

The Lived Experience of Undiagnosed Chronic Pain

by

Ronald Andrew Sumner

B.Sc., University of Waterloo, 1988

B.Sc., Physiotherapy, University of Toronto, 1992

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Supervisory Committee

Dr. Timothy Black, Supervisor (Department of Educational Psychology and Leadership Studies)

Dr. David deRosenroll, Departmental Member (Department of Educational Psychology and Leadership Studies)

Dr. Ryan E. Rhodes, Outside Member (School of Exercise Science, Physical & Health Educ.)

Dr. Elizabeth Banister, Additional Member (School of Nursing)

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ABSTRACT

When considering the impact of chronic pain on society as a whole, the statistics on the prevalence and societal costs associated with this phenomenon are nothing short of staggering. Traditionally, the research on chronic pain has predominately focused on the neurobiology of pain, pharmaceutical management of chronic pain, as well as the epidemiology and etiology of pain. However, relatively less attention has been given to the actual *lived experience* of individuals suffering from chronic pain, and a notable void was found to exist in the literature in terms of how one's pain experience might be affected by the absence of an accepted diagnosis. The purpose of this qualitative study, therefore, was to explore, describe, and *understand* the experience of individuals who find themselves in this challenging situation, asking the fundamental question: "What is the experience of living with undiagnosed chronic pain?"

In this study's investigation of the aforementioned research question, five individuals living with undiagnosed chronic pain participated in semi-structured research

interviews. These interviews generated rich experiential descriptions from the participants (captured via interview transcripts), and the resulting data was analyzed using a hermeneutic phenomenologic framework. This analysis generated 10 themes that were deemed to be ‘essential’ to the experience of living with undiagnosed chronic pain. Once these themes were compared with extant chronic pain studies, it was noted that this study’s themes of *‘I have tried everything’* and *‘Feeling exasperated’* had not been previously identified as independent phenomenologic themes, and as such, they offer a unique contribution to the literature. Although there remains a certain degree of ambiguity regarding whether these experiential themes are equally applicable regardless of whether or not one’s chronic pain is associated with an identified diagnosis, it would not seem to be overreaching to speculate that these lived experiences might be more potent if one were lacking a diagnosis to adequately ‘explain’ their chronic pain. However, it was acknowledged that for this assertion to be defensible, future studies would need to be done in a manner that enables stronger comparisons between the experiences of chronic pain sufferers who have, and do not have, an accepted diagnosis.

In terms of implications for praxis, an overarching motivation of the researcher was to generate new knowledge that would not only be applicable in counselling settings, but would also have value *across* disciplines, positively affecting psychological-counselling, medicine, and physical rehabilitative disciplines in terms of promoting deeper levels of *empathic understanding* regarding the experience of living with undiagnosed chronic pain, thereby giving a voice to this underrepresented portion of the greater chronic pain population.

TABLE OF CONTENTS

TITLE PAGE	i
SUPERVISORY COMMITTEE	ii
ABSTRACT	iii
TABLE OF CONTENTS	v
 CHAPTER I: INTRODUCTION	
Background to the Study	1
Purpose of the Study	5
Significance of the Study	6
 CHAPTER II: REVIEW OF THE LITERATURE	
Overview of Literature Review.....	8
 Part 1: Chronic Pain Overview	
• Historical Perspective	8
• Current Research in Chronic Pain	11
• Chronic Pain and Clinical Counselling	11
 Part 2: Biological Etiology of Pain	
• Common Biological Pain Conditions	13
• Types of Pain	14
• Neurobiology of Pain	16
• CNS Sensitization	17
 Part 3: Psychological Etiology of Pain	
• Overview	20
 Part 4: Living With Chronic Pain	
• Movement Towards Phenomenology	23
• Literature Touching Upon the Experience of Living with Undiagnosed Chronic Pain	24
 CHAPTER III: RESEARCH METHODS	
Qualitative Philosophical Foundation	28
Phenomenology as a Theoretical Framework	43
Hermeneutics as a Theoretical Framework	49
Hermeneutic Phenomenology Theoretical Framework	54
Purposeful Research Design	56
Participants	57
• Purposeful Sampling	57
• Criteria for Inclusion	59
• Interpretive Co-researchers	61

• Positioning of the Researcher	63
• Trust Within the Research Relationship	64
• Sample Size	68
• Participant Access, Screening, and Selection	69
Ethical Considerations	73
• Guiding Ethical Principles	74
• Ethical Considerations Specific to Data Collection Stage of Research	76
• Ethical Considerations Specific to Data Handling Aspect of Research	78
Data Collection	79
• Interview Process	79
• Interview Setting	85
• Symptom Accommodations during Interviews	86
• Data Management	86
Treatment of Data	87
• Data Management Model	89
Reflexive Process	91
Critically Analyzing the Research	94
• Credibility	96
• Prolonged and Substantial Engagement	97
• Peer Debriefing	99
• Progressive Subjectivity	100
• Authority of the Researcher	101
• Member Checks	103
• Transferability	104
• Dependability	105
• Confirmability	107
• Authenticity	108
 CHAPTER IV: RESULTS	
Results	109
 CHAPTER V: DISCUSSION	
Discussion	122
Comparison Between Major Findings and Existing Studies	123
Unique Findings	141
Limitations of Research	143
Implications for Future Research	150
Implications for Counselling Practice	165
Overall Significance of the Study	176

APPENDICES	
• Appendix A: Invitation to Participate Poster	179
• Appendix B: Information Form for Research Study ‘Host’ Sites	180
• Appendix C: Participant Informed Consent Form	185
• Appendix D: Victoria’s Community Counselling Resource List	190
• Appendix E: Potential Research Interview Questions	192
REFERENCES	195

LIST OF TABLES

Table 1: Characteristics of the participants	59
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CHAPTER I

Introduction

Background to the Study

Pain is the most ubiquitous of all medical symptoms. Indeed, I would consider it to be one of the most fundamental sensory experiences of life itself, as it is difficult to imagine anyone who would not be able to immediately identify with the concept of ‘pain’, and provide numerous personal examples of past or present pain experiences in his or her own life. Taking this notion of universality a step further, I believe it is reasonable to assume that most human beings have also had some manner of pain experience in which they were uncertain, even if just for a fleeting moment, as to what was the actual source of their unsettling pain experience. This *unknowingness*, and the associated cascade of thoughts and emotions, has always been a source of intrigue to me, and it is this fascination that served as the initial spark for my interest in this research topic.

In addition to my own personal experiences with pain, I have participated as a clinician in relationships with thousands of clients in pain, both diagnosed and undiagnosed, while working as a physiotherapist over the past 16 years. In this regard, I have noted time and time again that the clients who perceive that they do not have a clear, definitive diagnosis (i.e., lacking an ‘explanation’ for their pain) seem somehow *different* from the clients who have a confirmed, and accepted, diagnosis. I have discussed this phenomenon with numerous colleagues in the past, and have found that virtually every clinician can attest to the distinctive presentation of clients when

diagnostic uncertainty exists, acknowledging that although the exact nature of this distinction remains highly elusive, it is nonetheless ever-present.

Adding another layer to the consideration of this phenomenon is the issue of chronicity, as it has been my observation that suffering is greatest when clients with undiagnosed pain endure this state of unknowingness over a period of months, or even years. One might imagine how a sudden, perplexing pain would be disturbing to virtually anybody; however, if it quickly resolves never to return again, it is quite likely that the sense of emotional upset would also spontaneously recede. However, individuals with chronic undiagnosed pain are not so fortunate. Without actually living the experience first-hand, one can only speculate how it must feel to struggle with the many enormous challenges that chronic pain clients face on a daily basis; trying to manage and cope while not even being able to provide a succinct explanation to themselves or to others as to what is the actual *cause* of their pain and associated disability. Moreover, lack of clarity in diagnosis leads, by its very nature, to lack of clarity in treatment, as the choice of treatment is always dictated by the diagnosis of one's illness or injury. Clients lacking a clearly defined diagnosis for their chronic pain tell an all too familiar story of voluntarily attending, or being mandated to attend (e.g., by a third party insurance funder) a diverse battery of medical, psychological, and rehabilitative assessments and/or treatments, with little to no rationale for the referral streams selected. My professional experience has been that this 'shotgun' approach of trying anything and everything in treatment, all to no avail, often seems to escalate clients' feelings of frustration, hopelessness, and a sense that something is inherently 'wrong' with them. Thomas (2000) notes that although modern analgesic medications can sometimes offer a

modicum of relief, albeit temporary in nature, these medications cannot alleviate the profound suffering of these patients, which is often as much psychological and spiritual in nature, as it is physical (p. 685). I have personally witnessed the toll this clinical presentation seems to take on the individual, and have long felt that a lack of understanding, and appreciation, for the immense strain these clients are under prevents health care practitioners from providing a more optimal level of care and support. I see the potential for vastly improved care-giving to this population as being something that is primarily restricted by gaps in our knowledge-base, as opposed to other issues such as limited funding for health care services, even though these funding-related service provision issues seem to be garnering the lion's share of media and societal attention in recent times.

When considering the impact of chronic pain on society as a whole, the statistics on the prevalence and societal costs associated with this phenomenon are nothing short of staggering. Although the ability to accurately quantify the prevalence of chronic pain is mired within the challenges associated with operationally defining this phenomenon, there remains little doubt as to its vastness, both in overall scope and in the degree of impact it has on the human species. According to the World Health Organization (WHO), *pain* is the single most common reason for which patients visit their family physician (Gureje, Von Korff, Simon, & Gater, 1998). If one considers the literature as a whole, then the prevalence of chronic pain within the general population appears to take on near epidemic proportions, as prevalence rates have been quoted as ranging from 5.5% to 33.0% in studies within North America, European, Africa, Australia and Asian countries (Kerssens, Verhaak, Bartelds, Sorbi, & Bensing, 2002; Smith et al., 2001;

Verhaak, Kerssens, Dekker, Sorbi, & Bensing, 1998; Croft, Rigby, Boswell, Schollum, & Sillman, 1993; Kumpusalo, Mantyselka, & Takala, 2000; Purves et al., 1998; Seers, 1992; Gureje et al.; Blyth et al., 2001; W. A. Katz, 2002). In an attempt to better understand the makeup of the chronic pain population, these studies also demonstrate consistency in their findings of significantly higher rates of chronic pain amongst women and the elderly, higher prevalence of chronic pain in lower economic groups, as well as a large majority of these individuals reporting pain in multiple body regions. Not surprisingly, several of these studies also identified interference with daily activities (i.e., home tasks or hobbies) as a presenting feature in conjunction with chronic pain (Smith et al., Blyth et al., Kumpusalo et al.), as well as low self-ratings of overall health (Gureje et al., Smith et al., Blyth et al.). Certain studies have also looked at a range of other features, and identified an association between chronic pain and lower levels of completed education (Smith et al., Blyth et al.), higher levels of psychological distress (Smith et al., Blyth et al.), and the receiving of disability or unemployment claims benefits (Smith et al., Blyth et al.).

When considering the purely economic cost to society associated with chronic pain, many factors must be considered, including the financial implications of: disability claims, sick days, reductions in worker productivity, reductions in workforce morale, publicly-funded medical and rehabilitation interventions, as well as publicly-funded psychological interventions. Again not surprisingly, the literature reflects a high incidence of occupational disability associated with chronic pain (Gureje et al., 1998; Smith et al., 2001; Blyth et al., 2001; Kumpusalo et al., 2000; W. A. Katz, 2002; Pizzi et al., 2005). This factor of work absence, combined with the aforementioned costs to

society at large, can place an enormous strain on a nation's economy. A study completed by Pizzi et al. (2005) examining the economic cost of chronic pain on six large corporations within the United States of America estimated the total impact of chronic pain for each employer to be \$2.1 million per employer per year. Estimates within the literature place the overall financial societal costs at \$40 - \$70 billion annually within the United States of America (Buckle, 1999; Kerssens et al., 2002; W. A. Katz), and billions of euros per year in a number of less populous European countries (Sleed, Eccleston, Beecham, & Knapp, 2005; Maniadakis & Gray, 2000; Kumpusalo et al., 2000). Clearly, a voluminous body of research exists to support the idea that in addition to causing individual suffering at an intimately human level, chronic pain also has a deep-rooted impact on corporate and national productivity, and overall societal economic health.

Purpose of the Study

In the earliest stages of this study, I conducted a broad-spectrum literature search of the topic of chronic pain to better familiarize myself with this field, and to explore what was being investigated within both the psychological and physical realms of medicine. What emerged from this initial literature review was the finding that extensive research work was being done in the areas of the neurobiology of pain, coping strategies for chronic pain, pharmaceutical management of chronic pain, as well as the epidemiology and etiology of pain. However, not much attention was being given to the actual *lived experience* of individuals suffering from chronic pain, and a notable void existed in terms of the issue of how one's pain experience might be affected by the existence or absence of an accepted diagnosis. A subsequent highly focused literature search over multiple research databases did not identify a single published study that specifically

focused on the lived experience of individuals who have *undiagnosed* chronic pain. At that point in my explorative process I found myself wondering, “If I am beginning to feel frustrated and a sense of hopelessness for individuals living with undiagnosed chronic pain, how must *they* feel when their internal resources are exhausted, and all of their illness questions go unanswered?” At that point I made the conscious decision to channel my frustration and restless energy into a drive to provide a voice to this segment of the pain population that had, until now, remained silent within the research world. The purpose of this study, therefore, was to explore, describe, and understand the experience of these individuals, asking the fundamental question: “What is the experience of living with undiagnosed chronic pain?”

Significance of the Study

This study is expected to illuminate the experiences of a poorly understood segment of the larger pain population. A richer appreciation for the unique challenges of this population may pave the way to a better comprehension of a wide range of related issues such as patient motivation, compliance with prescribed treatment, and altered patterns of social engagement. Improved clinical conceptualizations may result for practitioners working within the field of chronic pain, subsequently aiding them in their choice of interventions and treatment plan formation. From a more pragmatic perspective, an enhanced level of insight globally also has the potential to facilitate improved insurance disability claims management, adding efficacy and fairness to the decision-making processes of third-party insurers, which can open up opportunities for claimants with undiagnosed chronic pain to access more appropriate clinical interventions. My past experience has been that the longer a client remains in the ‘system’ without a clearly

defined diagnosis attached to their disability claim, the less open members of the insurance industry become with respect to funding assessments or treatments, or to even providing cost-of-living funding for the claimant. Ultimately, it is my sincere hope that by giving voice to the deeply personal experiences and challenges of individuals living with undiagnosed chronic pain, the process of information sharing will foster greater levels of sensitivity, empathy, and *understanding*, which will enable health care practitioners (both physical and psychological), and society as a whole, to offer a better level of care and support to these individuals so greatly in need.

CHAPTER II

Review of the Literature

Research in the broad field of chronic pain is extensive and multidisciplinary, which reflects the very complex and multifaceted nature of pain itself. This selected literature review is focused on studies that are deemed to have relevance for this particular study, providing background information regarding current conceptual understanding and research within the field of chronic pain, as well as reviewing studies that embrace a phenomenological approach in their exploration of the lived experience of chronic pain. The literature review is organized into four sections. Part 1 provides a general overview of the chronic pain literature pool, including history, defining features, current trends in research, and the link between chronic pain and clinical counselling. Parts 2 and 3 examine the etiology of chronic pain from biological and psychological perspectives. Part 4 focuses on the ways in which chronic pain touches the life of the individual living the pain experience, including studies that have adopted a phenomenological approach to this subject matter. In reviewing these latter articles, the many challenges and burdens associated with living with chronic pain are brought to light, which serves to further reinforce the purposes and significance of this study as outlined in the prior chapter.

Part 1: Chronic Pain Overview

Historical Perspective

Chronic pain has been an enigmatic problem for humans since earliest recorded history. Gatchel and Turk (1999) note that the ancient Greeks identified the role that psychological factors play in understanding pain, with Aristotle conceptualizing pain as an emotion similar to depression and anxiety. These authors note that over the ensuing

centuries the emphasis placed on psychological factors in understanding pain has ebbed and flowed. The 18th century marked a transition point when evolving developments and discoveries within the field of sensory physiology had the effect of relegating psychological factors to secondary status, whereby disturbing cognitions or emotions were marginalized and viewed as mere reactions to nociceptive (i.e., painful) sensory stimulation. Wall (1999) notes that by the 18th century most causes for ill health that were not deemed to be purely physiological, including psychological as well as mystical causes, were largely dismissed in favour of diagnostic *explanations* defined by the new ‘scientific’ terms of the time. In that era, pathological sciences began to isolate diseased tissue and were starting to explain how the physiology of the body could enter into disordered states. As bacteria, viruses, and chemical anomalies were discovered, the entire thrust of medicine, including the understanding of pain, became pathology-driven. As Gatchel and Turk note, this biomedical stance dominated the literature until the mid-1960’s, when a surge of empirical research moved psychological factors from the periphery into a more central position within the study of chronic pain. The evolution of pain conceptualization that began in the 1960’s was quite robust and continues to be reflected in our present day approach to research and treatment, characterized by an ongoing movement towards an *integrated* focus, encompassing the psychological, biomedical, and spiritual elements of the chronic pain experience.

Although our understanding of chronic pain has come a long way over the centuries, there is little doubt that many mysteries of the pain experience have yet to be solved. I have observed, in my work as a physiotherapist, that the degree of emphasis placed on psychological-spiritual as opposed to biological factors in chronic pain varies widely

amongst both researchers and health care practitioners. Roy (1992) voices a similar perspective when he points out that despite significant progress in our understanding of the chronic pain phenomenon from various scientific points of view, and the emergence of a wealth of diverse and innovative treatment approaches, the basic puzzle that is the pain phenomenon remains only partly understood. Unfortunately, the recent explosion of inventions within the field of biomedical technology over the past 30 years has produced pockets of physicians who are so impressed with recent advances in pathological research, and the power of modern day diagnostic instrumentation, that they simply find themselves unable to accept the existence of ‘unexplained’ chronic pain. There seems to be a mindset amongst certain segments of the medical community that refuses to acknowledge the notion that pain can exist in an individual’s perception without an actual externally identifiable biological pathology to ‘explain’ it, and thus no specific diagnostic label to apply to it. Wall (1999) provides context for this dilemma when he states:

Some doctors take the hopeful approach that while the pathology has not yet been discovered, future work will reveal the basic cause. Even Sigmund Freud wrote that neurosis would eventually turn out to be a biochemical disorder but, in the meantime, he proposed that psychoanalysis was a productive approach. Other types of doctors, deeply frustrated by their inability to cope with diseases without pathology, turn on the patient and claim that the pains are self-inflicted by a faulty way of thinking. (p. 96)

Clearly, the mystery of undiagnosed chronic pain remains as relevant now as at any point in history, yet our actual *understanding* of this phenomenon remains ever elusive.

Theories and conceptualizations will undoubtedly continue to evolve, as it remains an area of focus for the biomedical, spiritual, and psychological arts and sciences.

Current Research in Chronic Pain

Current trends in research have shifted towards an exploration of chronic pain from a more holistic vantage point than was more traditionally seen in the literature. The essence of this less constrained approach is expressed by Bullington, Nordemar, R., Nordemar, K., and Sjostrom-Flanagan (2003) as follows:

Pain is a multidimensional phenomenon lying at the intersection between biology and culture. ... Our modern understanding of pain has moved forward from a simple one, viewing pain as a one-dimensional, anatomical, physiological body process, towards the recognition of pain as a complex biological, psychological, social, and existential phenomenon” (p. 325).

My belief is that this recognition of chronic pain as an inherently complex, highly individualized, socioculturally influenced, and abstract personal experience has been the driving force behind the recent trend towards selecting a *qualitative* research approach when investigating the chronic pain phenomenon. Indeed, a qualitative approach honours and attempts to capture the complexity and richness of the pain participants’ lived experiences, offering an approach that is relatively unconstrained as compared to that of quantitative research.

Chronic Pain and Clinical Counselling

Aside from pain itself, clients with chronic pain often present with a myriad of comorbid clinical issues that have significant overlap with other forms of chronic illness and disability. These may include, but are not limited to, the following: depression,

anxiety, substance abuse, sleep disruption, financial concerns, catastrophizing, self-blame attributions, learned helplessness, externalized locus of control, low self-efficacy, low self-esteem, challenging emotions such as anger, frustration, resentment, confusion, and ambivalence, fear-avoidance of physical activity, fear of future, health anxiety, as well as grief and loss issues relating to change of identity, loss of significant relationships, loss of work and associated vocational identity, and loss of former quality of life (Wall, 1999; Roy, 1992; Roy, 2002; Gatchel & Turk, 1999; Turk & Gatchel, 2002; Turk & Okifuji, 2002; Hadjistavropoulos, Asmundson, LaChapelle, & Quine, 2002; Pontefract & deLaplante, 2000; Simon & Folen, 2001; Verma & Gallagher, 2000; Grant & Haverkamp, 1995; Currie, Wilson, Pontefract, & deLaplante, 2000; Sullivan et al., 2001; Dysvik, Natvig, Eikeland & Lindstrom, 2005). The role of counselling in the healing process becomes even more complex when one considers that childhood abuse and neglect have been found to be associated with chronic pain later in life (Roy, 1992). The counsellor's role becomes further complexified when one considers the need for a counsellor to remain cognizant of the client's culturally influenced worldview and family of origin experiences, as these serve to shape their perception of, and reaction to, the experience of chronic pain and related disability.

In a clinical setting, the counsellor working with chronic pain clients will often adopt a clinical stance focused on facilitating the client to cope more effectively with their pain experience. This may entail a combination of psychoeducation and providing a safe therapeutic space for the client to explore their challenging emotions and cognitions. The establishment of a trusting therapeutic alliance between counsellor and client is an essential building block in the provision of such a space. It has been my experience that

cognitive behavioural therapy is the dominant treatment approach when working with chronic pain clients, particularly when treatment is externally funded by a third party payer. Within treatment the counsellor may be working independently with the client, or as part of a larger multidisciplinary team, which may include any or all of the following health care professionals: a physician, anaesthesiologist, psychiatrist, psychologist, counsellor, physiotherapist, occupational therapist, massage therapist, kinesiologist, or nurse. In addition to one-to-one counselling sessions that are often focused on emotional interventions such as anxiety defusion or depression management (and crisis intervention as needed), clients are often also exposed to a range of individual or group interventions such as: supervised exercise, goal setting, medication management, biofeedback, hypnosis, cognitive reframing, sleep hygiene psychoeducation, reconceptualization of their pain problem, as well as learning a range of skills such as self-pacing, distraction strategies, and various relaxation strategies, including progressive muscle relaxation, diaphragmatic breathing, autogenic relaxation, visualization, guided imagery, and meditation (Gatchel & Turk, 1999; Turk & Gatchel, 2002; Hadjistavropoulos et al., 2002; Simon & Folen, 2001; Grant & Haverkamp, 1995; Dysvik et al., 2005; Currie et al., 2000).

Part 2: Biological Etiology of Pain

Common Biological Pain Conditions

A wide range of biomedical conditions exist that are commonly associated with chronic pain (i.e., pain of long duration with no clear end-point that has the potential to significantly affect one's level of functioning). The most commonly cited diagnostic examples include: lower back pain (of various origins such as discogenic or myofascial

pain), arthritic joint conditions, headache disorders, whiplash-associated disorders, peripheral neuropathies, chronic bursitis, chronic tendonitis, cancer, systemic diseases, immunosuppressive diseases, assorted organ pathologies, assorted gastrointestinal pain syndromes, neuralgia, phantom limb pain, fibromyalgia, and myofascial pain syndromes (Katz, 2002; Roy, 1992; Gatchel & Turk, 1999; Turk & Gatchel, 2002).

Types of Pain

Loeser and Melzack (1999) provide us with a practical framework for organizing the multifaceted concept of pain. Their framework is based on a system classifying pain into three general categories. The first type is 'transient' pain, which is elicited by activation of the pain receptors in body tissues in the absence of any actual substantial tissue damage. This type of pain subsides once the stimulus is removed, such as one's skin becoming pinched without actually breaking the skin. This type of pain is ubiquitous in everyday life and is rarely a reason to seek medical attention.

A second type of pain is termed 'acute', which is, "elicited by substantial injury of body tissues, and activation of pain receptors at the site of local tissue damage" (Loeser & Melzack, 1999, p. 1608). Individuals with acute pain often seek medical attention because although reparative healing can typically occur in the absence of such attention, medical interventions can be useful in reducing pain and to speed up the healing process. A commonplace example to illustrate this concept is that of a deep laceration to one's finger that would very likely heal on its own, however, the rate of wound healing and pain resolution could be expected to be more rapid if sutures were applied by a physician. A critical element of this 'acute' categorization is that the pain can be expected to stop long before the actual tissue healing process has been fully completed.

Thus, in the prior example the finger may be left with a scar that slowly changes in its appearance (thus indicating ongoing tissue remodelling) for several months, even though the pain itself fully resolved within a few days or weeks. By way of contrast, when the pain persists for many months or years, it is not usually classified as 'acute'. However, it should be noted that exceptions do occur in the case of certain disease states, such as malignancy and metastasis, wherein the invasion of body tissues does have the potential to produce continuous pain over long durations, as new tissue damage is perpetuated on an ongoing basis. Essentially, in these less common scenarios the disease process remains aggressively active over time, and as such, the pain remains continuously acute.

The third type of pain is termed 'chronic', and may be perpetuated by factors beyond the original cause of the pain. Loeser and Melzack (1999) note that chronic pain is often unrelenting, with an intensity of pain that is out of proportion to the nature of the original injury or tissue damage. Although the majority of chronic pain clients do access health care resources, Loeser and Melzack indicate that these clients often exhibit a unique response to treatment. More specifically, normally effective treatment interventions only seem to offer transient pain relief, if at all, for these individuals. Moreover, an additional earmark of chronic pain is that the pain will almost always return when the treatment intervention stops. With chronic pain it is hypothesized that the central and peripheral nervous systems may be negatively altered by the original injury in such a way as to be unable to restore themselves to their original pre-injury state. Thus Loeser and Melzack state that, "it is not the duration of pain that distinguishes acute from chronic pain but, more importantly, the inability of the body to restore its physiological functions to normal homeostatic levels" (p. 1609). This concept is further elucidated in the following

discussion of the neurobiology of pain, particularly regarding the process of neurological pain ‘sensitization’.

Neurobiology of Pain

As a cursory overview one can envision pain of two sources: pain originating from target tissues, and pain associated with a central nervous system (CNS) that has been ‘sensitized’ to pain. The first scenario is the easiest to understand, and fortunately is the most common, being one that virtually any human can relate to. It is generally the result of mechanical forces and physiological processes that stimulate the firing of pain receptors. Such neurological pain signals are generally associated with the occurrence of injury, inflammation, and repair. This pain typically has a clear stimulus/response relationship, such that stimulus in the form of mechanical *loading* via pressure, stretching, tearing, or contracting of the target tissue will generally result in pain from neuronal firing; whereas mechanical *unloading* via the removal of direct pressure, release of tissue tension, or relaxation of contractile target tissues will generally result in pain relief. Typically, pain will increase or decrease proportional to the level of mechanical loading, tissue tension, or contractile force that is applied through the target tissue (Gifford & Butler, 1998; Wall, 1999). This pain response in the local target tissues is referred to as ‘primary hyperalgesia’, and one may expect this manner of pain response with both the ‘transient’ and ‘acute’ types of pain as defined previously section of this chapter.

Clinically, the potential for confusion begins to present itself when a patient’s localized pain or tenderness seems to spread after injury, and on examination appears to involve tissues that were not originally damaged. This is one potential way in which a

medical practitioner may begin to view a patient's pain as being a 'medical mystery' or 'unexplainable' (and thus, undiagnosable). When this scenario is noted on examination it is referred to as 'secondary hyperalgesia' (Gifford & Butler, 1998). This form of pain response represents one possible clinical presentation associated with 'chronic' pain, as defined in the previously in this chapter. A clinical rationale for this phenomenon is that it is believed to be due in part to a local seeping of pain-producing chemical into adjacent tissues. It is important to grasp the underlying concept that secondary hyperalgesia is in essence an abnormal chemical sensitivity of tissues that are fundamentally quite normal from a structural sense. This is a critical point, as this secondary hyperalgesic presentation can lead to increased likelihood of a medical practitioner making false-positive diagnostic interpretations of musculoskeletal examination results, only to later remove or revise their original diagnoses when they prove to be unfounded, or unhelpful in treatment planning. It follows, then, that this presence of pain in non-injured tissues becomes an important concept when one considers how the clinical presentation of certain patients may be quite confusing to health care practitioners, thus leaving these patients vulnerable to potential misdiagnosis, or even *non*-diagnosis, as the symptoms are simply relegated to the category of '*unexplained*' undiagnosable pain.

CNS Sensitization

The original 'gate control theory of pain' developed by Melzack and Wall (1965) emphasized the neurobiological mechanisms within the CNS that control the *perception* of noxious stimuli. Their theory incorporated a number of groundbreaking assertions, including the conceptualization that upward travelling afferent pain messages can become modulated by downward neurological outputs from the brain. However,

according to Loeser and Melzack (1999), “this theory did not incorporate *long-term* changes in the central nervous system to the noxious input and to other external factors that impinge upon the individual” (p. 1607). Research that was spawned by these early studies has gone on to offer evidence explaining the physiological means by which tissues that were not directly involved in physical trauma may actually present with pain. The term ‘central sensitization’ is applied when altered CNS circuitry and processing produce heightened pain sensitivity in the local area of injury, as well as the perception of pain in non-injured body regions (Gifford & Butler, 1998; Wall, 1999; Chapman & Gavrin, 1999; Backonja, 1997; Yunus, 2004; Ren & Dubner, 2002). It could be argued that the enormous plasticity of the CNS circuitry in this scenario actually has a maladaptive effect, as regions of the spinal cord become more efficient at transmitting pain messages. . This has the effect of making the CNS ‘sensitized’ for transmission of pain messages, allowing pain signals from the peripheral nervous systems to be transmitted to the brain for recognition, even at levels of neuronal stimulation so low that they would normally be perceptually ‘filtered out’ in a non-sensitized CNS. Therefore, even relatively weak neuronal pain signals may be perceived as ‘pain’ by the brain. Moreover, Gifford and Butler indicate that it may be possible that pain states actually become ‘imprinted’ within the CNS in ways similar to the process of memory acquisition. If this is tenable, the rather daunting clinical conclusion is that once a pain signal becomes neurologically ‘imprinted’ or ‘hard-wired’ in the CNS, it may be as hard to voluntarily remove as many of our memories.

Adding to the impact of these effects is the notion of neurological ‘cross-talk’ between neighbouring nerve pathways. As an illustrative example, an individual who

sustained an original wrist injury for which the phenomenon of CNS sensitization developed, may find that simple movements of their upper extremity such as reaching for a glass of water may produce not only wrist joint pain (i.e., the site of original injury), but also pain in their adjacent elbow or shoulder joints. In this hypothetical scenario, normal movement-receptor signals from the elbow and shoulder joints enter into ‘cross-talk’ with sensitized pain pathways from the wrist whose firing thresholds are lowered. Thus, movement of the uninjured elbow and shoulder could cause the individual to perceive a worsening of their original wrist pain (even if the wrist remains motionless), and hypothetically the individual could also begin to perceive pain in adjacent joints (e.g., elbow joint) that had nothing to do with their original mechanism of injury (Gifford & Butler, Wall, Backonja, Yunus). Once again, it is easy to imagine how these associations between pain in the injured and non-injured body areas may be highly confusing to health care practitioners, potentially paving the way to clinical misdiagnosis, non-diagnosis, or relegation to the ambiguous category of ‘*unexplained*’ pain.

A final point to consider regarding the phenomenon of CNS ‘sensitization’ as it relates to chronic pain is the concept that a diverse range of factors that impact our central nervous system may also have a vicarious impact on one’s perceptions of pain. If one envisions a neural meshwork capable of intricate intercommunication amongst the various regions of the brain and spinal cord, then it becomes quite easy to fathom how innately human processes such as accessing memories or experiencing intense emotions might modulate the pain experience in an upward or downward fashion. Loeser and Melzack (1999) give voice to this when they state, “it is likely that stress, environmental,

and affective factors may be superimposed on the original damaged tissue and contribute to the intensity and persistence of the pain” (p. 1609). Herein lies one of the ominous truths central to chronic pain, as expressed by Chapman & Gavrin (1999):

Chronic pain promotes an extended and destructive stress response that involves neuroendocrine dysregulation, fatigue, dysphoria, myalgia, and impaired mental and physical performance. Such states can lead to a vicious cycle of stress and disability; indeed uncontrollable pain is in itself a stressor. Pain and related stressors can make it impossible for an individual to sustain productive work, normal family life, and supportive social interaction. (p.2236)

It is this intimate interplay of CNS maladaptive changes, far-reaching lifestyle and identity transitions, as well as feedback loops interweaving emotions, cognitions, and pain perceptions that provide clear rationale for the need for multidisciplinary care incorporating medical, psychological, and social interventions to provide adequate support for the chronic pain client.

Part 3: Psychological Etiology of Pain

Overview

The assessment and treatment of chronic pain has been noted throughout the literature to be enormously complex, and perhaps more than any other area in medicine, worthy of incorporating a psychological component. Poppe, Devulder, Mariman, and Mortier (2003) express that, “the International Association for the Study of Pain (IASP) provides more and more scientific evidence that chronic pain is a biopsychosocial event, and that its diagnosis and treatment should be considered in a multidisciplinary frame” (p. 92). Expanding upon the previous commentary addressing the biological phenomena

of CNS sensitization, as well as the expressed interweave of psychosocial influences on pain perception, one must also remain cognizant of the potential for pain experiences to be predominately or entirely related to psychological factors. From this perspective, ‘somatoform disorders’ are characterized by the repeated presentation of physical symptoms, together with persistent requests for medical investigations, in spite of repeated negative findings and reassurances by physicians that the severity of symptoms cannot be explained by the extent of the physical pathology (Dolin & Stephens, 1998; Sharpe, 1997). Included in this rubric are: ‘somatisation’ (i.e., multiple recurrent and frequently changing symptoms), ‘hypochondriacal disorders’ (i.e., persistent preoccupation with the possibility of serious disease), and ‘somatoform pain disorder’ (i.e., pain in the context of serious emotional conflict or psychosocial problems).

Many of the counselling interventions outlined earlier in this chapter are equally applicable when working with clients who had an original physical injury that progressed to chronic pain, as they are to clients with a purely psychological etiology of pain. A rationale exists for using certain elements of these strategies to help clients with a purely psychological etiology to deal with a range of issues such as significantly distorted cognitions, emotional dysregulation, low distress tolerance, and comorbid cognitive-emotional states such as depression and anxiety. When considering the implementation of such interventions, Dolin and Stephens point out that in some cases, the inclusion of family members in therapy may be of great benefit, however, they also caution that psychological professionals need to remain aware of research findings that childhood experiences of deprivation, abuse, and excessive or unusual illness models may lead to inappropriate illness behaviour later in life. This does not automatically preclude one

from including family members in treatment, it merely suggests that one should be very purposeful regarding the selection of clients for which to extend such an offer, and remain mindful of the manner by which family systems treatment is administered.

Dolin and Stephens (1998) suggest psychological practitioners should also keep in mind that some clinical presentations, such as 'somatisation disorder', are generally recognized as having a relatively poor prognosis for responding to treatment. This prognosis is associated with elements inherent in the disorder itself, such as the clinical feature that these clients are often unwilling to entertain the possibility that there may in fact be a psychological dimension to their illness, and may therefore resist the clinician's attempts to have them become actively engaged in therapy. Maintaining a realistic sense of how much one can actually help certain clients can be crucial for a practitioner's treatment planning, as well as for their own professional self-care. Although early treatment termination cannot be regarded as a successful outcome, Dolin and Stephens offer a valuable perspective when they point out that for such psychiatric clients:

Defining and recognizing their condition can be helpful for medical staff who are thus able to withdraw, without feeling they have failed. The frustrating and fruitless rounds of consultation, referral, and investigation may be ended, and the task of containment in primary care identified as a new goal. (p. 318)

By choosing to view clients with certain psychological pain etiologies through such a lens, better clinical decisions can be made regarding when treatment should be pursued versus discontinued, thus saving unnecessary expenditures of health care dollars and resources, as well as avoiding unnecessary frustration and potential feelings of failure on behalf of both the client and the treating therapist.

Part 4: Living With Chronic Pain

Movement Towards Phenomenology

When initially reviewing the history of chronic pain research in the literature, I found myself struck by the relatively recent insurgence of qualitative studies in a field that was formerly dominated by quantitative paradigms. Doubtless, the earlier years of research mirrored the Cartesian dualism evident in the traditional medical model, wherein a patient's general expression of pain would likely be immediately followed by an inquiry as to whether they are referring to physical pain or mental pain (Wall, 1999). This history of dualism combined with a philosophy of reductionism shaped the medical and research worlds such that measurable *objective* information was perceived as having far greater value than *subjective* information. However, over recent decades an acknowledgment has been made regarding what is lost when one maintains a bias wherein quantifiable information is viewed as the gold standard, with little stock placed in non-quantified information, even if it taps directly into the human experience. Baron (1985) identified this deficit within medicine in his recommendation:

Our medical world view is rooted in an anatomicopathologic view of disease that precludes a rigorous understanding of the experience of illness. What we need to remedy this problem is not just the admonition to remember that our patients are people, but a radical restructuring of what we take disease to be. (p. 606)

A qualitative approach, most notably a phenomenological theoretical framework, offers the researcher with an opportunity to fully explore participants' *lived experiences* in all their richness and detail. The endeavour to remain curious and explorative while participants share the innermost aspects of their experience has enabled more recent

research to access a level of depth in the study of chronic pain that could never be approached within the rigid confines of quantitative research. This has generated a new and complex layering of themes related to the personal experience of chronic pain, to a degree such that this literature review can represent only a small portion of the burgeoning pool of phenomenological studies within this field (Osborn & Smith, 2006; Steen & Haugli, 2000; Thomas, 2000; Walker, Sofaer, & Holloway, 2006; Hellstrom, 2001; Clarke & Iphofen, 2006; Paulson, Danielson, Norberg, & Paulson, 1999; Osborn & Smith, 1998; Ribau & Marc-Vergnes, 2004; Vickers, 2000; Higgins, Madjar, & Walton, 2004; Raheim & Haland, 2006; Richardson, 2005; Walker, Holloway, & Sofaer, 1999; Kugelmann, 1999; Richardson, 2005).

Literature Touching Upon the Experience of Living with Undiagnosed Chronic Pain

As compared to the larger phenomenological literature pool, only a small fraction of these studies tap into the experiential aspect of living with chronic pain when diagnostic uncertainty exists. In fact, I was unable to identify any studies where the element of diagnostic uncertainty was an actual criterion of inclusion, and thus was a focus of the study. However, the issue of undiagnosed chronic pain did come to light by happenstance within several broader focused studies that were exploring the lived experience of chronic pain in a more global sense. For example, Steen and Haugli (2000) purport that within a phenomenological frame of understanding, the body may be viewed as a subject and carrier of meaning, and therefore generalized chronic musculoskeletal pain can be interpreted as a rational reaction to the totality of a person's life situation. They further note that some health care professions continue to be trained according to the aforementioned Cartesian split between mind and body, and as such, patients with

generalized chronic musculoskeletal pain of *unclear* origin may get little or no help from traditional biomedical treatments. They propose a change in power structures from the current model wherein the health care professional is promoted as the all-knowing ‘expert’, to one in which a more equitable relationship exists. In this revamped model the individual experiencing chronic pain is recognized as an expert on her/himself, and the health professional is an expert in strategies to help the patient to search for their own answers. These answers are sought out via the patient having an internal dialogue with their own body, as well as an external dialogue with the health care professional. In their phenomenological exploration of this topic Steen and Haugli bring to light an observation that seems obvious, yet is so often overlooked: the meaning of the pain is not necessarily immediately available for the patient, and therefore, of course, is not imminently available for the health care professional either.

Thomas (2000) completed a phenomenological study with 13 participants experiencing non-malignant chronic pain that gave voice to the frustrations of both the patient and the medical practitioner, as the medical system is exhaustively accessed with minimal positive result. This study by Thomas also noted that the many burdens of living with chronic pain are even weightier when physical dysfunction or deformation is not outwardly visible. In this regard it was noted that, “Despite the profound changes in their bodies, study participants ruefully acknowledged that the chronic pain was ... invisible, a ‘secret disorder’ with no outward manifestation” (p. 691). Participants expressed an inner sense of turmoil, some even longing for some manner of externally visible manifestation of disability that could provide greater societal legitimacy. My sense is

that individuals with chronic pain who have not been given a clear diagnostic label would share this same strong need for judgments of legitimacy by others.

The sense of suffering associated with chronic pain conditions that are invisible and ‘contested’ (e.g., by friends, family members, the medical establishment, and the insurance industry) was also identified in a phenomenological study by Richardson (2005). Participants in her study provided accounts of a range of disturbed emotions when facing what she terms ‘delegitimation’ of their condition, characterized by threats to their identities as credible, honest, hard working members of society. It should be noted that feeling marginalized, socially isolated, helpless, and in a constant struggle for legitimization are themes that expand beyond the boundaries of chronic pain, into the broader literature pool of chronic illness (Cohn, 1999; Ware, 1999; Hyden & Sachs, 1998; Malterud, 2000).

These themes of struggles with the invisibility of chronic pain, and the longing for legitimization were echoed in a hermeneutic-phenomenological study completed by Kugelmann (1999) that explored the experiences of 14 chronic pain patients attending an in-patient pain management program of a rehabilitation hospital. Participants in this study commented that the ambiguous visibility of pain, and the associated potential for disbelief by others, often has important medical, legal, and economic consequences. This study was unique in that it noted that pain can only ‘show itself’ through behaviour and expression, so in that sense it is a matter of self-display. “In this polarity pain can be shown to others only by showing oneself. Visible pain renders the self vulnerable, exposed in his or her weakness” (Kuggelmann, p. 1669).

A phenomenological study completed by Walker et al. (1999) that explored the experiences of 20 chronic back pain sufferers attending two pain clinics identified themes that have overlap with the aforementioned studies, as well as themes that would intuitively seem to be relevant for individuals with undiagnosed chronic pain. This study by Walker et al. focused on the lived experience of chronic pain as it relates to negotiating one's way through various societal 'systems', including medical, social security and legal systems. I found this study to be particularly impactful, as it gave voice to a number of challenges and sufferings that accurately mirror what I have personally observed when working with chronic pain clients. Over time it seems these individuals' lives become fully enmeshed with these bureaucratic networks of 'support' systems to the point where they are so deeply immersed in such systems that their experience of chronic pain cannot be separated from their experience of living within these systems. Most critically, this study captured a powerful sense of the fascinating irony that the very systems that were designed to treat or 'support' those who are ill or disabled are often implemented in such a manner that they effectively render those same individuals powerless, helpless, and angry.

CHAPTER III

Research Methods

Qualitative Philosophical Foundation

A 'paradigm' is commonly conceptualized a way of thinking about and making sense of the complexities of the world. Creswell (1998) notes that all researchers approach their area of study, either consciously or unconsciously, with a certain paradigm or worldview that encompasses a fundamental set of beliefs or philosophical assumptions that guide their process of inquiry. These assumptions are related to the one's beliefs about the nature of reality or knowledge (ontological assumption), the relationship between the researcher and knowledge (epistemological assumption), and the process by which the researcher will go about finding this knowledge (methodological assumption) in order to answer the research question under consideration. Given that these assumptions provide the lens through which the researcher's entire conceptualization of the research question and associated study is viewed, it is essential that there be a strong thread of *congruence* interwoven throughout these assumptions at each stage of the research process. What begins as a fundamental paradigmatic worldview and initial research question will ultimately translate into the researcher's final methodological decisions and research design.

Creswell (1998) asserts that throughout each stage of the research design process the researcher must return to the overarching question: 'What is the role of values in this study?' (axiological assumption), as this has implications for every aspect of the research effort. He also asserts that at the final stages of this process the researcher must ask: 'What is the language of this research?' (rhetorical assumption), as this will inform the

literary structure and style for the final write up of the study. Again, establishing a sense of congruency is key, as it is essential that the system of values and language of a study remain true to the nature of the research question, and to the foundational paradigm from which the researcher is conceptualizing and approaching the study.

When considering the essential elements of sound research practice, one element that cannot be overstated relates to the notion of the researcher remaining ever aware of the aforementioned philosophical assumptions, and thus remaining *purposeful* throughout the complex decision-making processes associated with designing a study. Patton (2002) speaks to this when he observes that paradigms are deeply embedded in the socialization process for each individual, and they inform each individual's perspective as to what is important, legitimate, and reasonable. Accordingly, paradigms also have a normative function, guiding one's interpretations, decisions, and actions. However, this particular aspect of paradigms can be construed as both a potential strength and weakness. The strength exists in that this normative element makes action relatively easy to instigate, yet a weakness exists in that the very reason for action is hidden in the unquestioned assumptions of the paradigm. Thus, when applying this to the world of research one can view strict allegiance to a particular paradigm as having an inherent element of risk, as paradigmatic 'blindness' have the potential to limit methodological choices, perceptual flexibility, and research creativity. Indeed, staying within one's 'comfort zone' via strict adherence to a particular methodological paradigm has the potential to lock researchers into unconscious patterns of perception and decision-making. Moreover, Patton reminds us that the 'unquestioning' nature of these patterns may disguise the biased, predetermined nature of their methodological

decisions. The obvious weaknesses inherent in blindly clinging to a paradigm based simply upon past tradition serves to reinforce the earlier assertion that the researcher must enter into the process of research design with a clear sense of purpose and commitment to finding the best means by which to answer the research question. At the very inception of the research question the researcher should be capable of articulating what paradigm they are operating from, as well as how this paradigm informs the theoretical framework they will call upon, and why that particular theoretical perspective is best suited to address the research question. This sense of pragmatism suggests to Patton that rather than maintaining a fixed stance that one approach is inherently superior to another, a more enlightened perspective favours the concept of ‘methodological appropriateness’ as the primary criterion for judging methodological quality, recognizing that different methods are appropriate for different situations. Simply put, ‘situational responsiveness’ entails designing a study that is most appropriate for a specific inquiry situation or interest.

If one takes a step back to consider a historical perspective, a salient point becomes evident as one realizes that philosophers of science have been engaged in a long-standing and vigorous ontological and epistemological debate about the very nature of ‘reality’ and knowledge. These philosophical debates have subsequently found their way into research and evaluation in the form of arguments over the goals of empirical studies and differences of opinion about what constitutes ‘good’ research. Patton (2002) notes that in its purest form this debate has centred upon the relative value of two different and competing inquiry paradigms: (1) using quantitative ‘experimental’ methods to generate and test hypothetical-deductive generalizations, versus, (2) using qualitative and

‘naturalistic’ approaches to inductively and holistically understand human experience and constructed meanings. Reflecting upon the historical roots of each research tradition can provide helpful context to foster a better understanding of the tension that has developed between the respective quantitative and qualitative camps.

‘Positivism’ as a quantitative research paradigm within the social sciences can trace its origin to theorists of the 19th and early 20th centuries who were heavily influenced by the traditional ‘experimental’ (positivist) physical sciences such as physics and chemistry that were widely viewed as the crowning achievements of Western civilization. Adherents to this positivistic paradigm espoused a belief system that in order for the field of social science to be perceived as legitimate it would need to be modeled upon the basic tenets of the physical sciences. In their view this would entail only recognizing objective (measurable) findings that provide causal explanations for observable human behaviour (Denzin & Lincoln, 2005). Essentially, the positivist researcher would seek the ‘facts’ or ‘causes’ of social phenomena apart from the subjective states of individuals. Taylor and Bogdan (as cited in Patton, 2002) note that positivistic theorists would encourage the social scientists of the time to view social facts, or social phenomena, as ‘things’ that exercise an external influence on people. The philosophical assumptions and underpinnings inherent within this positivistic paradigm mirrored those of the physical sciences, beginning with a fundamental assumption that there exists one correct ‘truth’ or reality that operates according to natural laws (realist ontology). Proponents asserted that just as atoms and molecules were subject to predictable laws and axioms, so too were patterns of individual behaviours and social interactions (Creswell, 2005). Denzin and Lincoln note that given this fundamental ontological

assumption, the positivistic researcher claimed to adopt a position of absolute objectivity in order to remain unbiased in the comprehension of that reality (objectivist epistemology). Accordingly, proponents of this approach also claimed that their work was done from within a value-free framework (axiological assumption). Given these ontological, epistemological, and axiological assumptions, it was purported that this singular reality could be quantifiably measured, controlled, and predicted by calling upon the process of deductive logic (experimental methodology). In practice, it was assumed that this measurable, singular 'truth' could fully transcend subjective opinion and personal bias.

The 20th century began with one major (quantitative) research paradigm within the field of social science, and ended with two major (quantitative and qualitative) research paradigms. This is not a case of one approach replacing the other; rather, it reflects the addition of qualitative inquiry to the aforementioned traditional quantitative approach (Creswell, 2005). The development of this new qualitative paradigm was spurred on by a growing awareness that a sole reliance on the deeply entrenched quantitative research paradigm was overly restrictive within the field of social science. Resistance grew as it became recognized that the quantitative view of social phenomena as a 'thing' that exercises an external influence on people, left little or no room for exploring the actual 'process' itself associated with social functioning. Critics posed basic philosophical challenges against the claims that quantitative researchers were able to remain purely objective, unbiased, and value-free, as opponents viewed such claims as simply unrealistic, particularly within the realm of social science inquiry. Perhaps most importantly within the field of social science, it was noted that a quantitative positivistic

paradigm was unable to capture the elusive ‘lived experiences’ of individuals, and was unable to access the viewpoints and personal *meanings* that individuals attach to these experiences. This discourse prompted growing support amongst social researchers for the promotion of a new paradigm that was a better fit for the unique complexities and inherent ‘humanness’ of the social sciences. Firstly, in support of a new paradigm of ‘best fit’, Krefling (1991) notes that within the qualitative framework there is a belief that behaviour and personal meanings are influenced by the physical, sociocultural, and psychological environment of the individual. This is the very basis for ‘naturalistic’ inquiry. Secondly, Krefling notes that there is an inherent assumption that behaviour and *experience* go beyond what is available for direct observation by the researcher, and therefore the goal should be for the researcher to access the subjective meanings and perceptions of each individual. On this note, Denzin and Lincoln (2005) offer the observation that the very word ‘qualitative’ implies an emphasis on conceptualizations, processes, and meanings that are not ‘experimentally’ investigated or measured (if measured at all) in terms of quantity, amount, intensity, or frequency.

Although qualitative research is difficult to narrowly define given its pluralistic nature (i.e., it has no one particular theoretical framework that is distinctly its own), Creswell (1998) notes that a ‘naturalistic’ approach does offer a basic set of ontological and epistemological beliefs, and associated methodology, that contrast sharply with the traditional positivism-derived quantitative paradigm. At the most basic ontological level, within a qualitative paradigm (as it is currently most commonly conceptualized) there is an acceptance of ‘reality’ as subjective, that is to say, a reality as perceived by each individual. There is no one singular ‘truth’, as multiple realities can co-exist, dependent

for their form and content on the individuals who hold them (relativistic ontology). Essentially, reality is co-constructed through language-based interactions with other 'social beings', and in the case of research, these other social beings encompasses the various individuals involved in the research situation. Thus, as social truth is co-constructed, it will subsume the realities of the researcher, those of the individuals being studied, and those of the reader or audience interpreting the study. Accordingly, proponents of this approach acknowledge that research is inherently value-laden, and that biases are inevitably present and should be openly acknowledged rather than discounted or denied (axiological assumption). Given these fundamental ontological and axiological assumptions, Creswell suggests that the qualitative researcher attempts to explore participants' experiences, understandings, and knowledge by developing intimate research relationships with each participant, fostering the creation of 'social knowledge' through the ongoing fluid process of co-construction between researcher and researchee (subjectivist epistemology). Attaining an understanding of this co-constructed subjective reality requires careful analysis of research interview transcripts. These written transcripts serve as records of the language invoked in the process of developing shared social knowledge, allowing the researcher to subsequently engage in richer exploration in an attempt to uncover deeper meanings (interpretive or phenomenological methodology).

The 'quantitative-qualitative debate' focusing on the relative merits and scientific credibility of each method has been the focus of much attention within the research world over the latter part of the 20th century, and this debate continues on into the 21st century. However, social philosophers such as Ken Wilber (as cited in Black, 2004)

suggest that this debate is inherently flawed, as it is based upon an inadequate definition of the term 'empiricism', and an incomplete understanding of the ways in which knowledge can and cannot be validated within the social sciences. According to Wilber, 'broad empiricism' makes a demand for verifiable experiential evidence that can be gathered through any of the three different 'eyes' of knowing: the eye of the flesh (sensory experiences of sight, sound, smell, touch, and taste), the eye of the mind (mental experience including mathematics, logic, reason, theory, etc.), and the eye of the spirit. A definition of 'narrow empiricism' stands in contrast, as the demand for experiential evidence is solely based in the sensory domain that can be seen with the 'eye of the flesh'. Thus, within the realm of narrow empiricism, knowledge is reduced to only that which can be seen, observed, or measured using the gross senses. This definition is problematic when an attempt is made to apply it to practice and research within the field of psychological counselling. Research within the field of counselling, perhaps more than any other area within the broader scope of the social sciences, attempts to study the *interior* experiences of individuals. However, an individual's cognitions and emotions cannot be seen through the 'eye of the flesh', and as such, these internal experiences remain invisible to the external gross senses of another individual. For example, an individual in chronic pain may exhibit tears while they verbally express feelings of frustration during a research interview. In this scenario, a researcher could use their sense of vision to observe and document the participant's facial expressions, or use their sense of hearing to note the quivering in the participant's voice. Alternatively, the researcher could use instrumentation to measure the chemicals released in the participant's tears, or the changes in their body temperature or heart rate comparing them

in the pre and post-crying states; however, none of these observations and measurements can inform the researcher about the individual's actual interior 'human' experience of frustration. Internal experiences are not visible to the physical sciences, but that does not mean that they are not *real*. Simply put, frustration does not 'feel' like the chemicals in a tear, and thus, any attempt to reduce the experience of frustration to the chemicals in a tear would be an example of what Wilber terms 'gross reductionism'.

There is a tradition grounded in the positivistic 'hard sciences' that if a phenomena is not directly observable or measurable then we cannot say for certain that it exists. In response to this line of paradigm-derived reasoning, Wilber (as cited in Black, 2004) asserts a counter-argument that mathematics does not exist as an entity in the immediately accessible sensorimotor world (e.g., one cannot 'see' or physically 'point to' mathematics), yet the positivism-based physical sciences have been quite comfortable in using mathematical theory and formulation to support a diverse range of scientific inquiry. This incongruence aside, an argument can be made that within the fields of social science the use of numeric-based data (e.g., psychometric test scores) has garnered a higher level of 'scientific' status primarily via the outward appearance of being closely linked to the historically validated 'hard' physical sciences. This linkage seems to be driven by the fact that they both speak the same *numeric language*. By using numbers as the primary symbolic codes for representation and communication of data, a certain faction of the academic research audience seems to gain a degree of confidence and comfort, which is further bolstered by the highly predictable behaviour of numbers when applied within quantitative statistical analyses. Yet blind acceptance of the implied 'scientific' superiority of quantified data fails to recognize the most basic fact: numeric

data can only represent (i.e., '*re-present*') internal experiences, which does not necessarily translate into real world significance. The fundamental mistake occurs when one comes to believe that numbers, used to represent a participant's internal experiential data, actually *are* the data.

This line of reasoning has been used by some to champion the qualitative research paradigm as being unequivocally superior within the field of social science. However, Black (2004) points out that when this reasoning is exposed to deeper scrutiny, certain flaws can also be exposed within the qualitative approach that have clear parallels to the criticisms levelled at the quantitative research paradigm. The fact that most counselling research deals with internal experiences means that the only way to 'see' the data is through the 'eye of the mind'. Referring back to the prior example of a chronic pain client weeping during a research interview, if one merely used the 'eye of the flesh' to make observations, there is the potential for interpretational uncertainty as to the individual's internal experience. Given the multiple possible cognitive-emotional states often attributed to the outwardly observable act of crying, one cannot be certain whether the individual's internal experience was one of frustration, sadness, anger, joy, physical pain, or any combination thereof. If one wants to truly understand what the internal experience is like for that individual you must try to 'see' the data through the 'eye of the mind' by asking that person careful probing questions, and engaging them in a dialogue that will tap into their deeply personal internal world. However, it is essential to remember that in this case words are serving as the primary symbolic codes for the representation and communication of data. Paralleling the assertion made previously regarding quantitative data, it would again be a fundamental mistake to believe that these

words, used to represent the internal experiential data, actually *are* the data. Therefore, whether numbers or words are used to represent internal experiences, neither method actually *directly* accesses measurable sensory data in the physical world. It is equally true then, that those quantitative representations of internal experience and qualitative representations of internal experience are exactly that, mere *re-presentations* of internal experiences.

Once one accepts the premise that internal experiences are invisible to any manner of direct observation, and therefore neither quantitative nor qualitative methods actually *are* the ‘real’ data, (i.e., they can only offer different symbolic re-presentations of the ‘real’ data), one can begin to see how it becomes problematic to make cross-paradigmatic comparisons (Black, 2004). Because there are fundamental differences in the modes through which the ‘real’ data is symbolically re-presented, the data obtained through quantitative-based methodology cannot be compared in any meaningful way to data obtained via qualitative-based methodology. As such, each method should only be compared with other data generated from within the same paradigm. Building upon this notion, one begins to see that the debate of scientific superiority becomes moot, as any assertions made or questions posed from one paradigm ‘camp’ toward the other essentially have no meaning. Denzin and Lincoln (2000) creatively illustrate this concept by describing this as “posing Catholic questions to a Methodist audience” (p. 175). Simply stated, paradigm-based questions one may pose have no actual meaning to the receiving audience, because the frames of reference are those for which they were never intended.

Taking this perspective one step further, if either the quantitative or qualitative method attempts to lay claim to scientific superiority, they can logically only do so under the aforementioned definition of 'narrow empiricism' in which the legitimacy of experiential evidence is solely based in the sensory domain that can be 'seen' with the 'eye of the flesh' (i.e., sight, sound, smell, touch, and taste). However, Wilber (as cited in Black) cautions that taking such an approach is associated with a critical flaw in reasoning. Specifically, this narrow definition that only data gathered via the sensory domain is 'real' actually *negates itself* based on the simple fact that this definitional statement is not actually sensory in nature (i.e., one cannot 'see' or physically 'point to' the actual essence of this narrow definition), and therefore the statement itself cannot be considered 'real' or 'true'. This offers perhaps the strongest argument in favour of closure of the ongoing superiority-driven qualitative-quantitative debate.

As a researcher I needed to consider these difficult paradigmatic questions and arguments at the earliest stages of designing this study, beginning with the process of specifying an issue to study and subsequently narrowing it into a specific research question. When I decided to explore the experience of living with undiagnosed chronic pain, I found myself reflecting upon which paradigm and theoretical framework I was operating from. A review of the methodological literature led to my realization that the interior world of my study participants would not be visible via means of direct access, and as such, their internal experience could only be 'seen' by engaging in some manner of verbal dialogue with the individuals under study. I wrestled with the philosophical arguments put forth by Wilber (as cited in Black, 2004) that it is conceptually immaterial as to whether this dialogue comes in the form of asking questions from a numerically

scored diagnostic test, or by verbally asking questions in an open-ended interview format, since neither strategy actually accesses the ‘true’ data. Numbers, words, visual images, or sounds may each point to the internal experience of the participant, but none of them actually *are* the experience.

Following the same reasoning, even at the earliest stages of research design I had to think ahead and negotiate my way through the philosophical considerations regarding how best to develop a written report for distribution to an academic audience once the study is complete. In this regard, I found myself asking: ‘what is the language of this research?’ (rhetorical philosophical assumption). When faced with the choice as to whether to re-present the data using the language of numbers or words, if I was to remain true to the aforementioned series of philosophical assertions, I had to accept that it is ultimately up to my own personal preference as researcher, as neither can claim *carte blanche* superiority over the other regarding the ‘realness’ of the reality that they are describing.

Once I was able to accept this complex series of philosophically oriented assertions, it became easier to accept the notion that a ‘positivistic’ quantitative paradigm and a ‘naturalistic’ qualitative paradigm (and their associated strategies of inquiry) both have the potential to be valid endeavours. Acceptance of this was liberating in the sense that it freed me up to move forward and consider which strategy of inquiry, in my personal opinion, is most appropriate for addressing my specific research question. By adopting a pragmatic stance as promoted by Patton (2002), I was able to consider how different approaches involving the broader topic of chronic pain might be a more natural ‘fit’ for one manner of inquiry. In this regard, I found it helpful to reflect upon various potential

research scenarios as a means of clarifying what assumptions I was drawing upon, and honing my methodological decision-making skills. For example, I concluded that if I were wishing to investigate the effectiveness of a new pain control medication, a quantitative study utilizing a double-blind, randomized experiment would seem the most appropriate. In this scenario, measured medication dosages and outcome interactions would need to be carefully documented, with the goal of quantifying efficacy, estimated safety, and generalizability to the greater population. By contrast, if I were wishing to investigate what individuals actually think and feel about taking this same medication, or wished to explore how taking this medication affects the way in which they think of themselves, then a qualitative methodology would seem more appropriate. Thus, it is appropriate to reiterate the concept of ‘methodological appropriateness’ whereby different methods are appropriate for different situations of inquiry.

Applying this pragmatic stance to my exploration of the experience of living with undiagnosed chronic pain, I found myself clearly gravitating towards a qualitative research paradigm. Although the complex history and pluralistic nature of qualitative research makes it difficult to narrowly define, I found elements contained within the definition offered by Denzin and Lincoln (2005) to be a solid ‘fit’ with the needs of my research topic when they state:

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive,

naturalistic approach to the world ... attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. (p. 3)

Accepting that qualitative research is indeed pluralistic, encompassing several variations of theoretical frameworks and associated research strategies, Moustakas (1994) recognized that these models do hold certain common features that distinguish them from the traditional, positivistic, quantitative theories and methodologies. He outlined these common bonds as follows:

1. Recognizing the inherent value of qualitative designs and methodologies, in that they allow for the study of human experience in ways that are not approachable through quantitative means;
2. Honouring a focus on the 'wholeness' of experience, as opposed to a positivistic reductionistic approach that dissects phenomena by focusing solely on its objects or parts;
3. Searching for *meanings* and *essences* of experience, rather than taking measurements and seeking causal explanations using deductive reasoning;
4. Obtaining descriptions of experience through first-person accounts derived from informal and formal conversations and interviews;
5. Regarding the data of one's *experience* as imperative in understanding human behaviour, and as legitimate evidence for scientific investigations;
6. Formulating research questions and problems that reflect the interest, involvement, and personal commitment of the researcher; and
7. Viewing experience and behaviour as an integrated and inseparable relationship of subject and object, of parts and whole.

Although the broader qualitative research paradigm has given rise to a number of subsets of theoretical frameworks and strategies of inquiry, the commonalities listed above enabled the current study to address the research question by exploring and making sense of the lived experiences of individuals with undiagnosed chronic pain. Within a qualitative philosophical context, this study called upon both phenomenological and hermeneutic theoretical frameworks to explore the participants' lived experiences, as well as the meanings they brought to these experiences. In the following sections I will outline how each of these theoretical frameworks informed my approach to this study, and how I drew from the strengths within each framework. At the end of this 'Research Paradigm' section, I will close by outlining why hermeneutic phenomenology offered an appropriate theoretical vantage point from which to address this study's research question.

Phenomenology as a Theoretical Framework

"Phenomenology asks for the very nature of a phenomenon, for that which makes a some-'thing' what it is – and without which it could not be what it is" (Van Manen as cited in Patton, 2002, p. 104). Although at first consideration this definition may appear to eloquently express the core element of this research discipline, this clarity fades rapidly once one delves deeper and discovers that the term 'phenomenology' has come to be widely embraced by various factions under the umbrella of qualitative research, to the point where its fundamental meaning has become confused and diluted. Adding to the confusion, Patton notes that the term 'phenomenology' has been applied in many differing ways including, but not limited to, the following: a philosophical perspective, an inquiry paradigm, a social science analytical perspective, and a research methods

framework; all of which has added to the tensions and contradictions currently inherent within this field of qualitative inquiry. Similar to the challenges associated with capturing the essence of qualitative research as a whole based on its pluralistic nature, I perceive benefit in recognizing that the various phenomenological variations do hold certain common features that distinguish them from other qualitative traditions. These common bonds include:

1. Exploration of how human beings make sense of lived experiences (i.e., ‘meaning-making’) associated with a particular phenomenon;
2. Exploration of the structure and core essence of these lived experiences; and
3. Exploration of how human beings transform their lived experiences into consciousness, both at an individual level and as shared meaning.

This requires a methodological approach (as described later in this chapter) that makes every effort to carefully and thoroughly describe and capture how individuals experience a certain phenomenon, including how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others.

Phenomenology as a philosophical tradition was first used in the development of a rigorous human science by the German philosopher and mathematician Edmund H. Husserl (1859-1938). His application of the term ‘phenomenology’ meant the study of how people describe things and experience them through their senses. Accordingly, his most basic philosophical assumption was that we can only know what we experience by attending to perceptions and meanings that awaken our conscious awareness. Van Manen (as cited in Patton, 2002) further explains how phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences:

Anything that presents itself to consciousness is potentially of interest to phenomenology, whether the object is real or imagined, empirically measurable or subjectively felt. Consciousness is the only access human beings have to the world. Or rather, it is by virtue of being conscious that we are already related to the world. Thus all we can ever know must present itself to consciousness.

Whatever falls outside of consciousness therefore falls outside the bounds of our possible lived experience. (p. 104)

Heidegger (as cited in Moustakas, 1994) observed that the word ‘phenomenon’ comes from the Greek word ‘phaenesthai’, meaning to flare up, to show itself, to appear.

Constructed from ‘phaino’, a phenomenon means to bring to light, to place in brightness, to show itself in itself, the totality of what lies before us in the light of day. What appears in consciousness is the phenomenon. In a broad sense, phenomena are the building blocks of experience, human science, and the basis for all phenomenological knowledge.

In order to more fully grasp the concept of ‘consciousness’ as it relates to the philosophical orientation of phenomenology, one must also consider the concept of ‘*intentionality*’, which served as one of Husserl’s foundational assertions. Creswell (1998) offers a concise overview of this concept when he states: “This idea is that consciousness always is directed toward an object. Reality of an object, then, is inextricably related to one’s consciousness of it” (p. 53). Building upon this, in phenomenological terms intentionality refers to the internal experience of being conscious of something; thus the *act* of consciousness and the *object* of consciousness are intentionally related. Knowledge of intentionality requires that we be present to ourselves and things in the world, recognizing that self and world are inseparable

components of meaning. Thusly, Moustakas (1994) asserts that every lived experience can be extended in a chain of *meaning* and fundamental essences. True to the philosophical assumptions associated with a relativistic ontological perspective, multiple realities can co-exist, dependent for their form and content on the individuals who hold them.

When referring back to the main features that were presented as common bonds within a phenomenologic framework, it becomes clear how Husserl's concept of 'intentionality' plays a critical role. Accordingly, when summarizing the challenges of intentionality, Moustakas (1994) outlines the following processes, deeming them to be key:

1. Explicating the sense in which our experiences are directed;
2. Discerning the features of consciousness that are essential for the individuation of objects (real or imaginary) that are before us in consciousness (Noema);
3. Explicating how beliefs about such objects (real or imaginary) may be acquired, how it is that we are experiencing what we are experiencing (Noesis); and
4. Integrating the noematic and noetic correlates of intentionality into *meanings* and *essences* of experience.

Through these four processes one is able to gain an appreciation for Husserl's philosophical movement away from more traditional ways of thinking. Reality, according to Husserl, is not simply divided into subjects and objects, thus shifting the Cartesian duality to the *meaning* of an object that appears in consciousness. Within this perspective there is an inherent denial of the 'subject-object dichotomy'. Creswell (1998) notes that this theme flows naturally from Husserl's concept of 'intentionality of

consciousness', such that the reality of an object is only perceived within the *meaning* of the experience of an individual.

When considering how to practically apply such phenomenologically-based concepts to real-life research scenarios, it is helpful to remain aware that all our understanding comes from the pure sensory experience of phenomena, but that experience must be described, explicated, and ultimately *interpreted*. However, descriptions of experience and interpretations are so intertwined that they inevitably become one. Patton (2002) reminds us that interpretation is essential to an understanding of experience, and the experience *includes* the interpretation. Thus, when subscribing to a phenomenological framework the researcher will focus on how individuals 'put together' the experienced phenomena in such a way as to make sense of the world and, in doing so, develop a worldview. True to the philosophical assumptions of phenomenology, adopting this conceptual framework requires one to accept that there is no separate or objective singular reality (relativistic ontology); there is only what people 'know' their experience is, and means. The subjective experience subsumes the objective 'thing' and, in effect, becomes the person's reality. Thus, there is a focus on *meaning-making* as an essential element of human experience, and as a critical focus of phenomenological inquiry.

There is one final dimension that differentiates a phenomenological approach from other strategies of inquiry within the qualitative research paradigm: the assumption that there is an *essence* (or essences) to shared experiences. These essences are the 'core meanings' that are mutually understood by more than one person through some manner of *shared experience*. Patton (2002) states: "The assumption of essence, like the

ethnographer's assumption that culture exists and is important, becomes the defining characteristic of a purely phenomenological study" (p. 106). At first consideration this may seem to be a contradiction to prior assertions regarding the very personalized way in which consciousness is associated with the synthesis of perceptions, and the bestowal of meaning, by a given single individual. However, the truth of these prior statements does not negate this newly presented concept regarding core essences. Eichelberger (as cited in Patton) attempts to offer clarity by stating that phenomenologists are:

Rigorous in their analysis of the experience, so that basic elements of the experience that are common to *all* members of a specific society, or all human beings, can be identified. This last point is essential to understanding the philosophical basis of phenomenology, yet it is often misunderstood ... some researchers are misled to think that they are using a phenomenological perspective when they study four teachers and describe their four unique views. A phenomenologist assumes a *commonality* in those human experiences and must use rigorously the method of bracketing to search for those commonalities. (p. 106)

Thus, to apply this concept to the current study, a researcher would be misled to think that they are using a true phenomenological perspective if they decided to study five sufferers of undiagnosed chronic pain and describe their five unique views about this experience, even if they were successful in providing an accurate representation of the experiences as described by each of the individuals. By way of contrast, a researcher adhering to the basic tenets of phenomenology would assume a *commonality* in those human experiences, and would seek out the *shared* elements expressed by *all* five pain

sufferers that seem to be a core part of the lived experience of undiagnosed chronic pain. In this way the researcher would remain true to Van Manen's statement (as cited in Patton): "Phenomenological research is the study of essences" (p. 106).

Hermeneutics as a Theoretical Framework

Hermeneutics is the theory and practice of interpretation. In a research context, hermeneutics provides a theoretical framework for interpretive understanding and the extraction of meaning, with special attention paid to context and original purpose. Patton (2002) writes that the term 'hermeneutics' is derived from the Greek word "hermeneuein", meaning to understand or interpret. There is a linguistic link between 'hermeneuein' and the Greek god Hermes. In Greek mythology, Hermes is the winged-footed messenger who served as the bearer of knowledge and understanding. It was Hermes' task to explain to human mortals what the decisions of the gods were. In modern day usage, hermeneutics offers a perspective for interpreting legends, stories, and other texts, most notably biblical and legal texts. In order to make sense of and interpret a linguistic text, it is important to capture what the author was trying to communicate, to understand intended meanings, and also to situate documents in a historical and cultural context. This latter point should not be underestimated in its importance, as the meaning of a written document depends to a sizable degree on the cultural context in which it was originally created, as well as the cultural context within which it is subsequently interpreted.

More recently within the field of social science, hermeneutics has arisen as an interpretivist philosophy with research applications beyond the interpretation of written text. From a historical perspective, phenomenology, of which Edmund H. Husserl (as

previously noted) played a key role, is central to the development of hermeneutics. In contrast to the more traditional 'positivistic' paradigm, Husserl promoted the idea of using phenomenological analysis to grasp and elucidate the meaning, structure, and essence of the lived experiences of individuals. However, although Husserl placed heavy emphasis on consciousness, the synthesis of perceptions, and the bestowal of meaning; these concepts were nonetheless predicated on the idea that there was, in fact, a 'true' essence or structure of the objects of experience that existed before the consciousness' construction of it. In this regard, the term 'intentional experience' as coined by Husserl refers to *real entities*, objects that actually exist. Coming from this philosophical vantage point, Husserl believed that it was possible for an outside researcher to grasp the pure form of the inside experience of an individual by setting aside all prejudgments, viewpoints, and assumptions, as part of a process of he termed 'epoche'. His claim was that this was methodologically possible by engaging in strategies of 'bracketing' and 'reduction', which are analytical processes whereby the researcher purposefully 'brackets out' the world and any presuppositions in order to identify the data in its 'pure form'. He believed that engaging in this purifying process of 'reduction' would leave the data uncontaminated by extraneous intrusions. Husserl further asserted that once the researcher was in this presuppositionless state, accurate phenomenological description can take place and phenomena can be presented *without interpretation*. In this way, although Husserl viewed himself as philosophically quite distant from traditional positivistic paradigms, he did actually continue to maintain one of the fundamental conceptual pillars of positivism (i.e., a realist ontology).

Martin Heidegger, in contrast, played a key role in challenging philosophical assumptions associated with the realist ontological perspective. Launching a pragmatic defence for his own assertions, Heidegger did not fundamentally believe in Husserl's conceptual strategies of 'bracketing' and 'reduction'. Specifically, he did not support the notion that it was possible for human beings to withdraw their presuppositions about the nature of phenomena; as though one's 'conditioned ways of knowing' could simply be placed on a metaphorical shelf at will. From Heidegger's philosophical vantage point, to be human *was* to be inherently interpretive. This core belief is why Heidegger's hermeneutical conceptual framework was referred to as 'interpretive phenomenology', and served as a significant step towards the development of philosophical hermeneutics (Van Manen, 2007). Heidegger asserted that knowledge occurs in an engagement of the world, a process he referred to as 'Dasein', which has the meaning 'being there'. This laid the groundwork for an approach characterized by researcher and individuals of interest acting as *co-participants* with individualized interpretations of their shared world. Such an approach required the purposeful development of intimate research relationships, fostering the co-creation of social knowledge between researcher and researchee (i.e., a subjectivist epistemology). An acceptance of the notion that the relationship between knowledge and the knower are inseparable in this model opens the door for acceptance of the notion that there are actually many interpretations of reality (i.e., a relativistic ontology).

Building upon the groundbreaking work of Heidegger, Gadamer argued that *understanding* is not a task-driven, procedure-governed, or rule-governed, purposeful

undertaking; rather it is a very *condition* of being human. Understanding *is* interpretation. Gadamer (as cited in Denzin & Lincoln) provided clarity in stating that:

Understanding is not an isolated activity of human beings but a basic structure of our experience of life. We are always taking something *as* something. That is the primordial givenness of our world orientation, and we cannot reduce it to anything simpler or more immediate. (p. 194)

Gadamer (as cited in Denzin & Lincoln) asserted that the goal of philosophical hermeneutics *is* philosophical, that is, to understand what is involved in the very process of 'understanding' itself.

The second important conceptual addition that Gadamer introduced was the notion that within the act of interpreting, sociocultural and historically inherited bias or prejudice is not regarded as a characteristic that an interpreter must strive to get rid of or manage in order to come to a 'clear' understanding. To believe this is possible is to assume that our sociocultural traditions, and the associated prejudgments that shape our efforts to understand, are easily under our control. Tradition in this sense is not something external that 'lives' in the past, but rather is a life-force that enters into all current understanding by conditioning our interpretations. Gallagher (as cited in Denzin & Lincoln, 2000) elaborates by stating that our sociohistorically derived traditions, "shape what we are and how we understand the world; the attempt to step outside of the process of tradition would be like trying to step outside of our own skins" (p. 195). Thus, reaching an *understanding* is not a matter of setting aside, managing, escaping, or even tracking one's own standpoint, biases, or prejudgments. On the contrary, understanding inevitably requires the *engagement* of one's biases (i.e., axiological philosophical

assumption). In fact, an argument can be made that prejudices are the very kind of prejudgments that are necessary and accessed in everyday thought, conversation, decision-making, and action. Therefore, Denzin and Lincoln suggest that the goal should not be to free ourselves of all such prejudgment, but to accept the inevitability of their existence, and examine our historically inherited and *unreflectively* held prejudices, and alter those that disable our efforts to understand others, and to understand ourselves. In a sense, this parallels a common element of the counselling process, whereby careful probing questions posed by the counsellor facilitates a heightened level of introspection and self-reflection on behalf of the client, enabling them to gain awareness of unconscious processes that may, unbeknownst to them, be affecting their conscious thoughts, feelings, behaviours, and decision-making in a counter-productive way. The organic process of understanding, be it in a counselling setting, research setting, or throughout our daily lives, is inherently participative, conversational, and dialogic. Denzin and Lincoln note that through this connection to language we can see that understanding is something that is *produced* in dialogue; it is something that is intimately co-constructed, and (departing from prior interpretivistic phenomenological assertions) it is not something that is merely *reproduced* by an interpreter through an analysis of that which he or she seeks to understand.

Interpretation is also always temporal, and always in process. Denzin and Lincoln note that we are always understanding and interpreting in light of our anticipatory prejudgments and prejudices, which are themselves always changing within the course of history. This is why Gadamer purports that to understand is always to understand *differently*. Thus, understanding can be thought of as being continually negotiated

between the interpreter and the subject of interpretation, against the backdrop of the interpreter's particular sociocultural and historical context. In other words, meaning is negotiated mutually in the very act of interpretation; it is not simply 'discovered' (Denzin & Lincoln).

Hermeneutic Phenomenology Theoretical Framework

Hermeneutic phenomenology is attentive to both core terms that reference its philosophical origin. Van Manen (2007) purports that it is a descriptive (phenomenological) approach because it strives to be attentive to how things appear, it wants to let things speak for themselves; yet it is also interpretive (hermeneutic) because it claims that uninterpreted phenomena do not exist. Upon first consideration one may perceive an implied contradiction in these overarching statements. However, this sense of contradiction can be resolved if one acknowledges that the (phenomenological) 'facts', or essential, invariant 'essences' of lived experience are always meaningfully (hermeneutically) experienced. These 'essences' of lived experience need to be captured dialogically through language, and this is inevitably an interpretive process.

In considering this complex process of interpretation within a research context, the researcher must remain cognizant that two different modes of linguistic-based translation are concurrently at play. The first mode of translation relates to the hermeneutical notion that as a researcher I am engaged in a continuous process of 'translating' everything I hear in an interview (and subsequently read in my written transcriptions); deriving meaning by consciously or unconsciously referencing the heard or written word against my own personal, social, familial, cultural, and historical context. The second mode of translation relates to Wilber's assertions (as cited in Black, 2004) that it would be a

mistake to believe that the words verbalized by study participants, as used to represent their internal experiential data, actually *are* the data. Simply put, an individual's internal life is not directly accessible to external speculators. Whatever a participant may communicate, the researcher must realize that their verbal representations of their 'lived experiences' are exactly that, mere *re-presentations* (i.e., translations) of their 'raw' and 'pure' internal experiences.

As was noted at the beginning of this chapter, the researcher must enter into the process of research design with a clear sense of purpose and commitment to finding the best means by which to answer the research question. Research can be understood as arising from a particular paradigm that provides context for the study's theoretical perspective that, in turn, shapes the choice of methodology. While there are a number of qualitative research orientations to which I could have turned in order to explore and make sense of the lived experiences of individuals with undiagnosed chronic pain, I chose the hermeneutic phenomenological approach. In this study, conceptual and methodological strength was drawn from the *phenomenological* element of analysis seeking to grasp and elucidate the meaning, structure, and 'essence' of the lived experience of the study participants. Complementarily, the study drew strength and honesty from the *hermeneutical* element of analysis, acknowledging that the best I can offer as a researcher is an expression my own unique language-based interpretation of the participants' experiences, based on their own unique interpretations of their lived experiences. This ultimately leaves the reader with the opportunity to digest the presented written material, a process during which they too will inevitably form their own unique interpretations. For all of these reasons I chose a hermeneutic

phenomenologic framework from which to study the lived experiences of individuals with undiagnosed chronic pain.

Methodological Considerations

Purposeful Research Design

An effective research design maintains clear focus on the research question and the purpose of the study, while asking the fundamental questions: ‘what information will most appropriately answer the specific research question?’ and ‘which strategies will be most effective for obtaining this information?’ Denzin and Lincoln (2005) note that a study’s research design provides a set of guidelines that serve a key function in connecting the study’s overarching paradigm (i.e., ‘naturalistic’ qualitative inquiry in the case of the current study) and theoretical framework (i.e., hermeneutical phenomenology in the case of the current study) to strategies of inquiry and methods for collecting empirical materials. A research design fundamentally *situates* the researcher in the empirical world, and also provides direction as to how the investigator will address the critical issue of legitimation.

A strategy of inquiry comprises a set of skills, assumptions, and practices that the researcher employs while transitioning from paradigm to the empirical world. Denzin and Lincoln (2005) speak to this process when they observe that strategies of inquiry put the researcher’s paradigm of interpretation into motion. At the same time, strategies of inquiry also connect the researcher to specific methods of collecting and analyzing empirical materials. Essentially, strategies of inquiry implement and anchor paradigms by grounding them in logically congruent empirical and methodological practices (Denzin & Lincoln).

Given this study's research question: 'What is the experience of living with undiagnosed chronic pain?' and the aforementioned paradigmatic and theoretical conceptualizations that informed the study's methodology, the following are five key assumptions that guided the design of this research study:

1. The multiple nature of reality (i.e., the ontological issue);
2. The close relationship of the researcher to the participants being researched (i.e., the epistemological issue);
3. The value-laden and bias-impacted aspect of inquiry (i.e., the axiological issue);
4. The personal approach to writing the study narrative (i.e., the rhetorical issue);
and
5. The emerging inductive methodology of the process of research (i.e., the methodological issue).

These fundamental philosophical assumptions served to provide a sound foundation, and a sense of congruence, throughout each aspect of this study's research design.

Participants

Purposeful Sampling

After a research question has been established, the researcher must consider who can supply the information that is needed to answer that question. In qualitative inquiry, the intent is to develop an in-depth exploration of a central phenomenon, and with this in mind, the qualitative researcher purposefully selects individuals and sites that can best help them understand or learn about the phenomenon central to their identified research question. Thus, in the context of this study I focused on accessing participants who have actually lived, first-hand, the experience of undiagnosed chronic pain.

Creswell (2005) notes that the standard used when applying the principle of purposeful sampling is whether the individuals or selected research sites are 'information-rich'. Within the methodology of qualitative research a number of potential purposeful sampling strategies exist. Their methodological appropriateness can be differentiated depending upon the nature of the phenomenon of interest and the associated research question, and whether they are employed before or after data collection begins. After taking these factors into consideration, I made the decision to use 'maximal variation sampling'. One characteristic of most qualitative research frameworks is the presentation of multiple perspectives in order to represent the complexity of our world. Creswell expands upon this notion by stating that the strategy of 'maximal variation sampling' attempts to build that complexity into the research by purposefully sampling individuals that differ on one or more characteristics or traits. Therefore, although my sampling efforts focused on securing participants with the commonality of undiagnosed chronic pain, I also endeavoured to 'complexify' what is known about this phenomenon by developing a sample of participants that contained a rich mix of genders, ages, levels of involvement with disability insurance systems, employment status, and social background. When considering this issue, it should be made explicitly clear that the primary motivation for maximizing variety within the sample was not to allow for a 'generalization' of the study's outcome results to the larger population (i.e., as per the intent of a quantitative research paradigm), but to endeavour to identify the common core elements, or 'essences', of the lived experience of undiagnosed chronic pain. More specifically, the goal was to identify the salient 'essential' elements of this experience that are found to be invariantly present

irrespective of contextual factors such as gender, age, insurance involvement, employment status, and social background.

Table 1: Characteristics of the participants

Participant	Age	Gender	Race	Work Status	Family Status	Insurance Involvement.	Litigation Involvement.
A1	43	Male	Caucasian	Not working	Married 2 children	Yes LTD Claim	No
A2	40	Female	Caucasian	Not working	Single 3 children	Yes WCB Claim	No
A3	50	Female	Caucasian	Not working	Married 3 children	Yes CPP LTD pending	No
A4	29	Female	Caucasian	Not working	Single 0 children	Yes CPP Claim	No
A5	38	Female	Caucasian	Not working	Single 0 children	Yes LTD Claim	Yes

Criteria for Inclusion

As a most basic of stepping-off points, Patton (2002) states that in order to gather the data necessary to sufficiently answer the research question, in-depth interviews must be undertaken with people who have *directly* experienced the phenomenon of interest; that is, they have had relevant ‘lived experiences’ themselves as opposed to reporting on second-hand experience. With this in mind, while also remaining true to the fundamental

research question, I compiled the following list of *inclusion criteria* for appropriateness to participate in this research study:

1. Experiencing a non-interrupted period of chronic pain for a minimum duration of six months (i.e., have never had a ‘pain-free day’ within that duration); and
2. Ability to provide a full, rich, and vivid description of their lived experience using the English language (i.e., as the researcher is only fluent in English), including an ability to verbally articulate thoughts and feelings; and
3. Willingness and availability to commit to spending the necessary time to participate in one or more interviews of 60 - 90 minutes duration each, as well as time to review written transcripts for accuracy; and
4. Willingness and availability to commit to ongoing participation in the study to its point of completion; and
5. No status as a current or prior client of mine, either in my professional capacity as a physiotherapist or as a counsellor; and
6. Perception on behalf of the participant that their chronic pain (as defined above) is ‘undiagnosed’. This will, to some degree, be a *self-selection* process, based on the individual’s interpretations of the ‘Invitation to Participate’ recruitment poster (as provided in Appendix A) and/or the associated information pamphlet, as well as a follow-up screening process completed by myself. Criteria for meeting the requirement of the chronic pain being ‘undiagnosed’ in this study are outlined as follows:
 - a) Client perceives that they have never been given a diagnosis for their chronic pain; or

- b) Client perceives that they have been provided with multiple conflicting diagnoses (from one or more health care practitioners) to ‘explain’ their chronic pain, and therefore, they do not believe that a single accurate diagnosis has been clearly identified.

Interpretive Co-researchers

The process of hermeneutic phenomenological inquiry respects the capacity of individuals for self-knowing and their ability to give ‘voice’ to their lived experiences. This study’s phenomenological search for the essential, invariant ‘essences’ of participants’ lived experience was inherently interpretive (hermeneutic) because it operated within a conceptual framework asserting that there are no such things as ‘uninterpreted’ phenomena. The participants’ lived experiences were captured dialogically through language, and this is an inevitably interpretive process whereby the researcher and participant function together, co-constructing a version of ‘reality’. As researcher, I offer my own interpretation of the participants’ experiences, based on their own unique interpretations and explications of their lived experiences. In this way, both individuals can be conceptualized as ‘co-researchers.’

In consideration of this, it should be acknowledged that issues at both the ‘micro’ and ‘macro’ levels undoubtedly influenced my interpretations, as researcher. With regards to ‘micro’ issues, the interpretations I derived depended upon the skills I called upon to facilitate each participant’s process of exploration within the research interviews. More specifically, this was linked to my set of interviewing and active listening skills. In this regard, I endeavoured to use verbal and non-verbal language that communicated to each participant that I was fully attending to his or her interview responses, as this

encourages ongoing open disclosure. As participants spoke I used the skills of clarifying, probing, and questioning to ensure I was not confused by what was said, and to ensure that key details were not omitted. After a participant spoke, I used the strategies of paraphrasing and summarizing to feed back to the participant my understanding of what they had just said, providing an immediate check-in for accuracy.

Also within the 'micro' level of issues, I endeavoured to remain aware that within any verbal communication exchange there is an 'interpersonal gap' (Westwood & Borgen, 1988) between the sender and receiver of each verbal message. For example, within the interior world of the 'sender' of a message (i.e., the participant speaking), there is an *encoding* process at play that involves translating their internal thoughts into externally expressed speech. Subsequently, as the 'receiver' of the verbal message (i.e., myself as the listening interviewer) there is a *decoding* process at play, that involves translating the auditory-received sensory stimulus into my own cognitive conceptualizations, which subsequently dictates my reaction to the perceived message. Within the research interviews, by paraphrasing messages immediately back to the participant before encoding it, I increased the likelihood of an accurate transmission of their intended message. In this regard, I believe it was important to remain aware that at a 'micro' level there was a constant encoding and decoding interpretational process at play within every verbal exchange during the research interviews. I perceive this has a parallel to Wilber's concept (as cited in Black, 2004) that it is never possible for a researcher to actually have direct access to a participant's interior world, and therefore the astute researcher remains cognizant that the participants' verbal representations of

their 'lived experiences' are exactly that, mere *re-presentations* (i.e., translations) of their 'raw' un-interpreted internal experiences.

Within the 'macro' hermeneutical level, it should also be acknowledged that my interpretations, as researcher, were undoubtedly influenced by the personal, familial, societal, cultural, and historical context that I brought to the interactions. This influence is inevitable, given that these factors are an inherent part of my way of 'being' in the world, and that our traditions, biases, and prejudgments enter into all of our current understanding by conditioning our interpretations.

Positioning of the Researcher

As has been noted previously, as a researcher my interpretations are inevitably influenced by the prior history and assumptions that I bring to the topic matter. Socioculturally, my worldview has been shaped by my life as a 42 year old, married, university-educated, Caucasian male, of English-European descent, who would fall into the 'middle class' socioeconomic category, and is employed in two overlapping health care professions as a physiotherapist and counsellor. More specific to this study's area of research focus, a direct influence would undoubtedly be exerted by my extensive prior professional experiences as a physiotherapist and counsellor working with clients who are living with undiagnosed chronic pain. This past work history as a clinician caused me to enter into the research setting with a belief that an ambiguous diagnostic status causes individuals to be faced with a series of specific life challenges. My pre-research perception was that these challenges occur both *internally* in terms of struggling with the lack of an explanation for pain which is having a dramatic negative impact on the sufferer's life, as well as *external* struggles regarding how these individuals interface

with various 'systems' within society (such as insurance, medical, and legal systems), as well as with other individuals within society. Prior clinical relationships have moulded my perceptions that individuals lacking a diagnosis for their chronic pain face a constant battle for legitimacy (particularly within the insurance and medical systems), frequently begin to question whether their pain symptoms might in fact be 'all in their head', feel socially isolated as they perceive that they do not 'fit in' with others as they used to, as well as feeling highly self-conscious in explaining to others that no known cause for their pain has been identified. Expanding outward from such issues, I also entered the research setting holding perceptions that these individuals are often engaged in a deep struggle both for and against 'accepting' their current lot in life, often hanging all hope on the idea that a diagnosis will eventually be revealed which will 'rescue' them from their plight and set them on a path towards a cure (and thus, a satisfying pain-free life).

Trust Within the Research Relationship

For the individuals involved in a research interview to function effectively as 'co-researchers' a combination of factors must be in place. Firstly, the researcher must have skill in conducting the interviews in such a manner that the questions which are chosen, and the way in which they are posed, sets the participant at ease and promotes thoughtful reflection and access to insights (i.e., cognitions and emotions) about their lived experiences. Secondly, and more foundational, is my belief that for the interview process to be fruitful in its full exploration of the phenomenon of interest, there must be a sense of trust and mutual respect between interviewer and interviewee.

In many ways the nature of trust within a hermeneutic phenomenological research relationship mirrors the 'therapeutic alliance' that I, as a counsellor, strive to develop

with my clients. I drew upon these finely developed skills during my interactions with participants, in order to gently lead them to a place of comfortable curiosity and willingness to proceed into deeper exploration of the phenomenon of interest. For example, in a counselling context, if one adopts the stance of 'expert counsellor' (i.e., whereby I portray that I am more of an expert on the client's feelings than the client themselves), a client may feel exposed or vulnerable, perceiving that they are facing an omnipotent individual within a context characterized by a significant power differential. Given these perceptions, it is not surprising that a client's level of trust and comfort with open disclosure may be greatly diminished. By way of contrast, if I adopt a stance of 'tentative counsellor' wherein I respectfully acknowledge that the client is the only true expert on his/her own thoughts and feelings, the sense of mutual trust and respect within the relationship tends to grow. Therefore, when conducting the research interviews I made every effort to adopt a 'tentative' approach in order to engender trust, and encourage each participant's process of exploring and sharing intimate elements of their lived experiences.

As noted by Johnson and Johnson (2003), the key to building and maintaining trust within any relationship is to behave in a trustworthy manner oneself. I believe this holds equally true in a clinical, personal, or research-based context. As such, I endeavoured to act in a trustworthy manner during every aspect of the research process. I also remained cognizant that by exploring and exposing very personal elements of their lived experiences, participants in the study were opening themselves up to both positive and negative potential consequences. Examples of possible positive consequences resulting from participation are that certain individuals might have come to a place of better

understanding about themselves, they may have experienced positive feelings stemming from the very act of self-reflection (e.g., the opportunity to process certain thoughts or feelings within themselves), or they may have felt good about the fact that they were contributing to a knowledge base that may ultimately result in the better provision of care for individuals who live with undiagnosed chronic pain. Conversely, by fully disclosing to the researcher, a participant is assuming a certain degree of risk for negative consequences. Examples of possible negative consequences are that a participant's anonymity could have potentially been breached, a risk that if I was not skilful enough the participant might have experienced harm in the form of significant and/or unnecessary emotional upset, and a risk that the information resulting from the final written report might in some way have negative implications for the participant. In this regard, during the process of research I endeavoured to remain aware of the following key elements of trust as identified by Johnson and Johnson:

1. The participant is in a situation where the choice to trust another person (i.e., the researcher) can lead to either beneficial or harmful consequences. Thus, there is an element of risk involved in trusting;
 2. The participant realizes that whether beneficial or harmful consequences result depends, to a large degree, on the actions of another person (i.e., the researcher);
 3. The participant expects to suffer more if the harmful consequences result than they will gain if the beneficial consequences result; and
 4. The participant feels relatively confident that the other person (i.e., the researcher) will behave in such a way that the beneficial consequences will result.
- This final point has important ethical implications, as it enables the prior harms

statement to remain congruent with one of the fundamental tenets of modern human research ethics, such that a favourable ‘harms-benefits balance’ is realized. More specifically, this tenet is that the foreseeable harms of research should not outweigh the anticipated benefits.

Taking these points into consideration, it should be acknowledged that the nature of research poses one additional and unique challenge associated with trust building. Typically, trust is a subtle entity that is gradually built up over time, and over multiple encounters. Trust between individuals is solidified based upon such a series of successive positive interactions where both individuals act in a trusting and trustworthy manner. Conversely, a bond of trust that has already been firmly established can be greatly weakened by a solitary incident of broken trust or betrayal. Therefore, as a researcher, it is essential to recognize that within the context of research, just as within the context of a counselling relationship (and life in general), every interaction will either increase or decrease the level of trust between myself and another individual. The unique challenge that this particular study’s research context posed was that I was required to ask relative strangers to trust me, after having had only minimal opportunity to engage in a series of trust-enhancing encounters. In recognition of this fact, and to foster a relatively rapid engagement of trust, during every single interaction with study participants I made every effort to conduct myself with the utmost integrity and to remain aware of these foundational elements of trust; striving to create a trusting climate that reduced any fears of betrayal, judgment, or rejection, while promoting feelings of acceptance, support, and confirmation.

Sample Size

It is typical in hermeneutic phenomenological research to study relatively few individuals in order to allow the researcher to provide a sufficiently in-depth picture of the experiences of each participant. This is consistent with the objective of presenting the fullest possible complexity of the information provided by each individual. Having stated this, when initially designing this research study it was difficult to know beforehand exactly how many participants would be required to attain a sufficiently rich level of exploration of the phenomenon of interest. The ‘target number’ for sample size is a function of many factors, such as which individuals happen to avail themselves to be participants in the study, the participants’ comfort level with disclosure in a research setting, and the researcher’s interviewing and analyzing skills. Clarifying these latter two concepts, Creswell (2005) suggests that in qualitative research methodology the term ‘saturation’ refers to the point where the researcher has identified the major themes of the study, and concludes that no new information or insights can add to the current list of themes or to the level of detail of the existing themes. Thus, one of the primary guiding principles for determining appropriate sample size is the criterion of redundancy. Given the aforementioned traditions of hermeneutic phenomenological analysis, as well as the specific research question of this study, I was originally aiming to secure six to eight participants. In the end, the study secured five participants, given that after being contacted by 14 interested potential candidates, only five were deemed to either adequately meet the inclusion criteria of the study, or felt able to commit sufficiently to the requirements expected of participants in the study. Fortunately, it was my observation that by the point of the final research interviews themes were arising

repeatedly, and no significant new branches of themes were emerging, such that I perceived by the fifth participant an adequate degree of thematic saturation had been attained.

Participant Access, Screening, and Selection

The participants in this study volunteered themselves for inclusion, although, as was noted previously, this study utilized the strategy of ‘purposeful sampling’. The recruitment process was ‘purposeful’ in the sense that I made selective contact with health care-related agencies, and various medical/rehabilitation clinics in the greater Victoria area that I perceived would be most likely to have clientele who are experiencing undiagnosed chronic pain. These sites included 11 of the largest physical rehabilitation clinics in the city, three naturopathic-oriented clinics, four health food stores, two psychologist’s offices, and 10 physician’s offices. The physician offices were randomly selected from a physician directory, and given the random nature of this particular selection process; these offices were naturally distributed amongst the various geographic/socioeconomic strata of the greater Victoria capital region district. When deciding upon recruitment sites, one challenge faced was the fact that a number of community medical/rehabilitation agencies are of the nature that most of their clientele would be reasonably expected to have a clearly defined diagnosis (e.g., the ‘Arthritis Society’), and therefore, their clientele would not be suitable for inclusion in this study given that they do not meet the criterion of their pain being ‘undiagnosed’. Thus, as was previously reflected in the list of criteria for inclusion, the presence of chronic pain itself is a ‘necessary but not sufficient’ factor for inclusion in this study.

A fundamental part of the process of gaining access to potential participants was the posting of an ‘Invitation to Participate’ recruitment poster (as provided in Appendix A), displayed in the aforementioned health care-related agencies and clinics, as well as an information pamphlet that was made readily available to any interested individuals. The recruitment literature provided a general overview of the nature and purpose of the study, the central research question, and a description of inclusion criteria for participation. These posters and pamphlets provided a telephone number and email address for contacting me, and were intended to encourage interested potential participants to contact me directly. During any such follow up communications I provided more in-depth information about the nature and purpose of the study, reviewed key aspects of the study design (i.e., assurance of confidentiality, right to withdraw, minimizing of potential harms, time commitment required, interview structure, report audience), answered any questions the individuals might have had, and assessed the individual’s appropriateness for inclusion in the study.

Within the same timeframe that the participant recruitment posters and pamphlets went on display within a particular facility, I also extended an offer to meet briefly with the facility’s staff members on one occasion to review the overall nature of the study and the inclusion criteria for participation in this study. This was offered so that staff members would feel comfortable in addressing basic questions that may arise from clientele after reading the “Invitation to Participate” recruitment poster and/or pamphlets displayed within their work environment. However, this offer was declined in all cases, except for one rehabilitation clinic, citing constraints in organizing their staff members and taking them away from their primary job duties as the primary reason for declining

my offer. Nonetheless, I emphasized to each individual who accepted my recruitment poster/pamphlets in each site that the recruitment process for this study was based on participant self-selection, providing clear direction that their staff members were not to actively solicit any clientele into participating in this research study. By adhering to this protocol I made every effort to essentially negate any potential for coercion or 'power over' issues because I was not directly reaching out to any person who had not already made the voluntary effort to contact me, and expressed interest in participating in the study, as a result of reading the posted recruitment literature.

I also endeavoured to identify one key individual within each research site who could facilitate the process of acquiring study participants by ensuring the recruitment posters and pamphlets were prominently displayed within a public viewing space, helping to enlist maximal cooperation of the facility staff, and serving as an initial resource for anyone who might need basic clarification about the information contained in the participant recruitment materials. Whenever possible, I attempted to develop a strategic relationship with one such individual at each site, who would function as a 'gatekeeper' for that site. In considering this, it should be noted that this gatekeeper was required to be an individual with whom I have no 'power over' issues, nor any prior direct relationship, thus drawing upon their sense of general goodwill within the health care community as a means to secure their voluntary assistance with this initiative. Creswell (2005) notes that in qualitative research where permission is required to conduct extensive interviews with participants at a given site, it can be quite beneficial to identify such a gatekeeper. A suitable person for this role was noted to be someone who has an official or unofficial role giving them 'insider' status whereby they are able to

provide a researcher with entrance to a site, and with the potential to also assist in the identification of locations to complete on-site interviews. In order to secure the support of a given gatekeeper I made a point of supplying sufficient verbal and written information (as provided in Appendix B) about the study to satisfy any questions they may have, and maximize their level of comfort with participation. Incorporating the guidelines offered by Creswell (2005), this information included the following:

1. An overview of the purpose of the study.
2. The rationale for why their site was chosen for the study.
3. An overview of what would be accomplished at the site during the research study (i.e., specific activities to be conducted, as well as projected time and resources required by participants, the on-site staff or volunteers, and myself as researcher).
4. An estimate of how much time I would spend at the site collecting data (i.e., per session and overall).
5. An assurance of my intention to make every effort to be minimally disruptive within their facility, while also acknowledging the realistic potential for my presence to be slightly disruptive (e.g., clients who attend on a regular basis may become curious when they see a researcher who is a 'new professional face' in the facility).
6. An assurance that I would be respectful of the staff, clientele, property, and possessions within the 'host' site.
7. An assurance that I would refrain from introducing issues that, to the best of my knowledge, may cause participants to negatively question any aspect of the 'host' organization (i.e., in effect, causing 'harm' to the 'host' organization).

8. An overview of how I intended to document and use the results of the study.
9. An outline of what provisions I had made to protect the anonymity of the study participants.
10. A sense of what the individuals at the site might gain from the study (i.e., the actual participants and/or the 'host' organization).

By providing this information I was communicating respect for those individuals acting in a supportive capacity for the study, as well as acknowledging and expressing a concern for the potential intrusion of the study into the workplaces and lives of both the participants and staff of the study 'host' sites. Additionally, it was hoped that the provision of this information would serve a facilitative function by setting the stage for realistic expectations on behalf of both the staff and study participants affiliated with each site. I perceived these initial respectful interactions, and the setting of realistic expectations, to be critical because it minimized the likelihood of a future breakdown in our working relationship, which might otherwise have caused the withdrawal of these agencies as 'host' sites for the study.

Ethical Considerations

When conducting hermeneutic phenomenological research it is imperative that the researcher be sensitive to the challenges and ethical issues associated with the process of gathering information face-to-face from participants, spending considerable time in intimate conversations with each participant, as well as the fact that the interview sessions may be taking place in very personal spaces, such as an agency that delivers health care services to that person. Additionally, given the potential for spending long periods of time at a given research site, and becoming closely affiliated with only select

attendees at that site, certain facility-specific issues existed that needed to be taken into consideration. The potential issues of concern are addressed within the following section, as well as within the previous list of issues addressed with the gatekeepers of each 'host' site.

Guiding Ethical Principles

Given the nature of this study, a Certificate of Approval needed to be procured from the Human Research Ethics Board (HREB) of the University of Victoria, before commencing research. The decision for the HREB to grant approval for research was based on their evaluation of the researcher's submission of an 'Application for Ethics Approval for Human Participant Research'. When evaluating research, the HREB adopts the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS). The TCPS sets the minimum standard required for ethics review of research that involves human participants. The guiding principles of the TCPS are summarized as follows:

1. **Respect for Human Dignity:** The cardinal principal of modern research ethics is respect for human dignity. This principle aspires to protecting the multiple and interdependent interests of the person – from bodily to psychological to cultural integrity. This principle forms the basis of the ethical obligations in research that are listed below.
2. **Respect for Free and Informed Consent:** Individuals are generally presumed to have the capacity and right to make free and informed decisions. Respect for persons thus means respecting the exercise of individual consent. In practical terms within the ethics review process, the principle of respect for persons

translates into the dialogue, process, rights, duties and requirements for free and informed consent by the research subject.

3. **Respect for Vulnerable Persons:** Respect for human dignity entails high ethical obligations towards vulnerable persons – to those whose diminished competence and/or decision-making capacity make them vulnerable. Children, institutionalized persons or others who are vulnerable are entitled, on grounds of human dignity, caring, solidarity and fairness, to special protection against abuse, exploitation or discrimination.
4. **Respect for Privacy and Confidentiality:** Respect for human dignity also implies the principles of respect for privacy and confidentiality. Standards of privacy and confidentiality protect the access, control and dissemination of personal information. In doing so, such standards help to protect mental or psychological integrity.
5. **Respect for Justice and Inclusiveness:** Justice connotes fairness and equity. No segment of the population should be unfairly burdened with the harms of research, nor should those who may benefit from advances in research be neglected or discriminated against.
6. **Balancing Harms and Benefits:** The analysis, balance and distribution of harms and benefits are critical to the ethics of human research. Modern research ethics, for instance, require a favourable harms-benefit balance – that is, that the foreseeable harms should not outweigh the anticipated benefits.
7. **Minimizing Harm:** A principle directly related to harms-benefits analysis is non-maleficence, or the duty to avoid, prevent, or minimize harms to others. Research

subjects must not be subjected to unnecessary risks of harm, and their participation in research must be essential to achieving scientifically and societally important aims that cannot be realized without the participation of human subjects.

8. Maximizing Benefit: The principle of beneficence is also related to harms-benefits and imposes a duty to benefit others and, in research ethics, a duty to maximize net benefits. This principle has particular relevance for researchers in professions such as social work, education, health care and applied psychology. As noted earlier, human research is intended to produce benefits for participants themselves, for other individuals or society as a whole, or for the advancement of knowledge. In most research, the primary benefits produced are for society and for the advancement of knowledge.
 - a) In support of the aforementioned ethical concepts, every participant in the study was required to sign a 'Participant Informed Consent Form' (as provided in Appendix C) before being permitted to participate in the study.

Ethical Considerations Specific to Data Collection Stage of Research

During the process of data collection (i.e., face-to-face interviews) many of the aforementioned ethical concerns are highly relevant; however, I was also aware of two issues specific to this particular stage of research that had the potential to arise. The first scenario for consideration was that during the process of explaining what it is like to live with undiagnosed chronic pain a participant might express the potential for significant physical harm, neglect, or death to come to the participant or another individual in society. In such a scenario my contingency plan was to default to the relevant 'limits to

confidentiality' that I normally apply during counselling; most notably that I would breach confidentiality in any of the following four scenarios:

1. I perceive my client to be at serious imminent risk of suicide, or
2. I am made aware of another person who is at imminent risk of serious physical harm or death (i.e., an ethical 'duty to warn' scenario), or
3. I am made aware of a baby/infant/child in need of protection from abuse or neglect, or
4. I am made aware of a vulnerable elderly person in need of protection from abuse or neglect.

Having stated this, in order to maintain high ethical standards, I informed each participant of these limitations to confidentiality at the beginning of their research interview session.

A second potential ethical issue associated with the data collection process was that of a client who might become significantly emotionally upset as a result of sharing elements of their personal story with me. This touches upon the aforementioned principle of 'non-maleficence' (i.e., duty to avoid, prevent, or minimize harms to others), and as such, I perceived myself as having an ethical obligation to ensure each participant was feeling emotionally stable before exiting the immediate interview area. To maximize the likelihood of this, I implemented a two-fold strategy. Firstly, if I perceived that a participant had become significantly emotionally 'triggered' as a result of the content of our research interview, I applied my counselling skills (as appropriate to the individual's presentation) to provide them with an opportunity to explore these feelings, while concurrently remaining focused on drawing them out of their state of deep emotion to a

more ‘surface’ level, so that they felt sufficiently composed to terminate the interview session. The focus of this strategy was not to provide therapeutic ‘treatment’ per se, but to offer support using my counselling skill set in order to facilitate the individual’s return to an emotionally stable place. The second strategy I used was to offer each participant written information regarding counselling resources available in their community (as provided in Appendix D), in the event that they wished to continue processing thoughts or emotions that the research interview might have inadvertently triggered. However, when providing this resource list, if a participant had requested to see me as a counselling client (i.e., in a clinical role, beyond the scope of the research study), I would have declined their request, and explained to them that I am unable to see them in the role of counsellor, because to do so would be a conflict of interest. Although this never transpired with any of the research interviews, it is important to note that a plan was in place in the event that such a request was expressed. Within both tiers of this strategy the overriding principle in place was that the research setting was not intended to serve a therapeutic function, nor was that congruent with my exploratory role as researcher; and thusly the aforementioned counselling-related strategies were solely used for the purpose of ensuring that clients did not leave an interview session, or the study in general, in an inappropriately vulnerable state.

Ethical Considerations Specific to Data Handling Aspect of Research

The handling of research data comes with certain ethical responsibilities to be borne by the researcher. Given the fact that the hermeneutic phenomenological framework of this study tends to create highly personal data as compared to many other research approaches, the rights, privacy, and well-being of this study’s participants needed to be

fully protected. To this end, I used a coding system to exclude participants' names from being visually available to others, which was critical given the fact that some of the research data collection was undertaken within public venues (i.e., identified 'host' sites). I assigned alphanumeric codes to each participant, and these codes were used to identify and label audiotapes, file folders, and typed interview transcriptions. A 'master list' of these codes (i.e., cross-referencing alphanumeric codes with participant names) was kept off-site in a separate, locked filing cabinet, within my own secure professional office. Only I (as sole researcher) was privy to the names and contact information on this list. Lastly, upon completion of the study and the related academic defence, all identifying information (i.e., master list, audiotapes, rough notes, transcriptions, and signed consent and intake forms) will be destroyed.

Data Collection

Interview Process

This study used a language-based means of data collection in which participants engaged in a series of interviews, with the goal of exploring their experience of living with undiagnosed chronic pain. Growing usage of interviews as a research instrument within the qualitative research paradigm suggests a growing acknowledgment of the philosophical conceptualization that 'reality' is *socially constructed* (i.e., consistent with a relativistic ontological perspective), and *language* serves as the primary medium for its construction. Remaining true to hermeneutical principles that understanding is inherently participative, conversational, dialogic, and interpretive; the research interview is a dialogue between the researcher and participant about the participant's understanding of the social construction of 'reality' and their experience of it (Kvale, 1996). Hermeneutic

traditions are therefore particularly pertinent within the process of engaging in interview research, as they strive to understand the *meaning* individuals give to their lived experiences. Within this study's overarching hermeneutic phenomenological framework, then, the research interview provided a venue for each participant to describe their lived experiences in rich, vivid, detail so that the invariant 'essences' and meaning of those experiences could be drawn out (i.e., phenomenologic tradition). These 'essences' of participants' lived experiences were thus captured dialogically through language, while always acknowledging that this is inevitably an interpretive process (i.e., hermeneutic tradition).

Elaborating on these concepts, Mason (2006) asserts that when using interviews as a means for data collection within qualitative research:

Your *ontological* position suggests that people's knowledge, views, understanding, interpretations, experiences, and interactions are meaningful properties of the social reality which your research questions are designed to explore ... you should have an *epistemological* position which allows that a legitimate or meaningful way to generate data on these ontological properties is to talk interactively with people, to ask them questions, to listen to them, to gain access to their accounts and articulations, or to analyse their use of language and construction of discourse (p. 63).

Therefore, it is essential that a logical congruency be interwoven throughout the ontological, epistemological, and methodological decisions surrounding the purposeful use of interviews within qualitative research. However, Mason also cautions that the researcher should:

Be fully aware of the epistemological implications of this approach, and you will have to be quite self-critical in judging how well interviews can provide all of this. For example, if you are interested in people's experiences or understandings ... these can only be *constructed* or *reconstructed* in interviews, and of course the interview method is heavily dependent on people's capacities to verbalize, interact, conceptualize and remember. It is important not to treat understandings generated in an interview as though they are a direct reflection of understandings 'already existing' outside of the interview interaction, as though you were simply excavating facts (p. 64)."

Giving consideration to these cautionary statements is essential not only for appropriate and effective use of data generated through an interview strategy, but also because they remind the researcher of the lens through which they are viewing every element of the research process. These statements are also congruent with concepts promoted by Wilber (as cited in Black, 2004) that a participant's qualitative representations of internal experiences are exactly that, mere *re-presentations* of internal experiences that are actually invisible to any manner of direct observation.

These considerations also served as a valuable reminder that although I was accessing some of my core counselling skills to facilitate effective communication during the research interviews, I was *not* adopting a counsellor mindset promoting any manner of therapeutic movement for the client. Simply put, my role was to remain scientifically curious and exploratory; not to act as an 'agent of change' for the participants.

A semi-structured interview model was utilized for this study in order to best meet the needs of the research question. If one conceptualizes potential interview approaches on a continuum, the semi-structured approach would fall in the mid-range, between the relatively casual engagement of an ‘unstructured’ interview (i.e., in which the researcher and participant exchange ideas and dialogue around an agreed upon topic, but without a rigid set of pre-planned questions or direction), and the ‘structured’ interview (i.e., in which the researcher poses a series of predetermined questions, and does not venture outside of the pre-planned set of parameters). By way of contrast, within a well-conducted semi-structured interview there should be a relative ease of dialogue, while concurrently maintaining a clear sense of focus. Mason (2006) provides an eloquent description of this when she notes that the participant should be left with a feeling like they have been engaging in “conversation with a purpose” (p. 67).

A key advantage to using a semi-structured approach to interviewing is that it provides a reasonable degree of flexibility for both the interviewer and interviewee to feel as though their communication needs are being met, while simultaneously accomplishing the primary task that brought them together in the research setting. I found it helpful to conceptualize the interview as a metaphorical ‘dance’, in which both partners had the opportunity to ‘take the lead’ at various points within our shared time together. As interviewer I was afforded the opportunity to introduce prepared questions or issues that I viewed as being important to the research question (as provided in Appendix E); however, ample space and flexibility was also made available for the participant to ‘take the lead’ and define the direction they would like the conversation to proceed in the exploration of their lived experiences. Johnson and Johnson (2003)

underscore the importance of this mutual, cooperative approach, asserting that it is vital for making the participant feel acknowledged, validated, and accepted by the researcher, which are essential elements in the building *trust*. Acceptance in particular is the key to reducing anxiety and fears about being vulnerable, and I felt it was pragmatically and ethically imperative for me as the researcher to remain fully aware that by delving deeply into a participant's lived experiences, examining the meaning they attach to these experiences, and sharing this information with me, the participants were allowing themselves to become highly vulnerable. Therefore, as a researcher within the context of a semi-structured interview I made every effort to fully attend to each participant's story and listen empathically, while acknowledging the trust they were placing in me.

The value of empathy in the context of a research interview is emphasized in the phenomenological doctrine of 'Verstehen', which means 'understanding', and refers to the unique human capacity to make sense of the world. Patton (2002) elaborates by stating that this Verstehen doctrine presumes that human beings have a unique type of consciousness as compared to other life forms, and this capacity for 'empathic understanding' combines cognitive understanding with affective connection, such that the researcher can take and understand the positions, feelings, experiences, and worldview of the interviewee. The tradition of Verstehen places emphasis on the human capacity to know and understand others through empathic introspection and reflection, based on direct observation of, and interaction with, these other people. I believe that the semi-structured interview approach provided an effective means for honouring this tradition of Verstehen.

From a more practical standpoint, although the semi-structured qualitative interview approach offers many advantages to the research process, it also presents a unique set of challenges for the interviewer. Rather than having the luxury of following a rigid predetermined 'script', the researcher operating within a semi-structured interview format must be prepared to quickly 'think on their feet' while remaining effective, coherent, and congruent with the spirit of their research question. Given the essentialness that the interview interaction actually generates usable, relevant data, the qualitative interviewer must simultaneously orchestrate the intellectual and social dynamics of the interview scenario to this end. The goal in this regard is consistent with the aforementioned concept of 'Verstehen' as outlined by Patton (2002), such that there is a concerted effort on behalf of the interviewer to establish a level of rapport, trust and empathic understanding that will enable the participant to feel sufficiently safe and supported to delve deeply into their lived experiences, some of which may be emotionally challenging or painful for them. Mason (2006) provides the astute observation that this is where effective interviewing shows itself as both an art and a science; striking a balance between simply having a pleasant interpersonal encounter whose content actually has little or no bearing on the intellectual puzzle which the research is designed to address, and the opposite end of the spectrum whereby excessive attention to asking the 'right' questions in the 'right' order can generate an awkward and unnatural social dynamic that may be equally unsatisfactory. Thus, as a qualitative interviewer I found myself faced with the challenging task of making on-the-spot decisions regarding the content, sequence, and tone of the interviews such that they

progressed smoothly, without sacrificing the organic ‘alive’ nature of this most human and personal of interactions.

Interview Setting

The formal ‘research interviews’ were arranged upon completion of the ‘screening interviews’ (i.e. the preliminary brief interviews conducted over the telephone to confirm each participant’s appropriateness for inclusion in the study). Each research interview was conducted at a time and location that were mutually agreed upon between the participant and myself. In the end, this ended up being either a reserved room in a rehabilitation clinic, or the use of my own professional office. Regardless of the location, I ensured that a private space was made available for the interviews where others could not observe or listen to our conversations. The importance of securing such a private space was two-fold. Firstly, it was an important step in ensuring the confidentiality of information divulged during the interview process. Secondly, it provided both the interviewer and interviewee with a space that was relatively free from distractions, in order to facilitate each participant’s ability to access deeper cognitions or emotions that might otherwise have remained inaccessible. My own experiences as a counsellor have taught me the value of ‘quieting’ my mind, remaining ‘mindful’ and fully present during counselling interactions. I have found that this sets the stage for establishing a deeper and more personal connection with my clients, which facilitates them in going deeper into their process, and enables me to follow. I perceive that for the same reasons, selecting a quiet, private, calming space was of benefit when completing the research interviews.

Symptom Accommodations during Interviews

Given the nature of this study, it was reasonable to assume that participants would be experiencing pain while engaging in the interview process, particularly if the nature of their symptoms are such that sustained static postures exacerbate their pain. Although this challenging element associated with participation in the interview process was unavoidable, accommodations were made in order to make the process as comfortable as possible. More specifically, participants were informed that they would not be required to remain seated throughout the entire duration of the interview, and should feel free to alternately stand or walk about the room as they are interviewed, which did occur on two occasions. Participants were also informed that they could be afforded short breaks as needed, in an effort to offset any fatigue that may develop as a result of the interview process, or to allow pain to settle. Lastly, it was decided in advance that if a client had reported that their pain or fatigue were escalating to a point where they felt they could no longer reasonably continue, the interview would be terminated and a decision would be made regarding rescheduling another session, depending on how close the interview had progressed towards its natural termination point. Although this never transpired within any of the research interviews, it is important to note that a plan was in place in the event that a participant had expressed such a request.

Data Management

I assumed the position of sole interviewer, to ensure consistency in approach, and to provide me with the opportunity to guide the direction of the interviews towards an end that would meet the requirements of my research question. Acting as the sole interviewer also provided me with the first-hand opportunity to observe changes in facial expression

or body language that provided valuable context to participants' spoken words. The interview sessions were audio-recorded, to prevent the potential for distractions and inaccuracies associated with the alternative of my taking extensive handwritten notes during the interview process.

The next stage in the management of the data was for the content of the audiotapes to be transcribed verbatim. I personally completed all of the transcriptions, as I viewed this as a golden opportunity to fully 'immerse' myself interpretively within the data. I subsequently mailed a copy of their respective interview transcript to each participant, and included a letter in the package requesting that they carefully read the transcript of their interview and verify that the text has accurately captured the experiences, thoughts, and feelings they were attempting to communicate to me within the context of their research interview. The accompanying letter also stated that participants have the right to request the removal of any text portions that they do not wish to be included in the analysis. Subsequently, I contacted each participant by telephone approximately two weeks later, in order to determine if there was a need to make adjustments to the transcribed text as per each participant's direction and guidance. In this regard, every participant indicated they were satisfied that the content of their transcript captured what they had attempted to communicate regarding their experience of living with undiagnosed chronic pain, and no requests were made to delete portions of text.

Treatment of Data

Before progressing to the specific data management model that was utilized within this study, a brief review is warranted to clarify the union between principles associated with the theoretical frameworks of phenomenology and hermeneutics. In an attempt to

resolve the inherent tension generated by the contrasting elements of these two approaches, it should be restated that hermeneutic phenomenology as a research approach remains attentive to both of the core terms that reference its philosophical origin. More specifically, when considering the treatment of data within the current study, it was a descriptive (phenomenological) approach because it strove to be attentive to how things appear, wanting to let things speak for themselves; yet it was also interpretive (hermeneutic) because it maintained the perspective that uninterpreted phenomena do not exist. Any initial sense of contradiction can be resolved if one acknowledges that the (phenomenological) ‘essences’ of lived experience are always meaningfully (hermeneutically) experienced. These ‘essences’ of lived experience need to be captured dialogically through language (in this case through the use of research interviews), and this is inevitably an interpretive process.

Adopting this perspective enables one to freely let go of certain more traditional elements of phenomenology such as Husserl’s original data management strategies of ‘bracketing’ and ‘reduction’ to which Heidegger vigorously opposed. The goal of the data management process in the current study was to come to a point of *understanding* of participants’ experiences of living with undiagnosed chronic pain, and to access the *meanings* they attach to the various elements of this ongoing life-process, by fully exploring each participant’s unique lived experiences, self-knowledge, and personal understandings, leading to the creation of co-constructed ‘social knowledge’ between myself as researcher and each participant. The original raw data generated from the research interviews was inherently participative, conversational, and dialogic, and it is through this connection to language that we see that ‘understanding’ is something

produced in dialogue. Having accepted this, it should also be acknowledged that the interview transcripts also fulfilled a pragmatic function, serving as records of the language invoked in the process of developing this shared social knowledge. These language-based records enabled a subsequent exploration of the data in an attempt to uncover deeper meanings, while remaining ever aware that each reader's personal interpretations would be formed against the backdrop of their particular personal, sociocultural, and historical context.

Data Management Model

The specific approach for analysis of data within a study must remain true to the nature of the research paradigm being adopted. In the case of this study, one of the primary goals of phenomenology is to elucidate hidden experiences and bring them into awareness, which involves refining the data in such a way as to reveal the *essence* of each participant's lived experiences. To this end, the data analysis procedure I employed was characterized by the following procedural steps:

1. Each of the participants' experiential descriptions (i.e., captured via interview transcriptions) was initially read once 'straight through' in order to acquire an overall feeling for what was being expressed. To clarify, this means that I read each transcript in its entirety without interrupting the flow by taking any notes, or by engaging in analytical discussion with colleagues.
2. For each verbatim transcript, I completed the following steps:
 - a) Considered each statement with respect to its significance for description of the 'target' experience (i.e., the lived experience of undiagnosed chronic pain).

- b) Recorded all statements deemed to be relevant to this 'target' experience.
 - c) Listed each non-repetitive, non-overlapping, relevant statement, and treated each statement as having equal worth. In phenomenology terms, these are typically referred to as the 'meaning units' of the experience.
 - d) Related and clustered these 'meaning units' into themes.
3. Considering transcript data from all of the participants, I completed the following steps:
- a) Cross-referenced themes across all of the participants' data, to identify which themes were present for every single participant (i.e., this was necessary to meet the criteria for an experience to be deemed 'essential' regarding living with undiagnosed chronic pain).
 - b) Synthesized and organized the themes that were present for every participant into written *textural-structural descriptions* (i.e., descriptive paragraphs of the meanings and essences of these invariant elements of participants' lived experiences). These written descriptions were founded upon the interpretations of the data developed through extensive collaboration between my thesis supervisor and myself.
 - c) Verbatim supporting quotations were assembled for the purpose of representative illustration. The criteria was that each quotation must be able to 'stand alone' in communicating the core experiential element(s) of the theme it was chosen to support.

In considering the above method, it should be noted that I was required to make a decision whether to analyze the transcribed interview data by hand, or through the use of

computer analysis. As such, I chose to complete a hand analysis of the data. I perceived this to be an approach that I was most comfortable with, given the manageable volume of data required for analysis, as well as my ability to commit the time and energy to this labour-intensive method of analysis, and the fact that I preferred to situate myself as intimately as possible in relation to the data. I subsequently found that the process of manually sorting, locating, organizing, and coding textual words and phrases afforded me the ‘hands-on’ feel for the data that I was seeking, avoiding the sense of distance that I perceive would have been instilled via the mechanistic intrusion of a computer analysis approach.

Reflexive Process

Given the highly personal nature of hermeneutic phenomenology, it is only natural to assume that as I listened to the thoughts and feelings of participants, an interrelated series of thoughts and feelings might be aroused within myself. Moreover, because researchers within this qualitative research paradigm believe that one’s personal views can never be kept separate from interpretations, the researcher’s personal reflections about the meaning of the data are deemed to hold great value within the broader context of the study (Creswell, 2005). In the spirit of this, I endeavoured to consistently engage in a *reflexive process* by monitoring my self-reflections both ‘in the moment’ of the research interviews, as well as immediately following each interview by using a personal journal as a recording and processing tool regarding any poignant thoughts or feelings that were aroused during the interview process. I found the exercise of journaling after interviews to be of particular value, as I believe that the cognitive exercise of translating internal thoughts into written word served to assist me in the process of thoroughly

synthesizing and integrating my experiences, cognitions, and affective experiences. The act of journaling itself also acted as a safeguard, keeping me consistently aware of the biases, presuppositions, and prejudices that I harboured as part of the 'lens' through which I viewed and interpreted every aspect of the research process.

As an example of how such reflexive processes were actually implemented during the research process, I offer two examples of excerpts from journal entries that were completed immediately following research interviews. The first excerpt refers to the interview that was conducted with participant (A3):

Throughout (A3)'s interview I found myself struggling with a 'second dialogue' going on inside my head, as she strongly reminded me of a prior physiotherapy client who had also been struggling with issues of chronic pain. From the moment (A3) walked into the office I was struck by the physical resemblance to this other individual, and when she opened her mouth I was nearly floored by the fact that even her voice was a near-match to this past client of mine. This required me to focus particularly intensely during her interview, as I found myself thinking thoughts such as: "That's just what (the other client's name) would have said!" ... and then I began to question to what degree this recollection might be colouring my listening skills and the very manner in which I was posing questions and interacting with (A3). I found that I was 'catching' myself from assuming that she had some of the similar life challenges as my prior client, such as being on the verge of marital break up, and financial concerns regarding potentially losing her house as a result of the income loss from her inability to work. It felt strange to be doing my utmost to

fully attend to (A3) while simultaneously having such a running dialogue in my own head ...

A second illustrative example of how I engaged in the reflexive process during and after research interviews can be offered in the following excerpt from a journal entry regarding my interactions with participant (A1):

I just finished the interview with (A1) and I am feeling a sense of relief, as much of our shared interview time was emotionally charged with his expressions of anger and frustration, most notably regarding how he has been treated by the insurance company and his family physician. I was also surprised by how agitated he became when describing his shock and disappointment over the lack of understanding he is receiving from his daughter. At various points throughout the interview (A1)'s volume of speech got so loud and with such an angry tone (including frequent use of profanity) that I was afraid someone from the office next door might knock on the door to make sure everything was okay. This made it quite difficult to concentrate at certain points, as I was feeling conflicted about whether I should request that he lower his volume of speech, yet I certainly did not want to restrict the spontaneous flow of his connection to emotions, or to censor the genuineness of his explanations of his lived experiences. As I write this journal entry I realize that although I did not feel any concerns for my safety, I must acknowledge that the intensity of (A1)'s emotions did diffuse into me somewhat, as I am now aware of a physical feeling of 'coming down' from a bit of an adrenaline surge ...

I have offered the above two journal entries to provide a sense of the nature of the content that I was recording in my journal entries, as well as to illustrate how my

cognitive-emotional reactions to each participant would inevitably become part of the process of co-constructing social knowledge. Building upon the this assertion, it should be reiterated that hermeneutic proponents assert that there is no question as to ‘*if*’ the researcher’s presuppositions will impact their interpretations of the interpretations being put forward by the participant (i.e., this is unavoidable, as it is an essential element of our humanness), but rather emphasize the need to be fully aware of one’s role in the co-construction of ‘reality’. Therefore, the researcher is ethically compelled to use the process of reflexivity in order to take every reasonable step to bring a sense of transparency to their relevant cognitions, feelings, and presuppositions, so that they can be openly acknowledged and weighed by both the researcher and the greater academic audience.

Critically Analyzing the Research

Throughout the process of data collection and analysis, a researcher, regardless of the research paradigm they are adhering to, should be concerned with ensuring that their findings and interpretations of data are as accurate or as representative as possible. However, there is widespread debate about how concepts such as ‘validity’ and ‘reliability’, which are fundamental tenets within the *quantitative* research realm, translate into the *qualitative* research realm. Some researchers state that these (and similar) conceptualizations can relate, although a process of ‘translation’ needs to occur such that the terms used to describe these concepts, and their associated meanings, are tailored to the qualitative paradigm. Other researchers refute the idea altogether, asserting that given the fact that the qualitative research paradigm is built upon completely different foundational ontological and epistemological assumptions (as

compared to the quantitative paradigm), traditional ‘positivistic’ concepts such as validity and reliability are completely inappropriate. Simply put, they purport that the basic concepts of ‘validity’ and ‘reliability’ have no actual meaning within the qualitative realm, because the paradigmatic frames of reference are those for which they were never intended.

Although the broader research world has yet to come to a point of consensus in this matter, I believed it was important to take a committed stance and implement some manner of formal strategy for critical analysis of my qualitative research, if, for nothing else, to hold myself accountable to the establishment of scientific merit (i.e. broad empiricism) and rigor within this research study. In this vein, I made the decision to adhere to a series of criteria based primarily on the work of Guba and Lincoln (1989). More specifically, these authors, having recognized the need for different language that would fit the specific needs of the qualitative paradigm, have provided a series of quantitative-to-qualitative linguistic and conceptual *translations* such that ‘credibility’ is equated with internal validity, ‘transferability’ is equated with external validity, ‘dependability’ is equated with reliability, and ‘confirmability’ is equated with objectivity. In order to meet the unique needs of the qualitative research paradigm, these authors also added ‘authenticity’ as a qualitative-specific criterion for the evaluation of rigor.

When considering the need for tools to assess the merit of qualitative research, it is important to remain cognizant that, as in virtually every aspect of qualitative research design, a ‘one size fits all’ approach is simply not feasible. Speaking to this issue, Krefting (1991) notes that given the pluralistic nature of qualitative research, and the fact

that the various methodologies within this paradigm have different purposes and methods, there is a need for multiple ways of determining the quality of this research, which entails a need for differing criteria of rigor. Keeping this in mind, and the nature of hermeneutic phenomenology, the following points outline the primary criteria and means for implementation that I decided were most applicable to the current study.

Credibility

Within a qualitative framework, credibility is offered as a parallel to the positivistic concept of internal validity (Guba & Lincoln, 1989). By way of contrast, when working within a positivistic framework, internal validity is based upon a fundamental paradigmatic assumption that there is single tangible reality to be measured (i.e., realist ontology). However, when working within a hermeneutical phenomenological framework, this assumption is replaced by the concept of multiple realities (i.e., relativistic ontology), and as such, the researcher's responsibility becomes one of representing those multiple realities revealed by participants as accurately as possible. In qualitative research, then, the credibility test asks if there is a strong correspondence between the ways in which participants actually *perceive* social constructs, and the ways in which the researcher *portrays* their points of view. Lincoln and Guba (as cited in Krefting, 1991) describe this as the 'truth value' of research, in that this criterion establishes how confident the researcher is with the truth of the findings based on the research design, the specific participants involved, and the research context. A study can be thought of as having high credibility or 'truth value' when it presents such a detailed and accurate description or interpretation of human experiential phenomena that people who also share that same experience would immediately recognize the descriptions.

Researchers have at their disposal a number of means and strategies by which they can enhance credibility, and should endeavour to utilize as many of these strategies as possible because the goal is to provide compelling evidence from multiple sources regarding the credibility of one's research. That being said, I will now outline each of the credibility strategies that I incorporated into the current research study.

Prolonged and substantial engagement.

This first credibility strategy called for me as the researcher to maintain 'prolonged and substantial engagement' with the participant (Guba & Lincoln, 1989). Within the context of a hermeneutic phenomenological study what constitutes a 'substantial' degree of engagement will be determined by the concept of 'saturation' as described previously within this chapter. More specifically, once I had confidence that the dialogic themes arising from the research interviews were repeating themselves instead of extending, and I perceived that no new information or insights were adding to the current list of themes or to the level of detail of the existing themes, a sufficiently substantial level of engagement was deemed to have been realized.

When engaging in this study I needed to remain aware that 'prolonged and substantial engagement' with study participants posed both benefits and risks as to the study's credibility. Spending extended periods of time with a participant can facilitate the development of a stronger rapport with the individual, leading to higher comfort levels and the sharing of more sensitive information than they might have volunteered at the beginning of the research interview process. This can be of great benefit as this process of sharing sensitive, or possibly even painful, personal stories may be essential for truly accessing core elements of a participant's 'lived experience'. However, Krefting

(1991) points out that a paradox exists in that the closeness of the researcher-participant relationship can also introduce a threat to the credibility and ‘truth value’ of a study via the deep enmeshment that can occur. Relationship depth to the point of ‘over-involvement’ can cause a researcher to have difficulty separating their own experience from that of the participant, compromising the researcher’s ability to interpret findings. In this regard, I strove to remain aware of this risk, and I used the process of *reflexivity* as a means to keep this threat in check. Reflexivity refers to a process of ongoing self-assessment of my own background, perceptions, and interests with regard to the way these factors influence my interpretive process. As has been noted previously, a researcher’s background inevitably will dictate the framework from which they will organize, study, analyse, and interpret research findings. In my case, it was important for me to remain cognizant of, and reflect upon, my prior professional experiences in working with a chronic pain population, as well as the influences of several roles I was concurrently assuming that are all directly related to the study topic. More specifically, I was simultaneously a researcher, a counsellor, a physiotherapist who has had a multitude of clients with undiagnosed chronic pain, and a human being who has had my own personal experiences with pain.

I also perceive that my use of a personal journal, as noted previously, played a crucial role in my ability to monitor my own process, cognitions, feelings, and presuppositions, such that I was able to connect deeply enough with participants so that their core experiences were accessible to me, yet not so deeply that I would ‘lose my way’ in the process. By doing so, I perceive that I was able to remain aware of, and

responsive to, possible threats to credibility, in order to maintain high standards of rigor within this study.

Peer debriefing.

A second credibility strategy involved the use of ‘peer debriefing’ (Guba & Lincoln, 1989). This entails the researcher engaging in extended discussions with impartial colleagues, including discussions of raw findings, the data analysis process, and conclusions. In this context, colleagues can play an important role in enhancing ‘interpretive credibility’ by checking thematic categories that were developed out of the interview transcript data, and looking for disconfirming or negative cases. In the current study these ‘debriefings’ included dialogue with both ‘interested’ peers (i.e., individuals with a vested interest in the research study) such as my thesis supervisor, as well as individuals that Guba and Lincoln would refer to as ‘disinterested’ peers (i.e., individuals with no vested interest in the outcome of the study) such as one colleague who is a psychologist, and my spouse who works in health care yet has no formal counselling or research training. By accessing these diverse individuals I was provided with a curious and informed audience with whom to share insights, perceived problems, and anticipated roadblocks. Rigor was further added by the fact that these peers made a purposeful effort to pose explorative questions that helped me, as a researcher, consult my own values and reflect upon the research process to date in order to optimally prepare for subsequent phases the study. Lincoln and Guba (as cited in Krefting, 1991) suggest that this is one way of keeping the researcher ‘honest’, recognizing an added benefit in that probing questions from one’s peers may also contribute to deeper reflexive analysis by the researcher, which contributes to the overall transparency and credibility of the study.

Progressive subjectivity.

A third strategy for enhancing credibility involved the use of ‘progressive subjectivity’, whereby as the researcher I made every effort to monitor my developing constructions, documenting the process of change from the beginning to the end of the study. This strategy has linkages to the aforementioned ‘peer debriefing’ process, as it enabled me to share my beliefs with selected peers so that they had the opportunity to challenge me if they perceived that I had not kept an open mind. Essentially, this process acts as a credibility safeguard by preventing a researcher from merely confirming what they expected from the very beginning (i.e., threat of their prejudgments becoming a *self-fulfilling prophecy* as to the study’s preordained conclusions). This is congruent with concepts promoted by Gadamer (as cited in Denzin & Lincoln, 2000) that the researcher’s goal should not necessarily be to free oneself of all prejudgment, but to examine one’s unreflectively held prejudices, and attempt to alter those that disable our efforts to understand others, and to understand ourselves. For example, given the fact that I had worked extensively with chronic pain clients for nearly two decades in a professional role as a physiotherapist, it was virtually a given that I would enter into the research setting harbouring certain preconceived notions about what it might be like for an individual to live with undiagnosed chronic pain. This undoubtedly had a conscious or unconscious effect on how I engaged in conversations with study participants, as well as how I interpreted the content of interview encounters. It would seem unreasonable to claim otherwise. Notwithstanding, by drawing upon Guba & Lincoln’s (1989) concept of ‘progressive subjectivity’, the issue of preconceived outcomes, when viewed as a threat to credibility, was deemed to have been kept reasonably in-check through the use of self-

reflection and frequent debriefing with my thesis supervisor over the duration of the study. By fostering awareness of my own cognitive constructions, and inviting insightful probing and questioning from my thesis supervisor, I was able to not only accept that prejudgments to some degree are inevitable, but also to offer them up for close examination. By doing so, I perceive that I did my utmost to avoid the study's results and conclusions from merely becoming a foregone conclusion.

Authority of the researcher.

Credibility was also be enhanced in a fourth way via the 'authority of the researcher', which refers to the concept whereby one can view the hermeneutic phenomenological researcher himself/herself as a human investigative instrument or measurement tool. Krefting (1991) asserts that the authority to serve as such a research instrument is based upon a researcher's background or special training that might be relevant to a given study. In the case of this study, I perceive that I brought authority based on my current Masters degree training in counselling, my years of background training as a physiotherapist, and my skills training that was undertaken specifically as preparation for this study.

I perceive that my counselling training was of great value, as it has given me a high degree of skill regarding active listening, effective interviewing, the capacity for empathic understanding, and the unique ability to develop trusting relationships with relative strangers within a short timeline. This ability to develop a personal connection with others was essential in order to provide participants with the sense of *safety* that they needed in order to go deeply into their personal process, and access core elements of their 'lived experiences'.

I perceive that my background clinical experiences as a physiotherapist were also of value by helping me to maintain a calm, relaxed, focused presence when facing individuals who were obviously in pain, thus not compromising my ability to keep mentally on-task with the purpose of the research interview, while concurrently being able to respond empathically to their physical and verbal pain presentation. One participant in particular (A4) was quite overt in her demonstrable behaviours that I perceived as signs of significant pain. Specifically, at numerous points throughout the interview she would wince or sharply inhale in what appeared to be a response to ‘jabs’ of back pain, and when (A4) decided to change her position by standing up at one point during the interview it was evident that her quality of movement when rising from her chair had become visibly slow and cautious in response to escalating pain. Thus, I perceived that my ability to remain calm and ‘grounded’ in light of such participant demonstrations of pain was of benefit by helping me to keep mentally focused during the interview process, as well as by helping the participants to maintain a reasonably relaxed state in spite of their discomfort.

Specific to this study, I also perceive that the skills-enhancement training that I undertook prior to initiating the series of research interviews also enhanced my effectiveness and credibility as a researcher. More specifically, my thesis supervisor worked with me to develop speech patterns and methods of inquiry that fit with the goals of qualitative research, and I also conducted mock practice interviews with my spouse. These training regimens honed my research-specific skill set, and sharpened the necessary distinctions between the interviewing and history taking approach that I would

typically utilize as a counsellor or physiotherapist, as opposed to strategies that were necessary for me to be an optimally effective interviewer in my role as researcher.

Member checks.

A fifth, and arguably the most important, strategy in the establishment of credibility in this qualitative study was that of ‘member checks’ (Guba & Lincoln, 1989). Member checking is a technique that consists of sharing research materials with study participants to ensure that the researcher has accurately translated the participants’ viewpoints into data. An example of a relatively informal check would be my paraphrasing of what a participant had said in their interview, such that the participant could immediately inform me as to whether I have accurately captured their perspective. Alternatively, in the current study a more formal use of the member checking strategy was invoked when I verified with each participant the ‘essential’ themes that had been extracted from the interview data. This requirement for every participant to verify every experiential theme before they were deemed to be ‘essential’ played a key role in ensuring a satisfactory degree of thematic credibility in this study.

Although member checking serves as a valuable strategy for the enhancement of study credibility, Krefting (1991) notes that this process does not come without certain risks. When feeding information back to participants I needed to be aware of the potential that certain participants might not be conscious of some of the information that the interview process may have accessed, and a potential existed for them to become cognitively or emotionally troubled when made consciously aware of it. Also, I needed to be cognizant of the fact that participants may potentially internalize some of the information that I have paraphrased back to them as part of the interview process of

checking for accuracy. This is a factor for consideration because if a participant internalizes *my* constructions as researcher, it could potentially affect their subsequent responses. Although I perceive these to be relatively minimal factors for concern given the nature of this study, they are still factors that I needed to be ethically and methodologically aware of.

Transferability

Guba and Lincoln (1989) offer transferability as a qualitative parallel to the positivistic concept of external validity. Within the quantitative research paradigm, external validity refers to the degree to which you can *generalize* the results to other situations and to the larger general population. By way of contrast, in qualitative research, the ‘burden of transferability’ is on the reader to make their own determination regarding the degree of similarity between the study context and the receiving context, whereas the researcher’s responsibility is to provide sufficient detail to enable the reader to make such a judgment. For the reader to be well poised in this regard, the researcher must provide what is termed ‘thick description’, supplied by careful and thorough description of the time, place, and context of the study and its participants, which I have endeavoured to do in the case of this study. Just as Gadamer (as cited in Denzin & Lincoln, 2000) introduced the notion that our sociocultural-historical traditions shape our own prejudgments and efforts to understand (i.e., both as researcher and academic reader), it is equally important for us to gain a clear sense of these elements as they relate to the research site and its participants. By fully absorbing the ‘thick description’ offered by the research author, a reader can make a determination as to how similar the context they are interested in compares to that of the study, and thus draw their own conclusions

as to the level of transferability or ‘fittingness’ that is merited between the study findings and their real-world context of interest. Lincoln and Guba (as cited in Krefting, 1991) express this quite simply when they suggest that it is not the researcher’s job to provide an index of transferability; rather, it is his or her responsibility to provide an adequate database of information to allow transferability judgments to be made by others.

Dependability

Guba and Lincoln (1989) identify transferability as a qualitative parallel to the positivistic concept of reliability. Within the quantitative research paradigm, reliability refers to stability over time or between researchers. Again, this draws upon the positivistic ontological philosophical assumption of a single reality, that there is some ‘thing’ or singular ‘truth’ out there to be studied that is unchanging, and as such, can be used as a benchmark for rigor. However, if one operates under a qualitative ontological assumption of multiple realities, this notion of reliability, per se, loses its relevance. In contrast to the quantitative mindset which places great value on stability and repeatability, within the qualitative paradigm change is fully expected, however, it should be carefully tracked and made available for public inspection. The key, then, to qualitative research is to *learn* from participants, rather than attempt to rigidly control them. As much as variability is fully expected within qualitative research, the concept of ‘dependability’ implies trackable variability, that is, variability that can be ascribed to identifiable sources. Therefore, although changes of focus and interpretation are entirely acceptable within this paradigm, an element of openness and transparency should be in place, whereby each aspect of change is documented to the degree that a ‘dependability audit’ could be conducted. Such an audit could be initiated by the researcher, or by

members of the greater academic community, in order to attest to the quality and appropriateness of the inquiry process, thus functioning as a measure of scientific rigor. Specifically, in this particular study a dependability audit trail would logically start with the original notes from early discussions with my thesis supervisor and my initial broad scope literature reviews within the realm of chronic pain in general, which ultimately resulted in the development of this study's research question. A second step in this auditing process would entail cross-referencing the content of the original audiotapes with the typed transcripts to ensure accurate data collection. One might also wish to review jotted handwritten notes where comments regarding participant body language or facial expressions were noted. The third step in this process would entail a review of my journal notes, which included thoughts and feelings that arose within me during the interview process, as well as during each stage of the subsequent data analysis process. A fourth step in this audit trail would involve examining the signed forms that were returned by each participant, which indicated they approved of the accuracy and content of their transcript, also indicating that they declined the offer to have any text portion(s) to be deleted from the data analysis process. The fifth step in such an audit trail would involve a review of the rough notes created during the processes of identifying meaning units from each transcript, and ultimately configuring these meaning units into representative themes. This step would also include a review of notes from meetings I had with my thesis supervisor, where various possible thematic interpretations were discussed and 'negotiations for meaning' were conducted. A final step in the audit trail would involve a review of the emails and telephone documentation notes whereby each participant confirmed that they were satisfied that each of the identified 10 'essential'

themes (and associated descriptive paragraphs) that had been forwarded to them did indeed serve as accurate representations of elements of their experience of living with undiagnosed chronic pain.

Confirmability

Guba and Lincoln (1989) identify confirmability as a qualitative parallel to the positivistic concept of objectivity. Within the quantitative research paradigm, objectivity is a foundational concept, such that the influence of the researcher's judgment, values, and biases are minimized in their comprehension of 'reality' (i.e., a central tenet of the objectivist epistemology). By way of contrast, confirmability within the qualitative research context adds scientific rigor by ensuring that the data and related interpretations are not figments of the researcher's imagination. I perceive that this strategy has linkages to the aforementioned 'progressive subjectivity' credibility strategy, whereby processes are in place to prevent the researcher from merely confirming what they expected from the very beginning (i.e., safeguarding against the study conclusions from becoming a foregone conclusion). The confirmability strategy requires that qualitative data must be able to be tracked to its original source (i.e., it is 'confirmable'), and the logic that the researcher used to interpret the data should be made explicit. Again, an element of openness and transparency should be in place, whereby the reader is made privy to the researcher's train of thought. Indeed, to this end, a 'confirmability audit' could be conducted in conjunction with the aforementioned 'dependability audit', so that the 'chain of evidence' between the original source of data and the subsequent interpretations could be adequately scrutinized. Thus as was noted previously, in the current study the interview transcripts, my data analysis notes, and my journal entries

could be made available to determine if the study conclusions are, in fact, supported by the original source-data.

Authenticity

Authenticity, when used as a criterion for judging the quality of qualitative research, does not have a direct parallel within the quantitative paradigm. Guba and Lincoln (1989) added this criterion category because they perceived the concept of authenticity as being critical to qualitative research, regardless of whether or not it has a quantitative equivalent. Essentially, this criterion refers to a study presenting a balanced view of all perspectives, values, and beliefs. It examines the degree of 'fairness' in the researcher's presentation of views. Within the current study this would address the extent to which different constructions are considered and honoured in the research process, including a consideration of divergent perspectives both within myself, and between the study participants and myself. For example, during the data management phase of the study there was a process of negotiation for meaning between myself as researcher, my thesis supervisor, and ultimately with the participants themselves as they ultimately had the 'final say' as to what themes would be deemed to be 'essential' regarding the experience of living with undiagnosed chronic pain. Acknowledging that there is no single inroad to truth, in order to meet the authenticity criteria of fairness, these varying viewpoints and angles of interpretation needed to be given appropriate consideration and fair representation within this final research report.

CHAPTER IV

Results

In this chapter the results of the data analysis are presented. As was noted previously, this involves provision of the 10 themes that were deemed in this study to be ‘essential’ to the experience of living with undiagnosed chronic pain, as well as the associated descriptive paragraph for each theme, and the offering of one supportive quotation from each participant that captures the essence of the associated theme. It should be noted that the researcher’s interpretation of these themes, and commentary linking these themes to the overall significance of the study, is provided in the Discussion chapter.

1. I have tried *everything*

Descriptive Paragraph: Participants conveyed a sense of having tried every feasible health care option; from seemingly endless doctor visits, to searching out and accessing a procession of allied health professionals such as physiotherapists, chiropractors, massage therapists, and counsellors ... yet even after this exhaustive search they find they are *still* suffering from their undiagnosed chronic pain.

- A1: “...you know, like I’ve been to my doctor 750 fuckin’ times in the last two years because of this pain in my back, but there’s nothing wrong with me according to my doctor, well, quote-unquote.”
- A2: “Because when you live with this, day after day after day, and you’ve tried just about everything under the sun. You’ve gone to doctors but they tell you it’s nothing, you’re fine, you’re ...*whatever*. You start to really question yourself, too.”
- A3: “And because I’ve seen *multiple* doctors over the years, and I’ve had everything from, ‘You have juvenile rheumatoid arthritis’, to, you know, ‘You have ankylosing spondylitis with degenerative disc disease and

fibromyalgia', to, 'Oh you have mild osteoarthritis and the rest is all clinical observation, so I'm not going to comment on it' ... and because my husband was military and we've moved a lot, and to be on things like arthritis medication and that, you always have to see a doctor, and you always have to start from square one. Like, no doctor takes another doctor's word for it."

- A4: "I think the reason I fought it so much was because I've actually had an enormous amount of counselling ... particularly, well, I've, I've, I've had *lots* of counselling, let's just say that, so I've been analyzed ... and I've done, uh, like, step-work around my family, and I've, I've worked through a lot of anger issues, with my father, you know, and I've done *a lot* of work ... and I *still* have chronic pain, so ... (large exhale) ... anyway, if it really were just *that*, I think I'd be okay by now ... I, I *think*, you know, my logic tells me that anyways."
- A5: "Um, so, what I have found is that, um, the frustration, my frustration level with *not* having a diagnosis, not knowing what's *causing* the pain, and having the pain getting worse instead of better, in spite of, you know, putting out *huge* amounts of money, and tons of time and effort into, you know, physiotherapy, um, the intramuscular stimulation, massage, chiropractic ... you name it, I've tried it."

2. The experience of loss

Descriptive Paragraph: Participants described experiences of loss that comes in many forms, with the potential to touch varying aspects of their life. The participants' losses associated with living with undiagnosed chronic pain ranged from pragmatic functional realms such as losing the ability to perform one's regular daily tasks with ease and losing the ability to participate in enjoyable leisure pursuits, to more cognitive-perceptual realms such as perceiving a loss of ability to relate to other people, feelings of a loss of normalcy, and feelings described as a loss of self-respect and a loss of self-worth.

- A1: "It's like, you know, like, I still have the pain, you know, it still causes me to have anxiety, it's still causing me occasionally to have panic attacks. It's like, it's like my life, up until then, it's just not normal

anymore. And I think it's like a *loss*, too, like, there is just not one second of my day, or time, or energy, that is what I would say is *normal* anymore. Do you get what I mean?"

- A2: INTERVIEWER: "But you, when you said that you lose your self-respect, can you tell me more about the self-respect piece? I just want to make sure I understand that." ... PARTICIPANT: "You have, okay, for an example; you have pride in your work. You have pride in what you're doing. You have a certain self-worth in what you're doing. When you live with pain day after day after day, and you do certain things, you know, I mean, as the saying goes, 'the sky is the limit', I *could* technically do ... The pain *stops* me because I know I can't physically get through most days. I lose my self-respect." ... INTERVIEWER: "Does it give you a sense of loss ... of lost potential, maybe?" ... PARTICIPANT: "Very much. Um, like I said, I lose a lot of the respect in myself, and it's not because, it's not because I can't do it. Well, it *is* because I can't do it. I *physically* can't do it. I, I just physically can't do it." (voice sounds choked up with emotion)
- A3: "I'm to the point where I can't even get my shoes on ... I can put them on, but I can't get down and buckle them up, so I need somebody to do my shoes up, you know, just to go for a walk. That's stupid." (voice sounds strained with emotion) ... INTERVIEWER: "That's upsetting, I can see that. Is it upsetting because you feel helpless, or embarrassed, or ..." ... PARTICIPANT: (interjects) "Probably a bit of both." ... INTERVIEWER: "A bit of both." ... PARTICIPANT: "And just, I've just turned fifty. You shouldn't be in this shape (sniffles) at fifty, unless there's a reason. (voice choking up with emotion) ... they can't give me a *reason*."
- A4: "I'm still having a lot of challenges ... what, what became apparent quickly, um, were two things. And one is that I'd *lost*, um, the ability to really *relate* to other people ... I had to relearn that ... like, um, before, it was easier to be around people it seemed ... and I don't know if it's because, um, I just cared less about what other people thought, I don't know, maybe that was it. But, uh, but *now* it's, I, I've had to work a lot harder and focus on, the thing is, it's so *complicated* now ... like when I described before meeting a guy, right? Like *before* when I met a guy, it was just *me*, and, you know, I had my stuff to talk about, like my, um, stories, because everyone has their stories ... and, and that was *it*. And that was *enough*. You know, I could be ... myself ... and *now* 'myself' is this whole, you know, serious, kind of like *complicated* thing right? Whereas before ... I don't know ..."
- A5: "Well, it's very lonely (voice strained with emotion), because, you know, here I am, like, in the prime of my life, and, and not able to enjoy

life, and, um, and not able, be able to enjoy the very same things my friends are enjoying, like, you know, having a spouse, having kids, um, going out and about and doing things they enjoy like hiking; all those things that *I* enjoy doing. Um, it, it creates a huge sense of *loss*, and, you know, um, and then again, um, sort of that, not only a sense of loss, a sense of, um, sort of fear about the future, like, am I going to, you know, be 90 years old and still be single, and still be in this much pain?"

3. Feeling invalidated by physicians

Descriptive Paragraph: Participants living with undiagnosed chronic pain all described having had experiences where they felt invalidated by physicians. This invalidation came in various forms; from physicians suggesting that the source of their pain might be purely psychological, to participants perceiving their physicians were skeptical that they were actually experiencing significant pain at all; however, all of these physician-interaction experiences shared the common thread of leaving the participants feeling that they were not being fully heard or taken seriously.

- A1: "... there's no one other than I guess psychologists now a days when finally your doctor says to you maybe you should go see a psychologist, and you're thinking 'Fuck okay this is just in my head now, you're telling me because you can't find something wrong with me it's just all in my imagination'."
- A2: "Um, for example, my doctor. Okay, if I go in there and say, 'Look, I'm in pain from head to toe,' and she's done all these tests, and she looks at you and goes like ... like people look at you as if, um, like, 'What do you think you're doing? Are you crazy? There's *nothing wrong* with you.' Um, they have that perception of you." ... INTERVIEWER: "So, you felt that a little bit from your doctor." ... PARTICIPANT: "I've felt it from pretty well from every physician I've seen. Like, there's nothing wrong with you, you're perfectly fine, go out and work, go out and do this, go out and, you know?"
- A3: "I've had my trust in doctors a bit shaken over the years, because I've had, you know, ones that have treated me like somebody that's actually in

pain, and then others that have gone, (patronizing tone) ‘*There, there dear ...*’ so, you know, and that’s, I find that quite offensive.”

- A4: “So I ended up coming off that and, um, at that point, that was when really, um, the whole ‘not taking me seriously’ thing really kicked in ... anything I had to say at that point was ‘the anxiety’, the mental illness part of it ... and, you know, them saying ‘If I, if I went back on Paxil I probably wouldn’t have chronic pain, blah, blah, blah, blah, blah.’ But the fact is, is that I *had* chronic pain the whole time I was on Paxil, so it really didn’t, you know what I mean?”
- A5: “Sometimes I’ve felt like, um, I haven’t been examined properly, because, you know, it almost seems like some doctors go, ‘Well, you *look* fine, so you must be fine’ ...”

4. Not feeling understood by others

Descriptive Paragraph: Living with undiagnosed chronic pain seems to come with a sense of not feeling fully understood by others. Participants described having this feeling not only while interacting with acquaintances, but also during their interactions with some of their closest friends and family members. The participants’ choice of words, facial expressions, and tone of voice all suggested that the feeling of not being understood by their loved ones was particularly difficult for them.

- A1: “It’s the fact that you need someone to talk to about it who *understands* it. Point in case, it was, it was like about two months ago, my daughter comes up to me and says, ‘What’s wrong?’ And I said well, you know, ‘It’s just the same shit that’s wrong all the time, I’m just not dealing with it very well today’ ... And she goes, ‘Well, what do you mean?’ And it’s like, you know it’s like, for Christ’s sake, I’ve been living with this for two years and you don’t *know* that for two years I’ve been in constant pain? It’s like, it’s not *real* to other people around you. Do you get what I’m saying? Unless, you know, unless you are writhing in agony on, on the floor, 24-hours a day, which you can’t do, because it’s not like, like what would be the point?”
- A2: “You feel so guilty because you *can’t* do it. And, um, and that just compounds the emotions that go with it, because, there again, you look at their faces. You see the disappointment and hurt in their faces, and they

don't understand. And, there's times when *I* don't fully understand why sometimes either, it's hard to explain to them that, like, 'Okay, mommy's just tired, or mommy's in pain today, we just can't go.'

- A3: "I think she's, because I can't give her a specific, you know, 'Wapiti-splash, *this* is what's wrong with me' that satisfies in her mind, you know, for instance, if I was in a car accident that would be *understandable*. Again, because there wasn't a (noise of hands slapping together simulating a forceful impact), you know ..." ... INTERVIEWER: (interjects) "Moment of injury." ... PARTICIPANT: "A moment of injury, um, a lot of people just don't *get it*. I don't think, I don't think like, people that I know well question it in the sense, like, 'It's in her head', or anything, but I do think there's a certain amount of, 'We really *don't* understand.'"
- A4: "Yeah ... something that I realized I did, a behaviour that I did, was, uh, *over-explaining* things to people, like, um, it's like, that's it, I don't know, I don't know how to explain it. Like, if I don't feel like I'm getting *empathy* from someone then I'll, I'll start, I'll repeat what I said but in a different way ... a different way ... a different way ... a different way ... and by the time I'm done that conversation I'm pretty drained, so it's like, it's better just not to happen." ... INTERVIEWER: "Do you, do you think that pattern came about because you didn't feel *understood*, and, trying different ways was just a kind of desperate attempt to try and get them to understand?" ... PARTICIPANT: "Yes, yeah."
- A5: "I think that support would have been very, very helpful, um, when going through this, because ... it would have, I think it would have been easier to manage the stress and to deal with this if I had, if I was getting support from someone who cared, and had some *empathy* and, um, and, and was *understanding*, and, you know, actually willing to help me ... I think it would have made things easier, much easier to deal with. I don't think I would be as at quite as low a point now, as, as I am, because you know ..." (trails off quietly ... long pause and sound of sniffles)

5. Experience of not being believed

Descriptive Paragraph: Participants living with undiagnosed chronic pain all described having had the experience of not being believed by various individuals in their life. A sense was conveyed that participants were engaged in an ongoing struggle for legitimacy whereby their honesty and integrity were being called into

question. This ranged from passively not being believed, to more direct challenges associated with accusations of ‘scamming’ or ‘faking’ of their pain and associated disability.

- A1: “... like say you talk to your insurance people, and they’re, they’re treating you like, you know, like you’re this lazy bum who wants to stay home and do fuckin’ nothing all day, because that’s your, um, view of an idyllic existence. Like, like they think you’re drinking margaritas and, you know, like sun-tanning in the sun on the beach with a beautiful blonde massaging your back all day.”
- A2: “I mean, that’s a downer for you. I mean, whether you believe me or not, right? Even, even talking about it with your family, and *they* don’t believe, like you know, they don’t believe you, they don’t ...” (trails off and sighs)
- A3: INTERVIEWER: “... does it leave you feeling ... um, sort of a need to prove your legitimacy? Would that be accurate?” ... PARTICIPANT: “Very much so, like, it’s like questioning my honesty, my work ethic, um, I mean I appreciate that there are people in this world that, you know, scam systems, I *do* understand that. I mean, I work with people who will do the least amount of work physically possible (chuckles). Um, and, I mean you can’t, I can’t live their lives for them, but that’s not *me*.” ... And, I guess I *resent* having to say, ‘Look at my work record’, you know? I am, I am *not* one of these people. I mean if I could still work, I’d still be working.” ... So yeah, it’s, it’s frustration and, and I guess *challenging* my honesty.”
- A4: “Um, so if you can imagine, it’s put me in quite a, um, *dependent* relationship with the medical establishment ... so I’ve had to really, really rely on *them*, um, accepting that what’s happened to me is *real*, in order to kind of function or cope with other people’s judgement. As, as long as I’ve been able to get medical documentation verifying, um, that what’s happened to me is *real*, that I’m not just lazy, and I’m not, you know, shopping at the mall (chuckles), you know, when I call in sick ... then um, then I’ve been able to kind of *live* with it.” ... INTERVIEWER: “So I’m hearing, you’ve had a bit of a struggle about like, workplaces, let’s say employers feeling that you had to legitimize ...” ... PARTICIPANT: (interjects) “Yes.” ... INTERVIEWER: “That there *was* really a reason why you couldn’t come into work.” ... PARTICIPANT: “Not just, it’s not just employers though, like my family, boyfriends, it’s *everybody*.”

- A5: “And that’s exactly the, the frustration, is that a lot of people make assumptions that you *look* fine, therefore you *are* fine, and, or you look fine therefore you must be *faking* this injury, or um, that kind of thing ...”

6. Feeling embattled

Descriptive Paragraph: A fundamental element of living with undiagnosed chronic pain seems to be the experience of having to engage in ‘battle’ on an ongoing basis. Participants described feeling embattled in numerous ways, including feelings of an *internalized* fight against the pain, as well as *externalized* fighting against a range of foes including unsympathetic employers and insurance companies who, rather than being cooperative and supportive, were perceived as assuming an adversarial battle-stance.

- A1: “... it’s amazing how much you can dis-associate [*sic*] yourself from stuff, I guess. You know? And that’s what I mean that’s part of the tolerance too, that I’ve been talking to you about this whole time. What if you just *can’t* tolerate that pain anymore? Because it *is* scary. It does tire you out. It does, um, wear you down. It does depress you. It does, you know, like, it *is* a battle.”
- A2: “And you *fight* with yourself.” ... INTERVIEWER: “Sort of that internal conflict,” ... PARTICIPANT: “Oh, it’s, it’s horrible. Because, you’re not really fighting yourself, you’re fighting the pain; you’re fighting the *results* of the pain. And it took me a long time before I could, before I actually figured that one out.”
- A3: “I don’t fit into any one diagnosis. You know? And, like I say, I see different specialists and I get a different diagnosis from each one of them ... so which one do I believe? The one that I like the best? The one that suits my purposes the best? I mean, to be truthful, if I wasn’t *fighting* with long-term disability and just needed something to keep the pain under control, I really don’t, I don’t want to say I don’t *care* about the diagnosis, but it’s not going to make a huge lot of difference in my life, in *that* sense.”
- A4: “Well because it didn’t *allow* for that, because I think ... like, in order for me to, to have gone through that ... it was a *battle* ... it was a

battle ... every day was a battle ...” ... INTERVIEWER: “At work? ... PARTICIPANT: “Yeah ... for validation, and to perform, and to, you know, complying with the regulations and the policies, and, and, a new, a new job situation every couple of months, you know ... and, and, you know, like, things like trying to get a decent chair ... you know, it was, every, *everything* was a battle ... So, so the result is that I’m this *battle-worn* person.”

- A5: “... to still, you know, have no relief, and no diagnosis, and, um, just a *battle* one after another after another over the years between, um, my employers, um, not, um, being very supportive, and making things *worse* in terms of my injury, um, so, so my work life has suffered, suffered, in fact I, I think I may have to change careers as a result of this.”

7. Feeling exasperated

Descriptive Paragraph: Participants living with undiagnosed chronic pain all described having emotional reactions to the seeming futility of their situation.

Sometimes participants used the word ‘frustrated’ to describe this emotional experience, however, the intonation and volume of their speech, use of profanity for emphasis, and their animated body language, all combined to convey a sense of *exasperation* which is captured in their quotations.

- A1: “Well, yeah. I think that, that’s a point, that’s certainly uh, an important attribute to this whole thing that you, you’re talking about, is that part of it is like, other people can’t *see* it, do you know what I mean? It’s like, once you go to every doctor in the world and you’re undiagnosed, you know, like, they’re not there, they don’t know how you’re feeling, they don’t know, like, you know, how well you’re coping, or how well you’re not, until you’re *not* ... And then they look at you and they go, ‘Well, what’s wrong?’ And it’s like, ‘Well, the same thing that’s been wrong with me this whole fuckin’ time, just right now I can’t deal with it. Do you get what I’m saying?’”
- A2: “I’m not psychotic. I’m not, (voice quivering) like I said before, I wish I *could* frickin’ say that I was insane, and (sniffles, and voice sounds very choked up with emotion) and then I could *understand*.”

- A3: “Well it’s *frustrating*, because it feels like, you know, your worth ethic and everything, is a negative.” (voice sounds choked up with emotion) ... INTERVIEWER: “Yes (comforting tone), I can tell that really hurts, because every time we bring up the work ethic, or the honesty being challenged, I can see it’s upsetting you ... is that one of the hardest parts of this whole ...” ... PARTICIPANT: (interjects) “It *is*, because how do you *prove* ... how do you prove honesty? (voice sounds choked up with emotion ... followed by long pause) And you’re right, that’s probably what bothers me the most.”
- A4: “...but there are times when I’m totally on the ball doing meditation, yoga, going to the pool, doing my rehabilitation stuff, and, and, I’m on top of my homework, and having good relations with people, and, and I *still* have bad days. Like, and those are the worst, worst, worst times with me because it’s like ...” ... INTERVIEWER: (interjects) “Because you feel you’re doing everything right but it still flares-up?” ... PARTICIPANT: “Yeah ... it’s like, it’s like saying, you know, I have absolutely *no control* over this at all. It is the *boss* of me ... it is *so frustrating*.”
- A5: “So, um, those challenges along the way have been, um, basically, you know, it’s hard enough to manage the pain level at the best of times that, you know, they get those kind of systems, um, in place, and, and you know, that, that *aren’t* supporting you and then it’s just like, you know, ‘Come on guys, I cannot do this, I can’t deal with this level of pain *and* all this extra crap’ ... so it just gets *really* frustrating.”

8. Undiagnosed chronic pain impacts virtually every aspect of the sufferer’s life

Descriptive Paragraph: Undiagnosed chronic pain becomes like an unwanted octopus whose tentacles meticulously work their way into virtually all areas of the sufferer’s life, from work life, to family life, to leisure life, to even the simplest activities of one’s daily existence.

- A1: “It affects *everything* you know, like right to, you don’t get any sleep, right down to you know, like you’re grouchy all the time, you get anxiety, you get panic attacks, because it’s like, it’s just totally, your life is totally disrupted ...”
- A2: “Yeah, it just, affects who you are. It affects inside, outside, it affects, um, it affects *everything* you say and do, sometimes.” ...

INTERVIEWER: “So it’s really all-reaching, it gets into all areas of your life.” ... PARTICIPANT: “Yeah, and no matter what you do to try to stop it, sometimes it’s just not possible.” ... INTERVIEWER: “Do you ever feel like, pain, kind of *becomes* your life?” ... PARTICIPANT: (Deep sigh) “I try not to let it, but yeah, um, sometimes it does.”

- A3: “You have no *control*. I mean, most adults have control over their life, I mean, to a degree, I mean we all have employers or responsibilities that we have to do, but, in that little piece of your life that’s *yours*, you usually have control ... I don’t have the control.” (voice sounds choked up with emotion) ... INTERVIEWER: “It sounds like that’s a very difficult part of it for you.” ... PARTICIPANT: “Well, you know, you want to go places, you want to do things, and when you have to cancel even dinner arrangements, because you, you know, or you go in to cook and you’re just so tired you can’t be bothered? I mean, all the things that you used to like to do ...” (voice quivering) ... INTERVIEWER: “They’re slipping away from you.” ... PARTICIPANT: “Pretty much. Like I don’t knit anymore, I don’t sew anymore. I don’t, I mean, we’ve talked about getting a dog again, but I don’t even know whether I could walk him. And is it fair to get an animal that you can’t really, you know, give the exercise that it needs? You know it’s just ...” (sighs) ... INTERVIEWER: (interjects) “This is another example of how it has to factor into every decision you make.” ... PARTICIPANT: “Yes.
- A4: “Yeah I’m ... it’s kind of like, um, everything I do ... I could, I could say this ... *everything* I do has been influenced one way or another by the chronic pain. Like everything from brushing my teeth ... to waiting at bus stops ... to riding the bus...”
- A5: “I’m still dealing with excruciating pain that’s completely limited my abilities, and uh, and affects *every* aspect of my life.”

9. Reduced social contact with others

Descriptive Paragraph: Undiagnosed chronic pain seems to be associated with a degree of reduced social contact with others. Participant descriptions reflected that sometimes this social isolation comes about from other individuals withdrawing from the pain sufferer, yet other participants describe a pattern whereby their desire to socialize with others has become negatively impacted by the pain, and accordingly, their social circle has grown smaller.

- A1: “Like, your brothers don’t, like you know my brother is renovating his house, like I don’t, he doesn’t call me on Saturday anymore and say, ‘I’m putting up the dry-wall today, will you come over and help?’, you know, because, you’re the invalid now, type of thing. And you hate *that*.”
- A2: “... you tend to not trust people. You tend to not trust physicians, doctors. You tend to, uh, well, *I* have tended to stay very close, I have very few friends, um, but I keep it that way, because over the last few years, when nobody tends to *believe* you (voice wavering with emotion) you just don’t want to, you don’t want to talk about it. You don’t want to discuss it with *anybody*.”
- A3: “Well, I think it, it defines, it really does draw a line on who are actual friends, and who are just acquaintances ... And I think it’s down to, I can count on one hand who are *real* friends, and others that are just acquaintances. I mean, I’ve been off work since September, and I’ve seen *one* colleague.”
- A4: “I’ve had many friendships that have ended because it’s ... (voice chokes up with emotion) ... sorry ... And so finally I just stood up and I said, (in loud voice) ‘Excuse me’ to everybody, and I said, ‘You know what, I’ve got chronic pain. I’ve had chronic pain for the last 10 years ... I’ve been off work ... I’m on CPP ... I’m technically disabled ... and I need your help, because I can’t do this anymore.’ And you know what? They all helped me. But you know what? Like it was, like to *have* to do that was *humiliating* ... like, it was *so* humiliating. It just ... and I haven’t seen them since.”
- A5: INTERVIEWER: “So, you know, we kind of talked about the isolation, from *your* end, have you noticed any changes in your circle of friends? How they interact with you, or have you lost any friends over this?” ... PARTICIPANT: “Um, I would say, I’ve, I haven’t *lost* friends over it, but, um, certain friends I don’t spend as much time with. Because, I do, I’m, I’m still friends with them but I don’t see them anywhere near as often...”

10. Pain is a fickle master

Descriptive Paragraph: Participants living with undiagnosed chronic pain describe their connection with the pain almost like a master-servant relationship, such that the pain is the master of their days, deciding at its own whim how the sufferer will be feeling or functioning. This sense of unpredictability mandates the sufferer to live

their life in small, contained units of time, remaining ever vigilant of how their body feels, while simultaneously remaining always aware that their master (pain) could change the quality of their life at any moment.

- A1: “I mean, like this is just for me, like I don’t know about other people maybe it is, like, one day it is, the pain is worse than the next day. But I think mostly it’s, it’s how well you tolerate that pain *that* day. And that depends on so much that it’s un-totally believable. I think that’s where your mental, ‘Oh my God, it’s amazing, I’m not insane’, comes in.”
- A2: “... it just would be nice to be able to, (voice starts to quiver), it would be nice to wake up one morning and just look forward to the day. Because, you *don’t* every day. You don’t look forward to tomorrow because, like, okay, ‘I have a doctor’s appointment at 9:30, I have a staff meeting from 10:00 to 2:00’, and it plays on your mind the day before. I mean, ‘What am, what am I going to feel like when I wake up tomorrow morning?’”
- A3: “Well, it’s like beating a dead horse. Like, what can you do about it? Like, going on and on and on about it’s not going to change it. I mean if I’m having a bad day then I just don’t do as much. If I’m having a good day, what seems typical with people with chronic pain, if you have a good day you try to do *way* too much, because you don’t *know* when you’re going to get your next good day.”
- A4: “Yup. Sometimes I have to have days where I don’t do anything ... and that, that’s what happens, and that’s why ... that’s the nature of my disability is that the amount of *work* it takes to live this life that I’m living ... *exhausts* me ... so, I have to have breaks from living, that way. Pretty regularly, otherwise, otherwise ... I’m, I’m the dog in the corner.”
- A5: “... because I have to just try and have the attitude of let’s get through one day at a time, because that’s the only way I can manage the pain level. It’s just try to take it minute by minute. Um, so I try not to think about it *too* much, but when I do think about the future, it just, um, seems a bit *overwhelming* as far as how challenging, um, that whole piece of it is.”

CHAPTER V

Discussion

Upon the writing of this document the author was unaware of any other research that specifically explored the lived experience of living with undiagnosed chronic pain. As was noted earlier, research in the broad field of chronic pain is extensive and multidisciplinary, which reflects the very complex and multifaceted nature of pain itself. Although one can find an enormous amount of quantitative studies that focus on biomedical models of explaining, diagnosing, and treating pain disorders, a review of the literature reveals that only relatively recently has there been a notable insurgence of researchers utilizing a qualitative approach in the study of chronic pain. Even less attention appears to have been paid to exploring the actual *lived experience* of individuals suffering from chronic pain, and a broad-spectrum literature search identified a notable void in the literature pool regarding the issue of how one's chronic pain experience might be affected by the absence of an accepted diagnosis.

When first venturing into this topic matter, I recognized that my past years of working with countless chronic pain clients in my capacity as a physiotherapist (as well as in my role as a counsellor-in-training, and a human being who has had my own personal experiences with pain) had caused me to develop certain assumptions regarding what this study might identify as 'essential' experiences of living with undiagnosed chronic pain. I felt a sense of liberation that I was adopting an approach that would allow me to be genuine and transparent in recognizing that my past professional and life experiences had undoubtedly shaped my opinions regarding the topic matter. This is consistent with Heidegger's aforementioned historical assertions when he adopted a

stance countering the prior dominant notion that it was possible for human beings to withdraw their presuppositions about the nature of phenomena; as though one's 'conditioned ways of knowing' could simply be placed on a metaphorical shelf at will. In review, from Heidegger's philosophical vantage point, to be human *was* to be inherently interpretive. As such, I endeavoured throughout this research process to engage in the process of *reflexivity*, remaining aware of my own background, perceptions, and interests with regard to the way these factors influence my interpretive process, without actually trying to control or censor the impact of my own lived experiences. I felt it was critical to recognize that my own background would inevitably influence virtually all of my decisions in some capacity, dictating the framework from which I would organize, study, analyse, and interpret the research findings.

Comparison Between Major Findings and Existing Studies

One of my primary assumptions from the outset of this research process was that the lived experiences of individuals suffering from undiagnosed chronic pain would vary in certain ways from individuals who experience chronic pain that is associated with a clearly defined diagnosis. Although I had expected there to be a significant degree of overlap between the lived experiences of chronic pain sufferers who do, and do not, have a diagnosis to 'explain' their pain, I had also expected this study to reveal some important *differences*. Specifically, I had expected that when considering individuals who have chronic pain that is *un*-diagnosed, there would be unique 'essential' shared core themes of struggling with acceptance (given the clinical ambiguity of their situation), strong feelings of helplessness, ebbs and flows in the experience of having hope for a diagnosis (and thus, a 'cure' for their unexplained condition), and a theme wherein the ever elusive

diagnosis is perceived as the metaphorical key to ‘unlock’ one’s suffering. My expectation was that after the ‘essential’ themes of this study’s participants had been identified, they could be readily contrasted with studies within the existing literature pool that involved a similar explorative process for participants suffering from chronic pain that had been assigned an accepted diagnosis. Unfortunately, this was not a straightforward process, as many studies associated with the lived experiences of chronic pain did not, in fact, include the existence or absence of a diagnosis as one of the inclusion criteria for the research. This is inherently problematic because it essentially leaves one at risk of metaphorically ‘comparing a basket of apples with a basket of apples and oranges’, given that if diagnosis is not given specific consideration in the inclusion criteria, then one might reasonably assume that the participants in prior studies encompass a *mixture* of individuals, some of which do have an accepted diagnosis associated with their chronic pain, and others who lack an accepted diagnosis to ‘explain’ their chronic pain experience.

Perhaps not surprisingly, a number of prior studies within the broader realm of chronic pain research have identified themes closely related to this study’s theme of ‘*The experience of loss*’. Given the inherently interpretive nature of phenomenology, different authors will undoubtedly describe participants’ lived experiences in their own unique way, however, it is nonetheless clear that themes associated with ‘loss’ occupy a prominent place in the general research on chronic pain. As highlighted by Walker et al. (2006), in a phenomenological study exploring the experiences of 12 male and 8 female chronic back pain sufferers attending pain clinics, loss emerges as a continuous thread throughout participant stories. They noted that the term ‘loss’ was contextually referring

to life events or life changes resulting in the participants perceiving they were deprived of something they valued, which is consistent with the sense of loss expressed by participants in their interpretative phenomenological study. In fact, Walker et al. found such a rich depth in this theme that they further divided it into sub-themes of: a loss of abilities and roles, employment-related losses, financial-related losses, relationship losses, loss of identity, and loss of hope. The more practically-oriented aspect of losses associated with an interference in the ability to complete one's normal daily routine in terms of home and leisure activities has also been well supported in epidemiological-focused studies by Blyth et al. (2001), Gureje et al. (1998), Kumpusalo et al. (2000), Smith et al. (2001), and Walker et al. (1999). Similarly, the inability to participate in one's normal employment capacity has been identified in epidemiological-focused studies by Blyth et al., Gureje et al., Katz (2002), Kumpusalo et al., Smith et al. (2001), and Pizzi et al. (2005). Moving away from the practical losses of function and more into the perceptual realm, a phenomenologic study by Thomas (2000) that involved interviewing 9 women and 4 men experiencing non-malignant chronic pain gives voice to a theme of 'the altered, recalcitrant body', which has parallels to the loss of normalcy expressed by participants within the current study. Specifically, Thomas notes that, "the chronic pain experience had profoundly altered participants' perceptions of their bodies. Once familiar and predictable, their bodies were now baffling." Exploring another aspect of perceptual change, Kugelmann's (1999) hermeneutic-phenomenological study that explored the experiences of 14 chronic pain patients (7 men and 7 women) attending an in-patient pain management program of a rehabilitation hospital spoke of significant loss and grief, capturing a sense of the range and depth of potential losses by stating that,

“with protracted pain, one loses one’s taken-for-granted way of life” (p. 1670), including the “loss of a customary world and of an ability to do things” (p. 1670).

This sense of loss at multiple levels is consistent with the findings of the current study focusing on undiagnosed chronic pain, wherein the theme of loss was found to be multi-faceted, ranging from pragmatic functional realms such as losing the ability to perform one’s regular daily tasks with ease and losing the ability to participate in enjoyable leisure pursuits, to more cognitive-perceptual realms such as perceiving a loss of ability to relate to other people, feelings of a loss of normalcy, and feelings described as a loss of self-respect and a loss of self-worth. When comparing the current study with the extant literature, it would appear that the theme of loss is significant and equally relevant regardless of whether or not the sufferer’s pain is associated with an accepted diagnosis.

The current study identified further themes that relate to how sufferers of undiagnosed chronic pain tend to experience changes in their social functioning. Specifically, the themes of *‘Not feeling understood by others’* and *‘Reduced social contact with others’* reflect negative shifts in one’s social experiences. In the current study of undiagnosed chronic pain, participants described ‘essential’ core experiences of social isolation, either as a result of the chronic pain sufferer withdrawing from others, or as a consequence of others withdrawing from the chronic pain sufferer. When opportunities for social interaction do arise, sufferers of undiagnosed chronic pain described a feeling of not being understood by others. Of particular note in the current study was that although this experience was a common component of social interactions with acquaintances, a much deeper sense of discontent and emotional hurt was conveyed

regarding the experience not feeling understood during social interactions with close friends and family members. When considering these lived experiences in light of the extant literature on chronic pain, one does find that these themes are represented, however, it is not uncommon for these socially-grounded themes to be subsumed within larger superordinate themes such as experiences of being doubted, disbelieved, ostracized, or invalidated by others. Again, given the inherently interpretive nature of phenomenology, different researchers will undoubtedly describe and organize themes associated with participants' lived experiences in their own unique way. Nonetheless, certain studies have more directly shone a light on these themes, such as the phenomenological study by Walker et al. (1999) which identified a theme of 'they don't understand' as one of five main lived experience themes expressed by sufferers of chronic back pain seeking help from pain clinics. A sense of social isolation was expressed in a hermeneutic-phenomenological study by Paulson et al. (1999), whose method involved the interviewing of 17 nurses and four physicians to explore experiences and impressions from the perspective of health care providers in their encounters with men suffering from long-term, non-malignant pain. Within a larger theme of 'Needing human support', this study describes impressions of the men's experience of 'feeling alone and forlorn' as a result of becoming withdrawn and losing touch with friends as a consequence of living with long-term pain. Similar descriptions of 'social isolation' were noted both in Kugelmann's (1999) aforementioned hermeneutical-phenomenological study of the experience of chronic pain (which did not address diagnosis in the inclusion criteria), as well as Ware's (1999) longitudinal study of 53 women and 13 men with a diagnosis of chronic fatigue syndrome. Similar to the

current study on the lived experience of undiagnosed chronic pain, participants in Ware's study expressed the impetus for their social isolation as potentially coming from others withdrawing from the sufferers, or from the ill individuals themselves. The aforementioned phenomenologic study by Thomas (2000) on the lived experience of sufferers of non-malignant chronic pain identified that a sense of isolation was an 'essential' theme expressed in all interviews. In this regard Thomas notes that participants:

... used terms such as locked off, roped off, and caged off. Pain had somehow reset their interpersonal parameters, creating separation and distance from the world and other people, even family members. They felt that they no longer had much in common with others, and no longer 'fit in'. Relationships in which they could be honest and authentic were few or nonexistent. (p. 692)

The exploration of prior research within the realm of chronic pain and chronic illness seems to indicate that negative shifts in social experiences, such as not feeling understood and feeling socially isolated, are virtually universal amongst chronic pain sufferers. This suggests that this element of the lived experience is more driven by the social consequences of the chronic pain itself rather than the lack of an accepted diagnostic label.

The current study's theme of the '*Undiagnosed chronic pain impacts virtually every aspect of the sufferer's life*' is often alluded to in the literature, albeit in terms of chronic pain in general, and not specific to sufferers who lack a diagnosis to 'explain' their chronic pain. Once again, an interesting trend is noted whereby the reader of studies gains a sense of this being true, although the author of the current study was unable to

identify any prior studies where this was identified as a stand-alone phenomenologic theme. In the current study of undiagnosed chronic pain this ‘essential’ experience was expressed by participants describing how their pain and related limitations had meticulously worked their way into virtually all areas of the sufferer’s life, from work life, to family life, to leisure life, to even the simplest activities of one’s daily existence. Depending upon how various prior researchers have interpreted and categorized data gained from participant interviews and surveys, there is also degree of overlap in the literature between the aforementioned sense of pain impacting virtually every aspect of the sufferer’s life, and the current study’s theme of *‘Pain is a fickle master’* whereby participants describe their connection with the pain almost like a master-servant relationship, such that the pain is the master of their days, deciding at its own whim how the sufferer will be feeling or functioning. The aforementioned study by Kugelmann (1999) conveys a similar sense in his rich descriptions of the chronic pain experience, although he draws upon a metaphor of the pain as a ‘prison’, summarizing participant reports as follows: “Pain is an existential situation. It was described as a confinement, symbolically as a prison” (p. 1671), while also providing participant quotations that portray chronic pain as a controlling factor that “leaves no aspect of the sufferer’s life untouched” (p. 1670). Similarly, Raheim and Haland’s (2006) hermeneutic-phenomenological study of 12 women’s lived experience of chronic pain and fibromyalgia make symbolic reference to ‘the prison of the body’. They describe the lived experiences of chronic pain sufferers using terms and imagery that align themselves well with the current study’s metaphorical representation of pain as a fickle master, as they describe the sense of powerlessness experienced by chronic pain

sufferers who are forced to live each moment 'at the will of the treacherous body'. In keeping with these themes, the aforementioned study by Thomas (2000) provides a powerfully descriptive contrast to the experiences of most 'healthy' individuals by portraying the lived experience of chronic pain sufferers as follows:

He or she is exquisitely and perpetually aware of the body. Within the body is housed the pain, which has become the most salient aspect of daily existence. For most of the study participants, every movement of the body produces twinges, aches, spasms, or other unpleasant consequences. They do not have the healthy person's luxury of moving the body spontaneously and thoughtlessly, and the body cannot be ordered to perform desired movements. Even when simple activities such as brushing teeth are carefully planned and calibrated, sharp reminders of disability capriciously occur. (p. 690)

When comparing the current study with the extant literature, it would appear that the themes of pain impacting virtually all aspects of the sufferer's life, and the metaphorical theme of pain as a fickle master are equally relevant regardless of whether or not the sufferer's pain is associated with an accepted diagnosis.

The current study's theme of the '*Experience of not being believed*' by others in the life of the sufferer of undiagnosed chronic pain has been broadly represented across the field of chronic pain research. In the current study of undiagnosed chronic pain this 'essential' experience was found to range from passively not being believed, to more direct challenges associated with accusations of 'scamming' or 'faking' of one's pain and associated disability. This theme of not being believed has been represented as an ongoing struggle for legitimacy in a number of prior chronic pain studies, and depending

upon how various researchers have interpreted and categorized themes, there is also overlap with this study's theme of '*Feeling invalidated by physicians*'. This thematic overlay is due to tendency for invalidation experiences to be associated with elements of skepticism on behalf of the physician, with this sense of disbelief leading to overt or covert questioning of the legitimacy of the patient's presentation. In this regard, Hellstrom's (2001) interpretative phenomenological study of 13 women and 5 men examining chronic pain patients' perception of the pain-future relation, draws specific reference to experiences of not being believed when interacting with the health care system. A sense of this is captured as Hellstrom states:

The experience of agency was a dominating dimension in all the interviews and is suggested to be an important factor in the interactions between the chronic pain patient and public health care and insurance institutions. Feelings of inferiority and of being disregarded and mistrusted were frequent. (p. 89)

Seers' (1992) clinical commentary on the treatment of non-malignant pain implores physicians to remain ever-cognizant of these aspects of their patients' lived experiences, as how they handle ambiguous patient presentations can directly determine whether or not their clinical interactions are helpful or harmful to the patient's well-being. The author of the current study would suggest that this is wise advice that would hold equally true to other health care providers within both the realm of physical medicine-rehabilitation, as well as the mental health fields of psychology-psychiatry and counselling. In this regard, Seers states:

Although general practitioners may not be able to cure a patient's pain, they can help the patient to come to terms with it ... From talking to sufferers, the most important

factor in coming to terms with their chronic non-malignant pain is that the pain should be *believed* in. It must be devastating if chronic pain disrupts a person's life and is then dismissed as imaginary. (p. 453)

Seers emphasizes the sense of responsibility that comes with being a health care provider to individuals suffering from chronic pain by cautioning clinicians to be aware that behaving in an invalidating manner can leave their patients with a hurtful sense of abandonment. Kerssens et al. (2002) in their study of the prevalence of unexplained severe chronic pain in general medical practice provide similar directives to medical providers, noting that whether or not a physician is perceived by their patient as actually caring about their pain and its relief are crucial factors in the effective management of chronic pain. Cronje et al. (2006) in their analysis regarding the use of pain terminology in medicine and its impact on clinical reasoning, echo similar sentiments by pointing out that virtually all chronic pain patients express the experience that at some point those around them, chiefly medical practitioners but also at times family members, come to question the authenticity of their experience of pain. However, the study by Cronje et al. adds another layer of insight to the experience of not being believed by offering a perspective on how the negativity of that experience might be further heightened by the physician's behaviours when there is an absence of an accepted clinical diagnosis. In this regard, they state: "if a patient's pain report or behavior does not mesh with a given clinician's prototype of *normal*, that clinician is more likely to delegitimize the patient's pain, particularly when medical evidence that would *explain* the pain is lacking" (p. 695).

An important related consideration regarding this aspect of the experience of not being believed has to do with what actually constitutes a 'diagnosis', in the minds of the chronic pain sufferer, their medical caregivers, and society as a whole. For example, Cohn (1999) provides accounts of the struggle for legitimization by individuals who have been diagnosed with chronic fatigue syndrome, which is one example of a diagnostic label that is not universally accepted, and as such, might be more vulnerable to delegitimization. As Cohn notes:

Illness is not only a time of crisis and potential ambiguity, but can also be a time of dispute. Doubtless there has always been debate over conditions not fully sanctioned as legitimate deviations from normal health. Yet, despite the progress of scientific medicine, it appears no clearer criteria can be provided, no firmer understanding gained, of what should constitute an illness. It is almost as though the advance made by biomedicine in certain areas has actually promoted the confusion in others; by demonstrating effective knowledge over mechanical and infectious disorders, those that are neither, appear further stranded from any means of legitimization. (p. 195)

Malterud (2000) offers similar assertions in her paper outlining theoretical and practical perspectives to assist medical residents in appreciating symptoms as a source of knowledge when treating medically unexplained disorders in women. Malterud specifies that certain persistent conditions such as fibromyalgia or chronic fatigue syndrome might be particularly problematic for certain health care providers, as the symptom diagnosis may announce that the physician does not understand what is actually wrong with the patient, adding that (perhaps not coincidentally) the cultural hierarchy of medicine assigns low status to these conditions. Malterud indicates that this opens the door for

disbelief on the part of the physician and feelings of invalidation on the part of their patient as, “patients complain of not being taken seriously by physicians as they struggle against the physician’s skepticism and insistence on the presence of psychiatric disease” (p. 603). Ware (1999) confirms similar reports from individuals diagnosed with chronic fatigue syndrome, as these individuals were noted to encounter delegitimation at every turn from friends, family members, work colleagues, and most often from health care professionals who often invalidate these individuals by relegating their complex symptom complaints to the realm of the ‘psychosomatic’. In light of these experiential commonalities of skepticism and invalidation, Malterud offers an observation that the unfortunate result is that within the context of “medically unexplained disorders the physician and patient frequently antagonize around the core issue of trust, and patients struggle to be heard and believed” (p. 605).

This brings into question another element of the chronic pain literature, as one must consider to what degree the chronic pain sufferer’s experience may be affected by the degree to which their diagnostic label is socially sanctioned. For example, the terminology ‘chronic low back pain’ can be found within the literature, and is often expressed as though this it is a diagnosis. In fact, in my own practice as a physiotherapist I have seen this phrase written on many referral scripts from physicians in the space where a diagnosis is to be provided. This begs the question, when a phrase as diagnostically vague as ‘chronic low back pain’ is applied with a diagnostic tone, does the individual suffering from the pain actually *perceive* this as a diagnosis? Of equal importance when considering vague diagnoses is the question: do other important individuals in the sufferer’s life recognize the applied clinical label as an actual

‘diagnosis’? Both considerations are equally important because they are inextricably intermeshed, given that how important others perceive one’s ‘diagnosis’ (or lack thereof) will undoubtedly impact how they interact with, and behave towards, the chronic pain sufferer, which will have a direct impact on the pain sufferer’s lived experience. One might speculate that whether or not one perceives a vague descriptive label as an actual diagnosis would depend entirely upon the perception of each individual, and this author would tend to agree, however, it is this author’s assertion that this factor needs to be more carefully considered within the chronic pain literature. Steen and Haugli’s (2000) study exploring the concept of generalized musculoskeletal pain as a rational reaction to an individual’s life situation recognizes the dilemma of ‘pseudo-diagnoses’ with respect to individuals suffering from chronic musculoskeletal pain, as they state:

The use of the described biomedical practice might be problematic both for the physician and the patient since the health problems can be characterized as a *description of symptoms* and not as a well-defined disease. The symptoms for many last for a longer period of time, but the medical examinations and tests do not give any specific findings or explanations. Chronic musculoskeletal pain, chronic fatigue syndrome, and whiplash are examples where the cause is not clearly defined. (p. 585)

Therefore, if the etiology of a set of symptoms cannot be clearly defined, this lack of a logical explainable *cause* for one’s symptoms brings the overall legitimacy of the patient’s presentation into question, particularly if a ‘label’ is applied that lies on the fringe of the domain of mainstream Westernized medicine. Steen and Haugli go on to note that the biomedical model most dominant within our health care system, particularly

in medicine and physiotherapy, has a strong impact on the way society views health and illness. Similarly, Hyden and Sachs (1998) after having reviewed a series of 15 audio-recordings of intake medical interviews with women and men in a special medical unit, note that a dilemma central to the diagnosis of chronic fatigue syndrome is the absence of a clear medical pathology causing the associated symptoms. They note that this typically leads to a process whereby physicians and patients “*negotiate* symptoms and diagnostic criteria in search of a legitimate diagnosis and illness” (p. 175). Hyden and Sachs go on to describe the need for patients with nebulous symptoms to present them in such a way that they fit into and fulfil certain criteria and preconceptions about disease and its treatment as dictated by the current medical model. In essence, they note that patients must actually *transform* their suffering in a way that enables them to seek help and be *accepted* as patients for medical care. This transformation is designed to shift the individual’s pain and suffering from the realm of the foreign and unknown to a realm of identified ‘objective’ illness, thus confirmed by someone such as a physician who has social authority in this regard. This is consistent with the assertion by Cohn (1999) that the validity of illness is based not on biological but *cultural* features, while also describing the inevitable contradiction in the use of biomedicine as the provision for societal sanctions when numerous conditions continue to exist that cannot be fully ‘explained’ by our current medical thinking or available diagnostic tests.

A final point for consideration that has conceptual linkages the current study’s theme of the ‘*Experience of not being believed*’ is that of the invisibility of pain. In this regard, several of the study participants spoke of the fact that their pain and physical problems are not overtly visible, which was perceived to contribute to their struggles

regarding achieving a status of legitimacy in the eyes of others. However, it should be noted that the issue of pain invisibility was not identified by all participants in the current study, which suggests that this might be a 'common' yet not 'essential' element to the experience of living with undiagnosed chronic pain. That notwithstanding, it can be noted that this issue of the invisibility of pain is either directly addressed, or is alluded to, in many studies exploring the experience of chronic pain sufferers not feeling believed. Kugelmann (1999) speaks directly to this issue in a hermeneutical-phenomenological study on chronic pain, noting that, "as a result of the ambiguous visibility of pain, the question of belief surfaced. Interviewees complained about not being believed when they claimed they were in pain" (p1669). He went on to note that given the invisibility of pain itself, the chronic pain sufferer often relies upon the expression of pain through speech or behaviours to serve as 'evidence' of their pain using mediums that *are* directly accessible to others. The 9 female participants in Osborn and Smith's (1998) interpretative phenomenological study on the personal experience of living with chronic benign lower back pain gave voice to similar experiences, as their inability to establish legitimacy and explain the ongoing persistent presence of their invisible pain can result in their feeling obliged to overtly 'appear ill' in certain contextual situations in order to conform to the expectations of others. Participants in the aforementioned phenomenologic study completed by Thomas (2000) expressed similar longings for external manifestations of disability that could provide a greater degree of societal legitimacy. Chronic pain was ruefully described as a 'secret disorder', whose invisibility can introduce day-to-day legitimacy challenges ranging from feeling invalidated by physicians, to more subtle unspoken accusations such as participants describing hostile glances received when

disembarking from vehicles parked in spaces designated for the handicapped. Vickers (2000) asserts in her phenomenological study of life and work experiences for individuals living with invisible chronic illness, that such experiences serve as evidence of the widespread stigmatization that is faced by individuals suffering from invisible chronic illnesses. In this regard, Richardson (2005) astutely points out that: “the perceived link between the *visible* and the *real*, both in clinical medicine and wider society, is acutely felt by sufferers of chronic pain” (p. 35). The resulting effect of the existence of pain being doubted because of its invisibility was noted to lead to consequent suggestions of malingering amongst sufferers. The qualitative research interviews that Richardson completed with 6 women living with chronic widespread pain provides compelling stories of individuals who have even considered having unnecessary surgery in order to have a visible scar to ‘show’ the world, noting that this search for visible bodily ‘proof’ of pain might also be indicative of a search for a physical, and therefore not psychological, explanation for their condition. Richardson draws a connection between the factor of invisibility and the aforementioned issue of social sanctioning of only select clinical presentations, alluding to the existence of an unspoken hierarchy of acceptability, where the legitimacy of one’s condition correlates with its degree of visibility, as well as the capacity for medicine to objectively confirm or disconfirm a given diagnosis based upon etiology and investigative clinical tests.

Richardson captures this sentiment when she states:

Having a physical ‘marker’ of pain opens up additional communication possibilities and allows sufferers access to a medical, and hence more culturally acceptable, discourse. Similarly, other chronic conditions are legitimated by the existence of a

diagnostic label even though they may have the same invisibility as chronic pain.

Friends and family would be unlikely to doubt the experience of someone diagnosed with multiple sclerosis or ... someone with a scar. (p. 36)

Making reference to the interconnectedness of many of the struggles faced by chronic pain sufferers, Richardson makes reference to the term ‘double delegitimation’, referring to both the ambiguity inherent in certain chronic illness presentations, as well as the invisibility of chronic pain itself. This term seems well suited as it captures the multi-faceted nature by which chronic pain sufferers experience direct and indirect challenges to the legitimacy of their symptoms, as well as facing questioning regarding their mental health, and skepticism regarding their core values of honesty and integrity.

As the aforementioned summaries note, compelling evidence exists that the experiential theme of not being believed by others, and the theme of feeling invalidated by physicians have both been identified in prior studies. However, it continues to remain unclear whether there might be somewhat of a subtle difference in the *nature* of these disbelief / invalidation experiences for individuals whose chronic pain is not associated with a clearly defined diagnosis. Although this manner of delineation between diagnosed and undiagnosed chronic pain in terms of disbelief-invalidating experiences seems to make intuitive sense, future studies that give more specific consideration to the issue of diagnosis within their inclusion criteria will need to be done to determine if, in fact, this conjecture is borne out.

The current study’s theme of the ‘*Feeling embattled*’ can be found widely across the field of chronic pain research. In the current study of undiagnosed chronic pain this ‘essential’ experience was found to include feelings of an *internalized* fight against the

pain itself, as well as *externalized* fighting against a range of foes including unsympathetic employers and insurance companies who, rather than being cooperative and supportive, were perceived as assuming an adversarial battle-stance. This sense of embattlement has been described using a range of terms and metaphors both within the current study as well as within the literature. Terms such as ‘battling’, ‘fighting’, and ‘struggling’ are commonly used to denote the sense of conflict that chronic pain sufferers engage in on a regular basis. For example, the aforementioned hermeneutical-phenomenological study by Raheim and Haland (2006) describes internalized experiences of ‘struggling to escape the treacherous body’, ‘fighting with or against the body’, and ‘fighting against the body and giving up’ in their exploration of women’s experiences of living with chronic pain and fibromyalgia. In the phenomenologic study of chronic pain by Thomas (2000), she paints a similar picture of a conflictual internal battle, whereby participants offered descriptions of, “Pain as a formidable opponent with whom they fought daily” (p. 689). Conversely, within a larger phenomenological theme of ‘In the system’, Walker et al. (1998) describe a more externally-driven ‘battle for benefits’ associated with struggles to obtain and maintain disability benefits when pain and associated functional limitations preclude participants’ ability to remain gainfully employed.

Although the aforementioned summaries substantiate that the experiential theme of feeling embattled has been identified in various capacities within the extant literature, it once again continues to remain unclear whether there might be subtle differences in the *nature* of these battles for individuals whose chronic pain is not associated with a clearly defined diagnosis. Given the importance that our society’s various ‘systems’ (insurance,

medical, legal) tend to place upon having a clearly defined diagnosis, the idea of facing somewhat different battles when one lacks a diagnosis seems to make intuitive sense. For example, more focused research in this area might reveal that all chronic pain sufferers regardless of diagnostic status experience the same degree of *internalized* battles (i.e., battles against the pain itself or the related functional impairments), whereas individuals lacking a diagnosis might face more *externalized* battles within society, including conflict-based relationships with the insurance sector, the medical establishment, and in rarer cases, the legal system. However, for this to be stated with any certainty, future studies will need to be done that enable more rigorous comparisons between chronic pain sufferers who have, and do not have, an accepted diagnosis.

Unique Findings

Although the current study's theme of the '*I have tried everything*' is alluded to in the literature, the author of the current study was unable to identify any prior studies where this was identified as a stand-alone phenomenologic theme. In the current study focusing on undiagnosed chronic pain this 'essential' experience was expressed by participants conveying a sense of having tried every feasible health care option; from seemingly endless doctor visits, to searching out and accessing a procession of allied health professionals such as physiotherapists, chiropractors, massage therapists, and counsellors, yet even after this exhaustive search they found they are *still* suffering from their undiagnosed chronic pain. Depending upon how various prior researchers have interpreted and categorized data gained from participant interviews and surveys, there is also degree of overlap in the literature between the aforementioned sense of having tried everything and a sense of chronic pain sufferers '*Feeling exasperated*'. However, this

too has not been isolated as an independent phenomenologic theme by researchers, although the extant chronic pain literature does offer examples of participant reports that appear to be expressing emotions of frustration in response to the ways in which their life has been negatively impacted by chronic pain. As an illustrative example, in the phenomenologic study conducted by Thomas (2000), she offers the following statement that appears to capture both a sense of chronic pain sufferers trying everything within their power to attain medical clarity, as well as a sense of frustration expressed by the chronic pain sufferers in her study:

By the time they earn the diagnostic label of *chronic pain*, these individuals usually have tried to get relief from a variety of self-care measures as well as a host of medical interventions. As they endure the gamut of physical examinations, diagnostic tests, exploratory surgeries, and a bewildering array of remedies, chronic pain patients progressively become more discouraged, weary, and angry. Both patients and caregivers become frustrated with one another when treatments are ineffective and suffering becomes prolonged. The cryptic advice ‘learn to live with it’ is often the final salvo of the health care provider to the departing chronic pain patient. (p. 683)

When considering prior chronic pain studies such as this, there remains a certain degree of ambiguity in the literature regarding whether the experiential themes of ‘*I have tried everything*’ and ‘*Feeling exasperated*’ are equally applicable regardless of whether or not one’s chronic pain is associated with an identified diagnosis. It would not seem to be overreaching to speculate that the lived experiences of feeling exasperated and perceiving that one has participated in an exhaustive procession of health care

interventions might be more potent if one was lacking a diagnosis to adequately ‘explain’ their chronic pain. However, once again it must be acknowledged that for this assertion to be defensible, future studies will need to be done that enable stronger comparisons between chronic pain sufferers who have, and do not have, an accepted diagnosis.

Limitations of Research

As was noted earlier in this document, a study’s research design (i.e., ‘naturalistic’ qualitative inquiry in the case of this study) and theoretical framework (i.e., hermeneutical phenomenology in the case of this study) *situate* the researcher in the empirical world regarding strategies for inquiry and information collection, while also providing direction as to how the investigator will address issues of legitimation and limits of research. When using interviews as a means of data collection within qualitative research, the epistemological position requires a close relationship between the researcher and the participants being researched, such that legitimate and meaningful data can be collected through interactive dialogue.

Given the aforementioned nature this study’s hermeneutic-phenomenological research framework, my skills as a first-time research interviewer would naturally represent one limitation to the research, as the interviewer’s skill has the potential to directly affect the richness and scope of data collected. As the sole research interviewer in this study, I was required to ask focused questions regarding the experience of living with undiagnosed chronic pain, listen intently to each response, and utilize strategies of paraphrasing, clarifying, redirecting, and probing as needed. These strategies were required to ensure accurate understanding on my behalf, as well as to gain as much

access as possible to each participant's accounts and articulations of their personal lived experiences, enabling subsequent analysis of the participants' use of language and construction of discourse to draw out representative themes. When considering this element of the hermeneutic-phenomenological process, one should also remain cognizant that research supports the concept that 'opening up' and allowing ones self to be somewhat vulnerable during a research interview, might be particularly challenging to individuals living with chronic pain. In this regard, Richardson (2005) speaks of the societal pressures to avoid being perceived as a complainer, adding that, "chronic pain is essentially a private and unnoticed experience unless the suffered decides to disclose it" (p. 37), going on to describe culturally imposed social sanctions wherein there is a certain amount of pain that can be 'acceptably' talked about, however, this has strict limitations. Participants in that particular study describe how it is perceived as unacceptable behaviour to dominate conversations with pain-talk, and Richardson summarizes this by stating: "The pressure not to talk about pain is not just felt from friends and family. Indeed, one suggested chronic pain management technique is 'to avoid talking about your pain as much as possible'" (p. 37). Given these insights, it is easy to imagine how a research interview experience might trigger certain individuals suffering from chronic pain to become engaged in an internal conflict, finding themselves balancing perceived societal pressures towards *concealment*, with immediate contextual pressures towards *disclosure* associated with the research setting. To my advantage, I perceived that I was able to access my core counselling skills to facilitate effective communication during the research interviews; however, upon reviewing the interview transcripts I did note a number of areas where I wish I had delved deeper

within the interview dialogue in order to more fully explore certain elements of participants' lived experiences, thus presenting an element of limitation in this study's data collection process.

When considering the process of communication, certain research limitations on behalf of the participants are unavoidable given the use of interviews to collect research data. For example, the nature of this study was such that every participant was a chronic pain sufferer, and as such, it is reasonable to assume that some of the participants might experience escalations in pain or fatigue near the end of a 60-90 minute interview, and as such, these symptoms might interfere with their ability to organize their thoughts, fully access relevant memories, push into areas of discussion that might be emotionally painful for them, or to express themselves with a degree of articulation matching their communication style when they were in a more rested or less painful state. This is problematic, as a sharp exacerbation in the symptoms of a chronic pain sufferer would have the potential to significantly impact their ability to fully participate in the interview process, thus leading to a loss of critical data. In an attempt to offset this, before the start of each interview participants were verbally informed that they would be able to rise from the chair and walk about the room, or take breaks as necessary, to keep their symptoms reasonably in check. Also, the 'Participant Informed Consent Form' indicated to participants that they had the right to terminate their interview at any time due to pain, fatigue, or emotional upset. This consent form also noted that participants would be afforded breaks as necessary if their symptoms escalated noticeably, with the option of resuming the interview after a break only if the participant felt capable of doing so.

Adding another layer of support to the idea of inherent human-based limitations as outlined above, one of this study's participants (A1) actually provided a brief letter when returning his interview transcript, describing how his participation in the interview process (and review of the resulting transcript) brought into awareness how difficult it can be for chronic pain sufferers to communicate what they are thinking, feeling, and experiencing. In this regard he stated:

I am quite surprised by how hard it seemed to be to be able to say exactly what I wanted to say ... you seemed to be talking to someone who couldn't seem to get a thought 'out there' ... It was, and is, unbelievable to me how much is going on in my mind dealing with all the issues that chronic pain has caused me to think about, while at the same time I am trying to be 'normal' and carry on a normal conversation with someone.

This participant went on to describe difficulties, "being able to express all the practical and emotional issues dealing and living with chronic pain." The fact that this participant committed the time and energy to offer his insights in the form of an unsolicited follow-up letter speaks to how important he felt it was to express the degree of challenge he faced when attempting to fully articulate the richness and complexity of his chronic pain experience within the context of a research interview.

Also worthy of consideration regarding the use of interviews to collect research data is the potential for data to be lost or inaccessible due to equipment-based limitation factors. From a purely mechanical aspect, the use of audio recording devices can present technical difficulties such as failure to record certain portions of text, or poor sound quality. In this study mechanical issues became a modest hindering factor in only one of

the research interviews, as subsequent review of the audiotape revealed an intermittent loud 'hissing' sound that rendered the occasional word or phrase inaudible. Fortunately, based on the context immediately before and after these inaudible portions, it was the author's opinion that no critical data was lost. The interaction between humans and mechanization can also introduce unique limitations, as certain individuals become uncomfortable when they are in the presence of recording devices, although I perceived that this was only a modest issue with two of the participants at the very start of their interviews. Nonetheless, it should be acknowledged that as a result of escalated anxiety and heightened self-awareness regarding one's dialogue, a certain degree of fluidity and spontaneity of both thought and speech has the potential to be sacrificed amongst certain participants. I made an effort to minimize these factors by ensuring that potential participant candidates were made fully aware both in the study's recruitment posters and pamphlets, as well as in the study's 'Participant Informed Consent Form', that the ensuing research interviews would be audio-recorded, thus providing an opportunity for individuals to opt out of participation if they were aware that such scenarios cause them to feel unduly uncomfortable. Within the actual interview setting I also spent the initial few minutes engaging each participant in friendly 'small talk' (e.g., about the weather, how their day was going, etc.) in an effort to ease any initial discomfort that they might be experiencing. I also turned on the recording device for a period of time before the actual formal interview was started in order to provide individuals with sufficient time to become desensitized to the presence of the recording device in the room. My impression was that these strategies were generally effective, as after a few minutes the participants did not seem to be attending to the recording device, and only when audiotapes ended

and needed to be turned over would the recording device seem to be momentarily drawn back into the participants' awareness.

Trust is extremely important when establishing any relationship with another individual, and as Clarke and Iphofen (2006) note, the issue of trust in research is particularly pertinent when asking participants to openly discuss intimate personal experiences that might have greatly affected their quality of life, caused loss in their life, or have had a strong emotional impact. The context of research itself presents some unique challenges and inherent limitations given the need to develop a workable level of trust within a short timeline with individuals who are essentially strangers. As such, this represented a limitation to this study, given that only sharing 60-90 minutes together with each participant naturally imposed a certain upper limit to the degree of trust and intimacy that could realistically be attained.

When further considering the issues of building rapport and trust, it should be acknowledged that when comparing myself to a novice researcher with no counselling background, I perceive that my counselling training did provide me with a certain degree of skill in establishing rapport, trust, and empathic understanding within the research interviews. This was of notable benefit as these relationship factors represent necessary components for participants to feel sufficiently safe and supported to delve deeply into painful aspects of their lived experiences. Nonetheless, aside from several 'practice interview' sessions, this study represented the first time I had actually applied these skills within the context of a research relationship. Therefore, as a first-time researcher, and a relatively inexperienced counsellor, I feel it is safe to assume that my burgeoning skills in the rapid building of trust and rapport imposed a modest limitation on my ability to

collect optimal information regarding participants' lived experiences in this study. To provide a temporal perspective, I perceive that with repeated research experiences my skill set would undoubtedly become significantly enhanced in this regard, which would be reflected in an enhanced quality and depth of data collected.

During the process of designing this study I became aware that during the research interviews the potential for 'prolonged and substantial engagement' with study participants would pose both benefits and risks as to the study's credibility. Developing a strong rapport with a participant can lead to higher comfort levels, facilitating them to share more sensitive information relevant to their lived experience than they might have volunteered at the beginning of the research interview process. However, Krefting (1991) points out that a paradox exists in that although the closeness of the researcher-participant relationship offers the potential benefit of accessing richer experiential information from participants, it can also introduce a threat to the credibility and 'truth value' of a study via the enmeshment that can occur. Relationship depth to the point of 'over-involvement' can cause a researcher to have difficulty separating their own current or past experiences from that of the participant, compromising the researcher's ability to accurately interpret findings. This represents an inherent limitation to this form of research, and as was noted previously, I strove to remain continuously aware of this risk, frequently engaging in the process of *reflexivity* as a means to keep this threat in check.

A final arguable limitation to the research concerns the lack of generalizability of the study findings, which relates to the degree of external validity in the study design. Studies are deemed to have external validity to the degree that their results can be extended beyond the limited research setting and the sample in which they were

obtained. If this concept were to be applied to the current study, this would require a consideration of how generalizable the findings are to real-life situations and the broader societal population of individuals living with undiagnosed chronic pain. However, when considering this, it is important to reiterate that external validity is inherently a quantitative concept that has positivistic roots that are *not* aligned with the qualitative approach used in this study. To the contrary, within this study's qualitative research framework, *transferability* is offered as a qualitative parallel to the positivistic concept of external validity. By fully absorbing the 'thick description' that is offered regarding the time, place, context, and sociocultural elements of this qualitative study and its participants, a reader is expected to make their own determination as to how similar the context they are interested in compares to that of the study, and thus draw their own conclusions as to the level of transferability or 'fittingness' that is merited between this study's findings and their own real-world context of interest.

Implications for Future Research

In this study's application of the tenets of phenomenology, there is an underlying assumption that there is an *essence* (or essences) to shared experiences. These essences are the 'core meanings' that are mutually understood by multiple persons through some manner of *shared experience* regarding a specific lived experiential phenomenon. Within the current study, the requirement for each of the themes to be deemed 'essential' was that every single participant verbally communicated those thematic elements when describing their experiences of living with undiagnosed chronic pain, and every participant subsequently verified those themes when the themes were presented to them in summary document. By adhering to this method, phenomenological *commonalities*

were identified in the participants' human experiences, providing insights into these 'essential' shared elements that seem to be a core part of the lived experience of undiagnosed chronic pain.

Although the aforementioned method is true to the phenomenological approach, it is nonetheless appropriate to leave space to provide a voice for certain themes that were noted to be 'common', albeit not 'essential'. These particular themes were communicated by several of this study's participants, however, given that not *all* participants expressed these elements in their descriptions of lived experiences, these themes do not meet the full phenomenological requirement for core *shared experience*. In considering this, it is important to remain cognizant that this document only represents data extracted from dialogue with these five particular participants at this particular point in history, and as such, certain commonly expressed themes might very well hold valuable information that could provide the impetus for further exploration in research. These common experiences might also offer valuable contributions to the clinical world where counsellors, physicians, or rehabilitation professionals would have opportunities to gain better insight into certain portions of their client caseload.

Several 'common but not essential' themes arose in this study that dealt with various challenging emotions expressed by those living with undiagnosed chronic pain. One such theme that was voiced by participants in the current study was feelings of 'sadness' or 'depression', which mirrors findings present within the broader pool of chronic pain literature. Simon and Folen (2001) as well as Verma and Gallagher (2000) speak of symptoms of depression amongst chronic pain sufferers, whereas one might argue that

the true sense of emotional *suffering* is better captured by the ‘story of despair’ as told by Osborn and Smith (2006), Raheim and Haland (2006), as well as Paulson et al. (1999).

Another challenging emotional theme that arose commonly (but not unanimously) amongst the participants of this study involved the perception of feeling ‘extremely stressed’ or ‘highly anxious’, which was communicated either directly through the use of descriptive phrases, or by providing rich anecdotal descriptions of life events and participants’ cognitive-emotional reaction to them. Simon and Folen (2001) speak of how chronic pain patients are also likely to have an anxiety component to their pain. Related to both the issue of pain and stress, Kugelmann (1999) as well as Turk and Okifuji (2002) speak of common tendencies of chronic pain sufferers to self-medicate via drugs and alcohol to promote relaxation and pain control.

Interrelated issues of apprehension about the future, and ebbs and flows in the experience of hope arose commonly throughout the interviews associated with the current study. Various manifestations of these themes can be found in the existing literature. Turk and Okifuji (2002) speak of how worries about the future play a central role in chronic pain, and Hellstrom (2001) describes in depth a number of ways in which chronic pain shapes and influences patients’ perceptions of the future. Thomas (2000) presents a phenomenological theme of ‘hope and hopelessness’, painting a picture of certain chronic pain sufferers valiantly ‘holding on’ or ‘hanging on’ to shreds of hope, whereas other sufferers have declined to a point where all hope is lost and thoughts of death are considered liberating from the intolerableness of life.

A related theme that has a relationship to the issue of hope is perhaps best described by using a metaphor of ‘diagnosis is the key to unlock one’s suffering’. Although a sense

of this permeated this study's interviews, it was not expressed definitively enough by all participants to be deemed an 'essential' theme. This metaphor also fits well with the aforementioned metaphorical description of chronic pain as a 'prison' that is found within the chronic pain literature. However, in the case of the current study's participants, a sense was conveyed that a clear diagnosis would have the immeasurable power of a warden's key that would open the imprisoning door, in effect freeing the sufferer from the prison of their tortured existence. In my own clinical experiences as both a physiotherapist and a counsellor working with chronic pain clients, the elusive diagnosis conceptually serves as the metaphorical 'key' for two critical reasons. Firstly, the diagnosis assumes a place of essential relevance because in medicine and rehabilitation the treatment plan is ultimately linked to the underlying diagnosis. In effect, once a correct diagnosis has been identified there is newfound hope for the identification of a 'cure'. Secondly, participants in this study conveyed a sense that simply having a diagnosis to 'explain' their chronic pain would, in itself, have a positive effect on their state of mind, given that part of their emotional suffering seems to be linked with their state of 'unknowingness'. The aforementioned study by Hyden and Sachs (1998) offers support for my own clinical experiences and interpretations in this regard, as they state:

In social psychological terms, this (diagnosis work) can be expressed as patients trying to get confirmation and recognition of their suffering from the doctor who is empowered to sanction it, e.g. in the form of a diagnosis and doctor's certificate of disease. Recognition in the form of a diagnosis also opens up the possibility of

treatment and the hope of relief from the suffering that threatens to fragment and perhaps disintegrate his or her own self. (p. 190)

This theme of ‘diagnosis is the key to unlock one’s suffering’ is a particularly fascinating one, as one can follow a logical train of thought to the point where one can understand how the sufferer of undiagnosed chronic pain might perceive that diagnosis is their missing key, yet it is equally apparent that there are many individuals in society with chronic pain who do, in fact, have a confirmed diagnosis, yet they too experience significant suffering. If one accepts the dichotomy of this observation, then another realm for future research opens up, involving a further examination of the potential for (and nature of) cognitive distortions in this regard, as well as an exploration of the path that ultimately leads individuals to the point where their ‘*if only ...*’ belief system hangs virtually all hope for an improved quality of life upon this one single feature of having a diagnosis.

A final ‘common’ theme that came to light within the current study can be described via a metaphor of ‘acceptance is a double-edged sword’. On the one hand, participants in the current study often acknowledged an understanding that some peace of mind might be gained if they were able to simply accept their lot, and move ahead in their lives working under an acceptance that their current pain status might not ever change. Indeed, one participant even noted that this very advice had been offered by a psychologist as a means to reduce angst and improve his quality of life in an emotional sense. However, there was clearly a shadow-side to this issue of acceptance, as several participants painted the concept of acceptance in a very negative light, often exchanging the word ‘acceptance’ for phrases such as ‘giving up’ or ‘resignation’, using language that

invoked negative connotations interpreted by the author as 'quitting the good fight'. As the interviewer I was left with a sense that acceptance was a powerful concept in the lives of these individuals, as the thought of moving to a place of acceptance clearly invoked fear in several individuals, given that this would require them to admit that their quality of life might never improve from its current status. Perhaps most importantly, I was left with the distinct impression that the conflicted nature of their relationship with the notion of acceptance actually serves as a further source of suffering for these individuals living with undiagnosed chronic pain.

When considering how the aforementioned 'common' themes might provide direction for future research initiatives, it is suggested that the possibility exists that some of these themes might, in actuality, be 'essential' themes that simply did not come up within the context of all of this study's research interviews. This again speaks to the issue of limitations inherent within the chosen research method, as one might reasonably assert that not every aspect of one's lived experience might be given a voice within a single research interview. Indeed, it is quite conceivable that if a participant's symptoms had been at a different intensity, or the interview had been conducted by a different individual, or if the stream of dialogue had simply gone in an alternate direction, then themes that remained covertly silent in this study's interview might have risen into overt verbal expression in another context. If one can accept this, it is fathomable that the same sufferer of undiagnosed chronic pain might very well present different information on different interview occasions, and this alone warrants further exploration of both this study's identified 'essential' and 'common' themes to ensure a full exploration of the topic matter.

A second rationale for further exploring the ‘common’ themes outlined previously is that there may be clinically valuable information identifying precisely why a certain feature may be quite common, yet not unanimously shared amongst sufferers of undiagnosed chronic pain. As an illustrative example, perhaps important contextual features could account for why many sufferers of undiagnosed chronic pain turn to substance abuse as a coping strategy, yet other individuals manage to avoid falling into this ‘trap’. A more focused exploration of this particular ‘common’ theme might identify key features about the individuals’ lives, or about the individuals themselves, that function as underlying ‘vulnerability factors’, increasing the likelihood of certain individuals turning to this negative coping strategy. If it was, in fact, possible to accurately identify these underlying factors, then this information could be disseminated to health care providers so that substance abuse is less likely to go overlooked within the spectrum of treatment. Similarly, definitive findings in this regard could potentially lead to the development of clinical tools such as a ‘screening questionnaire’ that could help clinicians to identify vulnerable individuals from the outset, so that *preventative* interventions could be layered into their medical, counselling, or rehabilitative treatment plans. Using this one illustrative example, it can be readily seen that potentially rich information could be gained from moving more deeply into focused exploration of this study’s ‘common’ themes, with outcomes that would be of equal benefit to the academic research world, as well as the world of clinical care giving for clients with undiagnosed chronic pain.

Opportunities for future research also present themselves by breaking down the larger population of undiagnosed chronic pain sufferers into smaller subgroups in order

to learn if any predictable patterns of variation arise. For example, in the current study the solitary male participant described feeling ‘emasculated’ by no longer being able to change a tire on his teenage daughter’s car, or carry groceries for his mother-in-law. In this spirit, he went on to describe how his pain-related functional restrictions have even impacted the relationship with his wife, as he is unable to fulfill certain physical tasks and complete chores around their home that he perceives to be part of his fundamental role as the ‘man in the relationship’. This suggests that certain elements of his experience of living with undiagnosed chronic pain might have been quite different if he was of the opposite gender. In this regard, it should be noted that within the general chronic pain literature there are existing studies that have included male or female gender as an inclusion criterion, but room exists for potentially enlightening research to specifically focus on *contrasting* the lived experience of males versus females who are living with undiagnosed chronic pain. Based on this line of reasoning, it seems quite reasonable to speculate that one’s lived experience might also vary along any number of other socio-cultural-demographic lines, such as socioeconomic status, culture, race, and age; keeping in mind that these factors might also impact how others respond to, and interact with the chronic pain sufferer, which will also undoubtedly shape their lived experiences.

This above suggestion to consider further subdividing the undiagnosed chronic pain population into smaller subgroups attains real-world relevance if the reader of such studies plans to use this information to positively influence the way in which they practice clinically. As was described previously in this document under the discussion of *transferability*, when a clinician reviews research-based information as a means to become a better care provider for their chronic pain clients, the ‘burden of

transferability' is on the reader to make their own determination regarding the degree of similarity between the study context and the receiving context (i.e., the 'fittingness' that is merited between the study findings and their own real-world context of interest), whereas it is the researcher's responsibility to provide sufficient detail to enable the reader to make such a judgment. Therefore, from a praxis standpoint, the more precise detail the researcher can provide regarding the study context, including the nature of the chronic pain population under consideration, the better positioned each reader will be to determine the 'degree of fit' between the study's findings and the chronic pain clients on their own clinical caseload.

Another area of consideration for future research concerns the 'invisibility' of pain, given that pain itself is not overtly visible. To this end, there are some individuals who report significant chronic pain that might be deemed to 'look perfectly fine', however, there are other individuals suffering from chronic pain who have physical deformations, significantly compromised movement patterns, or ambulatory aids such as wheelchairs that immediately 'signal' to others that their health is compromised in some way. Given that these 'signals' serve as social cues to others, it is reasonable to assume that the presence of these cues would impact the perceptions of others, and thus the way in which they interact with the chronic pain sufferer; all of which has the potential to exert influence on the lived experience of the pain sufferer in a meaningful way. Given that several participants in the current study identified the 'invisibility' of their pain as a contributing factor in their struggle for societal legitimacy, it is suggested that this might be a rich area for deeper exploration in future research.

A final critical issue with implications for future research concerns the irregular usage of operational definitions used within the literature which, as was noted previously, has made it difficult to cross-reference the current research findings with those of prior studies. This is a two-tiered problem, as inconsistencies are present within the literature with regards to usage of key terms, as well as the fact that some studies do not actually operationally define certain key terms. As a most fundamental example of how this is problematic, it can be noted that even the word 'pain' is actually open to varying interpretations, as one can imagine a continuum of intensity, whereby what one person might term 'pain' another person might define as simply 'discomfort', instead perceiving 'pain' as a more intense sensory experience. Alternatively, some individuals strike a distinction between 'pain' and other milder terms such as 'discomfort', given that they interpret 'pain' as being associated with a degree of related functional impairment. I have personally seen these issues arise in my own clinical practice as a physiotherapist when attempting to introduce a numeric pain rating scale, whereby at lower intensities certain individuals will tend to express reticence regarding actually referring to their unpleasant sensory experience as 'pain', offering explanatory statements such as 'well it's not so bad that I'd have to see my doctor', or 'it certainly wouldn't stop me from doing anything', or 'it's uncomfortable but I wouldn't call it pain per se'.

A second area of difficulty within the literature regarding operational definitions is the lack of consensus in the research regarding what criteria should be used to decide when it is appropriate to use the descriptor 'chronic' in reference to pain. This is a key methodological point because pain-timelines, for example, often become reflected in the

inclusion criteria of studies. The central problem is that the qualifying timeline for chronicity is not agreed upon, with a number of studies choosing 3 months, and the majority of studies choosing 6 months as the requisite duration for the perpetuation of the individual's pain experience to be considered 'chronic'. To provide a brief historical context, it should be noted that the International Association for the Study of Pain (IASP) developed an earlier definition of *chronic* pain (as cited in Pizzi et al., 2005) as: "pain without apparent biological value that has persisted beyond the normal healing time, usually *three months*." However, this definition has the potential to be problematic, given the potential for difference of opinion regarding the phrase 'normal healing time' and the associated timeline of three months. Based on my professional background in physiotherapy, I recognize that for non-complex soft tissue musculoskeletal injuries, a 3-month timeframe is generally considered sufficient for tissue regeneration, cellular remodelling, and the overall healing process to achieve a state of completion. However, there exists a wide range of other more complex injuries, ailments, and disease processes for which a much longer timeframe would be expected. Assumedly, it was a similar thought process that prompted the North American Nursing Diagnosis Association (NANDA) to slightly revise the wording of their definition (as cited in Thomas, 2000) to the following: "Chronic pain is an unpleasant sensory and emotional experience arising from actual or potential tissue damage or described in terms of such damage ... without a predictable end, and a duration greater than *6 months*." Based on these subtle wording changes, it appears the NANDA organization felt that the lack of a clearly defined endpoint to the pain state, and an extension of the minimum duration to 6 months, were worthy of inclusion in their definition. Although this appears to be a justifiable extension

from the original timeframe, I recognize that some individuals will argue that applying the 6-month timeframe is just as arbitrary. Nonetheless, this tension regarding the arbitrariness of assigning a ‘cut-off’ timeframe for chronic pain is, in my opinion, superseded by the greater importance of establishing standardization within the chronic pain literature. The benefits to be gained by standardizing a timeline for ‘chronicity’ are not only based on the need to facilitate ease of cross-study comparisons, but also to improve the ability to apply chronic pain research knowledge in clinical practice. To clarify this latter rationale it must first be acknowledged that the lived experience of individuals suffering from chronic pain could reasonably be expected to change over time. Specifically, if one enters into chronic pain research working under a fundamental assumption that ‘chronic’ pain is distinct in a number of pertinent ways from ‘acute’ or ‘sub-acute’ pain, they are most certainly also operating under the assumption that the pain-related changes associated with one’s lived experiences would tend to *evolve slowly over time*. If one can accept this assumption, then it stands to reason that it is inherently problematic to have wide variances in the temporal aspects linked to inclusion criteria for ‘chronicity’ in these pain-related studies. One could argue that this might be particularly problematic within the realm of phenomenology where the research is aimed at identifying ‘essential’ lived experiences that are, by definition, voiced by all of the study participants. As a simple illustrative example, it is feasible that an undiagnosed chronic pain sufferer’s feelings of frustration might be different at the 3-month mark, as opposed to the 6-month or 12-month marks, assumedly increasing over time as their pain and the associated life challenges do not abate. Therefore, if a certain study defined 3-months of consistent pain as a primary inclusion criteria to denote ‘chronic’ pain, then an

experience of frustration might not be reported by all participants, and thus it would not be deemed to be an ‘essential’ experience of living with undiagnosed chronic pain. However, the exact same participants might unanimously have reported significant feelings of frustration if 6-months had been the qualifying timeline, and thus, in this alternate scenario the emotion of frustration *would* be considered to be an ‘essential’ experience of living with undiagnosed chronic pain. This hypothetical example serves to once again illustrate the way in which operational definitions can have a praxis impact with respect to the *transferability* of study findings, given that this factor can affect which themes actually attain an element of significance by being deemed a core ‘essential’ experience. Therefore, the literature pool would be strengthened, and research findings could more easily *assimilated* by treating clinicians, if a universally agreed upon timeframe for ‘chronicity’ of pain could be established.

A final area of difficulty within the literature regarding operational definitions is the lack of discrimination regarding what constitutes an actual ‘diagnosis’, both in the mind of the researcher and in the mind of each participant. Once again, this lack of consensus not only has implications regarding the ability to compare findings between various research studies, but also regarding the issue of *transferability* via the application of research information to clinical practice. As was noted previously, there are numerous examples within the chronic pain literature where labels such as ‘chronic low back pain’ are presented as a diagnosis even though it is more accurate to acknowledge that they are simply phrases describing symptoms. Given that one primary element of the current study is to determine what, if any, is unique about the lived experience of having chronic pain in the absence of a *diagnosis*, this ambiguity in terminology becomes troublesome.

For example, two individuals could be given the label of ‘chronic low back pain’ by their family physician and one individual might perceive this as a definitive diagnosis that adequately ‘explains’ the chronicity of their pain and related functional disability, whereas the other individual might not be satisfied that this meets their personal criteria for what constitutes a ‘diagnosis’, and therefore they might not actually perceive themselves as being diagnosed. Indeed, in the case of the second individual it is quite possible that their way of ‘making sense’ of their situation, and thus their ‘lived experience’, might not differ significantly from what it would have been if the physician had said to their patient that he or she had no idea what was the cause of their pain symptoms. This same line of reasoning regarding the issue of diagnostic ambiguity within the perceptions of the actual chronic pain sufferer also expands outward to other important individuals in the pain sufferer’s life who may, or may not, recognize the applied clinical label as an actual ‘diagnosis’. Both considerations are equally important because they both have the potential to impact upon the chronic pain sufferer’s lived experience. Similarly confounding effects have the potential to arise when an individual is given a diagnosis that, although well defined, might fall into the category of diagnoses that are not universally socially sanctioned. Possible reasons for this lack of cultural recognition for a certain diagnosis is a lack of clearly identified etiology to ‘explain’ the symptoms, or a lack of objective diagnostic tests to offer definitive ‘evidence’ of injury or illness. Fibromyalgia and chronic fatigue syndrome serve as two common examples of such potentially contentious diagnostic labels. Once again, the fact that certain diagnoses have a lesser degree of social sanctioning might cause the sufferer’s experience of living with chronic pain to be perceived differently as compared to if they had received a more

‘mainstream’ diagnosis, and may also cause differences in perception by other important individuals in their life, thus affecting the chronic pain sufferer’s lived experience in multifaceted ways. This interplay of factors can become even more complex, as the chronic pain sufferer might not fully ‘accept’ a less socially sanctioned diagnosis and thus perceive themselves as essentially ‘undiagnosed’, whereas their physician might perceive them as being accurately diagnosed, and friends and family members might represent a mixture of interpretations; all of which has the potential to affect how others interact with the chronic pain sufferer, which will undoubtedly affect the chronic pain sufferer’s lived experience. As one delves deeper into this issue it becomes readily apparent that this issue of ‘diagnosis’ is not nearly as clear-cut as it might appear at first consideration. In the current study an attempt was made to account for this issue by having an operational definition of ‘undiagnosed’ (as well as associated inclusion criteria) that focused upon each participant’s *own* perceptions, such that if they themselves did not believe they had a diagnosis that sufficiently ‘explains’ their chronic pain, then they were deemed to meet the definition of ‘undiagnosed’ for the purposes of this study. The rationale for adopting this particular approach is that it focuses directly upon the chronic pain sufferer’s *own* unique perceptions, which is in effect their ‘lived reality’. However, this approach has not been adopted universally throughout the chronic pain literature, and given the potential limitations that ambiguity imposes regarding cross-study comparison and implications for praxis, it is this author’s assertion that this factor needs to be more carefully considered within the chronic pain literature.

Implications for Counselling Practice

Within the world of counselling psychology, there is virtually universal acknowledgment that the establishment of trust and the communication of a deep *understanding* of a client and their life challenges is a fundamental quality in the development of a positive therapeutic relationship. Egan (2002) speaks to the collaborative nature of helping, noting that within the counselling working alliance the clinician-helper and their client are collaborators with essentially shared goals. When one adopts this clinical stance, it becomes clear that helping is not something that helpers 'do' to clients, such as the concept of 'curing' the patient in the traditional Western medical model; rather, it is a process that helpers and clients work through together. Egan notes that for a counsellor to be effective in this alliance they must strive to establish an empathic understanding of their client, which requires the counsellor to gain an accurate sense of the client's 'inner world', strive to experientially feel what the client is feeling, and to communicate that sensing and understanding back to the client. By reflecting this learned knowledge back to the source, the client has the potential to gain a better understanding of themselves, their problem situations, their unused resources or opportunities, and their feelings more fully, so they can then begin to manage their feelings, thoughts, and life challenges in a more effective manner. Given this foundational element of counselling, one of the broadest implications for the current study is the role it can play in facilitating counsellors to develop a more accurate and deeper *understanding* of clients who are living with undiagnosed chronic pain. Again, the 'burden of transferability' ultimately falls upon each reader to make their own determination regarding the degree of fit between the 'essential' and 'common' themes

identified within this study, and the contextual factors of each unique counselling client, however, maintaining an underlying awareness of these themes in the back of one's mind can nonetheless inform the therapist's clinical practice. The advantages of having this knowledge could be demonstrated in a practical sense by guiding the counsellor into possible areas of exploration during their clinical dialogue with clients living with undiagnosed chronic pain, or by helping the counsellor to 'pick up on' areas of cognitive-emotional discontent that although subtly expressed or 'hinted at' by a client, might be worthy of more in-depth investigation. In essence, a sound knowledge of the themes identified in this study can help fine tune the counsellor's clinical 'radar', leading to fruitful areas of therapeutic exploration that might otherwise have been missed in the absence of this background knowledge, enhancing their therapeutic effectiveness when working with clients living with undiagnosed chronic pain.

Related to the process of counsellors moving to a place of empathic understanding of their client is the issue of trust building within the therapeutic relationship. As noted by Johnson and Johnson (2003), the more you accept and support others, the more likely they will disclose their thoughts, ideas, theories, conclusions, feelings and reactions to you. The primary factors necessary for communicating this acceptance and support involve the expression of warmth, cooperative intentions, and an accurate *understanding* of the client's lived experience. When working with clients living with undiagnosed chronic pain, this understanding can be built upon a foundational knowledge of the 'essential' themes identified in this study. Moreover, it can be argued that a counsellor has an ethical imperative to use whatever information is at his or her disposal to facilitate a richer understanding of each client's clinical presentation. In this spirit, by availing

oneself to this study's findings and communicating an accurate understanding of the various challenges associated with living with undiagnosed chronic pain, the counsellor has the ability to set off a positive cascade of trust building and relationship building interactions that can facilitate the client's disclosure of more intimately personal or painful thoughts and emotions. This back-and-forth interplay of clients feeling safe enough to be trusting, and the counsellor behaving in a trustworthy manner, will synergistically serve to deepen the degree of therapeutic intimacy, and thus will enhance the effectiveness of the counsellor-client relationship.

Another way in which the findings of this study have the potential to inform clinical practice involves a different configuration of the issue of understanding. One of the 'essential' themes of this study was the theme of *'Not feeling understood by others'*, which is somewhat of a double-jeopardy, given that this perception can also contribute to feelings of isolation within relationships. From a praxis standpoint, it is suggested that certain clients might be consoled, and thus might have a positive shift in cognitions or mood, simply by having their counsellor share information regarding this element of the current study. By coming to realize that it is not unusual to struggle with these feelings of not being understood, and in fact, such feelings actually appear to be a widely shared experience amongst individuals living with undiagnosed chronic pain, the client might inherently feel like less of an enigma within the larger society. Gaining this knowledge has the potential to shift perceptions, and the client might spontaneously gain a feeling of support from learning that they actually are part of a larger whole of individuals who share this common thread. A sense of this insidious therapeutic benefit was captured within this study by the written comments provided by one participant (A1). He had

written an email to confirm that this study's 'essential' themes were accurate reflections of his experiences of living with undiagnosed chronic pain, and within this communication he expressed the following:

I was truly fascinated by what you have done so far, and am in complete agreement with your 'themes'. Believe it or not, reading other people describe the exact same thoughts that you have, somehow seems to help. I don't exactly know why. Makes me feel like I want to personally tell all those people that at least they have one person who can truly understand. And perhaps through you, they will have another person to understand ... thank you again for the opportunity to feel heard.

The fact that these comments were unsolicited, and required time and energy to express in a written format, serves once again to underscore how important these issues can be to individuals living with undiagnosed chronic pain. Moreover, the sentiments expressed by this individual illuminate how the simple sharing of 'essential' themes can in and of itself have a therapeutic impact on clients, offering comfort and reassurance by making them feel that they are not alone in the challenging experiences they struggle with on a daily basis.

This study's themes of *'Not feeling understood by others'* and *'Reduced social contact with others'* have the potential to be drawn together within a counselling context by considering the option of adopting a family therapy approach, whereby a client's spouse and/or children are integrated into the therapeutic process. As was noted above, not feeling understood by others has the potential to be socially isolating, and participants within this study communicated that this was particularly difficult when this pertained to their closest friends and family members. Given the effect of reduced

relationship intimacy that these themes invoke, it is feasible that during counselling sessions a sizable portion of clients living with undiagnosed chronic pain might also express painful perceptions and experiences associated with ‘failing’ relationships within their closest social spheres. Moreover, it can be speculated that harbouring perceptions of ‘failing’ relationships with one’s spouse or one’s children has the potential to be perceived as *personal* failures by the client, compounding the stress which is commonly associated with chronic pain, and negatively affecting mood (e.g., decreasing feelings of self-esteem and self-worth, or increasing feelings of anxiety or depression). By having background knowledge from this study that these experiences of not feeling understood and feeling socially isolated are ‘essential’ elements to living with undiagnosed chronic pain, the counsellor can operate from a more informed place as they explore to what degree these issues might be troubling to a given client. Additionally, the counsellor has the option of sharing the thematic analysis of the current study with clients who might initially have reservations regarding including family members in their counselling process. Offering these themes for discussion might present an opportunity to enlighten reluctant clients as to the therapeutic rationale for including their family members in counselling, and by doing so, facilitate a willingness on the behalf of the client to do so. Alternatively, sharing this information with family members who are attending counselling sessions can open the door to therapeutic dialogue by, in essence, giving them social ‘permission’ to ‘admit’ that they have withdrawn from the client, or to acknowledge that they do not fully understand what their loved one is going through. These are difficult admissions to make, as they can be couched by feelings of shame, embarrassment, guilt, or blame on both sides, with the ironic consequence that these

disturbed cognitions-emotions tend to put even more distance between the client and their family. By learning that these are actually experiences widely shared by individuals living with undiagnosed chronic pain, it can be hoped that a certain degree of perceptual 'normalization' will be gained regarding these challenging elements of the client's lived experiences, reducing defensiveness and enabling clients and family members to feel sufficiently safe to openly discuss and face these important interpersonal issues.

Essentially, a merging of these factors on behalf of the client and family members has the potential to be of tremendous therapeutic value for certain clients regarding the establishment of a more effective counselling context characterized by healthy, honest, non-defensive dialogue between the client and his or her family members regarding the impact that the client's undiagnosed chronic pain has had on their relationship and the interconnected elements of their lives.

An awareness of this study's theme of *'The experience of loss'* has implications for clinical practice by enlightening counsellors as to the many ways in which their clients who are living with undiagnosed chronic pain might be dealing with loss, enabling the counsellor to adjust their clinical focus and choice of therapeutic interventions accordingly. For example, certain clients might express loss primarily in pragmatic terms relating to the loss of function with respect to an inability to complete tasks at work or home, as well as expressing discontent regarding limitations in their ability to fully participate in enjoyable leisure pursuits. In this context, the counsellor primarily assumes a supportive role, providing therapeutic space for the client to process their upsetting cognitions and emotions, with the potential to also engage the client in some practical problem-solving dialogue. This latter function might involve the counsellor facilitating

the client in prioritizing their daily activities of daily living (ADL's) such that they become more adept at selectively expending their limited energy and mobility resources in a way that at least covers off the ADL's that are most critical to their quality of life. In a related line of dialogue, a counsellor might also decide to engage a client in a discussion regarding other areas of their life where they actually are performing well, encouraging the client to take 'ownership' in these areas of success. This provides the astute counsellor with an opportunity to facilitate a process of positive affirmation, and the bolstering of perceptions of self-worth, by discussing the client's 'mastery' experiences, while encouraging the client to be specific in discussing and fully connecting with their associated positive cognitions and feelings. Certain other clients might gain notable benefit from the provision of psychoeducational information regarding strategies such as alternating tasks or incorporating micro-breaks into their daily routine to maintain pain and energy at manageable levels, thus maximizing their ability to remain reasonably functional over the course of a day. When considering this latter approach within a clinical context, it is recommended that the value of this seemingly straightforward psychoeducational dialogue should not be underestimated, as it has the potential to significantly impact the client's ability to complete life tasks that are most fulfilling to them, and as such, stands to have a dramatic positive impact on their cognitions, mood, and generalized sense of enjoyment from life.

When again considering this study's theme of experiencing loss, it should also be noted that therapeutic dialogue might very well lead into other areas that can have a more global impact on the client's general state of psychological homeostasis. For example, the fact that undiagnosed chronic pain causes many individuals to become

displaced from their employment has the potential to impact their vocational identity. This has the potential to be particularly psychologically troublesome to these clients given that the nature of this vocational transition is such that it tends to be unexpected, unplanned, and unwanted. Indeed, if one considers what it might like to be involuntarily displaced from one's chosen employment as a result of undiagnosed pain and related disability, as well as concurrently losing one's role around the home and the ability to participate in one's leisure pursuits, then the gained empathic understanding can enlighten the counsellor as to the many ways in which loss might be deeply felt by the client, to the point where a client's global identity could be affected and their very sense of 'self' may be in a state of crisis. Several participants in the current study expressed this as a perceived loss of normalcy that was associated with a sense of disturbing internal turmoil and displacement. The ensuing sense of ambiguity regarding one's identity, as one finds that they are no longer able to participate in any of the life events that 'made them, *them*', is an area of transition that is very amenable to counselling interventions. For example, this could involve the processing of a range of painful cognitions and emotions, such as feelings of sadness, bitterness, feelings of disenfranchisement, and various negative self-evaluations associated with a loss of self-respect, self-efficacy, and self-worth. Certain clients might also require elements of grief counselling, as their sense of loss might have moved them to a place of mourning for the lost elements of their life that were most central to their being. During the processing of cognitions and emotions associated with deep loss, the counsellor again has the option of sharing this study's findings with the client, particularly the idea that loss is an 'essential' theme for individuals living with undiagnosed chronic pain. This has the

potential for positive therapeutic effect by offering a degree of reassurance to the client, as it seems to be a basic human experience that we gain comfort from the knowledge that we are not alone in our times of grief and loss.

A final example of a way in which this study's findings have implications for counselling practice relates to the identified themes of the '*Experience of not being believed*' and the experience of '*Feeling invalidated by physicians*'. From a clinical perspective, the first step is for the counsellor to be aware that these negative experiences have been found to be 'essential' elements of the experience of living with undiagnosed chronic pain, and as such, to either directly inquire about them or to keep them in the back of their mind when taking a client history. In this regard, the counsellor can be in a more informed place to explore to what degree these issues might be emotionally disturbing to a given client. Secondly, the counsellor has the option of sharing the thematic analysis of the current study with a client, which has the potential to reduce feelings of 'personal attack' from others when considering invalidation or delegitimation experiences. Thirdly, when addressing these and related issues the counsellor should remain careful not to purposefully or inadvertently reinforce the 'social myth' that a person completely controls their own fate, as this leaves client's vulnerable to falling into (or maintaining) destructive patterns of self-blaming when considering episodes of ill treatment by others. While doing so the clinician must be equally careful to avoid promoting an overly externalized locus of control perspective, as this can parlay into perceived powerlessness and learned helplessness. Essentially, a high degree of skill is required on behalf of the counsellor, as they must *balance* the need to encourage their client to relieve themselves of responsibility for being the target of inappropriate

treatment by others, while concurrently not enabling unbeneficial patterns of apathy by the client or abdicating responsibilities that do fall squarely upon the client. As an illustrative example, if a client expressed emotional upset associated with a perception of having been treated in an invalidating manner by a physician, then the client might gain benefit from an exploration of this experience within a counselling context. Given the socially sanctioned 'power' that Western society imposes upon physicians, this form of invalidation has the potential to be particularly destructive to clients, as there is the potential for the client to *internalize* elements of the invalidating experience. This internalization can range from experiencing a transient sense of humiliation, to longer lasting harmful effects such as decreased overall feelings of self-esteem and self-worth, and a potential exacerbation of anxiety or depressive symptoms. As an alternate illustrative example, if a client expressed emotional upset associated with a perception that an insurance company was calling their honesty and integrity into question, they too might gain therapeutic benefit from an exploration of this experience within a counselling context. Similarly, the client might benefit from reconceptualizing the negative experiences that have transpired when interacting with representatives of insurance companies. In this scenario the counsellor might consider having the client express possible motivations for why an insurance carrier might adopt an adversarial stance, and what might be gained by the insurer from the denial of claims, such that the intensity of the client's negative cognitions and emotions are diffused as they come to realize that they are not actually being 'singled out', and that it is quite possible that this adversarial stance is commonplace within the insurance sector. Again, the client's acceptance of this interpretation can be facilitated by sharing this study's findings that

the experience of not being believed is actually an 'essential' theme for individuals living with undiagnosed chronic pain. In both the physician and insurance company scenarios, it can be seen that therapeutic benefit might be realized by adopting a counselling approach wherein the client is encouraged to appropriately externalize their attributions in order to promote a less disturbed internal cognitive-emotional environment.

As a further adjunct to the aforementioned counselling process, the client might also be encouraged to consider what broader societal stigmas and personal assumptions might be at play affecting the behaviour of the physician or insurance representative, thus reducing self-blaming patterns of cognition by depersonalizing the experience and breaking cognitive linkages between the negative behaviours of those other individuals and the client himself or herself. Further therapeutic benefit might be realized by having the client recall back to their own life before the onset of their chronic pain, encouraging them to consider if they themselves previously held any assumptions or biases towards individuals who might have reported having undiagnosed chronic pain, particularly if this caused them to be off of work or 'on claim'. If this introspective process triggers acknowledgement that they too have held uncharitable beliefs towards individuals in the same situation that they are currently living in, this enhanced understanding of the power of societal stigmas might foster more patience and tolerance towards the offending individuals, and open the door to the client viewing these as opportunities to affect positive change in others. By incorporating assertiveness training into the counselling process, the client has the potential to develop more effective communication skills and social confidence, enabling them to appropriately express their needs, and to offer appropriate resistance in social contexts where they perceive invalidation or that the

legitimacy of their pain presentation is being called into question. This has the potential to be particularly rewarding to the client, as successful application of these skills offers an opportunity to change not only how others might interpret the client's own particular situation, but also how these other individuals might interact with fellow sufferers of undiagnosed chronic pain in the future.

In both of these illustrative scenarios, by implementing a combined approach involving directed use of this study's findings, and the implementation of focused cognitive behavioural strategies, clients can be relieved of taking undue 'ownership' over various upsetting life events involving invalidation or having their honesty questioned, thus putting distance between themselves and the source of the upset, and redirecting the 'blame' away from themselves. These reframing processes have the potential to rebuild compromised self-esteem, as well as to nurture skills and motivation within the client that can change their outlook and means of interacting with individuals, as well as with society's various health and insurance 'systems' in future contexts. All of these benefits have the potential to merge in ways that will help clients achieve the superordinate goal of promoting more satisfying social and personal outcomes.

Overall Significance of the Study

This study was entered into with the expectation that it would serve to illuminate the experiences of a poorly understood segment of the larger chronic pain population, specifically those individuals who do not have an accepted diagnosis to 'explain' their ongoing chronic pain. By exploring, describing, and endeavouring to really *understand* the experience of these individuals, it was hoped that new insights could be gained that might have implications for clinical practice, as well as enhancing societal levels of

insight and sensitivity to facilitate improved insurance disability claims management, adding efficacy and fairness to the decision-making processes of third-party insurers when working with claimants who are dealing with undiagnosed chronic pain. From a purely clinical perspective as a counsellor, one of the foundational elements necessary to function effectively in the clinical role of a ‘helper’ is the ability to adopt a client’s worldview, of which the first step is attaining an understanding of the challenges each individual client faces on a daily basis. Thusly, the hermeneutic-phenomenological framework was selected, as it was deemed to be the optimal approach for moving to a place of better understanding regarding what represents ‘essential’ elements of living with undiagnosed chronic pain. In terms of even broader implications for praxis, an overarching motivation of the researcher was to generate new knowledge that could be applied *across* disciplines, positively affecting psychological-counselling, medicine, and physical rehabilitative disciplines in a way that would have meaningful relevance in terms of promoting deeper levels of *empathic understanding*, while concurrently improving the ability of practitioners to develop effective clinical conceptualizations and treatment plans. In this regard, it is the author’s hope that this study’s findings can raise clinicians’ awareness across disciplines as to how they interact with their patients and clients who are living with undiagnosed chronic pain, and influence social-clinical interactions such that they are maximally supportive and therapeutically helpful, as opposed to being invalidating and potentially harmful to the client’s cognitive-emotional well-being. An equally important impact of this raised awareness is that practitioners of physical medicine and rehabilitation stand to gain a deeper understanding of the cognitive-emotional challenges faced on a daily basis by their patients living with

undiagnosed chronic pain, and as such, they can consider the provision of referrals to adjunct counselling services in order to provide a more holistic and therapeutically effective approach to patient management.

In the end, it is the author's opinion that success was attained regarding the goal of enhancing a deeper level of understanding regarding what it is like to live with undiagnosed chronic pain, in effect giving a voice to this underrepresented portion of the chronic pain population. However, although this singular goal was achieved, the author experienced a sense of disappointment that widespread disparities amongst the extant literature interjected limitations that rendered it difficult to distinguish a clear delineation between what is truly unique to the experience of living with chronic pain that is undiagnosed, as compared when one has an accepted diagnosis. In the end, the final aspect of this research journey entailed an analytical process that resulted in the highlighting of numerous ways in which the broader pool of chronic pain research could be improved upon in order to provide easier access to cross-study comparisons, as well as to facilitate the process of transferability of research findings into clinical settings. This final aspect of the research journey was somewhat bittersweet; although the nature of the extant literature constrained the ability to identify what is particular to the experience of living with chronic pain when one lacks an accepted diagnosis, the resulting insights regarding ways to improve the literature might in the end be of equal value to the study's original goal, thus contributing to the positive 'footprint' this study may leave upon the always complex and fascinating realm of chronic pain research.

APPENDIX A: Invitation to Participate Poster

CHRONIC PAIN STUDY

University of Victoria

Dept. of Educational Psychology
and Leadership Studies

*this study represents partial fulfillment
of the requirements for the degree of
Master of Arts in Counselling Psychology*

If you are interested in participating in a study that has a goal of promoting a better understanding of how undiagnosed chronic pain affects individuals' lives, we would love to have you participate in our groundbreaking new study. Participants must fit the following criteria:

- You are currently experiencing a non-interrupted period of chronic pain for a duration of at least six months (i.e., you have never had a 'pain-free day' within that duration), and
- You speak English fluently, and are comfortable with the idea of participating in an audiotaped interview where you would be required to discuss your personal experience of living with undiagnosed chronic pain, and
- You perceive that your chronic pain is '**undiagnosed**', which may include either of the following criteria:
 - a) You have never been given a diagnosis for your ongoing chronic pain,
 - b) You have been given multiple conflicting diagnoses (from one or more health care practitioners) to 'explain' your chronic pain, however, you do not believe that a single accurate diagnosis has been clearly identified.

*Note: the purpose of this study is **not** to provide diagnostic information to participants.*

Note: participating in this study does not restrict you from exiting the study. You may withdraw from the study at any time without any negative consequences or any explanation.

Principal Investigator: Andrew Sumner
Phone: 661-2029
Email: asumner@uvic.ca

Research Supervisor: Dr. Tim Black
Phone: 721-7820
Email: tblack@uvic.ca

APPENDIX B: Information Form for Research Study “Host” Sites

Introduction to Researcher

Andrew Sumner is the primary researcher for this study. He is a graduate student in the Counselling Psychology Program within the Department of Educational Psychology and Leadership studies at the University of Victoria. You may contact him if you ever have any questions or concerns about the research process, by telephoning him at 661-2029, or by emailing him at asumner@uvic.ca.

As a graduate student Andrew is required to conduct research as part of the requirements for a Master’s (MA) degree in Counselling Psychology. This research study is being conducted under the direct supervision of Dr. Timothy Black. If you ever have any questions or concerns about the research process, you also have the option of contacting Dr. Black by telephoning him at 721-7820, or by emailing him at tblack@uvic.ca.

Purpose of the Study

The purpose of this study is to explore, describe, and *understand* the experience of living with undiagnosed chronic pain.

Primary Research Question

“What is the experience of living with undiagnosed chronic pain?”

Significance of the Study

It is the researcher’s hope that this study will:

- Shed light on the experiences of a poorly understood segment of the larger chronic pain population.
- Improve the ability of health care practitioners to develop effective treatment plans for their patients with undiagnosed chronic pain.
- Help the insurance industry gain more insight into the challenges associated with living with undiagnosed chronic pain, so that more effective medical management can be funded, and more fair claims management decisions can be made.
- Foster greater levels of sensitivity, empathy, and *understanding*, so that health care practitioners, and society as a whole, can offer a better level of care and support to these chronic pain individuals in need.

Why Your Facility was Selected as a Study “Host” Site

Your facility was selected as a potential “host” site for recruiting study participants, and as a potential site for conducting research interviews because the researcher felt your organization’s clientele may include individuals who are currently living with undiagnosed chronic pain (as defined below).

Inclusion Criteria for Participation in the Study

In order for an individual to be accepted as a participant in this study, he/she must match all the following criteria:

- The individual must be currently experiencing a non-interrupted period of chronic pain for a duration of at least six months (i.e., they have not had a ‘pain-free day’ within that duration), and
- The individual must speak English fluently, and must be comfortable with the idea of participating in an audiotaped interview where he/she would be required to discuss their personal experience of living with chronic pain, and
- The individual must perceive that their chronic pain is ‘**undiagnosed**’, which may include either of the following criteria:
 - a) A belief that they have never been given a diagnosis to adequately ‘explain’ their ongoing chronic pain,
 - b) They have been given multiple conflicting diagnoses (from one or more health care practitioners) to ‘explain’ their chronic pain, however, they do not believe that a single accurate diagnosis has been clearly identified.

Protection of Participant Anonymity

The researcher gives his assurance that every reasonable measure will be implemented to ensure that the rights, privacy, and well-being of this study’s participants are fully protected. To this end, a coding system will be used to prevent participants’ names from being visually available to anyone other than the researcher and his UVic supervisor. Number codes will be assigned to each participant, and these codes will be used to identify and label interview audiotapes, file folders, and typed interview transcriptions. A ‘master list’ of these codes (i.e., cross-referencing numeric codes with participant names) will be kept off-site in a separate, locked filing cabinet, within the researcher’s own secure professional office. Only the researcher and his UVic supervisor will be privy to the names and contact information on this list. Lastly, upon completion of the study, all identifying information (i.e., master list, audiotapes, rough notes, transcriptions, consent and intake forms) will be destroyed.

Research Activities That May Take Place at Your Facility

If you agree to participate as a “host” site for this study, some or all the following activities may be undertaken at your facility:

- a) The researcher (Andrew Sumner) will briefly meet with staff members / volunteers on one occasion to review the overall nature of this study and the inclusion criteria for participation in this study. This information will be disseminated so that staff members feel comfortable in addressing basic questions that may arise from clientele after reading the “Invitation to Participate” recruitment poster and/or pamphlet.
- b) The researcher may introduce his self to potential study participants and arrange for a ‘screening’ telephone conversation to confirm suitability for participation in this study.
- c) Research interviews may be conducted in a private space within your facility (e.g., an office or similar room where others cannot observe or listen to the interview dialogue). This private setting will ensure the confidentiality of information divulged during the interview process, and will provide both the interviewer and interviewee with a space that is relatively free from distractions.

Time Commitments for Participants, Researcher, and Members of Host Site

Study Participants: As a result of participation in this study, time commitments will be associated with the following activities:

- Participants will need to be available for a 5 to 10-minute ‘screening’ telephone conversation with the researcher in order to confirm suitability for participation in this study. This will not take place within your facility.
- Participants will be required to participate in one or more audiotaped research interviews of 60 - 90 minutes duration. Only interviews associated with participants who were ‘recruited’ from your facility would be conducted at your site. If a participant expresses a preference to be interviewed in an alternate location, suitable arrangements will be made. The total number of participants for this study (i.e., encompassing all host sites) is anticipated to be in the range of 6 – 8 participants.
- Participants will be required to review a copy of the typed transcript(s) of their interview(s) in order to verify the accuracy of the text. The time allocation for this task will vary depending on the length of the interview transcript(s), and each participant’s individual reading speed. This will not take place within your facility.

- After reviewing his or her interview transcript, each participant will be required to converse with the researcher over the telephone in order to obtain each participant's feedback about the accuracy of the typed transcript (i.e., so that revisions can be made as necessary). It is assumed that such conversations would be brief, however, the duration of each conversation will depend upon the number of areas for revision identified by each participant. This will not take place within your facility.

Researcher: The researcher anticipates that he will spend time at your facility conducting the following activities:

- The researcher will conduct a brief 5 to 10-minute meeting with your facility's staff members / volunteers on one occasion to review the overall nature of this study, and the inclusion criteria for participation in this study.
- The researcher may conduct one or more audiotaped research interviews (each of 60 - 90 minutes duration) for each participant affiliated with your site.
- The researcher will extend an offer to provide a copy of the study's final results with a contact-person at the host site, upon reaching the point of thesis completion.

Host Site Staff Members / Volunteers: It is anticipated that the time commitments for your organization's staff members / volunteers will be minimal. They will be invited to attend a brief 5 to 10-minute meeting on one occasion to review the overall nature of this study, and the inclusion criteria for participation in this study. Beyond that, the only time commitment would be to address basic questions that may arise from clientele after reading the "Invitation to Participate" recruitment poster and/or pamphlet. It is anticipated that such a discussion would only require a few minutes of their time, as the staff member / volunteer should encourage the client to *contact the researcher directly* via the telephone and email information contained on the recruitment literature.

Assurance of Minimal Disruption

The researcher gives his assurance that he will make every effort to be minimally disruptive to the staff members, volunteers, clientele, and day-to-day operations of your facility. All meetings with staff / volunteers, and the actual research interviews, will be conducted in private rooms in order to avoid distractions to your clientele. However, in the event that certain clientele approach the researcher with questions as to what his function is at that site, a brief yet polite answer will be provided, and the client will be directed to read the "Invitation to Participate" recruitment poster and pamphlets displayed within your facility as a source of more detailed information.

Assurance of Respect for the Host Site

The researcher gives his assurance that he will be respectful in every way to the clientele, staff / volunteers, property, and possession of the host site. Furthermore, he provides an assurance that if he finds himself engaged in dialogue with clientele (either study participants or otherwise) he will not make statements that he perceives could reflect negatively on the organizational values, reputation, conduct of staff / volunteers, or day-to-day operations of your facility.

APPENDIX C: Participant Informed Consent Form

The Lived Experience of Undiagnosed Chronic Pain

You are being invited to participate in a study entitled, The Lived Experience of Undiagnosed Chronic Pain that is being conducted by myself, Andrew Sumner.

I am a graduate student in the Counselling Psychology Program within the Department of Educational Psychology and Leadership studies at the University of Victoria. You may contact me if you have any further questions by telephoning me at (250) 661-2029, or emailing me at asumner@uvic.ca.

As a graduate student I am required to conduct research as part of the requirements for a Master's (MA) degree in Counselling Psychology. This research study is being conducted under the supervision of Dr. Timothy Black. You may also contact my supervisor at (250) 721-7820, or at his email address tblack@uvic.ca.

Purpose and Objectives

The purpose of this research study is to explore and give voice to individuals who are living with undiagnosed chronic pain, so that the essential elements of this experience can be identified and described. The central research question is: "What is the experience of living with undiagnosed chronic pain?"

The primary objectives are: (1) to provide a scholarly study that advances knowledge in an area where research is lacking, and (2) to foster greater levels of sensitivity, empathy, and understanding about the experience of living with undiagnosed chronic pain so that health care practitioners, and society as a whole, will be able to offer a better level of care and support to these individuals in need.

Importance of this Research

Research of this type is important because it explores an element of chronic pain that has to date received little scholarly attention, despite the significant number of individuals who live with undiagnosed chronic pain, and despite the profound human suffering and societal costs (both financial and quality of life) associated with this state of being.

Participant Selection

You are being asked to participate in this study because you meet the main requirements for this study. I am seeking volunteers who meet the following requirements: (1) they are currently experiencing a non-interrupted period of chronic pain for a duration of at least six months (i.e., have never had a 'pain-free day' within that duration), and (2) they do not consider themselves to have a clearly identified and/or accurate diagnosis to 'explain' the existence of their current pain experience.

What is Involved

If you agree to voluntarily participate in this research, your participation will include a 60-90 minute interview with me, Andrew Sumner, with a possible second interview as

needed (i.e., when spending further time with a given participant is deemed of value to the research process). I will be using a semi-structured interview technique, meaning I will use a series of pre-determined questions that I consider relevant to this research study's area of focus, yet there will also be flexibility for you to lead the conversation and determine the direction you would like our dialogue to follow. Your interview will be audiotaped so that the collected information can be subsequently analyzed. By way of consent, please provide your initials in the space provided indicating that I have your permission to audiotape our interview session(s): _____.

Your participation in this study will also require your time to review a copy of the typewritten transcript of your interview(s) in order for you to verify its accuracy. You will receive the copy of your interview transcript via mail several weeks after the actual interview process. Although each individual will vary, it is anticipated that it will require 1 to 2 hours of your time for you to carefully review your transcript. One week after receiving your interview transcript in the mail I will contact you by telephone to obtain your feedback. At that time you will have the opportunity to identify any perceived inaccuracies in the written transcript, as well as having the opportunity to request the deletion of any text portions that you do not wish to be included in the thesis analysis process. I will subsequently make revisions to the written transcript based upon your feedback.

Lastly, approximately 1 to 2 months later, you will be provided with a document summarizing the general themes that my subsequent analysis has extracted from the interview transcript(s). These themes will attempt to capture the essence of your experience of living with undiagnosed chronic pain. In a similar process to that outlined above, you will be required to review a copy of this analytical summary in order to verify the accuracy of the identified themes. Although each individual will vary, it is anticipated that it will require up to 1 hour of your time for you to carefully review your thematic summary document. One week after receiving your thematic analysis in the mail I will contact you by telephone to obtain your feedback. At that time you will have the opportunity to identify any perceived inaccuracies in the thematic analysis, and I will subsequently make revisions based upon your feedback.

Inconvenience

Participation in this study may cause some inconvenience to you. Firstly, there is the time and potential inconvenience associated with travelling to the interview location. Secondly, there is an inconvenience associated with the time commitment for you to: (1) participate in the interview(s), (2) review the written transcript of your interview and provide feedback to me, and (3) review the thematic analysis summary document and provide feedback to me. Lastly, there is potential inconvenience associated with escalated perceptions of pain and/or fatigue that may be triggered as a result of participating in the interview process. This may pose an inconvenience in the form of needing to curb one's participation in their normal activities of daily living for a brief period of time immediately following an interview session.

Risks

There are some potential risks to you by participating in this research, and they include the potential that the subject matter discussed during the interview(s) may engender upsetting thoughts, emotions, or memories; as well as a potential for a participant's pain and/or fatigue levels to escalate as a result of participating in the interview process. To prevent or to deal with these risks, the following steps will be taken: (1) Right to Pass: you are not required to answer / discuss any of the questions asked by myself during the interviews, (2) Right to Terminate: you may stop the interview(s) at any time if you feel this is necessary due to pain, fatigue, or due to emotional upset. It should be noted in this regard, that breaks will be offered as necessary to participants, with the option of resuming the interview after a break if the participant feels capable of doing so, (3) Support: I will be available during and after the interview(s) to debrief and provide emotional support as necessary and reasonably possible, (4) Follow-up: you will be encouraged to contact me directly in the post-interview period should you feel that you wish to discuss any issues arising from the interview(s), (5) Community Resources: you will be provided with a list of names and contact telephone numbers of agencies within the Greater Victoria community that offer counsellors and/or psychologists who may be of therapeutic assistance if you require emotional support exceeding what can be reasonably offered in a debriefing session / follow-up telephone call, or if you have a desire to more deeply explore issues that arose in your interview(s), and lastly, (6) Supervisor Contact: you will have the name, contact telephone number, and email address of my UVic supervisor should you have any questions or concerns about the research process, its intent, your participation, or myself.

Benefits

The potential benefits of your participation in this research include: (1) Advancement of Knowledge: information revealed in this study may further knowledge in a scholarly area where very little research has been conducted (i.e., promoting a richer understanding of the lived experience of undiagnosed chronic pain), (2) Improved Care Delivery: an improved knowledge-base may ultimately enable the provision of better care for individuals who live with undiagnosed chronic pain, (3) Your Role in Progressions of Knowledge / Care: you may experience positive feelings / thoughts as you realize that your participation in this study may play a contributing role to the aforementioned furthering of scholarly knowledge, and the ability for health care providers to offer better care, and lastly, (4) Self-Knowledge: by participating in the research interview(s) you may inadvertently experience positive feelings / thoughts stemming from the process of self-reflection. Specifically, you may perceive that you have come to a place of better understanding about yourself, or you may perceive the experience of processing certain thoughts / feelings within yourself as an inherently positive one.

Voluntary Participation

Your participation in this research study must be completely voluntary. If you do decide to participate, you may withdraw from the study at any time without any consequences or any explanation. If you do withdraw from the study, your data will only be included in the study with your expressed written permission, as indicated by the provision of your signature in the appropriate space at the bottom of this form.

Opportunity to Ask Questions

If you decide to participate in this research study, you have the right to pose questions to the researcher, or request clarification or further information from the researcher, at any point before, during, or after the study.

Ongoing Consent

To ensure that you continue to consent to participate in this research, I will inquire at the beginning of each interview as to whether or not you wish to continue as a participant in the study. You will be required to provide a signature in this regard to indicate your ongoing consent.

Anonymity

In terms of protecting your anonymity, I alone will transcribe (i.e. make a typewritten copy of) the interview audiotapes. During the process of transcription, your name will be replaced with an alternative (code) name. Similarly, the names of any other individuals mentioned in the interview will also be replaced by alternative (code) names. Any other possible 'identifying information' will either be removed or changed in the transcribed document. Only my UVic supervisor and myself will have access to the raw data (i.e., interview audiotapes) that will contain actual names and identifying information. The results of the study, both published and unpublished, will in no way contain your name, the names of others, or identifying information.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by assigning you an alternative (code) name which will be used to label audiotapes and transcripts of interviews. The raw data (i.e., interview audiotapes), as well as any paperwork containing your real name (e.g., this 'Participant Informed Consent Form') will be kept in a locked file cabinet within my secured professional office. All data from this study will be destroyed (see 'Disposal of Data') two years following the successful defence of this thesis.

Dissemination of Results

Participants retain the right to have the findings of the study shared with them after completion of the study, upon their request. It is furthermore anticipated that the results of this study will be shared with members of the general public and the academic community through my Master's thesis. Sharing of this data at some point in the future may also arise from the writing of professional / scholarly articles (i.e., both published and unpublished), as well as presentations at professional / scholarly meetings or conferences. In all such scenarios your anonymity will be fully protected as per the procedures outlined above.

Disposal of Data

Data from this study will be disposed of by the shredding of all paper materials, and by the incineration of related non-paper items such as audiotapes. Computer discs will be destroyed in a similar manner, and the computer hard drive will be cleared of any and all related material / files.

Contacts

Individuals you may contact who are directly affiliated with this study include: (1) myself, Andrew Sumner, as the primary researcher (telephone #: 250-661-2029, email: asumner@uvic.ca), and, (2) my supervisor, Dr. Timothy Black (telephone #: 250-721-7820, email: tblack@uvic.ca).

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice-President, Research at the University of Victoria via telephone at: (250) 472-4545, or via email at ethics@uvic.ca.

Your signature below indicates that you understand the above conditions of participation in this study, and you have had sufficient opportunity to have your questions answered by the researcher.

Name of Participant (PRINTED) Signature Date

Note: a copy of this consent form will be left with you, and a copy will be taken by the researcher.

Ongoing Consent - Prior to First Interview

By signing below you are indicating your consent to continue to participate in this research study as outlined previously in this document.

Name of Participant (PRINTED) Signature Date

Ongoing Consent - Prior to Second Interview

By signing below you are indicating your consent to continue to participate in this research study as outlined previously in this document.

Name of Participant (PRINTED) Signature Date

Consent for the Use of Data Following Withdrawal from Study

By signing below you are indicating your consent for your data to be included in this research study following your withdrawal from ongoing active participation in the study.

Name of Participant (PRINTED) Signature Date

APPENDIX D: Victoria Community Counselling Resource List

1. Crisis Intervention

- “NEED” Crisis & Information Line
- Phone 386-6323 (24-hour line)
- www.needcrisis.bc.ca

2. Addictions (Alcohol / Drugs)

- a) Alcohol & Drug Services (Victoria)
 - 387-5077
- b) Alcoholics Anonymous
 - 383-0417
- c) Youth & Family Services
 - Target Age: 12 – 19 years of age
 - Phone: 721-2669

3. Advocacy

- a) BC Coalition of People with Disabilities
 - Phone: (604) 875-0188
 - www.bccpd.bc.ca
- b) BC Aboriginal Network on Disability Society (BCANDS)
 - Phone: 381-7303
 - www.bcands.bc.ca

4. Child and Youth Services

- a) Child Abuse Prevention & Counselling Society of Greater Victoria (Mary Manning Centre)
 - Phone: 385-6111
 - www.marymanning.com

5. General Counselling Services

- a) BC Association of Clinical Counsellors
 - Phone: 595-4448
 - Professional regulatory association that will provide the public with referrals to Registered Clinical Counsellors in their region.
 - www.bc-counsellors.org
- b) Cascadia Counselling
 - Phone: 216-1569
 - Offers a range of services, including individual and family counselling, psycho-educational groups (e.g. anger management, parenting, couples), leadership development, and advocacy.

- c) Citizens' Counseling Centre
 - Phone: 384-9934
 - Offers a range of services, including individual, couples, and group counselling to adults. Counselling covers a range of concerns, with a focus on: anxiety, depression, anger management, communication, and relationships.
 - www.citizenscounseling.org

- d) Men's Trauma Centre
 - Phone: 381-6367
 - Offers individual and group therapy for male survivors of physical, emotional, or sexual trauma.

- e) Military Family Resource Centre
 - Phone: 391-4212 (24-hour line)
 - Services members of the armed forces and their families.
 - Provides information and referrals, as well as short-term and crisis counselling, employment counselling, and deployment support.
 - www.esquimaltmfrc.com

- f) Pacific Centre Family Services Association
 - Phone: 478-8357
 - Offers a range of services, including individual, couples, and family therapy. Counselling covers a range of concerns, including: crisis counselling, counselling for women who have been abused/assaulted, outpatient drug / alcohol treatment.

- g) Victoria Native Friendship Centre
 - Phone: 384-3211
 - Offers a range of services, including individual counselling, community outreach, addictions counselling, personal / family crisis counselling for issues such as violence, abuse, or neglect.
 - www.vcfn.ca

- h) Victoria Separation and Divorce Resource Centre
 - Phone: 386-4331
 - Offers a range of services, including individual and group therapy, legal support / information, grief counselling, transition support.

APPENDIX E: Potential Research Interview Questions

Note: interviews will be conducting utilizing a semi-structured format

1. I'd like you to share with me what your life was like **before** you began to experience your chronic pain.
2. How has your life **changed** now that you are living with undiagnosed chronic pain?
3. What are your greatest **challenges** in life at this point?
4. How has the fact that you feel your pain is undiagnosed **impacted** your life?
5. Do you feel adequately **supported** in your situation?
6. Do you feel adequately **understood** in your situation?
7. How has the fact that you feel your pain is undiagnosed affected your ability to **cope** with your chronic pain?
8. Does the fact that your pain is undiagnosed affect the way that others **interact** with you?
 - a) Has the way people respond to you, and interact with you, changed over time?
 - b) How does this make you feel?
 - c) Why do you think that change has occurred?
9. IF APPLICABLE – How has your **work life** been affected by your undiagnosed chronic pain?
 - a) When did you first have a sense that elements of your work life were changing? ... What was that like for you?
 - b) Why do you think that change has occurred?
 - c) How does this make you feel?

10. IF APPLICABLE – How have your **child caring** abilities been affected by your undiagnosed chronic pain (i.e., ability to complete parenting activities)?
 - a) How does this make you feel?

11. How has your ability to complete **home duties / responsibilities** been affected by your undiagnosed chronic pain (i.e., ability to complete household chores)?
 - a) How does this make you feel?

12. How has your **leisure life** been affected by your undiagnosed chronic pain (i.e., your ability to participate in enjoyable leisure pursuits)?
 - a) How does this make you feel?

13. IF APPLICABLE - Does the fact that your pain is undiagnosed affect the way your **spouse / partner** interacts you?
 - a) How has the relationship with your spouse / partner changed over time since you began to experience undiagnosed chronic pain?
 - b) How does this make you feel?
 - c) When did you first have a sense that your relationship with your spouse / partner was changing? ... What was that like for you?
 - d) Why do you think these changes have occurred?

14. IF APPLICABLE - Does the fact that your pain is undiagnosed affect the way your **children** interact you?
 - a) How has the relationship with your children changed over time since you began to experience undiagnosed chronic pain?
 - b) How does this make you feel?
 - c) When did you first have a sense that your relationship with your children was changing? ... What was that like for you?
 - d) Why do you think these changes have occurred?

15. Does the fact that your pain is undiagnosed affect the way that **medical or rehab** systems, or health care practitioners, interact with you?
 - a) Has the way the medical / rehab systems treat you changed over time since you began to experience undiagnosed chronic pain?
 - b) How does this make you feel?
 - c) When did you first have a sense that the medical / rehab systems, or their health care practitioners, were starting to treat you differently? ... What was that like for you?
 - d) Why do you think these changes have occurred?

16. IF APPLICABLE - Does the fact that your pain is undiagnosed affect the way the **insurance** system interacts with you?
- a) Has the way the insurance system treats you changed over time?
 - b) How does this make you feel?
 - c) When did you first have a sense that the insurance system was starting to treat you differently? ... What was that like for you?
 - d) Why do you think these changes have occurred?
17. Does the fact that your pain is undiagnosed make you feel the need to **legitimize** that you are really in pain or experiencing limitations?
- a) If “yes”, tell me more about this.
 - b) How does this make you feel?
18. Do you feel society **understands** what it is like for individuals like yourself to live with undiagnosed chronic pain?
19. How do you gain **meaning** or **enjoyment** from life at this point?
20. What steps have you taken to **improve** your life situation since you began to experience undiagnosed chronic pain?
21. What could be done to make life a little **easier** for individuals like you who are living with undiagnosed chronic pain?
22. What are your personal **hopes** for your future?
23. If you could go back in time to the start of your chronic pain, knowing what you now know, would you do anything **differently**?
24. Has anything **positive** come about in your life as a result of your experience of living with undiagnosed chronic pain?
25. If it were up to you to **change** the way the ‘system’ treats individuals with undiagnosed chronic pain, what changes would you make?
26. If you were given an opportunity to **address the world**, what would you want to say about your experiences of living with undiagnosed chronic pain?

References

- Backonja, M. (1997). The neural basis of chronic pain, its plasticity and modulation. *Behavioral and Brain Sciences*, 20, 435-437.
- Baron, R. J. (1985). An introduction to medical phenomenology: I can't hear you while I'm listening. *Annals of Internal Medicine*, 103, 606-611.
- Black, T. G. (2004). *Resolving the quantitative/qualitative debate in psychotherapy research: Applying Ken Wilber's work to the QOD*. Unpublished manuscript, University of Victoria.
- Blyth, F. M., March, L. M., Brnabic, A. J., Jorm, L. R., Williamson, M., & Cousins, M. J. (2001). Chronic pain in Australia: A prevalence study. *Pain*, 89, 127-134.
- Buckle, J. (1999). Use of aromatherapy as a complementary treatment for chronic pain. *Alternative Therapies in Health & Medicine*, 5, 42-51.
- Bullington J., Nordemar, R., Nordemar, K., & Sjostrom-Flanagan, C. (2003). Meaning out of chaos: A way to understand chronic pain. *Scandinavian Journal of Caring Sciences*, 17, 325- 331.
- Chapman, C. R., & Gavrin, J. (1999). Suffering: The contributions of persistent pain. *The Lancet*, 353, 2233-2237.
- Clarke, K., & Iphofen, R. (2006). Issues in phenomenological nursing research: The combined use of pain diaries and interviewing. *Nurse Researcher*, 13, 62-74.
- Cohn, S. (1999). Taking the time to smell the roses: Accounts of people with Chronic Fatigue Syndrome and their struggle for legitimisation. *Anthropology & Medicine*, 6, 195-215.

- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five Traditions*. Thousand Oaks, CA: Sage Publications.
- Creswell, J. W. (2005). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research*. Upper Saddle River, NJ: Pearson Merrill Prentice Hall.
- Croft, P., Rigby, A.S., Boswell, R., Schollum, J., & Silman, A. (1993). The prevalence of chronic widespread pain in the general population. *The Journal of Rheumatology*, 20, 710-713.
- Cronje, Ruth, J., Williamson, & Owen, D. (2006). Is pain ever “normal”? *The Clinical Journal of Pain*, 22, 692-699.
- Currie, S. R., Wilson, K.G., Pontefract, A. J., & deLaplante, L. (2000). Cognitive behavioural treatment of insomnia secondary to chronic pain. *Journal of Consulting and Clinical Psychology*, 68, 407-416.
- Denzin, N. K. & Lincoln, Y. S. (Eds.). (2000). *The Handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Denzin, N. K. & Lincoln, Y. S. (Eds.). (2005). *The Sage Handbook of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Dolin, S. J., & Stephens, J.P. (1998). Pain clinics and liaison psychiatry. *Anaesthesia*, 53, 317-319.
- Dysvik, E., Natvig, G. K., Eikeland, O. & Lindstrom, T. C. (2005). Coping with chronic pain. *International Journal of Nursing Studies*, 42, 297-305.

- Egan, G. (2002). *The skilled helper: A problem-management and opportunity development approach to helping* (7th ed.). Pacific Grove, CA: Brooks/Cole.
- Gatchel, R. J., & Turk, D. C. (1999). *Psychosocial factors in pain: Clinical Perspectives*. New York: The Guilford Press.
- Gifford, L. S., & Butler, D. S. (1998). The integration of pain sciences into clinical practice. *Orthopaedic Division Review*, 5-13.
- Grant, L. D., & Haverkamp, B. E. (1995). A cognitive behavioral approach to chronic pain management. *Journal of Counselling & Development*, 74, 25-32.
- Guba, E. G. & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Thousand Oaks, CA: Sage Publications.
- Gureje, O., Von Korff, M., Simon, G. E., & Gater, R. (1998). Persistent pain and well being. *The Journal of the American Medical Association*, 280, 147-151.
- Hadjistavropoulos, H. D., Asmundson, G. J., LaChapelle, D. L., & Quine, A. (2002). The role of health anxiety among patients with chronic pain in determining response to therapy. *Pain Res Management*, 7, 127-133.
- Hellstrom, C. (2001). Affecting the future. *Time & Society*, 10, 77-93.
- Higgins, I., Madjar, I., & Walton, J. (2004). Chronic pain in elderly nursing home residents: The need for nursing leadership. *Journal of Nursing Management*, 12, 167-173.
- Hyden, L., & Sachs, L. (1998). Suffering, hope and diagnosis: On the negotiation of chronic fatigue syndrome. *Health*, 2, 175-193.
- Johnson, D. W. & Johnson, F. P. (2003). *Joining together: Group therapy and group skills* (8th ed.). Toronto, ON: Allyn and Bacon.

- Katz, W. A. (2002). Musculoskeletal pain and its socioeconomic implications. *Clinical Rheumatology*, 21, S2-S4.
- Kerssens, J. J., Verhaak, P. F., Bartelds, A. M., Sorbi, M. J., & Bensing, J. M. (2002). Unexplained severe chronic pain in general practice. *European Journal of Pain*, 6, 203-212.
- Krefting, L. K. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, 45, 214-222.
- Kugelmann, R. (1999). Complaining about chronic pain. *Social Sciences & Medicine*, 49, 1663-1676.
- Kumpusalo, E., Mantyselka, P., & Takala, J. (2000). Chronic pain in primary care. *Family Practice*, 17, 352.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage Publications.
- Loeser, J. D., & Melzack, R. (1999). Pain: An overview. *The Lancet*, 353, 1607-1609.
- Malterud, K. (2000). Symptoms as a source of medical knowledge: Understanding medically unexplained disorders in women. *Family Medicine*, 32, 603-611.
- Maniadakis, N., & Gray, A. (2000). The economic burden of back pain in the UK. *Pain*, 84, 95-103.
- Mason, J. (2006). *Qualitative researching* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Melzack, R., & Wall, P. D. (1965). Pain mechanisms: A new theory. *Science*, 150, 971-979.

- Moustakas, C. E. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage Publications.
- Osborn, M., & Smith, J. A. (1998). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. *British Journal of Health Psychology, 3*, 65-83.
- Osborn, M., & Smith, J. A. (2006). Living with a body separate from the self. The experience of the body in chronic benign low back pain: An interpretative phenomenological analysis. *Scandinavian Journal of Caring Sciences, 20*, 216-222.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Paulson, M., Danielson, E., Norberg, A., & Paulson, M. (1999). Nurses' and physicians' narratives about long-term non-malignant pain among men. *Journal of Advanced Nursing, 30*, 1097-1105.
- Pizzi, L. T., Carter, C.T., Howell, J. B., Vallow, S. M., Crawford, A. G., & Frank, E. D. (2005). Work loss, healthcare utilization, and costs among US employees with chronic pain. *Disability Management Health Outcomes, 13*, 201-208.
- Poppe, C., Devulder, J., Mariman, A., & Mortier, E. (2003). Chronic pain therapy: An evolution from socio-interventions to a holistic interdisciplinary patient approach. *Acta Clinica Belgica, 58*, 92-97.
- Purves, A. M., Penny, K. I., Munro, C., Smith, B. H., Grimshaw, J., Wilson, B., et al. (1998). Defining chronic pain for epidemiological research: Assessing a subjective definition. *Pain Clinic, 10*, 139-147.

- Raheim, M., & Haland, W. (2006). Lived experience of chronic pain and fibromyalgia: Women's stories from daily life. *Qualitative Health Research, 16*, 741-761.
- Ren, K., & Dubner, R. (2002). Descending modulation in persistent pain: An update. *Pain, 100*, 1-6.
- Ribau, C., & Marc-Vergnes, J. P. (2004). Towards a phenomenology of persistent pain. *Presse Medicale, 33*, 449-452.
- Richardson, J. C. (2005). Establishing the (extra)ordinary in chronic widespread pain. *Health, 9*, 31-48.
- Roy, R. (1992). *The social context of the chronic pain sufferer*. Toronto: University of Toronto Press.
- Roy, R. (2002). *Social relations and chronic pain*. New York: Kluwer Academic Publishers.
- Seers, K. (1992). Chronic non-malignant pain. *The British Journal of General Practice, 42*, 452-453.
- Sharpe, M. (1997). Cognitive behavior therapy for functional somatic complaints. The example of chronic fatigue syndrome. *Psychosomatics, 38*, 356-362.
- Simon, E. P., & Folen, R. A. (2001). The role of the psychologist on the multidisciplinary pain management team. *Professional Psychology: Research and Practice, 32*, 125-134.
- Sleed, M., Eccleston, C., Beecham, J., Knapp, M., & Jordan, A. (2005). The economic impact of chronic pain in adolescence: Methodological considerations and a preliminary costs-of illness study. *Pain, 119*, 183-190.

- Smith, B. H., Elliot, A. M., Chambers, W. A., Smith, W. C., Hannaford, P. C., & Penny, K. (2001). The impact of chronic pain in the community. *Family Practice, 18*, 292-299.
- Steen, E., & Haugli, L. (2000). Generalized chronic musculoskeletal pain as a rational reaction to a life situation. *Theoretical Medicine, 21*, 581-599.
- Steen, E., & Haugli, L. (2000). The body has a history: An educational intervention programme for people with generalized chronic musculoskeletal pain. *Patient Education and Counselling, 41*, 181-195.
- Sullivan, M. J., Thorn, B., Haythornthwaite, J. A., Keefe, F., Martin, M., Bradley, L. A., et al. (2001). Theoretical perspectives on the relation between catastrophizing and pain. *The Clinical Journal of Pain, 17*, 52-64.
- Thomas, S. P. (2000). A phenomenologic study of chronic pain. *Western Journal of Nursing Research, 22*, 683-705.
- Turk, D. C., & Gatchel, R. J. (2002). *Psychosocial approaches to pain management: A practitioner's handbook* (2nd ed.). New York: The Guilford Press.
- Turk, D. C., & Okifuji, A. (2002). Psychological factors in chronic pain: Evolution and revolution. *Journal of Consulting and Clinical Psychology, 70*, 678-690.
- Van Manen. Retrieved February 22, 2007, from <http://www.phenomenologyonline.com/glossary/glossary.html>.
- Verhaak, P. F., Kerssens, J. J., Dekker, J., Sorbi, M. J., & Bensing, J. M. (1998). Prevalence of chronic benign pain disorder among adults: A review of the literature. *Pain, 77*, 231-239.

- Verma, S., & Gallagher, R. M. (2000). Evaluating and treating co-morbid pain and depression. *International Review of Psychiatry, 12*, 103-114.
- Vickers, M. H. (2000). Stigma, work, and 'unseen' illness: A case and notes to enhance understanding. *Illness, Crisis & Loss, 8*, 131-152.
- Walker, J., Holloway, I., & Sofaer, B. (1999). In the system: The lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. *Pain, 80*, 621-628.
- Walker, J., Sofaer, B., & Holloway, I. (2006). The experience of chronic back pain: Accounts of loss in those seeking help from pain clinics. *European Journal of Pain, 10*, 199-207.
- Wall, P. (1999). *Pain: The science of suffering*. London: Weidenfeld & Nicholson.
- Ware, N. C. (1999). Toward a model of social course in chronic illness: The example of chronic fatigue syndrome. *Culture, Medicine and Psychiatry, 23*, 303-331.
- Westwood, M. J., & Borgen, W. A. (1988). A culturally embedded model for effective intercultural communication. *International Journal for the Advancement of Counselling, 11*, 115-125.
- Yunus, M. B. (2004). Suffering, science and sabotage. *Journal of Musculoskeletal Pain, 12*, 3-18.