. Specialized programs for pain and pain clinics usually require a history. If you have the history, then they know that you are not faking—they know you. I have changed doctors a couple of times. For my history… this is not helpful. (John)

4.6.2 Variations in GPs’ Training, Experience, and Behaviour around Chronic Pain

Interviewees reported significant variations among GPs regarding their knowledge, training, and willingness to work in partnership and provide support to CP patients.

> We should not depend on just our doctors being good or not good… There should be people that work with people with lots of pain. I have no strength to work on finding a good doctor. I don’t know where I would find one… I don’t know a lot of people that I can ask if they know a good doctor. All doctors should be good. They should be the same but they are not. (Eva)

The quality of care and support provided to people with CP is clearly not uniform or standardized in terms of treatment strategies, protocols, or guidelines. Furthermore, interviewees are left with the impression that accountability with respect to the quality of care provided and outcomes is lacking.

Interviewees also point out that the “quality of their GPs” has a great impact on the type of treatments and support services they are offered, making a big difference in how they manage their condition, and raising equity issues.

> The most challenging thing here is that you assume all doctors know the same things and act the same way, offer the same treatments and want to work with you. They don’t. Appalling! How do you work with these differences? (Tomash)

> GPs may offer appropriate treatment if the knowledge is there. It depends on their willingness and even resources available since accountability is checkered at best. Up to now, there are no systems in place that measure the impact on quality of life and health outcomes of specific treatments, or patient satisfaction with the effectiveness of treatments or satisfaction with the level of access to non-narcotic treatments to pain. Chronic pain management guidelines and protocols are not always in place. (Kenswella)

GPs fail to make appropriate referrals

The general issues discussed above are compounded by a number of other circumstances/ aspects concerning the availability, training, and attitudes of GPs in Ontario. One critical factor, interviewees noted, is GPs failing to make appropriate referrals to other specialists and allied health care providers for CP management. Many participants perceive GPs as reluctant to make referrals, especially if not trained and knowledgeable about chronic pain. This lack of referrals, they argue, reduces their access to options that might prove helpful for them in managing CP.

> Over a decade with arthritis and pain; my doctor had yet to send me to see the rheumatologist. (Carl)
>
> I never saw a chiropodist, even though the pain I feel is intolerable and I can barely walk; my feet hurt so much, especially in the morning or when I walk. Makes no sense. (Tomash)

Beyond specialists, GPs often do not provide referrals to occupational therapy, physiotherapy, or some type of physical treatment to help keep CP patients on track in their recovery. Consequently, for some of the interviewees, the entire medical treatment to manage progressive diseases, such as arthritis and CP, is reduced to the prescription of some type of pain medication.

> When [GPs] don't know a thing about pain and they don't know what to do with, then they let you stew in it with just ibuprofen and Tylenol. After a few months, one is the happy owner of a new disease. So now one is with chronic pain; [GPs] still do nothing. More pills or no pills, depends on their mood or how much they know. So, shopping for the ones that know more helps. They'll refer you to a rheumatologist or a pain specialist faster as they know what it's all about. Right? (Lloyd)

Access to specialists, certain treatments, and services is largely dependent on individual family physicians' degree of training, exposure, and interest in CP and arthritis.

> I changed three doctors. One I saw for almost 14 years and it didn't work. The second one didn't help me either. Now the third one helped me because he understood my problem. He specialized in pain. He knew all the pain clinics. He referred me more than once to pain clinics…. He also sent me to an occupational therapist and to see a psychologist. He got me into creating a pain support group for those like me. (Carl)
>
> I went [to] a pain specialist once…, I asked my family doctor and was told that six years ago I saw one and that he (pain specialist) already gave him (GP) a report and that he is giving me all the pain killers, and I don't need to go anymore. But I am in pain all the time. Just a patch is not enough. Pain is not his field. (Milton)

In most cases, interviewees report that antidepressants are over-utilized and are almost always prescribed by the GPs. Only three interviewees receive psychotherapy or see a psychiatrist on a regular basis. Eight interviewees saw a psychiatrist or a psychotherapist at some point in their history of chronic pain, and this was mostly during their dealings with WSIB or while attending a pain clinic where psychotherapy was made available. The remaining interviewees never saw a counsellor or another mental health specialist, such as a psychiatrist.

> With my doctor it's "yes" to antidepressant; "no" to therapy. Antidepressants make me feel dead. (Lloyd)

In other cases, GPs are perceived as making referrals in an untimely manner. Delayed referrals and lack of information about available services and social and community supports resulted in participants not accessing timely treatments and other medical, psychological, or social interventions that could improve the management of their condition and reduce or delay further deterioration of their health status.

> My family doctor does nothing to help me. He claims he did everything. When I started to have pain, I got some muscle relaxant and Tylenol 3. I complained that I could not walk and move, and I was in bed all day for a year before I was referred to a pain specialist. After the referral, it took two months waiting to see a pain specialist. [The specialist] examined me and took tests and gave me medication [Fentanyl], but it was not effective. Then the pain specialist wrote a report and sent it to the doctor saying the arthritis was advanced and there's damage, and nothing can be done. So my family doctor keeps prescribing the same painkiller, but my body is used to it and it doesn't work. My family doctor will not help. No new painkiller—just Fent [Fentanyl] and a "Get used to [pain]." It's the way it is. (Paul)

Shortened time with physicians results in inefficient care

The majority of the interviewees (15) alleged that the time spent with doctors during appointments is too short, or that doctors have too many clients or appear to be too busy to provide them with the clinical attention they deem appropriate. Thus, GPs are perceived as providing inefficient care. According to these interviewees, the average visit to a GP lasts five to 20 minutes. Only six interviewees reported spending 30 to 45 minutes with their family physicians during a visit. Their physicians are community health centre based in five of those cases, and the remaining physician is part of a family health team.

Interviewees also reported feeling as though the GP is too busy to pay attention to their specific concerns:

> Our appointment is for 45 minutes, and she is always late. So the appointment is never more than 10 minutes long. Nobody rates her performance for being late. (Paul)
>
> The visit is for 30 minutes, but he spends like 10 minutes writing stuff. He has to get me out of there fast. There are always about 10 people in the waiting room. (Gus)

Long waiting lists, shortage of services and resources affect access

Limited and restricted access due to the shortage of services or long waiting lists creates more chaos, stress, and uncertainty for people whose lives are already largely defined by instability, insecurity, and uncertainty. Even where referrals are made appropriately and the GP has a good bond with the patient, shortfalls in services and resources and the ensuing long waiting lists—together with the need to make scarce resources, treatments, and services equally available to as many individuals as possible—results in limited access to services, inconsistent services, and a lack of continuity. (See section 4.2. Access to Services).

4.6.3 Lack of Coordination and Continuity

Interviewees often noted that they access effective health care services through a secondary care provider, i.e., pain specialist, rheumatologist or during a hospital stay—only to lose access when returning to a primary care setting, i.e., nurse practitioners, GPs, or physician assistants.

> My family doctor sent me to a pain clinic nearly seven years ago as part of the CPP (Canada Pension Plan) disability case discovery. All the good support I got during that couple of months disappeared right after. I was never sent again to a pain clinic to help me in some way, and the treatments with physio that were helping were stopped. My family doctor would not give me narcotics, and he said that was not his thing. So I got nothing but a few pills (referring to NSAIDs), and they don't work. (Dan)

As in the above example, most interviewees flag a lack of integration and continuity in their treatment. Disruptions in the client's treatment continuum are most prevalent when treatment involves several health care providers or multi-level health care organizations.

> I think [GPs] only want to stabilize you (through the services of a pain specialist) and then they take every treatment and medication away, and when you get worse, but really worse [GPs] want to re-stabilize you again (by sending you back to a pain specialist), and when you get there, they take everything away again, so you go up and down, up and down, and no continuation in treatments other than painkillers. Like getting a schizophrenic, and then as soon as they guy starts being OK, taking the drugs away so he is drug-free. Let me be addicted if that means that I will have some kind

> of life. But in our case it happens when we go from the pain clinic to the family doctor, and then back to the pain specialist and back to the doctor. It's a joke. (Paul)

Clearly, a more multidisciplinary and integrated model of care that delivers coordinated services across primary, secondary, and tertiary health care organizations and community support agencies is needed. Although Ontario's health care system provides for this in theory, interviewees (14) noted a much different practical reality.

> Multidisciplinary teams? Trendy. As trendy as the patient-focused care. Empty words. My doctor is not working with a group of other people. I do not have a nurse, or a nutritionist, or a foot doctor. I only see my doctor. And when things get bad, I am referred to the rheumatologist at the hospital. The rheumatologist sends me to a physical therapist, and I get nerve-blocker shots and water therapy as well. This works... The pain goes down then I am sent back to my doctor. All the treatments stop. I go back to my Tylenol and no multidisciplinary… nothing. (Vicenzo)
>
> I saw a nurse practitioner for a Pap smear and nothing else. That is all the multidisciplinary care I received… has nothing to do with pain management. (Eva)

This lack of teamwork or communication between primary and secondary health care providers is a problem for many interviewees.

> The rheumatologist and my GP don't communicate—both think differently, offer different treatments and drugs. When I go to the rheumatologist, I get one treatment and then my GP will do something different. Sometimes it's not all his fault. If he sends me to rehab, as he does not work in a hospital, I would have to pay... I'm seeing a psychiatrist, but he just talks with me. They do not communicate with each other. He doesn't work with my GP as a team. (Dan)

Moreover, information about available treatments, resources, and support services provided by community-based organizations and other wellness and social services to help patients to better manage pain and support their personal independence is not easily accessible and often not offered to patients by their primary health care providers. (See section 4.2. Access to services.)

> It took years in the system before I figured out that there were other services that I could use in the community. It would have been helpful to know about [them earlier] … Common sense. (Carl)

Where an integrated approach is made available to participants, they report positive results. However, these programs are usually not accessible on a long-term basis.

> I used to experience that teamwork at the pain clinic at Toronto Western Hospital. Everybody I saw knew what was going on with the physiotherapist, and the behaviour therapist, or with the rheumatologist. That was such a good program… I felt empowered. I felt that I could get somewhere. But that was nine years ago. Much is different in my life now. With arthritis, as time goes by you get worse… I am worse off now, but with less help to work all this out. (Tomash)
>
> I was referred to the Sunnybrook [Hospital] Chronic Pain program. A true multidisciplinary care for pain. Everybody worked together on my file. Besides, there was counselling and coaching… and rehab and classes. This was a critical moment in my case. Learning to manage pain triggers was best. But all the support disappeared when I finished the program. I need that support now. I need it tomorrow and will need it most when I get worse. (Maira)

Services by organizations offering more holistic and specialized pain management treatment options are often only available on a one-time basis to CP patients.

> Programs in pain clinics are amazing, but you can only access them for a short period of time. We have arthritis and chronic pain for decades. It's a progressive illness. We get more and more disabled as we grow older. These programs should be offered on an ongoing basis. (Jerry)

The lack of continuity and coordination of services during the transition from specialists to family physician care, or from one specialist to another, can be particularly troublesome, disorienting, and sometimes chaotic. Fragmentation of care and treatment are cited as difficult when interviewees are transferred from a rehabilitation centre, or from a pain clinic/hospital setting, to the care of another specialist or the family physician. Interviewees related that changes in treatments that are not based on how well the pain condition is being managed, but more on how willing or capable the family doctor or new specialist is to provide the same treatment or therapy, can be detrimental to their health outcomes and quality of life.

> [There is] something wrong with this system. They should communicate better. I dread leaving the hospital and coming home. I know everything will change. It's at the system level. Your doctor cannot and is not willing to give you the same drugs or send you to the same programs you get when you are at the hospital. In the hospital, you don't pay for those programs. They are free… When you are out you must pay if you need more sessions than OHIP will pay. To top it up, your doctor is not prepared to give you the same drugs the specialist gives you because he could get in trouble. In the end, we pay because our system is screwed up. They need to find a solution out of this cycle because it's creating disability for us. This costs them more. They want to

> save money and deny us treatments, and then they spend more money with the thousands of cripples they create every year. (Vicenzo)

4.6.4 Widespread Perception that Necessary Care is Unavailable in Ontario

Most interviewees (17) reported that they are often not able to access coordinated or appropriate medical services in Ontario due to the barriers discussed above. Because of lack of treatment options in Ontario, some interviewees feel forced to pursue other avenues in order to try to achieve some quality of life.

> Try seeing a rheumatologist in Ontario. You'll wait a long time. Doctors are not inclined to send you to a rheumatologist. That is because there are not many rheumatologists here and only the lucky ones get through. (Chola)

Experiencing frustration as their chronic pain remains unrecognized, undertreated, or improperly treated, some interviewees choose to avail themselves of medical service or other types of healing services and modes of care either in other parts of Canada or other countries despite tremendous inconvenience and expense.

> I'm from Hungary. It's cheap there to get treatments. I have to pay for the trip... it's worth every bit. My family helps me pay for the tickets. I believe [arthritis is] not progressing. In Budapest, the government is not so bothered with prescription drugs. I get them there. At least I get them from a doctor and not in the street... and I never got addicted. I follow what my doctor says. I trust her. It's a better [health] system. They are more into anti-inflammatory and muscle relaxants, not so into antidepressants like here. You get relief from pain. In [Canada] it's not the case. But I have to go there (Hungary) two or three times a year. I have done this now for the last three years, and I have been able to get back to work after two years in horrible pain. I had to stop working then. (Maira)

One interviewee, who continually tested negative for rheumatoid arthritis (RA) despite living with very painful inflammation and osteophytes (bone spurs), discusses his frustration with the treatment options available in Ontario:

> [Rheumatologists] knows that not all people with rheumatism get positive tests. But in Canada, you can't be treated if you can't prove that you truly have that illness? … My younger sister offered to take me to a rheumatologist at the Mayo Clinic in the U.S. Guess what? I started getting treatment for RA right away. It's working. But it costs money. How can you explain this? I have to go to the U.S. and this is expensive. It's helping me with the pain though… and will help stop deterioration. They sent me to a chiropodist as soon as they saw that my feet… joints are warped. They put me on a special diet and an exercise program. This is helping and protecting the joints. I can

> do this because my sister is footing the bill. And because they give me enough painkillers so I can exercise. (Birnie)

Self-medication

Over half of the interviewees (15) in this study indicated that they choose to self-medicate—use alcohol (6), marihuana (4), or other self-soothing forms of behaviour—to treat untreated and often undiagnosed pain, mental distress, stress, and anxiety. Self-medication is often seen as empowering and a step towards independence from the perceived shortcomings of the conventional health care system.

> I tried it all: herbs, MSM, chondroitin, ginger, curcumin, and whatnot. I think they work, but alone they can't make a miracle happen. Food is my drug of choice. I eat obsessively. I use food because it calms me. The more the pain, the more the anxiety, the more I eat. I feel good eating. But I am not happy with my weight. (Nelida)

> I never drunk until I lost my job. Then my wife left and I was here locked up at home disabled with pain. Drinking helped me grieve. Am I an alcoholic? You see, I'm neither here or there. I drink a couple of beers a day. I am not lost. I just need a break. (Jerry)

Self-medication appears to be treated in part as a stopgap measure because the more traditional forms of health and self-care are not explained or made available to interviewees on a consistent basis.

4.7 Category Seven: Stigma

In all cases there are claims of stigma attached to suffering from a chronic pain condition. Common stereotypes encountered by participants include being perceived as malingering and manipulative to gain access to drugs or avoid work, having addictions, having a mental health disorder, or simply suffering from a penchant for calling attention. These assumed or perceived causes of chronic pain are themselves strongly stigmatized.

4.7.1 Stigma in Society

All participants claimed that talking about pain causes backlash. Whenever they share information about their CP condition, it is not uncommon for them to receive negative feedback from others.

> Is that right? Is it that bad, or you're looking for attention? … You should take on a hobby… You are the only person I know that complains so much about pain. (Kathleen)

> They do not believe you; worse, they don't accept you... They tell you that you are too negative, and that's why you are not OK. They even accuse you of not wanting to let go [of the] attachment you have to your own pain. (Jerry)

Because of negative feedback from others, interviewees described feeling forced to hide their pain from others to avoid stigma, discrimination, and prejudice.

> So you kind of hide your pain because you know it's not a visible disability and because this way you avoid society's discrimination. The society does not understand that way, and the bullshit they would put us through—it's not worth it. They succeed if they can eliminate you. To share with society does not help me. (Vicenzo)

To stave off stigma, interviewees sometimes engaged in normalizing or pretending to feel satisfactory, as well as avoiding all references to pain.

> You must act like you are fine and healthy. Hide that you aren't well if it helps avoid issues. Better to feel alone with it than to be made wrong and crazy. (Pavitra)

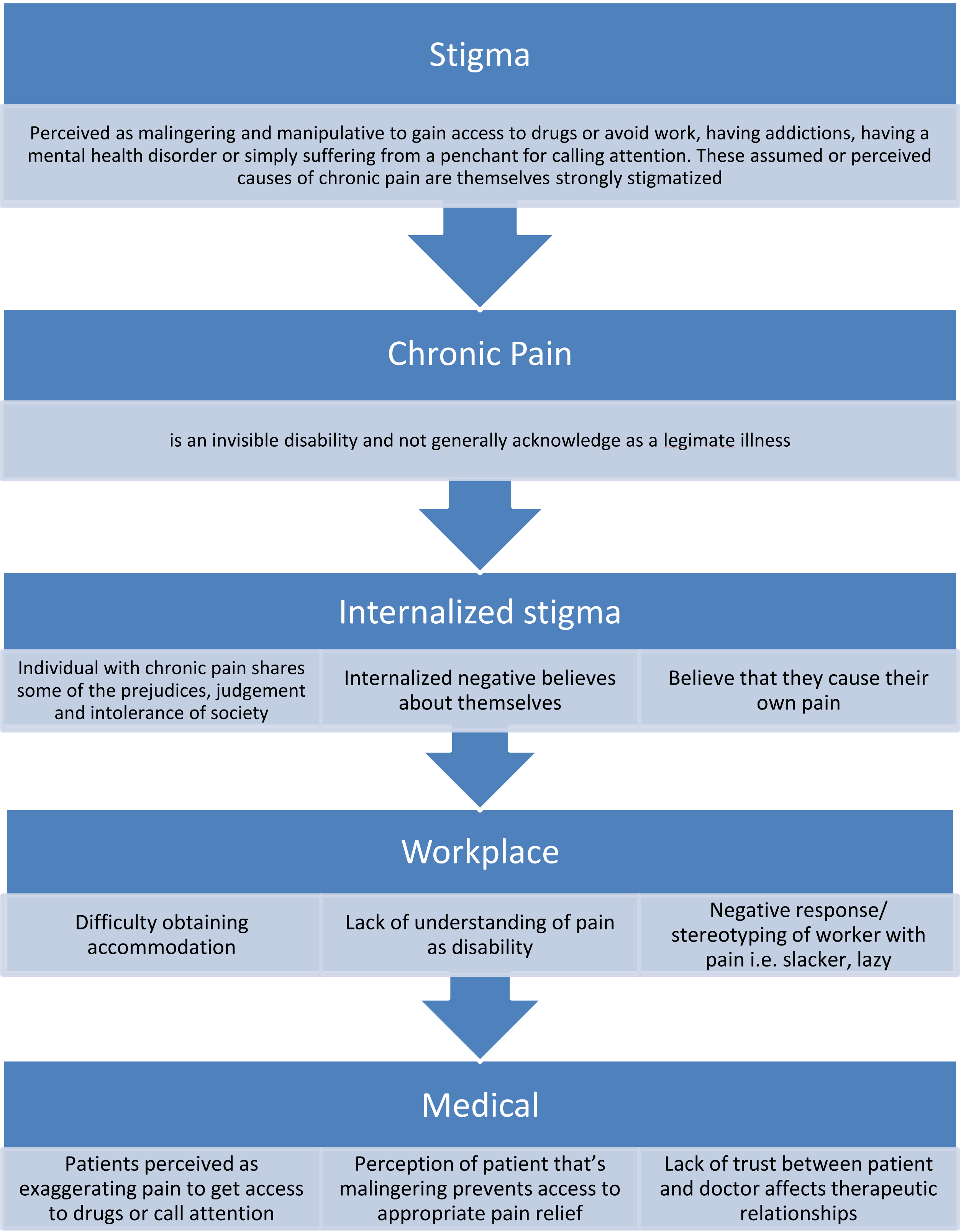
Stereotypes of people with CP as mentally ill, addicted, or simply malingering

Because chronic pain is mostly an invisible disability, and because arthritis is not generally regarded as a serious disease, arthritis-related chronic pain is not generally acknowledged as a legitimate illness. Participants reported that they are often stereotyped as having a mental illness, or using pain to attract attention, gain favours, or obtain drugs.

> People think you got a mental addiction that makes you talk about pain, pain, pain. Society cannot accept that. (Vicenzo)

> I can't prove I have pain, and when there is no proof, everybody starts thinking that you have a reason to complain… that we are insane, or we want to stop working so we create a story about pain… These are common ideas about us. They mostly think we are freaks. (Luca)

Figure 6. STIGMA



Stigma

Perceived as malingering and manipulative to gain access to drugs or avoid work, having addictions, having a mental health disorder or simply suffering from a penchant for calling attention. These assumed or perceived causes of chronic pain are themselves strongly stigmatized

Chronic Pain

is an invisible disability and not generally acknowledge as a legimate illness

Internalized stigma

Individual with chronic pain shares some of the prejudices, judgement and intolerance of society

Internalized negative believes about themselves

Believe that they cause their own pain

Workplace

Difficulty obtaining accommodation

Lack of understanding of pain as disability

Negative response/ stereotyping of worker with pain i.e. slacker, lazy

Medical

Patients perceived as exaggerating pain to get access to drugs or call attention

Perception of patient that's malingering prevents access to appropriate pain relief

Lack of trust between patient and doctor affects therapeutic relationships

Consequently, individuals with chronic pain often wish for proof and evidence to corroborate their claims of pain and to make pain visible, because corroborating their claims is a means to legitimize their pain. (See further discussion in 4.4. Treatment)

> I wish I would have a wound that bleeds or a big ulcer so that my husband would understand when I tell him that it hurts so much. (Kathleen)
>
> I share the same fantasy as other people with chronic pain—we all want something to show how much pain we have, something that makes it clear to others… especially to our families and doctors that we aren't horse-shitting them… that there is something wrong. (Paul)

4.7.2 Stigma among Friends and Family

The general stigma attached to people with CP is intensified within their personal circles. Participants report that there is a palpable uneasiness with the subject of pain. While negative and unsupportive comments are common responses when participants share their experience with pain, participants believed such responses are more pronounced among friends and family and include more accusations of exaggerating pain or "making it up."

> Nobody likes people talking about negative stuff again and again. But if you have cancer and you need to talk about [it], they might accommodate your need. With chronic pain it's different. Unless you have a deadly illness attached to the pain, nobody wants to hear you talk. They tune you out. Neither my husband nor my sons believe this is true. They are most hurtful… and they don't hide their contempt… they want you to know how they feel. (Maira)
>
> Friends and family are the nastiest because you love them and you expect them to know that you would not be making this up. What a surprise you get when no one is on your side, and they tell you, "Stop exaggerating" … It can't hurt that much. (John)

Internalized stigma

In some cases, interviewees themselves share some of the same prejudices, judgments, intolerance, and the stigma that society attaches to individuals with pain.

> My mother doesn't like me because I have pain just like her. She doesn't even want to hear me talk about it. But she talks about her pain every time we meet… She hates herself because she's in pain, and she hates me for that too. But seriously, I find it hard to listen to her talking about it too. (Kendra)
>
> I should open a support group for chronic pain and self-hatred. We hate ourselves because everybody keeps telling us that we are lunatics… we can't stand ourselves.

> We wanted to convince them that we are in pain, but they convinced us that we can't be trusted. I think we sooner or later believe them. (Birnie)

A few interviewees report not attending or concealing their attendance at pain support groups because of stigma about chronic pain or not wanting to be defined by belonging to the group.

> I go to the [support] group often… but I'm quiet about it. (Eva)

> Mind you, it's like ethnic groups—you get involved in a clan, a sect, you go to those groups that offer support with chronic pain. In fact, I have no problem to be defined by pain and go to support groups for help. But I think society, and in my own community, in my work, and in my own ego, showing pain is a weakness. (Vicenzo)

Indeed, some interviewees also claimed being discriminated against, even within pain support groups, when pain is not caused by "serious diseases."

> Almost like they sit smug and talk about pain with pride. We talk about discrimination; they say they don't get us. After the meeting, once I shared a ride with a member, and he told me I didn't realize how lucky I am I don't have cancer. That that is real pain. (Jerry)

Feeling that they themselves are to be blamed for having pain

Some interviewees reported feeling that perhaps they cause their own pain since that is what others appear to think:

> But I must consider this: My wife thinks I'm a baby for complaining. It's in my head, she says. My mother is 71 and is a traffic control officer outside a school. She still works half a day all week. I'm 46, and I am not working. I am a big man. You are not allowed to cry about pain when you are six-feet-five-inches tall and you look like me. I must have created it. If all the people that know me think that I did it, I must have. I've got to look into it. I'm considering it. I think quite a bit about this. (Paul)

4.7.3 Stigma in the Workplace

Some interviewees explained the cycle of trying to hide pain to avoid stigma from coworkers and employers.

> Once it's clear that the reason you are slowing down at work is not because you have a heart problem or they amputated your arm or leg, but just that you are in pain, you are considered a lazy maggot who is there to take a job from someone who really cares. (Gus)

4.7.4 A Diagnosis Can Help Stave Off Stigma and Prejudice

A lack of or delayed diagnosis frequently impacts how interviewees perceive themselves, since they are often being told that there is nothing wrong with them. However, there is something wrong: they are in constant pain. Besides, interviewees often feel that not having a diagnosis also affects how others deal with their repeated complaints about pain and disability. They often appear to be healthy and present no visual signs of physical injury and no diagnosis to fully support their complaints. This outward appearance of health and vitality, they allege, reduces their credibility in the eyes of those around them.

> Still, nothing explained why I had so much pain. I lay in bed for a complete year. My husband couldn't understand why I was in so much pain. Some of my co-workers came to visit after I quit my job. They were acting as if I was crazy when I would not be able to give them a diagnosis that made sense and explained why I felt so bad. (Rose)
>
> It helps me to know that it is not all in my head. I am still in pain but feel vindicated. I kept thinking that perhaps they were right. I was in pain and nothing was wrong. Maybe I was nuts after all. (Pavitra)

4.7.5 Stigma and treatment options

Participants in this study reported that because they often must rely on the use of narcotics in order to try to preserve some semblance of normality, they in turn risk being stigmatized for drug use. (For further discussion see section 4.4.2 Opiates and Pain Management.)

4.8. Category Eight: Lack of Negotiating Power

Given the many challenges for participants, both due to their compromised health status and the limitations of the current healthcare system, it is no surprise that they all described themselves as lacking negotiating power in many life circumstances.

4.8.1 Imbalance of Power between Patients and Physicians

Among participants, there is a perception of GPs as having unfettered discretion to offer or refuse treatment for relief of pain.

> I felt helpless, scared that I may offend her and be denied something that I need. I was held hostage to my medication. It felt like my physician had too much discretion in deciding how much pain I was supposed to feel before she gave me treatment… They run no risks, and they can choose to believe or not believe you. (Dan)

Interviewees like Dan, perceive their negotiating power as diminished and claim they feel more vulnerable due to the discretion that doctors have to refuse treatment, prescribe or not prescribe adequate pain medication, and to serve as gatekeepers by providing required referrals to specialists and diagnostics. Such perception of the family physician's discretion as unfettered appears mostly to be related to the nature of arthritis and chronic pain. Both diseases are difficult to diagnose and are not always fully diagnosed; both are usually long-term, progressive diseases that are not commonly considered life-threatening. It should be noted, however, that when not treated properly, arthritis and chronic pain can cause great distress and negatively affect mental health and quality of life.

> It's not easy to prove that they are denying you treatment. If you have an infection and your GP doesn't prescribe the appropriate antibiotic, she will be held accountable, and if you have difficulty breathing, and they do not prescribe you a drug to help increase your lung capacity and help you pull through, they will also be held accountable. But if you complain about pain or inflammation, and your GP gives you Tylenol even as you tell her that it doesn't work, your GP will not get in trouble. They can get away with not giving you treatment because pain can't be measured, nor is the suffering you are experiencing because there is no relief. (Kenswella)

Lack of trust

Most interviewees (17) clearly articulated their lack of trust in physicians and the "patient-doctor relationship" within the unregulated and unconstrained context of the consult visit. According to their accounts, the system has built-in power imbalances that coalesce to undermine their trust in relationships with doctors. These were due to lack of dependable accountability and oversight, along with insufficient training of physicians to deal with CP. In some measure this is an unfortunate product of the deeply entrenched and systemic conceptualization of doctors as all-powerful within the health care system in particular, and society in general.

> It is a non-issue when a client calls and makes a complaint that a doctor is rude, or didn't listen, or was disrespectful, or never documents their symptoms…. Doctors can always cook up a file. They can call the client obsessive, difficult, oversensitive, or too needy. Ultimately, unless the doctor really screwed up with the treatment, there aren't many ways to prove if they weren't in fact doing a good job taking care of the patient instead of being interested in their pocket and doing minimal work, like … huh … seeing client, filling charts with minimal information to move on to next client. Ka-ching, ka-ching, ka-ching. (Maira)

> The system is against the consumer. I am not denying that there are accountability systems, such as chart audits and other types of performance reviews, but the only way to get doctors to be responsible enough with their clients is to have some system to track their interactions with clients, the effectiveness of treatments and how complaints about health issues, especially in cases with chronic pain, are dealt with or if there's a follow up on those issues. That's difficult. Even factory workers and salespeople are not left to their own devices. There are training workshops about how to deal with patients, but this is not happening often enough within the health system. Being exposed to them is not enough. Physicians must be held accountable for following through. Nurses, we are more monitored, better trained. (Kenswella)

Patients' co-participation in care at risk

Patients have the capacity to provide input and the assertiveness needed to act as co-participants in their care and treatment; however, they are stifled by an imbalance of power. As a result, interviewees reported feeling reticent or reluctant to bring up any issue that could potentially be open to controversy. This is especially true when such questioning might be perceived by the health care provider as an affront on the part of the patient and is likely to cause tension, defensiveness, or resentment in the provider.

> I can't trust a doctor that disregards any of what I say. When I was listing my symptoms for [GP] to have a full health history, she only wrote about my hands being swollen and stopped there. No more history taking, I suppose. When I told her I was feeling pain in my feet, hips, and back, she stopped me and said not to worry, that the ibuprofen would take care of all the pains I have and not only the pain in my hands. Did she think I believed I needed a different painkiller for each site? How insulting. She got the next patient in as she was saying "bye" to me, so there's nothing written about the sites of pain after my visit is done. She meant that she didn't need to write down all the sites where I have been having problems with arthritis. So how does she keep track of progress? How will she know next time if the pain spread to other sites? … They get trained, right? Do they get supervised anyhow? It's like you are naked there. No way to do anything to protect yourself from them. They are prima donnas. Once they graduate and get the letters next to their names, they have the power to do anything … Not accountable to anyone, I think. Unless I videotape them, I don't think I would be believed. Doctors have muscle. You need them; they don't need you. You go away; there are 200 patients looking for doctors… Now I have a new doctor. She's better. (Chola)

The current shortage of GPs specialized in treating chronic pain may also adversely affect the negotiating power that CP patients have with their own GPs, especially when taking into account the intricacies of finding a new physician if their relationship with their current family physician deteriorates (See section 6.1.2 Difficulty finding a new GP).

Shortage of physicians treating CP

The critical shortage of GPs in the field of CP further erodes the negotiation process for patients. Interviewees speak about being painfully aware of the shortage of physicians with training in CP in Ontario and believe that doctors likely perceive people with chronic pain as "undesirable" clients because they are regarded as "complex cases" and as "difficult clients" that can be more taxing on the time, energy, and medical resources of physicians.

> She's been my doctor for 20-something years. It's hard to change doctors, but I don't think she thinks too much of me. Anyway, there are no doctors out there, especially for someone like me with my [medical] history. They see people like me as bad patients… we take a lot of work because we are always in pain and asking for help. They don't want difficult patients. They prefer new patients to be easy and [relatively] healthy. (Kendra)

One interviewee discussed the inability to negotiate a treatment with his GP:

> [GP] never liked me or never believed me; so she never sent me to a pain specialist. I often asked for a referral to a pain clinic or at least a pain doctor. I brought her two names. She hinted that I was exaggerating the pain—well I guess she was pretty open about it. When I said that I could not sleep because of my hip hurts, she pointed that it could not hurt that bad since I am still walking, and she said this only a month before my hip surgery. I was so exhausted and had not slept for days, that I started crying. I felt bad—men are not supposed to cry. But having to convince them that I need treatment is humiliating. I had no power and knowing that someone can have so much power over you. Finding a doctor trained to deal with pain is like looking for a needle in a haystack. (Milton)

Physicians assert personal expertise

Interviewees also reported that GPs often wield the power of their knowledge by making certain the patient knows who is the expert and, therefore, in charge of the situation. This, participants argue, increases their sense of powerlessness and frequently prevents open participation and collaboration.

> He has the need to crush me. He's always reminding me that he is the doctor and I am the patient. I must tell him only my symptoms… and only when he asks… but he is the one that will decide what the best treatment is for me. Up to now nothing has worked, and I can't open my mouth or make a suggestion without him asking, "So when did you go to medical school? What year did you graduate?" (Lloyd)

In some cases, the vulnerability created by a fear of rejection by the GP raises barriers for the person with CP in communicating realistically about their situation:

> If my doctor made a suggestion, I followed it. But he doesn't make many suggestions. And I don't push him so that he doesn't reject me... He could get upset if I take his time. I can see some impatience when I repeat that I can't take it anymore. (Ekua)

4.8.2 Imbalance of Power in the Workplace

Increasingly higher levels of disability caused by CP itself (as discussed above in Categories One and Three**)** lead to inability or reduced capacity to be gainfully employed. Most interviewees argue that it is the lack of clear diagnosis, along with the only quasi-legit stance of chronic pain itself and the often invisibleness of their condition, that frequently gives rise to a distinct power imbalance in the workplace. This, they claim, sometimes results in termination of employment on terms not chosen by them.

> If you are on the way to dying of cancer, they'll care about you at work, but only so much. We all know you will still be treated as a leper. But the situation is worse when you have chronic pain—something about chronic pain that nobody understands or likes. My colleagues treated me as a slacker, the proverbial lazy bum. Bosses mobilize and try to consider your needs when they believe you are truly ill. But I had no diagnoses. WSIB said I should be returning to work. Soft tissue damage does not count for insurances. You have nothing backing you up that can make bosses run to help you out. They soon enough take to moralizing lectures and show how your lack of effort affects the morale of your coworkers and productivity. It is not lack of effort. I am not able to work as fast. But how can you negotiate a job change, or even a demotion, when nobody believes you? It didn't help that I was nauseous all the time for the morphine and not awake at the wheel some of time because my doctor had me on loads of antidepressants… and I only needed to take antidepressants to deal with the anxiety of being bullied and powerless. I was fired after some time. (Birnie)

In order to preserve some semblance of workplace normality and of agency, some people with CP must resort to normalizing their situations.

> I was a nurse working within the system. I was well aware of how they treated others with pain. I never disclosed it. When I missed a work day, I told them I had a flu. I didn't need my colleagues thinking I was high with painkillers while taking care of patients. Once they decide that you are not OK, they will make sure you quit or they'll get you fired. We have a saying "nurses eat their young." But not only young nurses are at risk. If you are ill, they will start undermining your confidence and competence. Eventually, you are in distress… physical and mental. You start apologizing all the time, even when you are not at fault. If you are known to have a pain condition, you lost all power. (Kenswella)

4.8.3 Imbalance of Power within Personal Relationships

As discussed above in Categories One: Social Impact of Pain and Three: Etiology of Pain and Its Effect on Relationships, participants experience many changes in their personal relationships. CP often altered their economic standing or threatened economic independence due to its debilitating nature and the consequent increase of disability. A higher degree or even total and swift economic dependence are not uncommon.

Loss of financial independence

Grappling with the loss of financial independence is certainly complicated and often hard on participants as well as those closely related to them, and frequently results in distinct power imbalances. Interviewees revealed experiencing humiliation, ineptitude, uselessness, depression, and low self-esteem. Furthermore, they frequently claim that friends and family only add to these feelings of inadequacy and powerlessness, as they are less likely to respond in a positive or understanding manner, but with aloofness, contempt or even condescension.

> Ha, marriage is a delicate thing. When something changes, the whole relationship changes …. We are not equals … we rent a movie and because he pays for it, he gets to choose which one we'll be watching—same with TV, restaurants … With his friends, he goes to expensive restaurants; with me I have a choice of fast food outlets. All frills are gone. As soon as I stopped paying for my half of the bills, all my choices were cut off. It's humiliating and depressing. (Pavitra)

The lack of negotiating power within relationships caused by a chronic disease's disabilities can create a sense of personal worthlessness or a feeling of being damaged and, therefore, a need to "compensate" for these deficiencies.

> When you know you are damaged, you try to compensate… like an old man with a younger woman—he must compensate with money, presents, or with lots of charisma, and sooner or later he will need to turn a blind eye when she stops sex because it's too difficult to feel attracted to oldness and she needs an affair on the side. I feel that way too. I buy him presents. I smile all the time… it's like a tic. I smile even if don't want to. It became a habit. I laugh at his jokes, even when they aren't funny…. I give back to create balance, you see. My children tell me that I became a doormat…. What do they know… they are not me. (Chola)

One interviewee described feeling the need to conceivably buy some commitment from her partner to provide her with some care in the event that her disabilities would call for that.

> That same year I bought a house in September, and, even though I paid for the down payment and was paying for the mortgage, I thought it was fair to put the house under her name too, so that she would know that I honestly loved her. We had been barely four months into the relationship. We were not living together. I think I always bought my women with money. I was always aware of my health and how boring it is to be with a sick person. I wanted them to like me anyway. I wanted them to be there for

> me if I ever got worse. I was always afraid of being alone and not being able to get out of bed and end up in some hospice with people who do not give a damn about me. (Kendra)

As discussed above in Category One, 4.1.3. Social --->Friends and Family, in some circumstances the need to get and to hang on to a partner appears to be of particular consequence to people with chronic pain, as their disabilities are likely to increase with time, and the prospect of being alone, helpless, or destitute is not only frightening but dreadful. To increase the likelihood of partners sticking around, interviewees report normalizing their behaviour so as to feign wellness and hide illness by becoming more solicitous, over-compensating for their disease, or compromising excessively and silencing how they feel. In some cases, they try to instill guilt to keep a partner's attention or even buy their partners' loyalty with money, trips, and gifts—all in a bid to ensure that they will have a support person available when they need one.

4.9 Category Nine: Empowerment

Participants identified circumstances, conditions, behaviours, events, relationships, personal characteristics, treatment modalities, therapies and approaches they deem as helpful, desirable or necessary/required if they are to manage their chronic pain in a manner that is effective and successful.

4.9.1 Primary Health Care Providers

Interviewees reported that there is a definite need for empathetic and supportive GPs who are trained specifically in how to best assist people with CP. Physicians should:

a. Seem interested and ask relevant questions

> My new GP knows very well how to ask relevant questions: How are you actually doing? How are you sleeping? Are you able to do this or that thing? How much pain do you have on a scale of 1 to 10? Does this new painkiller allow you to still think straight or is it too killing your mind? But most [doctors] don't probe that deeply. (Birnie)

b. Stay informed about medical and social supports in the community

> Finding my GP was a miracle; she always has information about what can help, and where to buy things cheaper, and the agencies that can help me in the community…and she has sheets with places and [phone] numbers, I know where I can get help. That is helpful, very helpful. (Kathleen)

c. Provide prompt referrals to specialists for follow-up and greater support

> When he doesn't know something, he sends me to a specialist right away. He is the best, the best I ever met. I don't know what I would do without him. (Marc)

> You need to see a pain specialist before you fall apart or the pain becomes chronic. A referral at the right time can save you. (Rose)

d. Display compassion and possess good communications skills

> I feel he cares about what is going on. He asks questions about my health and my life, my family and how I feel, and he listens, and he remembers what I said in my last visit. He understands what I need and what I can do and my weaknesses, and I never felt judged. It's a good bond. I trust him because I see he cares. (Dan)

e. Show engagement and willingness to provide clear direction

> Ideally my doctor and I would both be knowing my level of pain, the sites, how it affects me, and what I can do to change… all steps clear so that when I'm overwhelmed there is some route I can follow that can give peace of mind. (Carl)

4.9.2 Pain Treatment within the Primary Care Setting

The sense of empowerment (or lack thereof) felt by participants is strongly related to the quality and adequacy of treatment received at the primary care level. Interviewees shared specific requests for improving pain treatment.

a. Increase access to pain relief medicines and narcotics when appropriate

> At my [chronic pain management] support group we have been told that doctors should always provide treatment for pain management, but when I go to my doctor I get told that where he works (walk-in clinic) they have a policy of not prescribing narcotics. Then, there has to be a policy that obliges doctors to provide treatment or a place that people with chronic pain can go to and get effective treatment. It will help to have access to other doctors. If your family doctor can say no to narcotics, then you should be provided with a second family doctor who is trained to prescribe narcotics or to treat chronic pain in some other way. (Luca)

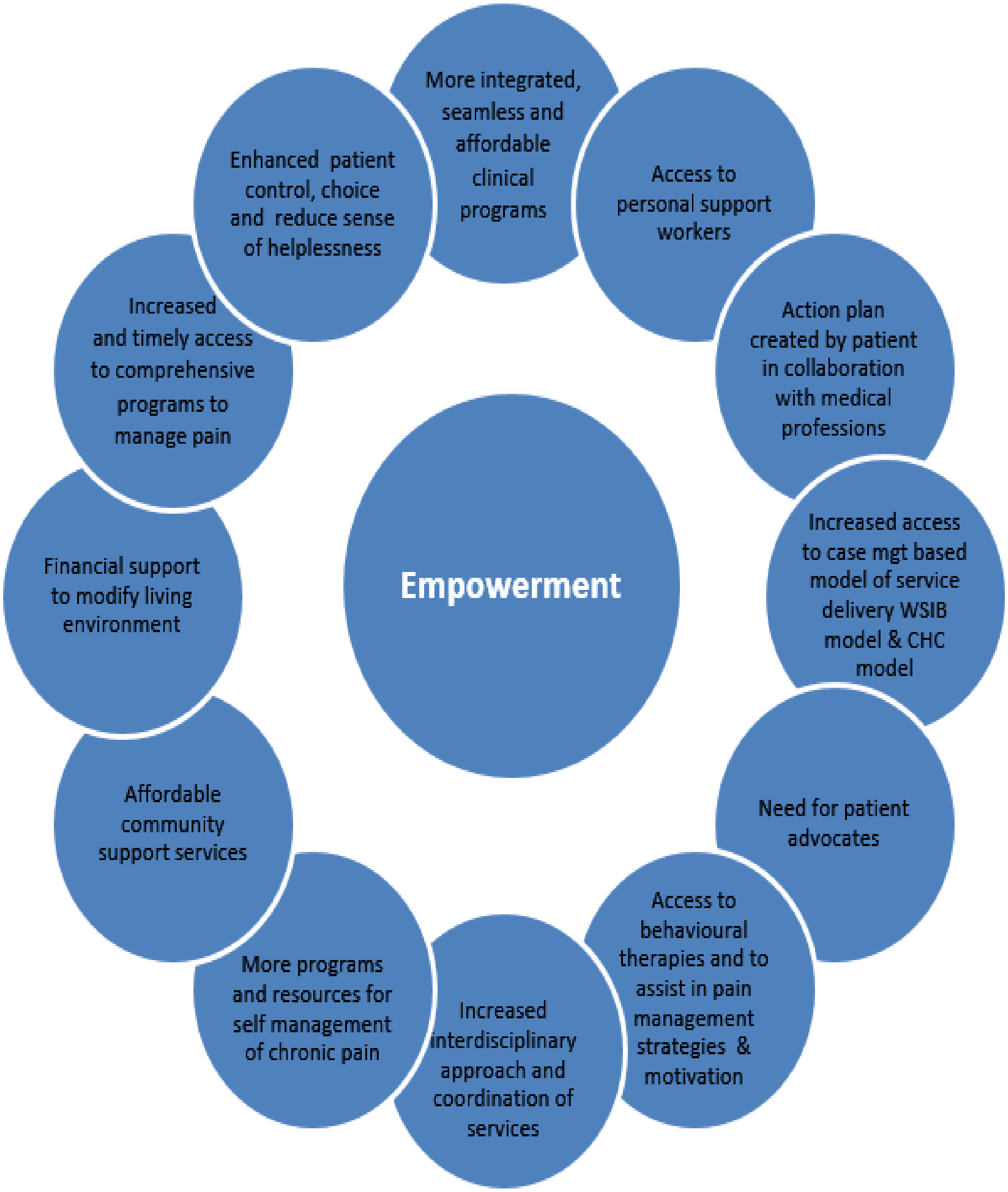


Figure 7. EMPOWERMENT

b. Increase monitoring and rotation of drugs for people receiving) Opioid-based treatment

> It’s important to find a doctor that is into monitoring and rotating to another painkiller every so often to prevent addiction. After a while, everything stops working. You have to rotate. I found that doctors that are willing to monitor and rotate [narcotics] are also more into helping us with pain. (Tomash)

c. Do not assume antidepressants or other mental health treatments alone will alleviate pain

> I found that most people with pain are not against anti-depressants. They have a place in treating pain. However, we want painkillers along with the antidepressants. Becoming a zombie does not kill pain—just helps us with the anxiety and insomnia caused by much pain. Though I found that I will not sleep when I have pain no matter how high the dose of anti-depressants is; I will only have my mouth and nose so dry I can barely take it. But no sleeping when I am in pain. (Marc)

d. Stop “blaming the patient”

> Shaming us for addictions is not useful. It only helps doctors stop prescribing drugs and feel that they are doing the best they can. Work with us so that we can use narcotics and stop the addiction. Monitoring is good, but only if done respectfully and without blame. I know all of us, or at least most of us, will be working with our doctors if we know they want to help and that if there is addiction we will look at it together and work to stop it together. (Carl)

> Feeling like a criminal or being at fault for being addicted is no solution for anyone. Doctors should be monitored more… to have them make sure people have less pain so they won’t go off the wagon out of desperation… become more educated and stop blaming the patient for everything… for having pain and for not managing it and for complaining and the list goes on. (Maira)

e. Provide more appropriate and timely referrals to specialists and community-based services

> Knowing the way into the social system, the services in the community for us, is important. A good doctor sends you to someone to help you know all this and to give you information on how to get help in your house. Some organizations have teenagers that can help you buy the groceries once a week. They are volunteers. You don’t know about these things if your doctor or the nurse don’t tell you. It took me years to know the system. (Gus)

> Once I was referred to a pain clinic everything changed in my little world. I learned how to deal with pain. I wish I had that referral early on. It took years. With pain, with chronic pain, timing is important. (Birnie)

f. Standardize the level of expertise of GPs to treat chronic pain

> All doctors should provide similar standards of care. Either you train all GPs to work with people with pain, or people with pain should be referred to GPs certified to deal with patients with chronic pain. (Kenswella)
>
> GPs should have same levels of knowledge and training about pain. We can't keep shopping for the good ones to get decent care. Decent care should be a given with any doctor. (Dan)

g. Create a roster of family physicians and other health care providers knowledgeable and experienced in treating chronic pain as an illness

> A roster should be readily accessible to people with CP rather than leaving patients struggling to find this information through word of mouth or by trial and error. (Kenswella)
>
> They should have a list of trained doctors on the LHIN's website or in hospitals. Somewhere. We should know who are the family doctors that work with chronic pain people. I do not know how to find one. (Chola)

4.9.3 Increased Education about Chronic Pain for Physicians

Chronic pain is a complicated disease, difficult to diagnose and treat. If the needs of individuals with pain are to be met, physicians need a higher level of expertise regarding chronic pain and to take an active role in shaping clinical practices. Participants suggested that increased education will ensure the following benefits for sufferers of CP.

> It's a well-known fact that universities don't prepare doctors to work with chronic pain. It would be good if family doctors could work with chronic pain. They can become better trained and will have more exposure and understand pain better. (Tomash)

a. Doctors that treat chronic pain as a stand-alone disease

> It's important that the medical profession and society get up-to-date about chronic pain. All doctors should know that it is a disease itself. (Tomash)

b. Doctors that have more expertise on the effective and safe use of narcotics to minimize apprehension towards prescribing

> It all comes down to education. Bias against narcotics and feeling uncomfortable prescribing [them] has a bit to do with GPs feeling that they don't know enough and have not enough education or training about narcotics and something can go wrong. The more they know it helps. (Maira)

c. Doctors that focus on providing effective pain relief at all times

> Refusal to provide pain treatments that work because doctors do not feel comfortable or do not believe in narcotics should be made illegal. (Paul)
>
> Addicted people also need pain relief. Educated doctors find a way to help with painkillers while circumventing the addiction issue. Otherwise, they are torturing patients. (Kenswella)

d. Doctors that communicate more effectively with patients

> I would rather the doctor explains that there are no resources or services than make me guilty because I can't get better on my own. We need more supports and less intolerance. (Gus)
>
> I doubt you can teach [doctors] to care. Either they care or they don't. It's nature. But they could be trained to appear to care. It's fake, but better than what we get. (Birnie)
>
> Train physicians to behave as if they were working in private clinics. Give them incentives and resources… this will help them feel better and will make them more interested in people with pain. (Vicenzo)

4.9.4 Specialized Care and Support Programs within the Ontario Health Care System

As they offer specific recommendations for empowerment, participants underscored the importance of patient-centred care through access to programs that focus on CP and furnish support and assistance necessary to the successful treatment and management of a disease that is chronic in nature.

a. Increased availability of more integrated and affordable clinical programs

> Too much pain creates disability. I want more treatment… of many kinds. The AIM pain clinic offers that. They help you first with the pain, and… to lose all the weight you got from not moving around… help with stress and anxiety management… AIM has a great program, but I don't have insurance to cover it. (Gus)
>
> It's the painkillers, the psychologist, the physiotherapist, the occupational therapist, the massages, the yoga and organic diets… all these could help me but I don't have them. I want more access. (Dan)

b. Access to personal support care at all stages of treatment/illness

> There are CCACs in Ontario, but they only work with the more fragile patient. They offer help and services in your home for free and they have caseworkers. If you are on the way to become a fragile patient, they don't work with you and you get no free supports. But we need the same system before we are totally disabled. They wait until we are good for nothing to get us resources. It's late and costs more. (Gus)

c. Financial and educational supports to help modify living environments and increase independent living

> I modified my home. I am a designer at heart and that's how I look at things. Just as physiotherapists teach people to work, how to modify body moves, it's a valuable program. But how do you modify your kitchen so that your life is easier? I keep most things in small containers or bags so it's easy to lift things, small things are all grouped together. I did it all on my own—designed that way… There is a strong need to have a consultant to help modify homes. There is a need to conserve energy. I pulled things out of cupboards and reorganized—first, in the front, the things I use or need daily; then things I use weekly and then monthly. I got rid of all that was not very necessary, simplified. My kitchen is more functional. All this is common sense, but when in pain they do not think about it. That is why it is important to have programs to teach us and to help us with our home design. [This] is necessary for people with chronic pain. (Birnie)

d. Affordable community support services to increase self-sufficiency and autonomy

> I want to stay in my home. I have help with Meals on Wheels, and a lady cleans my home and helps me take a bath once a week. Besides that, I get transportation. But this is all very expensive. My income is very low… sometimes I don't go to the doctor because I must pay almost $22 to get there. (Jerry)

e. Increased and timely access to comprehensive programs for pain management when the prospect of curing pain may not be feasible

> Saying pain cannot be cured is not acceptable. We need different treatments, and we need treatments as soon as we are in pain, not after years of suffering. (Luca)
>
> One should have simple, uncomplicated access to all types of treatments that are good for pain. The Wasser Pain Clinic changed my life. Many treatments were open to me there that reduced the pain. I felt much better. But most people will not have access to a program like this. The system has no capacity. (Carl)

f. More health care providers committed to supporting people with CP to reduce their sense of helplessness and increase compliance and collaboration

> At my pain support program, they introduced me to a counsellor… He is everything to me. I think I would have committed suicide if he was not there for me when my knees and feet hurt like hell and I feel like dying. Being there for me, reassuring me the pain will stop or become more bearable soon. He says you can't see it right now because you are in too much pain. But there is a solution. We can help you deal with the pain better. It will be all right. That calms me. That gets me going. He cares and that helps. (Chola)

g. More options and supports for self-management

Knowing how to manage pain and to somehow feel in control of the future, despite the wretchedness and agony that constant pain can bring about, is a crucial necessity for all. Participants emphasized the need for more access to programs that focus on self-management.

> This is [a] chronic condition. It's quite likely it's not going to disappear. Programs and treatments must focus on self-management, on acceptance. Our attitude matters. It helped me to learn that I can always do something to help me feel better. People can be taught to prevent peaks in pain and have less pain. We can learn to believe that we can enjoy some part of our life. We can learn to be empowered. These programs exist, just that we need to attend them every other year at least and not once in a lifetime. (Carl)

h. Early and continual exposure to **innovative chronic pain management approaches** such as acceptance and surrender.

> We need to accept that pain is here to stay and surrendering to it is something that they teach you at a pain clinic. A simple act… but changes one's perspective. Once we accept… we can begin to focus on how [to] manage pain and how to make our lives enjoyable even when there may be pain. We can still have a good life despite the pain, unless it's too intense that you can't even think of a life. Though we do not learn this just because we are told to do so, or through shaming us when we complain about pain or feel down. A behavioural therapist can help. (Maira)

i. New **skills and tools to increase capacity to successfully manage pain condition** and positively affect health outcomes**.**

> How to stand up, how to get up from your bed without hurting your back, how to pick up an object… it's helpful—also using a walking stick and a rolling utility cart to do the groceries without the bag's weight hurting my fingers. (Matt)

> Managing triggers is one of the best resources. Learning how to identify triggers can be challenging... You do not know that you do not know. (Kenswella)

j. Heighten awareness of local services available as pivotal in impacting access to services and community-based programs that can further assist self-management of pain conditions.

> Nothing beats knowing which agencies and centres will give information and answers for support or treatments. Plugging to this network of information is important. You need to know how to get help in your own area. We are tired and disabled. Commuting is exhausting. (Dan)

> An information sheet with all the services and programs in our area would be a start. (Rose)

k. Increase **access and use of information and communication technology to link to health care and health-related resources** to help facilitate chronic disease management.

> There are programs in Europe I access [to get information about chronic pain on the computer]. They are more advanced that way. There are support groups on the Internet and social workers that manage your case online and look for community centres, or programs close to your home when your doctor can't help you get a social worker or nurse advice online. (Dan)

l. **An action plan created by the person with CP in collaboration with medical professionals**

> An action plan created in collaboration with your doctor or a nurse to set goals for pain management and keeping pain diaries and mood tracking… and your doctor and you decide together what action or steps you can take like, "exercise 5 minutes every other day," "walk for 5 minutes a day" …are very helpful. (Kenswella)

m. **An "interdisciplinary" approach to assist people with CP in coordinating services**

> Interdisciplinary programs like those offered in pain management clinics should be available to people in pain. These integrated treatments must be provided as necessary…and not as a last resort. (Kenswella)
>
> Access to self-management programs is obviously the answer. They help you change your lifestyle… but first things first—without pain relief people don't choose self-management. Access to interdisciplinary services will help bring relief and then you can enroll in self-management. (Maira)

n. **Access to behavioural therapists assists with strategies and motivation**

> Behavioural therapy can help stop negative thoughts. When I learned to stop thoughts that discouraged me I felt better and acted differently. It helps with the stress and anxiety. This therapy should be a must. It was without question a blessing to me. (Marc)

o. **Patient advocates who act as liaisons between patients and healthcare providers**

Patient advocates can document the information conveyed to the patient, request information, help the patient make decisions and assist the patient communication with the health care provider in ways that can contribute to improving or sustaining a high quality of health care.

> I want to have somebody that cares about me when I see my doctor. That way I will have a better idea of what happened and I believe my doctor will listen more. (Luca)

p. **Increase access to integrated, seamless, and coordinated care**

> We can't be expected to think about every aspect of our health. We need someone to coordinate this and to help us connect to the next specialist, to the counsellor, to a support group… basically, keep a map of our whereabouts around treatments. Did the patient see the physiotherapist in the last 3 years? What is the patient mental health like—are they depressed or just anxious? And what is going on in their homes and with work? Was the patient fired because he stopped being productive? Are antidepressants helping or hurting the patient functionality? And how many services are patients accessing? Who helps them exercise? Are [they] totally isolated? Do patients have enough resources to manage the disease or are they just expected to manage without? Are their doctors talking to the nurses, social worker and the physiotherapist, and are they making sure that patients have access to treatments they need? Who looks into this? (Kenswella)

Overall, participants consider it essential to have dedicated and supportive health care and community professionals to help navigate the health care system. Consequently, they suggested **a "case management" model to assist people with CP in accessing integrated**, **seamless care and coordinating services** (informed by the WSIB and CHC models).

Two currently existing successful approaches in Ontario's system, the Ontario Workplace Safety and Insurance Board (WSIB) and the Community Health Centre (CHC) models, were flagged as examples of health delivery models that empower those dealing with CP.

WSIB model

According to participants who experienced the WSIB service delivery model, access, consistency, and continuity in services was significantly increased.

> WSIB requires you to go to a program at the Toronto Western Hospital where they have a Rehabilitation Assessment Centre with physiotherapists, psychiatry behaviour, GP, and pain specialist. They have a functional restoration program where they teach you how to become functional, get you grooming, cleaning, and that kind of thing. Through the WSIB we got a detailed program—three hours each weekday for six weeks, with [a] one-hour resting period. There was a team approach… to take care of you. You had a doctor, pain specialists, psychologists, physiotherapists, kinesiologists, behaviour therapists—seven types, I think—some of them basically saw you mostly every day. At the end of the program, they looked at all your records, and if you have permanent restrictions they give you recommendations for increasing activities. That was excellent. (Tomash)

> In my experience, a major reason that the WSIB care helped me is mostly because they had someone managing my file; case managing is the key. You cannot run from one place to the other and no one knows what is going on. (Birnie)

Also, interviewees point out that after being out of the WSIB system, they experienced a diminished access to services and had difficulty with waiting periods to access those services that were still available to them. They were as well cognizant of the lack of coordination of services and that consistent access was either spotty or non-existent outside the WSIB system.

> One cannot experience both systems and not notice a huge difference—from having an emotional backup, psychotherapy, social worker, physio, a pain specialist, painkillers that worked, and help with every aspect of my life… to seeing a doctor who would provide me with a patch as the only approach to pain management. I was filled with fear and felt abandoned. (Marc)

Overall, these interviewees perceived the services of WSIB to be more suitable and appropriate than those provided by their physicians and the broader heath care system, in that they increased their chances to deal more successfully with pain and loss of function and to restore health.

CHC Model

Three of the interviewees also reported positive results with access and coordination of services where their GPs were working at Community Health Centres (CHCs).

GPs based in CHCs, according to these interviewees' accounts, work as part of a multidisciplinary team. Participants were readily referred to nurse practitioners, physiotherapy, dieticians, chiropodists, and social workers. In addition, they were provided with information about community support services offered in their geographic area and afforded access to recreation activities and other social supports to reduce isolation.

> Community health centres are new models. That's why I chose to see a doctor there. I knew that I would have more access to physiotherapists and chiropodists. More… it is free. If you see a doctor elsewhere and he refers you to a physiotherapist, you have to pay for the service yourself. They even have a lab on location so you get blood tests at the same place. Those special blood tests that you pay for in other places are offered for free at my CHC. I also took a chronic disease self-management course that my nurse practitioner recommended. I'm glad I did. It was very helpful. I just wish that it would run all throughout the year. It's about 12 weeks and is not enough to build a habit… and with self-management, one needs constant support. Knowledge alone doesn't cut it. (Kathleen)

In sum, according to these participants, both the WSIB and the CHC models better meet their need for coordination, continuity, and consistency within the current health care system. In addition, they point to a more comprehensive and timely access to services that assists them in the successful management of their chronic pain condition. Such consistency is by and large currently lacking to the great detriment of people with CP. (Please note that some of the participants that experienced the WSIB program are currently seeing the CHC-based GP, namely Kathleen, Maira, and Birnie).

4.9.5 Social Support

The significance of community and social support does not escape participants, who unanimously believe this to be crucial to their well-being and quality of life.

a. Development of contacts and participation in support groups

> Networking with other people that have the same problem is important. The best is to find a support group for people with pain. They give you information. Someone knows a good doctor that cares, someone knows about a place to go to get help with chores or about an exercise that works, or a new way to sleep in bed so you can avoid the pain in the morning. These groups are the best places to go. You can never find too many people that know so much about pain under the same roof. Professionals come to support groups like mine to teach us about new things that are important for pain. (Jerry)

> Recreation and socialization are important. I did not realize how isolated and depressed I was until I found a drop-in center. (Rose)

b. The importance of 'at least one person' (relative, a friend or a health professional) that really cares about the CP patient

> Having a good relationship with someone balanced me, helped me feel grounded. I had good friendships and a good relationship with my wife before I got sick. As I got worse and the pain disabled me, I felt fear… fear of being alone. I felt fear of my own vulnerability and no one to be there to support me. This is no small thing. It's FEAR with capital letters. I got anxiety attacks. Eventually, I found a great doctor. He got me to see a therapist. I can sincerely say that [the therapist] saved my life and got me back on track. I started trusting myself again because he trusted me. Now I stand on my own. But the bond I have with him is totally important. (Marc)

c. Commitment to maintaining a social life with supportive people

> The world of work shrunk; social contacts shrunk for a few years as it gets harder to get out of the house. I now realize that, so I increased the contacts because I learned different ways of doing it. I used to do dinner for friends many times a year. I now do only two to three times, but it takes three to four days to have all things for the dinner ready. Now I have people over for tea instead, snacks instead of dinner. I ask people to come over and ask for help. Yes, you can mash the potatoes; yes, you can bring dessert. A modified social gathering is better than no gathering. (Paul)

d. Eradicating stigma

The stigma attached to people with CP, like any other form of discrimination, will be very difficult to eradicate. Interviewees believe that the following steps might help in that direction: more public education and media awareness about CP and the struggles of those who live with it; and information and training catered to families, friends, and caregivers to increase understanding and to discuss strategies for being a supportive presence for loved ones with CP.

> We shouldn't have to explain to our families or coworkers and friends what it's all about. We already have enough as it is. Coaching… support to help heal relationships with family mostly, and even friends...more awareness, education. (Kendra)

e. Workplace support

Workplace-based supports are needed to help people with CP get the necessary accommodations to continue working where possible without having to fight for this on their own. Participants suggested the following: Advocacy for those with invisible and strongly stigmatized disabilities such as CP to receive necessary and timely accommodations in the workplace; and educating employers and coworkers about the best ways to support and relate to people with disabilities.

> The sick are always bullied in the workplace, and things only go south when you have chronic pain. HR [human resources] have to make sure that co-workers have more information about pain and how it affects us. (Kenswella)

> WSIB should offer courses to employers and co-workers so that they treat you better. (Dan)

Only through understanding the nature of CP and the limitations of the system addressing the needs of people with CP can positive change begin to happen. Systemic changes are clearly needed to effect change.

Chapter Five _ Interpretive Analysis

This chapter provides an interpretive analysis of the core category of alienation as a contingency theory. This analysis of the many accounts of patients' lived experiences is rich information that allows the mapping of the process of alienation as experienced by the patient within the medical system and the consequences to their health status and lives.

5.1 Alienation as the Core Category

The categories that emerged from the data analysis contained different thematic subcategories. These corresponded to a process of identifying those mechanisms present in the interaction between the CP patient and the health care system that either hindered or facilitated the individual's capacity for choice, control, and self-determination in the treatment and care of their condition. Such mechanisms are important because they ultimately determine the actual decision-making capacity of the CP patient to actively participate and collaborate in the management of chronic pain.

Across the various categories, a conceptual core category emerged: that of alienation of the CP patient. The core conceptual category, in grounded theory methodology, is the main theme, story-line, or process which subsumes and coalesces all thematic subcategories; encapsulates the data efficiently at the most abstract level; and, is the category with the most solid explanatory power (Madill, 2008). In this capacity, the concept of alienation signifies the erasure of elements and contextual social conditions that promote self-determination in the CP patient. Thus, 'alienation', understood in its widest sense as the antithesis of self-determined regulation, is especially suited to describe and explain the process which emerged from this study. Though many theorists consider the term 'alienation' ambiguous (Churchich, 1990; Geyer 1994, 1996), it was deliberately chosen to describe situations that necessitated a closer look at often apparently minor but powerful social mechanisms that caused the patient disempowerment, lack of control, vulnerability, helplessness, and insecurity.

As such, the construct of alienation was found to encompass powerlessness, estrangement, isolation, normlessness, oppression, meaninglessness, social rejection, marginalization and disenfranchisement as reported and described by participants. According to this framework, patients feel alienated at critical junctures within the experience of care where decisions and participation are expected, where there is a chasm or fracture between events and the CP patient's sense of internal control, autonomy, competence and relatedness, to understand and act within such context.

The state of alienation in this study reflects dysfunctional communication or dysfunctional use of power within a civilized society (Langman and Kalekin-Fishman 2006); refers both to a personal psychological state (subjectively) and to a type of social relationship (objectively); and, embodies the absence of aspects and social circumstances that support self-determined regulation.

Alienation, as emerging from the data presents the following types:

'Powerlessness': defined as perceptions of self as lacking the means to achieve intended or desired goals (Rotter, 1954; Langman and Kalekin- Fishman, 2006). Alienation in the sense of a lack of power refers to the feelings held by the individual that his own behaviour cannot bring about the outcomes, or reinforcements he seeks" (Seeman, 1959; Langman and Kalekin-Fishman, 2006).

'Meaninglessness' as "characterized by the actor's low expectancy that satisfactory predictions about the future outcomes of behaviour can be made"[17] (Seeman, 1959:786) as juxtaposed to a sense of meaning, understood as "the individual's sense of understanding events in which he is engaged" Seeman, 1959:785).

'Self-estrangement': defined as a feeling of being disconnected from oneself (Seeman, 1959), of having become a stranger to oneself or some part of oneself, or as a problem of self-knowledge (Marx in Kalekin-Fishman, 1996: 97).

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[17] Note "Whereas powerlessness refers to the sensed ability to control outcomes, this refers to the sensed ability to predict outcomes. In this respect, meaninglessness is closely tied to powerlessness; Seeman posits that "the view that one lives in an intelligible world might be a prerequisite to expectancies for control; and the unintelligibility of complex affairs is presumably conducive to the development of high expectancies for external control (that is, high powerlessness) (1959:786)".

‘Estrangement’: defined as a lack of engagement in social activities, apathy caused by lack of communication or dysfunctional communication, particularly a psychological disconnection from family or other institutions in society (Johnson, 1975), insecurity and vulnerability as caused by dysfunctional families and socioeconomic oppression creating or causing states of alienation (Laing, 1967).

‘Social isolation[18]’: refers to “the feeling of being segregated from one’s community” (Kalekin-Fishman, 1996: 97).

‘Normlessness’: defined as a situation in which social norms regulating individual conduct have broken down or are no longer effective as rules for behaviour” (Seeman, 1959:787). Normlessness derives partly from conditions of complexity and conflict in which individuals become unclear about the composition and enforcement of social norms. “Sudden and abrupt changes occur in life conditions, and the norms that usually operate may no longer seem adequate as guidelines for conduct” (Neal and Collas, 2000: 122).

Core Category: ALIENATION:

> Alienation is a sociological and psychological complex state which not only has social, economic and psychological repercussions, but can also affect health and aggravate existing mental and physical conditions
>
> Barclay and Moncivaiz, 2016

‘Social exclusion’: defined as “a multidimensional process of progressive social rupture, detaching groups and individuals from social relations and institutions and preventing them from full participation in the normal, normatively prescribed activities of the society in which they live”[19] (Silver, 2007:15).

‘Disenfranchisement’: defined as the (social/health system) failure to make adequate provision of services and supports, and the ongoing failure to respond to identified shortcomings,

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[18] Neal and Collas emphasize the centrality of social isolation in the modern world: “While social isolation is typically experienced as a form of personal stress, its sources are deeply embedded in the social organization of the modern world. With increased isolation and atomization, much of our daily interactions are with those who are strangers to us and with whom we lack any ongoing social relationships (2000: 114).”

[19] Social exclusion is first and foremost a multidimensional conception of disadvantage. It transcends the narrow conception of material poverty, whether conceived in terms of income or the fulfillment of basic needs. Social exclusion is less concerned with the distribution of material or monetary resources than with other forms of social disadvantage or group memberships that are related to poverty. Indeed, social exclusion is most frequently defined in contrast to poverty (Silver, 2007, pg. 15).

resulting in the blocking of social, economic, human or legal rights and negatively impacting health status.

Alienation, as represented in the core category, encompasses several dimensions:

i. alienation from the **body** (powerlessness, helplessness or impotence and sense of betrayal by the body in pain, loss of control over the body);
ii. alienation from **self** (internalized stigma and reduced self-worth, disrupted biographies, loss of identity);
iii. alienation from **family and society at large** (feeling judged, belittled, disapproved, blamed for illness, condemned, stereotyped as addict, hypochondriac, or having a mental illness);
iv. alienation from **work**-related responsibilities or working life (stigmatized, bullied, disallowed, ostracized, stereotyped, difficulty accessing work-place accommodations to increase functional level or continue employment due to prejudice);
v. alienation from **medical providers** (experiencing powerlessness, domination, oppression and indifference by those that are to provide them with care);
vi. alienation from **treatment** (meaninglessness, anomie, not understanding decisions taken by doctors around treatment (i.e., provision of high dosage of addictive antidepressants and other mood-altering drugs while denied opioid-based pain killers because of their assumed as addictive nature); not furnished with information on how to access necessary treatments and health support services and illness related knowledge; not given sufficient support to engage in self-management, denied adequate pain relief medication because of lack of bio-medical proof of pain); and,
vii. alienation from **institutions and social supports** available to other members of society (disenfranchisement: not eligible for income supports, insurance coverage for treatments, function-enhancing devices to increase independence and ergonomic equipment to help them continue working; chronic pain not considered a legitimate illness, has less influence with government officials, politicians, medical associations and regulatory bodies to receive the same levels of research and other funding that other so-called "legitimate" illnesses attract (i.e., heart disease, cancer), and commitment to higher training and resources for GPs providing care for this condition).

This study’s findings on alienation and its various dimensions are presented hereafter according to three main areas: a) the individual's context: the patient’s life-world and the effect of the illness on the individual; b) the social context in which the individual lives and in which the system of health care is embedded; and, c) the medical context of the individual interaction with the health care system.

5.2 The Individual’s Context: The Patient’s Life-World and the Effect of the Illness on the Individual

Alienation here takes the shape of powerlessness, vulnerability, insecurity, social isolation and estrangement from individual’s own body, family, working life and society at large. Individuals experience a lack of control over their bodies and lives caused by pervasive pain and suffering, reduced functionality, higher levels of disability, and the often-attendant depression, anxiety, insomnia, and exhaustion. This is accompanied by a declining capacity to function in the private or public domain resulting in i) grappling with a limited or lost ability to maintain the source/s of their livelihood and the ability to be gainfully employed; and ii) a decline in social roles at home and/or in the community at large, as well as changing relational dynamics due to higher physical and/or economic dependency on family and society.

This research also pointed to a sense of isolation due to the need to hide one’s condition because others, including family members, responded negatively to their accounts of feeling pain. Furthermore, this study found evidence of disabled bodies, deteriorated family functioning, loss of capacity to perform roles as parents, spouses, and creators of economic self-sufficiency, and resulting feelings of guilt, shame and humiliation. A sense of purpose and value, and the feeling that one is leading a meaningful and productive life was diminished as well.

5.3 The Social Context in which the Individual Lives and in which the Health Care System is Embedded

The etiology of pain, and stigma attached to it affect the social environment of those suffering from this condition. The levels of alienation present in the social context are particularly relevant to this conceptual analysis if only because the health care system and social institutions providing treatment, care and supports to the CP patient are themselves socially embedded.

The Etiology and Stigma of Pain

Both the nature and etiology of pain are poorly understood. All participants share a profound sense of vulnerability in that their chronic pain is difficult to diagnose, assess and manage, and because their pain condition, though generally non-life-threatening, is likely incurable and extremely taxing. Most problematic is that pain presence and intensity do not necessarily correlate to the level of tissue damage. The lack of bio-physical damage or insufficient physical proof to support the claim of pain, resulted in stigma and prejudice. Common stereotypes encountered by participants include being perceived as malingering and manipulative to gain access to drugs or avoid work, having addictions, having a mental health disorder, or simply suffering from a penchant for calling attention to oneself. These assumed or perceived causes of chronic pain are themselves strongly stigmatizing.

Researchers working with the concept of liminality indicate that "'betwixt and between' ambiguous beings are seen by those around them to threaten prevailing definitions of the social order and that certain features of chronic pain result in the perception of sufferers as transgressing the categorical divisions between mind and body and as confounding the codes of morality surrounding sickness and health, turning them into liminal creatures whose uncertain ontological status provokes stigmatizing reactions in others" (Jackson, 2005:332).

Chronic pain is considered liminal for several reasons. That it cannot be classified into a specific category, such as needing either medical or psychotherapeutic care, or as having either physical or emotional problems has been problematic to many clinicians who simply prefer to classify patients categorically (Corbett, 1986). Further, pain, given the often-uncertain etiology and the lack of correlation between its intensity and the presence of tissue lesion, conflicts with the allopathic western medicine biomedical model, and is therefore considered as neither here nor there, thus becoming ambiguous in its classification, diagnosis, and treatment, and frequent variations are found among those health professionals dealing with this condition. This difficulty to measure pain objectively also confers upon CP patients an ambiguous moral status as it pertains to their entitlement to the help they are receiving, whether it is the treatment or disability funds which are often seen as only encouraging pain sufferers to hold to their 'sick role'. Indeed, in some literature, they are referred to as hypochondriacs, secondary gain seekers, and malingerers

(Jackson, 2005; Goldberg, 2010). People with chronic pain, too, occupy this liminal space because of their uncertain status vis-à-vis powerful narcotic based medication. The moral stance ranges from severe disapproval of those health care providers seen as inappropriately withholding relief to the disapproval and opposition to any policies perceived as facilitating dependence and addiction, as well as strong support for policies and public health initiatives and laws to curtail the use of narcotics (Goldberg, 2010, Vallerand and Nowak, 2009, 2010). Moreover, the relatively uncertain prognosis attending the pain condition also situates the CP patient in 'the out of place' space, even if temporarily, as there is no clarity on the possibilities of improvement, deterioration or remaining the same (Goldberg, 2010). The high stigma attached to chronic pain is related, at least in part, to social labeling and social control processes, and that CP is located in a 'no man's land' between real and imaginary and between innocence and irresponsibility. It is a condition that is neither physical nor mental creating consequences that can be defined both as guilty and innocent (Jackson, 2005; Goldberg, 2010).

Consequences of stigma and pain invisibility in the wider social world

Generalized stigma, widespread stereotypes, rejection, and indifference in the wider social context negatively impact:

i. the patient's social environment, weakening existing social supports and networks, compromising already eroded family relations, and causing a higher sense of insecurity, fear, isolation, and vulnerability;

ii. the patient's work environment, including:
   - Reluctance on the part of employers to provide disability-related accommodations[20] based on a condition that is often contested or perceived as lacking legitimacy and highly stigmatized,
   - Prejudice and stereotypes linked to chronic pain that lead coworkers to reject, ostracize, become unresponsive, indifferent or even bully pain sufferers. This has resulted in high

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[20] Accommodation is a means of removing barriers for someone with a disability so that they can work effectively. In most cases accommodations are inexpensive and involve workplace flexibility rather than capital expenditures. i.e. flexibility in the start or end of working hours to accommodate effects of medication or for medical appointments; allowing employee to take more frequent breaks or to work at home) /www.mentalhealthworks.ca/employees/faqs/accommodations/types Retrieved January 20, 2015, from http:/ Office of Disability Employment Policy, US Department of Labor. "Work-site accommodation ideas for people with psychiatric disabilities." Job Accommodation Network.www.jan.wvu.edu/media/Psychiatric.html.

levels of distress, depression, marginalization and disenfranchisement for patients, as well as a sense of being flawed'

- Sufferers engaging in normalizing and pretending to be fine to stave off stigma;

iii. the patient's engagement with his/her institutional environment. This refers to disenfranchisement at the hands of various social institutions as in the case of not meeting or having difficulty in meeting eligibility criteria for **insurance coverage** that would:

- **Provide ergonomic work and home environments,** furniture, technology and assistive devices to help the pain sufferer to continue paid employment and to live independently at home.
- **Pay for treatments and drugs** commonly available to people dealing with other health conditions and/or with limited incomes (i.e., massage, physiotherapy and musculoskeletal rehabilitation to help individuals regain their strength, physical abilities, and independence).
- **Provide income support or income replacement from private** disability insurance plans, employment insurance (EI), and the Ontario Disability Support Program (ODSP), since such payments are usually triggered when the insurer can establish a specific disorder or cause for disability. Pain is highly subjective and therefore, difficult to corroborate. For those with a disability, restricting eligibility to conditions that present evidence as defined by biomedical models often results in limited access and leads to inequities.

As well, disenfranchisement of pain sufferers on the part of social institutions is also evident in the allocation of funds to address the chronic pain condition. First, despite the significant burden of CP on individuals, their families, health care systems, the economy, and society at large, pain[21] research is still grossly under-funded (Lynch et al., 2009).

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[21] In Canada, chronic pain is associated with significant direct health care costs, "estimated to be $6.02 billion per year (in year 2000 dollars) for individuals suffering from chronic pain. Of this total, $4.25 billion are excess costs beyond those expected for Canadians without chronic pain. By 2025, with the aging of the population, these costs can be expected to rise to $10.29 billion per year, of which $7.26 billion will be excess costs. These estimates do not include significant societal costs related to disability and lost productivity. There is a critical need to address the needs of this population, but the challenges are significant. In Canada pain research is grossly underfunded with less than one per cent of total funding provided by the Canadian Institute for Health Research and only less than 1 %. Merely 0.25 per cent of public and private funding for all health research is allocated to research about pain". Lynch, (2014); Schopflocher, D., et al. Research funding for pain in Canada. Pain Res Manage 2009; 14:113-115. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2706647/ accessed on Jan 31, 2015

Second, levels of care, treatments, and supports for CP management as well as access to self-management programs continue to be utterly inadequate. This has been the case even though pain is associated with the worst quality of life when compared with other chronic diseases such as chronic lung or heart disease (Schopflocher et al., 2011; Schopflocher and Jovey, 2010, Schokking, 2014).

Third, medical training in chronic pain management remains unreservedly poor, affecting doctors' skills and techniques to help patients in a timely way. One study[22] found that Canadian veterinary students received five times more training in pain management than Canadian medical students (Watt-Watson et al., 2009). In this regard, chronic pain has been termed "an orphaned condition in medicine." (Negraeff, 2014) It has also been noted that "currently there are no standards in the country for doctors who manage chronic pain… [and] Ontario does not fund pain management as a discrete medical sub-specialty[23], which reflects the challenge of lack of awareness of the problem of pain" (Morley-Forster, 2014).

5.4 The Medical Context: The Direct Interaction of the CP Patient with the Health Care System

Stigma attached to the invisibility of pain, and the biomedical bias in the care model significantly affect the medical context of care and medical praxis, in particular the patient-

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[22] "Major Canadian university sites were chosen where health science faculties included at least medicine, nursing, dentistry, pharmacy physical therapy and/or occupational therapy. These disciplines provide the largest number of students entering the workforce but are not the only ones contributing to the health professional team. Veterinary programs were also surveyed as a comparison. The Pain Education Survey, developed from previous research and piloted, was used to determine total mandatory pain hours. **RESULTS:** The majority of health science programs (67.5%) were unable to specify designated hours for pain. Only 32.5% respondents could identify specific hours allotted for pain course content and/or additional clinical conferences. The average total time per discipline across all years varied from 13 h to 41 h (range 0 h to 109 h). All veterinary respondents identified mandatory designated pain content time (mean 87 h, range 27 h to 200 h). The proportion allotted to the eight content categories varied, but time was least for pain misbeliefs, assessment and monitoring/follow-up planning" (Watt-Watson et al., 2009; Morley-Forster, 2014).

[23] The first two residents in Canada's first accredited pain medicine program started their training July 2014 at Western University's Schulich School of Medicine & Dentistry. People with pain will soon be able to be seen by a " certified and recognized pain specialists, but they will have had two years of training that encompasses psychiatry and rehabilitation and palliative care and pediatric pain," says Dr Pat Morley-Forster, the medical director of the Pain Management Program of St. Joseph's Health Care London and a professor at Western, where she has led the charge for the program to be approved by the Royal College of Physicians and Surgeons as an accredited sub-specialty program (2014)

Currently there are no standards in the country for doctors who manage chronic pain. "When a patient went to a pain clinic, they could have somebody who was a family doctor, who perhaps attended a few weekend courses or a month course, or they could have had somebody who is a long-term specialist," Morley-Forster said. However, the school has found funding for these first two residents, but there is no guarantee for next year. CBC contacted the Ontario Ministry of Health to ask if the province was considering new funding for the new program, but the initial response from a spokesperson in an e-mail appeared to indicate they were unaware of the program's existence. "Ontario does not fund pain management as a discrete medical sub-specialty, as there are currently no Royal College accredited pain medicine programs in the province (or the rest of Canada). However, residency training in anesthesia — which can have a pain management focus — is funded by Ontario" (Morley-Forster, 2014). Morley-Forster says the response is frustrating and shows the challenge of a lack of awareness of the problem of pain.

physician relationship. There are several aspects of this dimension of alienation that are indicated by this study.

5.4.1 GPs' failure to communicate effectively prevents patient participation and real choice

Unfortunately, the relationship with GPs was considered by the participants in this research to be the greatest hurdle in patient-centred care and the achievement of effective pain relief.

Bio-medical bias in the practice of medicine, along with the invisible nature of pain, its uncertain etiology, and the stigma and co-stigmas (i.e., mental illness, addictions) attached to this condition have contributed to inimical relationships between GPs and patients, with the latter often reporting being discounted, ignored, unsupported, shamed and chastened by providers. Indeed, some studies have found chronic pain patients are regarded as the least likable[24] patients by GPs, who frequently find it challenging to provide care to them (Prkachin et al., 2007; Frischenschlager and Pucher, 2002; Prkachin et al., 2007, in Pickering and Gibson, 2015).

> *Chronic pain syndrome is not obvious to see, identify or accept, which often creates a feeling of being "invisible" from the patient's perspective. In fact, from their perspective, the GP acts the gatekeeper that separates the «visible» patients from the «invisible» ones. The first ones are diagnosed, can fit in the health care system, and are officially acknowledged as having an objective and credible condition to explain, to justify even, their pain. The second ones, on the other hand, feel relegated to some medical and social limbo, and struggle to fit in a society that simply will not believe, trust or accept them.*

Being silenced, disbelieved, or told they take too much time particularly when they complained that the care provided made no difference, presented a barrier to open collaboration and patient empowerment according to the findings of this study.

GPs who often acted frustrated and irritated usually affected the patient in negative ways, as they felt more vulnerable, ridiculed, and neglected. Moreover, patients felt that having to cope with the physician's negative attitude and feelings was both emotionally and physically exhausting. Also, it prevented clear communication and a sense of connection.

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[24] "When you associate dis-likability with a person, it's like you change an observer's perception such that they just don't pay close attention to (the person's pain-related) behaviourany more" (Prkachin, 2011).

Although there is both public and professional support for involving patients in decisions, viewing the world from their individual stance, and regarding them as partners in the process of care, many research studies show that the medical profession operates from a stance of authority, control and directives (Lester, 2005, 2006; Campion et al., 2002; Britten, et al., 2000; Barry, et al. 2000; Elwyn et al., 2005).

Even though physicians endorse the principle of client centred-care and client participation, many appear to resist or ignore these ideas and the development of the necessary knowledge and skills. (Blakeman et al., 2006). Both patient-centred and the shared decision-making models are idealistic structures developed by policy makers and academics, and which operate well in controlled conditions, in which patients are afforded more attention and their issues and views are accommodated with more sensitivity. However, in time-pressurized and incentivized clinics as those in primary care settings, physicians revert to a modus operandi focused on attainable and realistic goals,, and arrange their efforts according to priorities, utilizing a range of discourse devices that hone in on a set of practical issues for which they can confidently generate solutions (Maynard, 1991). Austin posits that physicians are not necessarily poor communicators and that they are highly skilled in such matters, nor do they lack the skills to do it properly, but that they are goal oriented and not patient orientated (1962), and function in an environment where efficiency and achieving biomedical indicators or proxies are the norm. The patient-GP communication process is therefore geared to a different set of goals (Elwyn 2004; Edwards, 2006). Not that a patient-centred and shared decision models cannot be integrated into this environment but it requires more exploration, analysis, and incentives.

5.4.2 GPs' unfettered discretion in the provision of pain relief treatment creates power imbalances in the patient-doctor relationship

Pain does not enjoy legitimacy and credibility in the eyes of all GPs, who act as gatekeepers to the entire system of care, separating 'visible' patients from 'invisible' ones, by providing or refusing a diagnosis of pain as an objective and credible condition. This study found that for these participants, GPs are the key not only to treatment and pain relief, but also to social acceptance and legitimacy. GPs are the givers of the 'diagnosis' that opens doors to specialized care through referrals (i.e., seeing a pain specialist, accessing pain clinics), insurance coverage, social assistance, workplace accommodations and community-based supports otherwise denied. The role of the doctor in making CP 'visible' is so critical in this context that it often creates an imbalance in the patient-doctor relationship. Further, power imbalances resulting from GPs' unfettered discretion in making CP 'visible' and the provision of adequate relief of pain available are all the more consequential in the context of a contested illness. Such power imbalances were clearly perceived and described with little variation, by the majority of the participants interviewed. They typically described feelings of being at the mercy of their GP for her/his time, trust, respect, diagnostics, prescriptions, or referrals.

One can go from invisible to visible…Or from visible to invisible for that matter, at the discretion of the doctor. In this context, it is little wonder that some people will go to great lengths to get and remain in the good graces of their GP, even if this entails suppressing potential irritants – such as complaining about an ineffective treatment or making more demands on the doctor's time.

5.4.3 Emphasis on Patient's Responsibility for Successful Pain Management

Participants found that the emphasis on their responsibility to manage the pain condition and the consequent blaming when they failed to achieve the outcomes set by GPs led to stress, alienation, and disempowerment. Biopsychosocial therapies are relevant here because they emphasize the management of pain rather than its cure and assign far less responsibility to the health care provider (Jackson, 2005:344), as well as the expectation of a fully engaged patient who participates in the care provided and is responsible for the self-management of his condition (Jackson, 2005; MOHLTC, 2007). To become better, the patient must agree to be actively involved in the process.

Such is the assumption with Ontario's *Chronic Disease Management and Prevention Strategy* which involves a client-centred model that emphasizes the **patient's central role** in their health, as active participants in their care and the achievement of successful health outcomes (i.e., patients as 'members of the care team', 'shared decision-making' and engagement in the pain condition self-management) (Ontario's Chronic Disease Prevention and Management Framework, 2007). The physician is viewed as simply 'co-managing' the problem with the patient (Taylor, 1995:594). Thus, the patient can be considered responsible for the failure to successfully manage their pain, which represents a shift of the physician from healer to manager (Taylor, 1995; Salmon and Halls, 2003; Marks, 2005). Finerman and Bennet point out that these "new responsibility and blame focused explanatory models have the added consequence of stigmatizing and further victimizing the victim by making the patient responsible for personal failures to manage their condition" (1995:1).

Understanding Responsibility, De-politicization and the Bio-psycho-social model underlying Medical Praxis

Such social constructs of health, illness, and individual responsibility are based on neo-liberal models, the adoption of an abnormal/normal binary (i.e., good citizen/bad citizen; right type of care/wrong type of care; bio-medical model/bio-psychosocial model) and social discourse to enacting control, surveillance and governance at the societal level (Hartwell, 2013).

Responsibility in such context refers to the self-reflective, autonomous individuals who monitor their own health and risks in order to promote psychological, social, physical and overall health for themselves and others and minimize the use of health care resources available to society. The concept of responsibility is further enacted with the social construction of the archetypal citizen and upheld through the neo-liberal model[25]. Such model, within the context of health and illness, espouses the ideology that citizens are free to exercise their autonomy and underscores the entrepreneurial individual who can properly take care of themselves (Beck, 1992; Giddens, 1991; Mol, 2008).

Control is thus exercised in the manner in which some individuals will strive to seek membership in the grouping of 'good citizens' by meeting social and medical expectations; while those who may not comply, or are unable to access care, services or resources to do so are rendered 'bad citizens.' However, this understanding of risk and responsibility entails that individuals have an array of choices and thus agency. Consequently, their shortcomings are a result of their own actions and therefore they are to be held accountable and responsible for doing so (Giddens, 1991). Unfortunately, such discourse polarizes patients into two groups - those with the capacity to take

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[25] Neo-liberalism refers to the replication of liberal principles prescribing that citizens are autonomous actors within a state that should abstain from intervention so that citizens can govern themselves. In Western societies, the archetypal citizen refers to "the participatory, autonomous, self- knowledgeable citizen that is privileged in neo-liberalism (Lupton, 1999, p. 298)."

care of themselves, access to self-help and social supports to attain good health (good citizens), and those without the capacity to attain or to access those resources (bad citizens) (Giddens 1991; Nettleton, 2006 in Hartwell, 2013).

This emphasis on the agency side of the classic sociological dynamic – between the individual and society, downplays structure. Mills notes that there is massive one-sidedness in social discourse that emphasizes the freedom of individuals to choose their own lives and create their own destinies (1959). Structure and context aspects of the dynamic remain hidden but are not irrelevant to the patient decision-making capacity. Rather, the patient capacity to choose 'right' is taken for granted while contextual issues are sidelined. Individual differences in education, occupational and economic status, abilities, personal experiences, family and other social supports as sensitizing concepts to better capture the wealth and complexity of patients' lives as they present themselves to the care providers are not considered.

Chronic pain patients are thus saddled with the high expectations the medical system, and health providers, in particular, place upon them and the hurdles they are expected to negotiate in order to access appropriate care and supports to manage their condition. These expectations spread beyond the medical praxis to the broader social sphere (i.e., the individual is faced with the responsibility to find a way to educate themselves and establish themselves in the labour market even when they must transition to work that is doable given their changing capabilities and new levels of functionality). Failure to achieve these results leads to more blame.

When medical models only focus on the ideal role of the patient in the context of chronic disease, they fail to consider the manner in which individuals construct their own life course trajectories, how they make choices and decisions, their social location and personal capacities by cobbling together a do-it-yourself approach, with little reference to the availability of resources to do so. These models assume that patients will respond in the same manner to the same frameworks. In doing so, they deny the personal histories and social contexts of patients consequently creating further alienation. "Exclusive focus on individual choices and decisions as dis-embedded from social circumstances and structural contexts seems to take conditions at a structural level as given" (Brannen and Nilsen, 2005:416). "While the lives people live continue to be processually and contextually embedded, people may find the external and structural forces that shape their lives more difficult to comprehend and therefore talk about" (Brannen and Nilsen et al., 2005:421). As such, power structures become invisible (Bertaux, and Thompson, 1997).

Patient responsibility in achieving health outcomes in its current meaning and usage can therefore also be construed as serving an ideological purpose in shaping perspectives about life. To disregard structure is to dismiss the actual inequalities and differences in resources that are systemic and systematic rather than individual and random (Brannen and Nilsen, 2002). Modalities of language embedded in social structure and linguistic strategies of control which emphasize only the agency (self-regulatory) side of the agency/structure dynamic are largely the result of the depolarization of choice and decision-making and consequently self-determination. In that capacity, they contribute to the further suffering and alienation of the patient.

5.4.4 Patient Image Management in the Context of Contested Illness

Likewise, because CP is not perceived as a 'legitimate' disease, and therefore "not good enough" to guarantee access to proper pain treatment, this study found that the patient is unsure of the appropriate "role" to play, i.e., whether to minimize pain symptoms and pretend to be fine, or to appear vulnerable and broken. Consequently, engaging in "patient image management" to increase likability in hopes of getting some relief through treatment is fairly common.

Several factors were weighed by participants in the context of the therapeutic interaction (medical visit) such as: a) keeping in mind that frequent complaints about chronic pain often result in prescriptions for high dosages of antidepressants and fewer pain killers; b) allaying their own concerns that treatment would be withheld if pain does not appear to be severe is problematic; c) suppressing apprehension about asking for pain killers for fear of being accused of addictive behaviour and dependency; and, d) apprehension about GPs who appeared to be alarmed about addiction to opioids but not about highly-addictive anti-depressants, anti-anxiolytics, and sleeping pills. These concerns proved exhausting to the patients in my research. Such balancing acts require an extraordinary degree of diplomacy and energy not often at a patient's disposal. The patient-doctor interaction is thus fraught with meaninglessness, normlessness, and estrangement, further preventing open participation and requiring self-restraint, self-censorship, and even social shrewdness in order for the patient to maintain some sense of self-control and determination.

5.4.5 Lack of Standardized GP Training and Accountability Regarding Quality of Pain Management Care Provided

Moreover, this study suggests that the interaction of the patient with the system through primary care is also riddled with a lack of confidence and minimal expectations about the care and effectiveness of arthritic chronic pain management. This was based on patients' perceived lack of (system) direction and oversight of GPs' typical performance (i.e., documentation, assessment and medical condition monitoring protocols, coordination, drug monitoring protocols, referral directives, etc.). This was further compounded by patients' growing uncertainty about GPs' observance of these protocols and guidelines, brought about by the wide variance in care and delivery models, referral rates, care performance, health outcomes and GPs' knowledge about and training in chronic pain and arthritis. This, in turn, adds to the burden of the **pain-sufferers who are painfully aware that** access to the right care is dependent on their capacity to shop for 'a good doctor' and being lucky enough to find the "right one".

5.4.6 Misconceptions about the Availability of CP Management Programs

Another element indicated by this study to be considered in the alienation of the CP patient is the wide-spread misconception by the general public and GPs alike that a broad range of non-drug pain management treatments is widely available to those with chronic pain. However, self-management programs are only available to a small number of CP patients and for a limited time. A comprehensive multidisciplinary approach to care is limited to a handful. Currently, coordinated approaches to CP management are often only available through participation in a pilot project and are not a widespread practice.

In this context, GPs' expectations that the patient will somehow find a way to manage their pain condition regardless of the inadequacy of information, education, treatments and supports made available (or accessible), along with existing systemic fragmentations and deficiencies, is derisory. As well, this expectation implies a shift in the responsibility for the successful management of disease to the patient, which simply adds another layer to an intricate system, and merely amounts to further oppression and victimization. As such, the patient-centred model of care as applied to this group of people with chronic pain, creates an iatrogenic effect on the patient.

That is, it amounts to toxic care. It inflicts more pain, given the inbuilt biases and control mechanisms and social mindsets that induce further suffering, marginality, and alienation.

> *Not only is the patient prevented from successfully adhering to treatment, therapeutic regimens and self-management strategies but the levels of blame, shifted responsibilities, and expectations placed on them while denying access to the very elements that would allow such expectations to be fulfilled creates an untenable situation for the patient, who now feeling alienated and at loss is most likely to succumb to despondency, increased disability rates, depression, mental unbalance, and the adoption of negative coping mechanism, which often found participants turning to addictive behaviour (i.e., overeating, abusing alcohol, smoking, or accessing prescription drugs through unorthodox paths*.

5.7 Table 4: Alienation

Alienation: Impact of Ontario's health care system on management of chronic pain			
	Situation	Impact on Patient and Patient Behaviour	Impact on Patient Feelings
Estrangement **Powerlessness** **Vulnerability and Insecurity**	• Over-extended and under-resourced healthcare system often riddled with waiting lists and service shortages. Access to care affected by affordability, availability and referrals. • Scarce access to pain clinics, rheumatologists and other specialists, often due to lack of timely, appropriate referrals. • Self-management programs only available to a negligible number of CP patients. Multidisciplinary approach to care limited to a handful. • Most pain management therapies limited to antidepressants and other mood-altering medication and pain killers (opioid and non-opioid based). • Different physicians provide different levels of care and ranges of treatment, with some not even providing a CP diagnosis. • Despite all the literature and announcements by Ministry of Health officials about a wide array of therapies, these are often only available through participation in a pilot project and are not a widespread practice. • Lack of standardization in treatment strategies, protocols and guidelines regarding care and support. System navigation hindered by inadequate information regarding availability of services and support, and lack of coordination. • Great variation in GPs' training, experience, and willingness to work in partnership with, and provide actual support to, CP patients. Lack of resources available to physicians (time, expertise, supports, allied interdisciplinary teams) result in inefficient care.	• Lack of, or limited access to, care, as well as uncoordinated and fragmented care, affect patients 'capacity to manage pain and increase their levels of disability. Increased disability leads to reduced social engagement (work, friends, support networks, economic dependence, identities disruption…) • Patients told they have access to supports that are indeed unavailable, creating the assumption that they are not accessing services willfully. This creates further estrangement. • Lack of understanding about how to navigate the system unsettles those with disabilities and limited functioning.	• Chaos • confusion • disorientation • helplessness • insecurity • lack of clarity about… • perplexing • stress • turmoil • uncertainty • unsettling

Social Context of Alienation - Impact on the GP-patient relationship

	Situation: GP Actions	Impact on Patient and Patient Behaviour	Impact on Patient Feelings
Normlessness **Powerlessness** **Meaninglessness** **Disenfranchisemen**t **Discrimination** **Estrangement from health care provider** **Estrangement from treatment and from themselves** **Insecurity** **Powerlessness** **Vulnerability** **Prejudice**	• GPs uncaring, inattentive, too busy or uninformed to help patient. GPs often wield power, making sure patient knows who the expert is, and is therefore in charge, preventing open collaboration. • GPs are the key not only to treatment and pain relief, but also to social acceptance and legitimacy. GPs are the givers of the 'diagnosis' that opens doors to insurance coverage, social assistance and supports otherwise denied. • Power imbalances are caused by GPs condescension, lack of receptivity and prompt silencing of any dissenting comment or questioning about the care provided. • GPs don't engage patient in a therapeutic plan with clear actions, steps and objectives effectively to manage CP. • CP does not enjoy legitimacy and credibility in the eyes of all GPs, who act as gatekeepers separating "visible" patients from "invisible" ones, by providing, or refusing, a diagnosis of pain as an objective and credible condition. • GPs highly alarmed about addiction to opioid pain suppressants, and not about highly-addictive anti-depressants, anti-anxiolytics and sleeping pills. • GPs are inadequately educated in pain management during their medical training; after graduation, there is a further lack of emphasis on GPs gaining expertise in pain management	• Relationship with GP considered to be the greatest hurdle in patient-centered care. • Because disease itself is not enough to secure treatment, patient unsure of the appropriate "role" to play - i.e., whether to minimize pain symptoms and pretend to be fine, or to appear vulnerable and broken. Engaging in "patient image management"to increase her/his likability, in hopes of getting some relief through treatment. • Patient feels that s/he cannot predict how own actions and behaviour can build trust with physician, or bring legitimacy to her/his situation. • Concern that treatment will be withheld if pain does not appear to be severe. • Access to a "good" doctor viewed as an issue of luck. Access to the right care dependent on shopping for a good doctor and being lucky enough to find the "right one". • Patients negotiate from position of vulnerability given GP's unfettered discretion to prescribe or refuse adequate pain killers and act as gate-keepers through referrals. • Patients are rushed, not listened to, silenced, dismissed, discredited, discounted and disbelieved by GPs. Patients are interrupted, told they are inaccurate, inarticulate and/or taking too much time. GPs failure to communicate prevents patient participation and real choice. • Complaints result in prescriptions for high dosages of antidepressants and fewer pain killers. Patients concerned about asking for pain killers for fear of being accused of addictive behaviour and dependency.	• confusion • debasement • diminishment • estrangement • from health care provider • resentment at having to play "the good patient" • dependence • helplessness • sense of futility • demeaned • discredited • dishonoured • defensive • disoriented • embarrassed • frightened • frustrated • oppressed • patronized • powerless • shamed • shunned • worthless

Social Context of Alienation - Impact on social supports			
Situation		Impact on Patient and Patient Behaviour	Impact on Patient Feelings
Social Isolation **Social Rejection** **Social Exclusion**	• Those with CP not believed to have a legitimate illness. • Patients are accused of fabrication, exaggeration, causing their pain by being stressed and/or bored, hypochondriacally. Using pain to call attention to themselves. • Patients are not included in activities andconversations. Not listened to.	• Patients not allowed / encouraged to talk freely about their pain condition. • Patient normalizing pain condition to stave offprejudice, stigma. • Patient acting obsequiously to prevent beingostracized, or rejected. • Patient needs unmet as a result of having to self-sensor themselves around family and friends. • Patients avoiding outing out of fear of not being able to keep up or being rejected, shunned if not being able to put up. • Patient experiences a shrinking of social networks. • Patient family relations deteriorate as a result of lack of acceptance, • Patient experiences lack of negotiating power, particularly with partner and spouses. • Patients hide their pain condition to stave off stigma. • Pill-popping, self-medication. • Lack of self-belief (self-reliance), as symptoms and impairment increase while patient is told thateverything is alright.	• damaged • discounted • disparaged • feeling rejected • helplessness • hurt • insulted • internalizing stigma and believing that they deserve being rejected and ignored • isolated • not belonging • put down • unworthy • withdrawal from others • worthless

Social Context of Alienation - Impact on the capacity to be gainfully employed			
	Situation	Impact on Patient and Patient Behaviour	Impact on Patient Feelings
Disenfranchisement **Estrangement** **Institutional Discrimination** **Marginalization** **Powerlessness** **Prejudice** **Social Rejection**	• Those with CP not believed to have a legitimate illness. • Stereotyped as being lazy, having a mentalillness, seeking attention, being a hypochondriac or malingering for personal gain, having anaddiction, seeking drugs. • Ineligible for ergonomic redesign, private disability insurance, employment insurance (EI), and Ontario Disability Support Program (ODSP) for income supports since such payments areusually triggered when insurer can establish a specific disorder or cause for disability. • Employers don't make accommodations to allow sufferer to continue working. Invisibility of pain and lack of diagnosis prevent eligibility for insurance coverage for environmental assessments and adjustments, acquiringassistive devices.	• The stigma and co-stigmas of pain cause **r**ejection by employers, managers and coworkers, exclusion from group activities, being ignored and/or rejected in a group setting. Being bullied. • Having to normalize and pretend to be fine in order to stave off stigma. • Having to quit work or getting fired. • Loss of, or limited, economic independence (loss of housing, loss of food security, bankruptcy), increased poverty, increased economic dependence on others; increased vulnerability and helplessness.	• ashamed • bullied • damaged • debased • discriminated against • disgraced • fearful • feeling ostracized • marginalized • ridiculed • scorned • shunned • smeared • anxiety and distress over economic hardship impacting wellness, quality of life, sense of direction, and social engagement. • vilified

Social Context of Alienation - Impact on research in, and treatment of, chronic pain

	Situation	Impact on Patient and Patient Behaviour	Impact on Patient Feelings
Disenfranchisement **Institutional Discrimination** **Lack of Security** **Powerlessness** **Social Exclusion** **Vulnerability**	• Pain is not treated as a stand-alone disease but rather as a symptom. • There is a disproportionate focus on deviant behaviour (malingering, drug abuse, addictions), while curtailing access to opioid-based therapies and disregarding the lack of other treatments and supports for successful CP management. • Expectation that patient will find way to manage pain regardless of the lack of education, treatment and support made available. • Despite the significant burden of CP on individuals, their families, the health care system and society at large, pain research is grosslyunder-funded, and levels of care, treatment and support for managing CP is utterly derisory.	• A bias can affect the rights of pain sufferers and manifest itself in various degrees of seriousness. • **Biomedical bias makes it harder to get into care, affects patient's capacity and willingness topursue, and adhere to, treatment, and to acquire the skills needed to self-manage condition;affects commitment of government and experts to pursue research in the field.** • **Inadequate pain relief hurts sufferers physically, socially, emotionally, psychologically andeconomically. Under-treatment of pain also causes stress, decreased social functioning, and incapacity to work.** • Lack of appropriate care robs CP sufferers of their sanity, and of social supports fundamental to their wellbeing.	• anger • anxiety • disability • distress • pain • reduced personal and economical independence • reduced self-worth • resentment

Chapter Six

Self-Determination Theory (SDT) Application Results

This chapter presents the results of using the SDT model to examine the extent to which the interpretive themes in the data matched the key features of each SDT dimension and illustrates how the CP patient's basic needs for autonomy, self-competence and relatedness are met or hindered in their interactions with the Ontario health care system.

SDT focuses on the contextual contingencies and dispositional orientations that give rise to motivational state and subsequent behaviour (Ryan, 1985, 2000). SDT is a theory that has been proven efficacious in identifying contingencies that affect motivation and behaviour in several domains, including health.

One of the central tenets of SDT is that the quality of social context influences the motivation, performance, and well-being of those who operate within them.

These findings embody a further analytic stage that entailed comparing the data to the three main dimensions of SDT 'autonomy, competence, and relatedness' and were thus used as a template to guide this process and reveal the degree to which contextual contingencies and dispositions in the CP patient's social and medical context are perceived to be autonomy, competence and relatedness supportive. As such, they encompass elements beyond the clinical encounter[26] and other interactions between patient and the broader health care system, to identify mechanisms impinging on participants' self-determination.

6. 1 Autonomy

Autonomy relates to the degree of volition one feels in pursuing an activity and the need to feel congruence between that activity and one's values (Deci and Ryan, 2000, 2008, 2013). Autonomy with respect to a particular health behaviour entails that an individual feels that his/her actions are the result of his/her own choosing and not of pressure to do so by others (Deci and

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[26] Elements and mechanisms include the life world of the CP patient, and the social context in which the health care system is imbedded, as brought up by the participants during the interviews.

Ryan 1989, 2000). Patients are autonomously motivated to the extent that they have volition and choice. Clinicians who encourage patients to make a choice to follow a treatment plan can increase patients' feelings of autonomy, dignity and self esteem (Ryan and Deci, 2008).

In all cases, participants experienced autonomy supports, both in their private and social spheres to be very low, in varying degrees. High levels of disability, debilitating pain, loss of control over the body, limited or no capacity to be gainfully employed, disrupted identities and shifts in family, work and social roles, along with attendant high levels of stress, anxiety and depression were reported to have had a negative impact on participants' sense of control and autonomy. In addition, economic and physical dependence on family members, caregivers, government agencies, and/or private insurance increased their sense of vulnerability and insecurity, and greatly limited their choices and decision-making ability.

Most participants indicated that clinicians' support for their autonomy was almost non-existent. Often their perspectives and preferences were dismissed, concerns were unaddressed; initiatives not supported, collaborative action plans unheard of, access to specialized care and necessary resources limited; and, treatment options were not discussed or were limited, and alternatives rarely offered. Health care professionals often relied on controlling methods such as behavioural contracts, orders, or demands, with the physician-patient power imbalance such an integral part of the therapeutic encounter that effective participation, open dialogue and decision making became all but impossible.

On the other hand, six participants stated that their physicians fully supported their choices, provided full information about their treatments and acknowledged their perspectives and preferences, allowing for higher input and participation in their care as well as a higher sense of empowerment. These participants explained that they had not always had access to physicians that listened to them and ensured that the treatments addressed their needs. Much of the exposure to autonomy-supportive clinical environments took place because:

i. they 'shopped' for physicians that had chronic pain-related expertise and experience, and an interest in working collaboratively with them;

ii. their family physicians worked in community health centres, which are primary health care models created to provide greater multidisciplinary care to clients and increased community-based supports. Unfortunately, these centres only provide services to a small number of patients, have defined catchment areas and long waiting lists; and,

iii. they temporarily experienced a higher than average autonomy-supportive environment in the health care system through their participation in an Ontario Workplace Safety and Insurance Board (WSIB) setting. Once they completed the program, they found themselves without the support, treatments (i.e., behaviour-based therapy, counselling, rehabilitative care, physiotherapy) and timely responses to which they had grown accustomed.

In addition, participants indicated that a wide range of issues contributed to lowered autonomy: difficult to navigate health care system, with uncoordinated and often fragmented care; limited access to specialized care and pain management-related resources; low integration of clinical programs; increasingly delisted treatments (i.e., behavior-based therapy, counselling, physiotherapy); and, unaffordable or unavailable services often affecting equitable access. Chaos, stress and uncertainty created by difficulties in navigating the system and barriers to needed treatments and services often reduced patients' capacity to obtain pain relief, manage care, or adhere to prescribed therapies. This, in turn, increased their sense of helplessness, insecurity, powerlessness and internal locus of control.

6.2. Competence

'Competence' relates to the need to feel capable of obtaining intended goals (Deci, 1975). Perceived competence increases intrinsic motivation when it co-occurs with perceived autonomy (Fisher, 1978; Ryan, 1982). People who feel responsible for engaging in an activity are more likely to care about their performance. Perceived competence is based on the assumption that there is a link or dependency between behaviour and outcome. Hence, individuals are more likely to believe that if they engage in specific behaviours (i.e., maintaining an active and healthy lifestyle, adhering to prescribed treatment, taking daily medications), they will eventually achieve the desired health outcome – being pain-free or reducing pain levels, increased mobility and functionality, etc. Consequently, perceived competence is about an individual's personal belief in his/her capacity and competence to carry out the behaviours required to reach a better health outcome. Providing instrumental support to increase a patient's own perception of competence increases the likelihood of successful health-related outcomes (Ryan et al., 2008).

All participants in this study relayed that access to information, training, and resources related to pain management was grossly inadequate. Information about services available in their area was not readily available or provided by GPs. Access to chronic disease and chronic pain self-management workshops was limited to a few lucky individuals. Also, participants reported that these workshops typically run for only a few weeks and are not enough to effectively change behaviour. Currently, there are no long-term programs that can assist patients in increasing their coping skills and competence/abilities to successfully manage their condition as it progresses. Indeed, participants claimed that they often received negative or humiliating evaluations of their performance and virtually no assistance on how to acquire needed and relevant skills to carry out self-care tasks.

Only those seven participants who had access to 'chronic pain management programs' across the spectrum of intense multi- and inter-disciplinary treatments employing behavioural/cognitive techniques and physical restoration approaches, funded by third parties (workers' compensation, car insurance after a car accident, etc.), were afforded the opportunity to effectively increase their self-competence in ways that are not available anywhere else within the primary health care setting. For instance, cognitive behavioural therapy helped provide pain relief in a few ways (i.e., changing how they viewed their pain; reducing negative thoughts, emotions, and behaviours related to pain; learning or improving coping strategies; fostering good life skills; and, encouraging a problem-solving attitude and learning to take action against the pain – no matter what that action is– to feel more in control and able to impact the situation). Functional restoration approaches provided them with the knowledge and skills that increased functionality (i.e., "how to" skills: how to groom, clean or tidy up their homes, get up from their beds without hurting their backs, pick up heavy objects, or take something from a shelf, recognize pain triggers, pace activities to avoid pain, as well as providing recommendations to increase physical activity without harming joints, etc.).

According to these seven participants, learning skills that increased functionality was most helpful in increasing their capacity to self-care, adjust to new situations and manage their conditions. Some participants suggested the following programs, which they either found helpful or wish they could access to increase their capacity to achieve proposed health outcomes and increase their quality of life:

i) More education about CP as a health condition to increase patient understanding of its nature and the strategies to deal with it;

ii) Increased awareness/information about treatment and local services available as pivotal in impacting access to services and community-based programs that can further assist self-management of pain conditions;

iii) Increased access and use of information and communication technology to link to health care and health-related resources to help facilitate chronic disease management;

iv) Increased access to behavioural therapy, stress management programs, mindfulness, yoga, exercise, and fall prevention to assist with pain management strategies and motivation;

v) More coaching and guidance to help adopt and maintain healthy lifestyles, healthy eating and exercise regimes, or access to a social worker or counselor that 'helps them keep on track';

vi) Patient advocates to increase patient competence at communicating and navigating the system;

vii) Financial and educational supports to help modify home living environments and increase independent living; and,

viii) Early and continual exposure to innovative chronic pain management programs to learn new skills and access tools and devices geared to increase functioning – these programs should be accessible on a needs basis and not as a last resort.

6.3 Relatedness

'Relatedness' refers to a need to feel supported, connected and have access to important others, as well as vital networks and resources (Ryan and Deci, 2000). Relatedness is linked to the need for interpersonal involvement, emotional involvement with others and the feeling of belonging to a larger community. It is also about the human personal need to sincerely care for others and have others care about them. Safety and security are a crucial and necessary requirement for people to be able to explore their own environment and experiment with new behaviours (Baumeister and Leary, 1995; Ryan et al., 1995; Moller et al., 2010). Relatedness also refers to the need for regular, frequent and continuous caring (Baumeister and Leary, 1995; Moller et al., 2010). SDT suggests that relatedness pertains to the willingness of individuals holding positions of authority, such as health care providers, and in the case of this research, primary health care practitioners (i.e., family physicians, nurses) to bestow psychological resources (i.e., time, energy, and affection) on those they interact with (Deci and Ryan, 1991 and 2002; Moller et al., 2010). SDT also implies that relatedness would be further enhanced by providing access to medical knowledge, health and community-based supports and resources, and the provision of quality health care and allied health services, in a timely, effective, coordinated and appropriate manner to the meet the needs of patients (Ryan and Deci, 2008).

All participants claimed that their personal and professional relationships have suffered because of the many changes caused by increased disability, economic dependence and shifting family and work roles. Participants also felt that the relationships with those closest to them such as partners, spouses, children, and friends have been the most negatively impacted, and deteriorated due to their health condition. In all cases, social supports and networks have shrunk, and every participant reported varying degrees of isolation even in those cases where they rated their spouses and families as supportive. Participants' sense of belonging and being part of their family and community was mostly affected by the invisible nature of pain (i.e., a lack of capacity to objectively prove pain presence and measure pain intensity). The perception by 'others' of pain as a non-legitimate illness and as most likely 'all in their heads' led to further stereotypes that pain sufferers are hypochondriacal, malingering or mentally ill. Participants claimed that talking about pain was largely unwelcomed and frequently 'others' responded with contempt, indifference and harshness. Even when support was offered, participants felt little warmth and much resentment. Participants reported being stereotyped, discriminated against and unfairly judged by their families, friends, coworkers, and employers alike. This caused them great distress, depression, anxiety, a heightened sense of powerlessness, and alienation.

Unfortunately, the participants' sense of vulnerability and alienation was exacerbated by an even more inimical relationship with their family physicians. Indeed, the relationship with their

GP was regarded as the greatest hurdle to patient-centred care by every participant, including the ones that who felt they had ‘a good doctor.’ Most participants recounted that their relationships with health-care providers were fraught with lack of trust, power imbalances and poor communication. They reported feeling rushed, not listened to, dismissed, discounted and discredited by GPs, who often were uncaring, inattentive, indifferent, too busy or uninformed to offer help. Most participants felt that GPs’ unfettered discretion to prescribe or refuse adequate pain killers and serve as gate-keepers to specialized care undermined the patient/doctor therapeutic relation and the ability to create strong bonds. This was confounded by the patient’s sense that GPs typecast them as malingering to avoid work/family-related responsibilities, or as having addictions and only being interested in obtaining narcotics. This, participants claimed, created a further breach in their mutual trust, rupturing their sense of being cared for and alienating them from their health care providers as well as from the treatments and care received.

Only six out of twenty-three participants indicated that their GPs were caring, and provided them with medical knowledge and timely access to health and community-based supports and resources. They also reported that these GPs ensured they had access to wider social networks in their community and were invested in having them learn skills to self-manage their condition. This increased their sense of safety and security, allowing them to become more involved in their treatment and particularly in self-care. In turn, this affected how much they trusted themselves and their own ability to change circumstances in their lives to positively affect their pain condition. Also, many participants (13), even those who felt totally unsupported by their GPs and isolated, reported that having at least one person in the system that ‘looked out for them’ (i.e., social worker, nurse, physiotherapist) and to whom they mattered, was one of the most important contributions to their lives. They claimed this strengthened their sense of power and quality of life.

Relatedness beyond the clinical encounter was also affected by the nature of pain and stigma attached to it. This mostly manifested in lack of support by institutions that were supposed to assist the CP patient, such as housing and social assistance programs (i.e., ODSP; Employment Insurance; and private health insurance agencies) which often denied temporary or long-term wage loss benefits; coverage for drugs and treatments or other supports based on chronic pain related impairment and disabilities not meeting eligibility requirements. This undermined the CP patient material, physical and emotional well-being, as well as equitable access to care, thereby increasing their sense of alienation.

In summary, the results of applying the SDT model to the interpretive themes in the data show that for these participants, autonomy, self-competence and relatedness in their interactions with the Ontario health care system are limited by the quality of their relationship with their physicians, short-comings in the wider health care system, and stigma attached to chronic pain and chronic pain sufferers. As a consequence, chronic pain patients feel that their capacity for control and decision-making regarding treatments and management of their pain condition is seriously undermined.

Chapter Six presented the results of using the SDT model to examine the extent to which the interpretive themes in the data matched the key features of each SDT dimension and illustrates how the CP patient’s basic needs for autonomy, self-competence, and relatedness are met or hindered in their interactions with the Ontario health care system.

Chapter Seven: Conclusion

In Ontario, a chronic pain patient's capacity for choice and self-determination regarding the care and treatments they received is significantly affected by stigma attached to pain, social control and agency responsibility concepts upheld by a neoliberalist ideology, and biomedical bias inbuilt in the definition of the illness and medical knowledge.

This socio-political framework contributes to the alienation of those who suffer from chronic pain through:

a) Systemic marginalization, discrimination and disenfranchisement resulting in social inequities and barriers to services (care and supports) by organizations on whom they depend for economic, social and health supports and therapeutic care;

b) Recrimination, disapproval, discrimination and prejudice by family members, friends and community at large leading to the weakening of personal and social support networks and increased levels of vulnerability and isolation.

c) Inimical and conflicted relationships with their GPs leading to decreased capacity to collaborate and act as an equal partner in the care and treatments received and inequity in access to health care.

7.1 Discussion

Findings in this study show that participants' quality of life, achievement of positive health outcomes and relative success in managing the CP condition are strongly related to the quality of their interactions with their physicians.

All participants identified the quality of their relationship with their GPs as instrumental to their sense of autonomy, control, and capacity to make and partake in the care and management of their condition. Those with more positive relationships and stronger bonds with physicians reported feeling more empowered, and perceived themselves as more capable of controlling their condition, and as having a better quality of life. Conversely, those with weaker or more negative relationships felt disempowered, helpless and at a loss, and defined their capacity to manage pain as poor or negligible.

These findings support Hudson et al.'s qualitative study, which shows that in chronic illness, from the patient's perspective, a partnership with family physicians is the most important aspect of enablement and that physicians' enabling attitudes and behaviours were significant in fostering their own empowerment (2013). It is also supported by several studies that claim that the perceptions of control a person had over their care could be hugely influenced by the support and belief of a singular health professional who they (patients) felt, cared and believed in and would be there when needed (Quilliam, 2011; Kelley et al., 2914, Curran, 2007).

Being understood, believed, and listened to were defined as significant features of empowering therapeutic interactions by participants in this study. These characteristics have also been documented by earlier studies as positively impacting the quality of communication with health care providers as well as patient satisfaction, adherence, and health outcomes (Savage and Armstrong, 1990, Curran, 2007, Ryan and Deci, 2008; Fong et a., 2009, Lubkin and Larsen, 2014). However, all the participants of this study reported regularly being rushed, silenced, dismissed or discounted, with opportunities to provide feedback and input in their care described as rare. Thus, they stated that their subjective experiences of the pain condition (i.e., frequency and intensity of pain, symptoms and impact of pain on their lives), and perspectives around treatments and their effectiveness, were regularly banished from the therapeutic encounter. This, participants claimed, was particularly true when they showed dissatisfaction with treatment efficacy, or ability to provide relief from pain. Participants also reported that such physician behaviours lead to a greater sense of estrangement, anxiety, and helplessness.

"The patients' esteem and trust in their health professionals are directly tied to the health professionals' ability to listen to and integrate the patient's explanations of their illness management as legitimate and informative" (Allen et al., 2011:133). Indeed, not being able to participate and have input in their care, and acknowledgement of their views alienated patients who often shut down as a means of protecting themselves (Campbell and McGauley, 2005; Zolnierek and DiMatteo, 2009; Adams et al., 2012).

In their 2004 study involving patients with rheumatic disease, Haugli et al. note that while being seen and believed are key elements in effective medical encounters, patients also sought to be ‘seen as a whole person.’ Having physicians recognize their subjective experiences as valid information as well as understanding their own beliefs and attributions about pain aetiology and treatment were paramount to the patient’s sense of well-being and impression that they have a shared understanding. Not having a shared understanding was cited as a source of stress (2004). Further, Allen et al., in their 2011 study[27] found that adversarial relationships with health professionals stemmed from three areas of tension: between patient knowledge and medical expertise; between whole person care and ‘assembly line’ treatment; and, between shared decision-making and ‘digging to find out’. Their study concluded “that these adversarial relationships are indicative of a lack of trust stemming from clinicians’ failure to interact with patients as whole persons with unique expertise on their bodies, their experience of illness and, their lives” (2011:129).

According to Arnold and Forrow, the experience and perspectives of patients are often undervalued by physicians and this is likely to remain an issue so long as patients’ perspectives continue to be seen as peripheral to effective patient care (1990). Patients are most satisfied if they are able to control outcomes that are important to them and become disgruntled, irritated and distressed when their efforts to control their own lives are thwarted (Powers, 2005; Carey and Spratt, 2009:217). Also, Nimmon, and Stenfors-Hayes indicate that physicians generally exert control within the therapeutic encounter over communication with the patient (2016), and are more apt to listen to and act more patient-centered with patients they perceived more satisfied, and more likely to adhere to treatment, and to dismiss or disregard those who they perceived as less satisfied (Street Jr. et al., 2007).

Such alienating behaviours on the part of physicians as outlined above were echoed by all 23 participants who, regardless of the quality of their bond with their present or past GPs, unequivocally stated that their GPs did not want to hear them complain about pain or the ineffectiveness of a prescribed treatment.

Further, participants that reported having good bonds with doctors also stated that they

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[27] Allen et. al, in their 2011 study[27] focused on understanding haemodialysis patients’ perspectives regarding challenges and solutions to living with chronic illness and taking action to improve their quality of life

learned to ‘shop’ for a good doctor and/or knew how to manage their relationship and ‘good patient image’ by not angering their care providers with complaints about their pain, and by figuring out who and what their doctors wanted them to be.

The inverted order of collaborations/support reflected in participants’ statements is stark. It is the patient who assists the GP in keeping up the image of ‘effectual or successful expert’ as a means to attain/receive the much-coveted sick status and with it, access to treatments and supports. It is the patient and not their health care providers who appeared to put much effort into the management of therapeutic bonds as a means to empower themselves within a system that most experienced as vexatious and alienating. Participants’ narratives clearly articulated the power imbalances they experienced and perceived within the health care system. This stands in sharp contrast to the lofty policies and principles that appear in Ontario government and health care agency statements, documents and websites that talk about patient-centred care, patient empowerment/engagement, etc.

This study found that the participation of patients as self-determined ‘equal partners’, with capacities to affect the course of action (where feasible) of their treatment and therapeutic plans, and to provide input regarding what is working and not working (as indicated in MOHLTC, 2007) is hardly present in the actual clinical model. This has created a deep sense of alienation, powerlessness, and vulnerability, with participants frequently describing their interactions with GPs as difficult or even contentious. Jackson notes that the therapeutic relationship between health care practitioners and patients with chronic pain is considered the worst in the field of medicine (2005).

A common source of disenfranchisement and estrangement from their physicians and the care patients received **was related to the positioning of chronic pain as a contested disease.** Having a contested disease, as suggested by participants of this study, was not only detrimental to the patient-physician relationship and the quality of treatments received, it also resulted in limited or no access to care, insurance benefits, and economic and community supports.

Issues around biomedical bias, the legitimacy of chronic pain as a stand-alone disease[28], the stigma attached to pain sufferers, and the politics around narcotic use for non-malignant pain, all conflated to increase the vulnerability of this type of patient. Within this ideological setting, CP patients are required to continuously **negotiate their sick status** in the context of the mostly unfettered discretion of the physician as a key gatekeeper to care and supports, thus converting the therapeutic relationship into a battleground.

According to participants, **several contingencies related to the nature, aetiology and taxonomy of chronic pain played havoc on their relationship with doctors**. Among them, the chronicity of their illness; the invisible and subjective character of pain, and consequent difficulties related to ascertaining its presence and intensity; the uncertain aetiology of chronic pain; and, the widely diverse definitions of pain which often resulted in vast variation in diagnosis, assessments, and treatments offered to the patient. All these factors appear to stem from **adherence to the biomedical requirements of physiological or biological tissue damage as a legitimatory device**, and the diverse medical fields perspectives (i.e., mental vs. physical) which contributed to aggravating the standing of chronic pain as **a contested disease.**

Conrad and Baker state that contested illnesses by definition represent disorders that many physicians do not acknowledge as distinctly medical (2010). Because of the highly complex set of symptoms without defined biomedical causes and mechanisms, or diagnostic tests, these illnesses usually lack a specific medical definition, present disputed causation (often between psychological and biological) and competing approaches about the proper care and treatments (Brown et al. 2011; Conrad and Barker 2010).

Further, the diagnosis and conceptualization of pain by individual practitioners such as family doctors, or by institutions such as pain centres are quite diverse and the treatment and supports provided by them hinge on those definitions. Pain medicine is not a unified field. Lack of consensus on crucial diagnostic criteria leads to interactions between practitioners and pain

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[28] Lack of recognition of pain as a stand-alone disease instead of merely a symptom related to another disease often lead to an inadequate focus on pain relief since the physician's efforts concentrated on treating the OA condition. Only a handful (5) participants were diagnosed with chronic pain, despite the fact that most of them have suffered chronic pain for over a decade.

patients that can result in feelings of failure, frustration, and ambiguity because those interactions instantiate the fundamental medicine anomaly that pain currently represents (Jackson, 2005). The biomedical world-view of mind-body dualism and the need for biological proof contribute to substantial stress and alienation in patients (Bates et al.,1997; Fair, 2010).

This is particularly so for patients without sufficient or any biological proof of chronic pain, who commonly reported that to be believed they needed to be able to obtain a useful somatic diagnosis, that is, one that did not imply that the aetiology of the pain was psychological. **Those unable to attain such diagnoses reported more stress in their interactions with GPs** (Haugli et al., 2004).

Diagnosis and Access to Services

Brown et al. indicate that there is general uncertainty and an undeniable shred of doubt for most clinicians when dealing with a contested illness, especially one with psychosomatic symptoms. So long as the condition remains 'medically invisible,' it is possible to dismiss it as psychosomatic, and therefore less 'real' than physical diseases (2011). In the absence of a detectable physiological substrate of non-health, it is dependent on the professional's response as to whether to provide a diagnosis (Werner and Malterud, 2003; Ludwig, 1991). For participants in this study, this presented a very tangible risk. Attaining a diagnosis denoted being believed along with legitimizing the pain condition as real and not just in their heads. Unfortunately, obtaining a diagnosis proved impossible for most of the 23 participants, leaving them with the huge emotional burden of not being believed by their physicians, who ironically constituted their only means of accessing care, and most importantly, pain relief.

This is supported by Jackson and Kroenke's research study, which found that lacking a medical diagnosis is associated with perceived difficulty as it entails relegating the provision of care to a condition often medically unexplainable (Jackson and Kroenke, 1999; Weisberg and Clavel, 1999). These patients are generally treated less respectfully. Diagnosis is anchored in a bio-medical understanding of disease, and as such it adheres to the normal/abnormal binary. It also locates in that it allows the medical system to label and deal with people on behalf of society (Brown, 1995; Fair, 2010; Hartwell, 2013). In addition, the absence of objectifying tests to support a specific diagnosis places the patient in a vulnerable position, since the clinician has the power to 'objectively grant' or 'deny' the sick role status based on a patient's illness, as well as subsequent interpretations by the physician (Ludwig, 1991). This study found that not being granted a sick role status not only precluded access to health care services, but commonly resulted in further social and institutional disenfranchisement with deleterious consequences to the patient.

Participants reported that the denial of diagnosis and/or sick status imposed barriers to:

a) economic resources (i.e., lack of eligibility for financial support for disability such as the ODSP, Canadian Pension Plan Disability (CPP-D);
b) capacity to remain employed (i.e., difficulties negotiating for flexible time, and access to work-related ergonomic equipment and adjustments; facing stigma and discrimination by co-workers and employers who do not believe they are ill);
c) capacity to remain independent (i.e., lack of access to community-based and/or personal support care that are based on sick status, such as free or subsidized housekeeping; and,
d) insurance coverage for additional care and treatments, as well as for personal ergonomic devices (i.e., hydraulic lifting cushions, carrying tools, walking devices, grip handles, etc.).

Also, **lack of sick status increased stigma and prejudice in their life-world.** Most participants reported experiencing discrimination, not believed and dismissed by family members, friends, caregivers and employers alike. This resulted in greater isolation and mental health conditions (i.e., depression, despondency, anxiety) for most participants in this study.

Numerous studies indicate that lack of sick status significantly impacts interpersonal relationships, thus negatively affecting bonds with family members and close **social networks (**Moss and Teghtsoonian, 2008, Prince, 2008 and 2004).

Another factor, closely related to the biomedical bias inbuilt in medical practice, and seriously impacting interactions with physicians and access to care is **the stigma attached to pain and** the **assumption of deviance on the part of those who present with chronic pain**. Ulterior motives such as malingering, avoidance of responsibilities, hypochondria, attention-seeking and addiction driven behaviours and shenanigans were often attributed to the participants of this study, often resulting in lack of pain relief therapies.

Further ontological and epistemological issues stem from/surround chronic pain (Moss and Teghtsoonian, 2008). The poorly understood aetiology of pain and the difficulty of measuring it objectively confers upon chronic pain sufferers an ambiguous moral status as it pertains to their entitlement to the help they are receiving -i.e., treatment or disability funds, which often are seen as only encouraging pain sufferers to hold to their sick role (Jackson, 2005, Moss and Teghtsoonian, 2008; Goldberg, 2010; Vallerand and Nowak, 2009, 2010).

Stigmatization of those who suffer chronic pain generates healthcare inequalities that affect the health outcomes and quality of life of the CP patient (Jackson, 2005; Moss and Teghtsoonian, 2008). Further, the ramifications of stigma and discrimination are enduring, potentially disabling, and appear to interfere with care-seeking, rehabilitation participation, and potentially, rehabilitation outcomes (Slade et al. 2009:143). Brown et al. claim that **stigmatizing** practices present in clinical settings also appear to arise from the *attitudes* of health care providers (2011). Contested illnesses place a heavy burden on physicians who are charged with working very closely with patients to generate treatment strategies in a perceived vacuum of knowledge. Creating these highly-individualized structures of care can be particularly taxing for physicians who lack expertise in treating chronic pain or are not familiar with this disease (Brown et al., 2011; Conrad, 2010). However, the stakes are higher for those patients besieged by debilitating pain (Bradby, 2012).

According to Parsons, the role of doctors is socially constructed as that of providing competent medical care in an objective fashion and always acting in the best interest of the patient[29] (1951). However, this is hardly the reality of the participants of this study. Moreover, Bradby claims that such idealized scripting of doctor-patient roles in the therapeutic interaction does not acknowledge that there are several factors that can make this relationship fraught with complexities

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[29] Parson posits that the doctor patient relationship is part of a social system that ruled by societal norms, structures and processes that were beyond individuals involved and its intended effect is social cohesion. Within the therapeutic interaction, Parsons notes that doctors and patients have a mutual obligation, with doctors acting in the best interest of the patient, by providing competent care in an objective fashion and the patient fully cooperating with the doctor in seeking prompt recovery. This interaction, Parson posits, is understood as consensual and reciprocal, with a doctor's diagnoses regulating access to sickness benefits (sick leave, treatment) to reduce deviant illness behaviour, (i.e. hypochondria & malingering) and reduce social costs (1951)

and conflict, usually mediated by features of the patient[30] (i.e., race, gender) along with the nature of the illness, such as chronicity and likelihood of recovery – which may increase the difficulty in bestowing sick role status (Bradby, 2012). Also discarded in this benevolent therapeutic bond is the notion that doctors' stance to all conditions is one of neutrality and therefore the same treatment is conferred to the patient. Such a notion disregards the stigma attached to some conditions and the willingness that doctors have towards providing treatment in particular instances, as it has been the case of HIV (Brooks et al., 2005) and those who have overdosed on illegal drugs, and the dispensing of narcotics to treat pain of uncertain aetiology (Schatman, 2006).

Consequently, because of biomedical biases inbuilt in medical knowledge and the Ontario health care system, stigma, and the contested nature of chronic pain, participants of this study found themselves **negotiating access to their sick status on an on-going basis**. This resulted in emotional turmoil, vulnerability and a sense of oppression. The power of the physician loomed large, accentuated by their unfettered discretion to deny adequate pain relief and the systemic ideologies and structures that seemed as invisible and compelling as the participants' pain.

Because of their role as gatekeepers to health care services and therapies, GPs are the most powerful/influential in any therapeutic encounter converting the therapeutic encounter into a de-facto asymmetrical relationship (Hayward, 2008; Willems, 2001; Andersen et al., 2011). However, for those with chronic pain, efforts to obtain care and treatment for their condition are more analogous to a struggle than a consensual unfolding of mutually agreed roles (Jackson, 2005).

Relationships between patients and physicians, as well as **access to adequate pain relief** were also **impacted by physician level of expertise, the stigma attached to opioid-based therapies, and current socio-political debates** related to the use of narcotics. Even though all participants expressed anxiety and uncertainties about addiction risks, they felt that narcotics have a place in the treatment of their conditions. Conversely, participants claimed that physicians often felt uneasy about prescribing narcotic drugs and refused them access. Also, those who prescribed

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[30] In addition to features of illness, the characteristics of the patient can also affect their entry to sick role. Stereotypes attached to certain patient characteristics, often influenced by race, class, gender and highly stigmatized and contested illnesses entail that some people seeking help with their condition may encounter more difficulties to have their symptoms considered more seriously than others, or in accessing care, for instance the stereotype of black people as having less tolerance for pain and a higher risk of opiate addictions (Mahajan et al., 2003; Najman et al., 1982).

narcotic drugs often did not follow guidelines (i.e., rotation) and protocols to ensure that the treatments were effective. According to Vallerand and Nowak, most physicians lack the training and experience to properly prescribe, rotate and monitor patients who use these powerful narcotics (Vallerand and Nowak, 2009, 2010).

Furthermore, participants alleged that they were often denied opioid-based treatments that could offer effective relief of pain due to physicians' **lack of trust in the legitimacy of their pain complaints**, physicians' belief that they were engaging in devious behaviour, or because of physicians' fear of legal repercussions. Under-treatment of pain often arises from poor understanding or knowledge on part of the physician about the extent of pain experienced by the patient, or the lack of competence regarding procedural interventions and drug programs and therapies that are most effective in leading a particular patient to better control or end pain (McGee et al., 2001; Schatman, 2006).

A weighty factor in the under-treatment of pain is physicians' manifest anxieties in relation to likely medical and legal implications and consequences stemming from the use of opioids as medical cases comprising several risks (Vallerand and Nowak, 2010, p. 8). Consequently, the patient-physician relationship is often corrupted by the various moral, ethical, legal quandaries and ideologies which may result in physicians adopting a defensive posture in order to shield themselves from ensuing demands and burdens of the newly construed interaction. Such stance is diametrically opposed to the profession of pain medicine as based on the avowal to help patients in their best interest, as a beneficial care (Schatman, 2006; CPC 2014). Defensive medicine leads to under-treatment and deprives the CP patient of due equity of care and denies respect for them as persons. Additional complications, susceptibilities, and health disorders can develop as a result of this inequity of care and the consequent disenfranchisement (Schatman, 2006). Also, patients may turn to unconventional modes of medicine and healing, as well as engaging in addictions and substance abuse and other self-medicating behaviours/forms in order to get some control over their condition and their lives, or simply as a coping mechanism (Schatman, 2006; Moore, 2015; Mallek, 2015).

Vallerand and Nowak indicate that while opioid analgesics have been shown to decrease pain intensity, restore levels of function, and improve quality of life for adults with chronic pain, the use of opioid-based pain suppressants for the management of chronic non-malignant pain is a highly-questioned treatment modality (2009, 2010). This is partly based on the high risk for addiction they pose and is compounded by the taxonomy of chronic pain. According to Vallerand and Nowak's argument, this ongoing debate has resulted in increased **stigma being associated with both the treatment modality and those individuals who receive** it. A consequence of these stigmas is the increasing number of barriers in accessing adequate pain relief through the use of narcotics (Vallerand and Nowak, 2009, 2010). However, many ethical and policy analyses of the devastating under-treatment of CP leave unaddressed the role that stigma played, notwithstanding the notion that such stigma exists is well-documented (Goldberg, 2010). Unfortunately, while illness stigma can be ameliorated, there is little evidence of such progress in the under-treatment and stigmatization of CP sufferers (CPC, 2014; Goldberg 2010).

Participants pointed out that there is a drawback to all the new protocols to deal with reducing prescription drugs abuse: limiting their use in the treatment of non-malignant chronic pain unnecessarily precludes consideration of how to overcome present system shortcomings. Among others, these include lack of access to adequate pain relief, non-opioid-based care and alternative therapeutic devices to assist the management of pain conditions. Furthermore, new protocols do not provide any sort of standards or general guide for action in the provision of effective pain relief, leaving GPs to deal with this matter at their own discretion. This, participants found most worrisome, as it often translated into lack of availability and access to non-narcotic based treatments, and increasingly disabling pain levels.

Another impact on **patient empowerment and self-determination** are discourses that **redefine patient participation into the expectation of the patient as an active agent with responsibility for health outcomes.** As stated earlier, participants in this study expressed great interest in control and participation in their care. They interpreted this as having the capacity to provide feedback about the effectiveness of treatments received and input about preferences, beliefs, personal experiences and circumstances that affected their condition, as well as being provided with enough information to make decisions that better fit their needs. Participants also reported wanting choice and control in terms of the type of access, levels of supports, and acquisition of skills that can allow for better control of their condition. However, all participants felt that 'participation,' in the manner they understood it, was not available to them. The only participation allowed was one of (meeting) physician imposed expectations. Most claimed that physicians held them responsible for controlling pain behaviours and pain sensations, They felt disempowered and alienated by the expectation that they are to successfully manage their pain and are held responsible for health outcomes. In addition, this shift in responsibility, they claimed, was not accompanied by the necessary supports, education, behavioural therapies and economic or financial support needed to ensure that they could potentially manage their condition.

Current psycho-social discourse locates responsibility with patients by regarding them as active agents in the management of their condition. Professionals thus refer to patients as taking control over their health afflictions or treatments and stress the importance of encouraging or empowering patients to take this active role (Entwistle et al, 1998; Coulter, 1999; MHLTC, 2007, 2010, 2012, 2014). This is also related to socio-cultural discourses of individual autonomy and rights (Brownel, 1991; Towle and Godolphin, 1999, Halliwel 2014). But the legitimacy of constructing the patient as an agent is widely unquestionable. Regardless, its emergence and close relation to cultural and political ideas makes it suspicious instead of supportive. Further, the discourse does not blend with current health-related ideologies such as evidence-based medicine (Armstrong, 2002, Schofield and Hope 2002 in Salmon and Hall, 2013). Choice, control, and empowerment were stifled by political, medical, organizational and attitudinal variables.

The data in this study bear out that trying to portray this model as empowering in its engagement of the patient as co-manager is intrinsically disempowering. This supports findings by Byrne et al. (2002), and Salmon and Hall (2003) that show that patient control and empowerment helps free health care providers from responsibilities for the suffering for which they can or wish to do little. According to Deccache and Van Ballekom, until 1995, patient centred initiatives were driven by both a focus on patients' well-being and on health care effectiveness. However, the rising influence of economic considerations has reoriented such initiatives. Thus, most of today's governmental health objectives are guided mainly by economic needs, and concepts such as empowerment, participation, and 'responsible patient' have been redefined and are being used in order to push people to respond to political and economic expectations and mandatory demands. As such, there is a **market-driven vision of care** taking place with significant changes in perspectives and role definitions[31] (2010).

The 'patient as an active agent' discourse loses its benevolent features and validity when embedded in current medical ideologies, particularly evidence-based medicine (Armstrong, 2002, Ford et al., 2002). It does not blend well with current political and cultural ideas of the biomedical model that places the disease outside the individual (Longabaugh and Mortgenstern, 1999, Moss and Teghtsoonian, 2008, Conrad and Barker, 2010). Patient empowerment, choice, and self-determination, when accounted for, is not in a manner that meets the needs of the patient but rather the needs of medicine (Salmon 2003, Robertson et al., 2011), public economy (Salmon, 2003) government and the system.

Lack of integration of patients' personal and social circumstances into the care and strategies to manage chronic pain was also identified as a factor **impact**ing **participants' capacity to self-determine.**

The impact of social and economic variables (such as unemployment, poverty, difficulties securing housing, food security, complications in closest relationships[32] due to higher degrees of personal and economic dependency, shrinking social support networks, and declining social roles at home and/or in the community at large) was not addressed in therapeutic encounters. Not recognizing these vexing factors and their effect on the capacity of the patient to self-manage pain only results in more human suffering and alienation. This was particularly so, participants claimed, because they were held responsible for the successful management of pain and blamed for failing to do so.

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[31] "Many practical propositions are guided towards care cost control and reimbursement, patient instruction and compliance…with keywords such as autonomy and empowerment appearing but with no evidence that they will form/be part of the core objectives of care. …. The early nineties saw the emergence of the concept of treatment adherence, as a means to create space for patients' participation, and thus replace compliance as a goal. Fifteen years later alliance and negotiation (of care as well as educational objectives) started being used by patient educators. But this interpretation of the concept or participation was not the only one, for health policy makers and insurance managers were interested in participation of patients more as an increased financial contribution to growing costs. Patient participation started replacing autonomy as a keyword, supported by government declarations. Little consideration was given to the fact that patient participation differs from autonomy, the first being a process concept, and the latter a result… Besides, autonomy, is the ability to make one's own decisions in life, is often more applicable (Deccache& Van Ballekom, 2010)."

[32] Jackson states that patients with chronic pain can provoke an intense feeling of **hostility in caregivers, because of relationships that have severely deteriorated** (2005).

Personal and social circumstances within which patients live are crucial to their decision making and compliance with prescribed therapies, and are essential to maximizing patient control (Donovan and Blake, 1992; McWilliam et al., 2009). The relationships between social determinants of health and poor health outcomes are well-documented (Metzl and Hansen, 2014). However, there is a lack of comprehensive, evidence-based clinical models for addressing complex trauma, chronic stress, and physiologically significant exposures that are the downstream sequelae of poverty and inequality (Boyd, 2014; Metzl and Hansen, 2014). Clinicians need to transform the invisible forms of social inequality and stigma by addressing them in the context of clinical intervention. This would make an otherwise silent but powerful force in the patient's capacity to participate and self-determine a component of the care provided within the primary care setting (Boyd, 2014). It would not only validate the forces that drive the pain sufferer's choices and capacity to actively engage in the management of their condition, but would significantly prevent the cognizant and socially aware provider from engaging in further alienating behaviours. Further, these new clinical models would allow both physicians and patients to accurately assess the patient's level of accessibility to food, housing, health-related information, care, treatments, community-based services and supports, while minimizing misconceptions about responsibility (Boyd 2014; Metzl and Handle 2014).

A further element contributing to **added vulnerability and an undermined sense of control and autonomy** is **the complex nature of the Ontario health care system itself – overextended and fragmented, with sometimes ineffective, poorly coordinated and integrated processes and models**. Participants reported that serious shortcomings in the health care system often resulted in a lack of access to timely, relevant and effective care and exacerbated feelings of helplessness and powerlessness. Notwithstanding Ontario's significant investments in primary care, which brought about a reinvigoration of the sector and produced new inter-professional teams, in Ontario, patients frequently cannot get appointments with their family physicians on short notice. Also, too many patients depend on walk-in clinics and ERs for care even though they do not need emergency treatment. Further, a high number of patients fall through the cracks when multiple health-care providers are involved in their care (ICES[33], 2014; Glazier et al., 2012; HQO[34], 2015, 2016).

A January 2014 report released by the Health Council of Canada found that only 42 percent of Ontarians are able to get a same-day or next-day appointment with a family doctor and 58 percent have difficulty accessing care on weekends and evenings, causing them to make use of ERs. The primary care system in Ontario also lags behind that of international peers on the delivery of chronic care, wait times, use of IT and provision of team-based care. Lack of access to timely and efficient primary care services results in higher health costs (Martin, 2014; Health Council of Canada 2015 and 2016). In Ontario, patients are currently waiting anywhere between 33 days to two and a half months to have access to a specialist after their family physicians make a referral (Jaakkimainen et al., 2014), and many patients still do not receive sufficient follow-up care after hospital discharge. These include those with mental health problems and addictions among others (HQO[35], 2015).

Canada's health system is currently under major stress and almost at a crisis level (Prada, 2015). This can only be made worse by a rapidly aging population with chronic and degenerative diseases, simply because chronic diseases are the main socio-economic burden on health care systems. "Discrepancies across the country, lack of coordination, restricted access to or narrow eligibility for programs or facilities, and lack of funding for priorities were identified as challenges in health services for these populations." These gaps in assessment and care represent a considerable oversight as they result in higher levels of unmet needs, stressed caregivers and social inequalities (Verbeeten et al., 2015).

Summary

The findings in this study illustrate the process of structural alienation that takes place in the course of the provision of care, and how this process is determined in the patient and health care professional's interaction, reinforced by the socio-political and institutional context. In-built biomedical biases and stigma present in medical knowledge, institutional structures, clinical

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[33] Institute for Clinical Evaluative Sciences (ICES)
[34] Health Quality Ontario (HQO)
[35] Health Quality Ontario (HQO)

models and health care praxis lead to the construction of pain as a contested disease and affect the manner in which clinicians and the entire health care system respond to CP patients and their needs.

Being pain-free, feeling safe, being believed, having input and a sense that they mattered to those in charge of their care were CP patients' most critical goals as identified in this research. However, the level of distrust and conflict in patient-physician relations[36] often lead to punitive gatekeeping[37]. Inadequate access to timely pain relief and effective therapies, coupled with the near absence of non-narcotic based therapies and supports undermines CP patients' sense of empowerment.

Further, the de-contextualization and appropriation[38] of clinical models of care, including the delivery of services by neoliberal ideologies of patient as an active agent, with responsibility in the successful treatment and management of their condition, proved hazardous to the already delicate/vulnerable social position of the CP patient. Over-reliance and focus on steps and behaviours that CP patients can take to improve their health, devoid of considerations for the actual material, social and political disadvantages faced by this group, commonly resulted in a victim-blaming approach that reinforced the established power imbalances between patient and clinicians.

In addition, the data indicates that **stigma**, **ideologies and medical and diagnostic imperialism (values) not only influence the medical praxis but in a continual dialectic relationship, medical praxis influences the public and private sphere of the patient**, contributing to further economic and social barriers that include weakening of family and social supports, institutional disenfranchisement, and economic disruptions.

Thus, ensuing inequality within the health care system reflects a combination of negative exposure and lack of resources held by the chronic pain patient, along with systematic

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[36] There is a great deal of circularity within the health care system that might impact GP behaviours. Just as the GP is the "gatekeeper" of the health care system, the health care system itself impacts the physician's decisions about care and treatments, including the type of pain medication (i.e. narcotic or non-narcotic based pain suppressants) patients should receive.

[37] A term borrowed from Wilson (2001) that indicates that the care provided is not neutral but affected by socio-political values, ideologies and beliefs.

[38] Psychosocial approaches can be particularly vulnerable to de-contextualization and appropriation by "regressive political agendas" (Wilkinson in Lynch et al., 2000:1204). Emphasizing what patients can do to help themselves to improve their health, without accounting for the real material, social and political disadvantages experienced by these populations, frequently results in a victim –blaming approach that reinforces the established power imbalances. (Crinson & Yuill, 2008).

underinvestment in chronic pain research and services and systemic disenfranchisement by health care and social institutions which frequently do not recognize disabilities, impairments and the resulting needs of CP patients.

Data in this study suggests that much of the misery, clinical, cultural and social damage experienced by the CP patient is due to iatrogenic[39] effects (or iatrogenesis) caused by a purported clinical model of empowerment and patient/person-centred care where shared decision-making does not translate into empowerment but, to the contrary induces suffering and alienation. This form of alienation, according to this research, affects patient autonomy, sense of empowerment, and social connection. Consequently, the CP patient capacity for choice, self-determination and sense of control are radically undermined, negatively impacting their health outcomes and quality of life.

7.2 Research Conclusion

The results of this study suggest a pathway from stigmatization, biomedical biases and neoliberal ideologies stressing agency and responsibility as psychosocial generative structures to social and health care inequalities that affect the health outcomes and the quality of life of the CP patient. The dangers of increased social control and its conflict with autonomy and self-determination and human rights are real.

Understanding of the vulnerability and the action of empowering patients with chronic diseases remains a long-term dilemma for the Ontario health care system despite the various strategies deployed in the implementation of chronic disease strategies.

The complex ideology of patient-centred care planning, in all its manifestations, is essentially rationalist in approach, erroneous in conclusions and lacking in its praxis. Underlying this faith in a clinical model to address the needs of CP patients by providing care that is ‘client centred’ and allows and expects the patient to ‘participate’ stands in stark contradiction to the

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[39] Iatrogenesis " refers to any effect on a person, resulting from any activity of one or more persons acting as healthcare professionals or providing care, products or services as beneficial to health, that produce clinical, social or cultural damage that far outweighs their potential benefits (Illich, 2010)

notion that patients besieged by chronic pain cannot simply ‘choose’ to naturally engage in the management of their conditions, and/or are impeded in this pursuit by deeper cultural, economic, personal, or political issues and ideologies. Such false and particularly apolitical assumptions belying patient empowerment, are problematic in their simplicity and can have serious implications for the intended beneficiaries (i.e., the patients).

Implicit in the Ontario *Chronic Diseases Care Strategy* is the aggressive reliance on a medical model that is assumed to be in place. It is this notion of the empowered patient with unobstructed access to therapeutic care, effective pain relief, caring clinicians, and supportive economic and community services to successfully control the condition that triggers the de-politicization of choice and self-determination.

In practice, over-reliance on the biomedical model; endorsement of neoliberal ideologies of patient agency and responsibility for health outcomes; and, stigma attached to chronic pain sufferers along with co-stigmas around mental health, addictions and narcotics use, all combine with political and socioeconomic agendas to render patient empowerment initiatives ineffective. Further, these particular circumstances, and the dismissal of the actual material, social and political disadvantages faced by those suffering from chronic pain, simply conspire against the realization of a patient-centred care by creating further inequities in access to health care, economic and social supports, along with social alienation and institutional disenfranchisement.

For Ontario, making care more effective will require much more than committing more resources and increasing integration and coordination between different junctures of the health care continuum. It will require addressing practical, material, ideological and political obstacles, including institutional pathologies (i.e., diagnostic imperialism and its impact on self-determination) and the differences in social and economic circumstances of each patient.

7.3 Significance of Findings

As presented in the literature review and the findings of this research, chronic pain is a widespread, dreadful affliction with devastating consequences to individual sufferers, their caregivers and their families (Reitsma et al., 2012). Moreover, the economic burden of CP moves beyond the individual and increasingly affects all of society with multi-billion losses in productivity and health care expenses in Canada alone (Reitsma et al., 2012, Boulanger, 2007). However, the need for efficient, effective, qualitative and timely care for those with chronic pain continues to be unaddressed. Over seven million Canadians suffer from chronic pain (i.e., one in five). Yet CP remains among the most neglected and misunderstood of all health conditions (Cooper, 2015, Reitsma et al., 2012, Boulanger, 2007).

The immediate threat to the future of Ontario's (and Canada's) publicly run health care system, already under financial stress, coupled with population growth, steep population aging, and further pressure as arthritis and chronic pain rates more than double in the next two decades is undeniable (Health Canada, 2013). In addition, reports indicate that the ongoing and widespread system failure to provide adequate pain relief for acute pain occurrences will generate a growing pool of people developing chronic pain conditions (Jovey et al., 2003; CPS 2002; Boulanger at al., 2007; Daher 2010, IASP 2012). Without major changes and strategies to ensure better and equitable access to quality care, adequate pain relief, and increased patient capacity to better manage these conditions, the Ontario health care system is likely to face greater chaos and increased service and resource shortages which could bankrupt a system that is already over-leveraged, and could potentially result in further erosion of the health status and quality of life of CP patients.

The findings of the current study provide Ontario health care practitioners, educators, planners, policy makers and administrators with significant insights into the experience of self-determination, choice and decision-making capacity within the Ontario health care system among 23 individuals living with chronic pain. It adds to a growing body of knowledge about the importance of viewing self-determination and a patient's sense of control and decision-making capacity regarding their care, treatments and management of their health condition as an essential element of health services. The substantive knowledge developed through grounded theory about **structural alienation** as manifested in the interaction of the CP patient and the primary health care system, and its reverberations into the wider social environment of the patient has the potential to contribute to guiding the practice of medicine.

The findings of this study suggest that despite Ontario’s major investments in client-centered care models, patient empowerment and patient self-determination, many chronic pain patients continue to be without timely access to care and adequate pain relief, and are increasingly facing barriers to access health care services, health-related community and home supports, government based social, financial (disability funds) and community-based resources, to name a few. This study’s findings suggest that Ontario’s adoption of client-centered models of care have taken place in the absence of routine measurement of primary care service delivery within private, group and community-based practices; and with limited accountability for how the principles of patient empowerment are implemented or accounted for, in particular when pertaining to CP patients.

Ontario’s strategies for chronic disease management, including policies, standards, and clinical models place a high emphasis on the provision of client-centered care, aimed at increasing patient self-determination, empowerment and self-competence (MOHLTC, 2007, 2012, 2015). However, in the case of chronic pain, stigma, entrenched ideologies and prejudices about the use of opioids (particularly because of their addiction forming qualities), magnified by the contested nature of pain; the presumption of deviousness towards those who need opioid-based pain suppressants; lack of adequate access to effective non-narcotic-based treatments; in-built biomedical bias in the medical field whereby illness status and legitimate access to treatment for chronic pain must be negotiated on an on-going basis; along with a neoliberal ideology that seeks to hold patients responsible for healing themselves, limit or constrain access to adequate care, and lead to health inequities. Further, and compounding this predicament, are the lack of appropriate implementation strategies, standards and accountability mechanisms for tenets of the Patient-Centred Care (PCC) model; along with no clear guidelines to diagnose chronic pain; unfettered discretion in the provision of adequate pain relief; and, the apparent lack of resources allotted to effective pain care, which together, contribute to further inequities in health care access and make the provision of patient-centered care unachievable. This all results in the alienation of the patient through reduced self-determination and an undermined sense of autonomy, control, self-competence, and connectedness. It is worth noting that lack of self-determination impacts patient capacity to actively participate in the care and self-management of their health condition – two of the most significant elements in achieving positive health outcomes and satisfactory quality of life for those suffering from chronic conditions, and important requirements of the patient-centered care model.

As such, this study also adds to bodies of literature on the ‘chronic pain’ and ‘patient centred care models’, by providing new and unique understandings of structural barriers to success in delivering quality care to CP patients, how these barriers operate, and their impact on the health status and quality of life of the patient. Further, by revealing the forces constraining clinical relationships and the provision of care, this study can assist in advancing the dialogue between health care stakeholders to increase the effective management of this condition and increase the level of satisfaction and quality of life of CP patients.

The findings also provide a detailed and in-depth insight into the perceptions and needs of CP patients in their interactions with the primary health care system. The most significant contribution of this study is the new body of knowledge arising from this research. Structural Alienation offers a comprehensive understanding of CP patients’ circumstances. It also provides a new lens for viewing their experiences, and offers an abundance of detail through many accounts rich in information that allow the mapping of the process of alienation as lived by the CP patient within the medical system and the consequences in their lives.

This study specifically illuminates how health care inequities and impinging ideologies have resulted in lower health status, patient disempowerment, and social, economic and institutional disenfranchisement for CP patients beyond the realm of the health care system. It reveals barriers to social and supportive networks, financial assistance, community and social services, insurance coverage, and access to health-related resources. This research and its central message propose that in Ontario, alienation of chronic pain sufferers is widespread, being more prevalent when patients perceive themselves as having low control over the care and treatments they receive. Chronic pain sufferers have weak and ineffective bonds with their health care providers and suffer from stigma and discrimination at the hands of institutions they rely on for resources, supports or care. Indeed, the relevance of this research hinges on its ability to lay bare the workings of power and ideology within the health care system in regard to the chronic pain patient.

Although previous studies in the field of chronic pain identified the importance of such factors to patients' quality of life and well-being, the researcher knows of no previous study that describes how such factors affect Ontarians' capacity to make choices and self-determine, or elucidates their impact on the capacity of Ontario health care system to offer patient-centred care.

As this study posits, PCC (patient/person-centered care) as a seemingly unproblematic commitment of Ontario to patient participation and patient empowerment appears to ignore the many contextual factors and power divisions impacting the marginalized community of those who suffer from a contested and highly stigmatized chronic disease such as chronic pain. Solving this institutional, professional and health care dilemma is of critical importance for Ontarians with chronic pain.

This dissertation has made an effort to revisit how that contention is anchored in neoliberal ideology, stigma and bio-medical imperialism. Indeed this research puts forward for consideration that the tendency to ignore and/or de-politicize chronic people's choices and capacity to self-determine; the contextual constraints on the physician/patient interaction; and, the organization of the health care system and its response to contested and/or stigmatized illnesses, are anchored in or arise from definite and identifiable beliefs, mistaken assumptions about patient empowerment, and social control ideologies removed and dissociated from their social and material environment, and detached from the psycho-social structural determinants of health and well-being in the life of the patient. In this context, these clinical models effectively provoke further disenfranchisement, discrimination, and disempowerment of those it is purported to help, thereby shaping the developing character of a **current practice which has simply resulted in unequal access to services, more suffering, more disability, and lower patient satisfaction and health-related quality of life.**

Patient-centred care strategies regarding pain do not necessarily yield the intended results of patient's locus of control, patient enablement, patient active participation in the therapeutic process and most important, patient capacity to effect positive changes to the system and to be included in decision-making processes that affect them in such deeply personal manner.

Noteworthy is that these findings also seem to indicate that chronic pain is yet to be widely recognized by physicians as a disease in its own right, and that the provision of timely and adequate pain relief is yet to be considered a necessary goal in the care of pain, leading to great despair, estrangement and lack of trust between patient and clinicians. These findings are also significant in that they expand on the social and medical literature pushing for governments and health-care practitioners around the world to consider the provision of chronic pain relief as an inalienable human right (Brennan and Cousins, 2004; Daher, 2010; IASP, 2010), not to mention the need to ensure that this is the case in Ontario.

Moreover, and equally important, is that this research indicates specific treatments, strategies, and services that these chronic pain sufferers considered beneficial in assisting with the management of this condition. This research also puts the emphasis on more equitable access; recognition of pain as a disease in its own right and the right to pain relief as an inalienable human right; the provision of case management, patient advocacy and an alternative array of effective non-narcotic based pain management care as well as on-going access to self-management resources and supports. Finally, the findings in this study are significant in that they provide Ontario health care administrators, planners, public health professionals and clinicians endorsing client-centred models of care, with a tool to begin to address barriers to increased CP patient participation and commitment to health-seeking behaviours. Also, the findings of this study suggest further opportunities for research into comparative treatment approaches to assist CP patients in becoming empowered by increasing their capacity to actively engage in the treatment of their condition.

7.4 Recommendations on Further Research

There is a need for further research into the overt and covert behaviours of health care professionals that result in patient disempowerment through stigma and bio-medical biases, and the root causes of such behaviours. More research in this area might provide a broader understanding of the issue at hand and may suggest more effective ways to eradicate these behaviours.

In addition, the impact of ideologies of patient responsibility for their health status or the successful management of their illness should be examined, with a special focus on their impact on clinical models, and institutional and clinician behaviours and responses to those patients who, suffering chronic diseases, fail to adequately manage their condition. A deeper understanding of these ideologies' impact on patient-centered care and the expectation of active engagement of patients in self-care, can assist clinicians in considering how such expectations may inhibit or negate the intended goal of patient-centered care and empowerment. It is also recommended that the model of client-centered care be analyzed in the context of contested illnesses, particularly chronic diseases which necessitate the active and continuous engagement of the patient at the practice level, to optimize strategies that minimize patient alienation and take into account those mechanisms that will ensure increased choice and self-determination.

Finally, while these contextual factors that affect patient self-determination were derived from osteoarthritis-related chronic pain, they likely have broader applicability to people living with other lifelong contested diseases and/or highly stigmatized diseases (i.e., HIV). Further research would be needed to determine similar and/or unique or differing structural factors that impact on how the health care system responds to patient needs and the inequities they create in care provided and in their influence on the patient's socio-economic and cultural circumstances.

7.5 Implications for Medical Praxis

The findings in this research suggest that there is a need to explore and institute more effective and precise accountability mechanisms to increase transparency and identify practices that belie patient empowerment and active decision-making in therapeutic encounters and medical practices and processes. There is a need to find more effective ways to operationalize[40] elements of patient-centered care and medical strategies to ensure that evidence-based practices and

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[40] To operationalize a concept or a variable is a process of defining the measurement of a phenomenon that is not directly measurable, though its existence is indicated by other phenomena. It is the process of defining a fuzzy concept so as to make the theoretical concept clearly distinguishable or measurable, and to understand it in terms of empirical observations. In a wider sense, it refers to the process of specifying the extension of a concept—describing what is and is not a part of that concept (Wright, 2007)

knowledge translates into medical praxis and makes patient self-determination and decision-making capacity a tangible, concrete and unassailable component of medical practice.

It is also important to find a set of strategies that work in a variety of contexts, improve the social relationships and experiences of control and self-determination of individuals with chronic pain, and provide a diversification of mechanisms that lead to patient empowerment.

Furthermore, patient input and evaluation of the care received should become a safe, user-friendly, *de rigour* practice readily accessible to the patient as a feedback mechanism on issues of timely and adequate provision of pain relief, respect, empowerment, satisfaction, and impact on their perceived quality of life. Patients must be encouraged to provide input on an on-going basis (by making this process safe and user-friendly). Without these mechanisms, patient empowerment is moot.

It seems prudent to explore the potential of instituting a national registry of pain specialists and a tracking system of chronic pain sufferers that can assist in gaining a better sense of who is (and isn't) receiving pain care and their health outcomes according to care received, as well as a solid and comprehensive research program to help develop better treatment, support and understanding of successful services and care as indicated by patients. Also, the potential of instituting a national registry of primary care physicians that are specialized in chronic pain care and have successful records providing effective treatments as per their own patients, to help facilitate other CP patients access those professionals with the knowledge and experience required to treat their condition would be of benefit.

To further address health care inequities, ideological and politicized issues that create economic, financial, and social barriers must be dealt with to minimise marginalization and oppression within the medical context as well as in the wider social arena (i.e., insurance coverage, social security, employment rights). A starting point is to explore how the medical system, policy makers and health professionals can best address the social, cultural and scientific issues that contour the structure and organization of care and shape health professionals' responses to pain patients' needs and the level of care they are provided, as well as how this phenomenon manifests in further social and health inequities for the patient.

To this end, it is recommended that Ontario health administrators, policy makers, health experts and health care providers seek ways to incorporate structural competency into clinical models and the entire medical praxis in an effort to broaden the understanding of the institutional pathologies of the health care system and the policies that impinge on the provision of care, and the behaviours and bodies of the pain patient. The incorporation of structural competence clinical models can help root out the institutional inequalities that negatively impress population health. Metzl and Hansen contend that addressing the forces that influence health outcomes at levels above the individual interactions may help promote population health equality (2014). Also, Geronimus et al. posit that changing features of the setting in everyday life, rather than seeking to change individuals, can help eliminate stigma and help minimize health inequities based on stigma (2016) and other ideologies.

The findings in this study further suggest that focusing on the depoliticization caused by neoliberal ideologies and biomedical hierarchies, and re-politicizing the context of the provision of health care can help promote empowerment and self-determination in care recipients. This should follow a growing body of social epidemiological evidence showing that structurally-based biopsychosocial factors/forces have population health effects (Oakes and Kaufman, 2017; Metzl and Hansen, 2014; Martikainen, 2002; Berkman and Kawachi, 2014).

Last, findings in this study put forward for consideration the need for increased training for clinicians to adopt clinical models that engage stigma and inequality. Metzl and Hansen note that clinical models could help transform the intangible forms of social inequality and stigma by addressing them in the context of clinical intervention in order make the otherwise silent but powerful factors in the patient's capacity to participate and self-determine a component of the care provided within the primary care setting (2014).

Clinical models that include structural competence would assist health care providers in making fundamental connections between larger forces in society and the health status of the patient by converting those forces into accessible, clinically-relevant language. Clinicians would thus be able to conceptualize the structural framework in which patients live, work, and play within a medical model (Boyd, 2014).

For CP patients, these models have the potential to not only validate the forces that drive their choices and capacity to actively engage in the management of their condition, but would significantly prevent the cognizant and aware provider from engaging in further alienating behaviours. Moreover, it would allow both parties to accurately assess the level of accessibility to education, services, treatments, supports, and necessary resources, thus minimizing misconceptions about responsibility, and in the process, curtail instances that may lead to further alienation of the care recipient.

Further, these clinical models can potentially strengthen the bonds between health care providers and patients, increasing patients' sense of belonging, connectivity, and level of engagement. As Goldberg cleverly states, "If stigma is fundamentally an alienating experience, and if illness and pain are especially likely to exile the sufferer, it follows that bringing the pain sufferer back into a sense of community may provide a key pathway for ameliorating some of the suffering that attends chronic pain (2010:434)."

7.6 Closing Statement

Despite Ontario's adherence to a chronic disease framework that endorses patient-centred care and empowerment to promote and support autonomy and self-determination, the necessary policies, care standards and program conditions have not been adequately adopted and implemented on a provincial scale. Economic, cultural, social, and structural barriers now restrict wider implementation of functional, practical, client-centred, autonomy and supportive, empowering care. In examining some of these barriers and how they have either been overlooked or partially addressed, additional conditions for securing CP patients' self-determination become visible, and a future agenda for change becomes clearer. Discrimination, marginalization, and disenfranchisement persist, even if medical and clinical models of care have been reworked/revised to ensure participation and respect for the tenets of patient self-determination, empowerment, satisfaction, and safety.

In a time of ever more aggressive labour markets and declining number of government-funded services, self-reliance, personal responsibility, and independence appear to increasingly be the hallmark defining the good citizen. The lack of capacity of the system to become bias-free, reduce health care inequities and positively impact CP patient's quality of life and self-determination intensifies this dilemma more than ever. When a patient's capacity for decision-making depends on supports for full inclusion and active engagement, without which they cannot achieve the cultural standards of self-determination, then equity within the Ontario health care system seems debatable. Patient/person-centred care and shared decision making then are nothing more than a sham in the face of the lack of adequate access to pain relief, care, services, and the lack of supports and structures that these models demand/entail.

Until a more inclusive, sensitive to individual differences, and bias-free clinical model is adopted, the conditions required to attain patient self-determination are likely to remain on the periphery of the health care system. The toll will be the disavowal of equality and fairness to a growing segment of our population and further reduction in their quality of life.

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