DEVELOPMENT AND TESTING OF A

CHRONIC PAIN INTEGRATION QUESTIONNAIRE

DEVELOPMENT AND TESTING OF A CHRONIC PAIN INTEGRATION QUESTIONNAIRE

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Lay Abstract

A questionnaire titled the Chronic Pain Integration Questionnaire (CPIQ) was developed and then given to 201 adults living with chronic pain in order to gain a better understanding of how these adults have adjusted to living with chronic pain. The responses that these adults gave on the CPIQ were then compared to responses they gave on additional questionnaires related to their physical and mental health, acceptance, and social support. These comparisons allowed for the detailed examination of people's adjustment to living with chronic pain. It is hoped that the CPIQ, which has now been developed and tested, will continue to allow health care professionals to gather more information about the life of someone living with chronic pain. It is also hoped that the CPIQ could be used in future research to identify effective strategies that improve the overall quality of life of the person suffering with chronic pain.

Abstract

Background. Understanding how people adjust to living with chronic pain is paramount because of the negative impact of chronic pain on quality of life. Chronic pain integration has been proposed as a new construct that may enhance understanding of chronic pain adjustment. Integration, as defined by people living with chronic pain, is an ongoing process in which the person with chronic pain evolves becoming a mentally and physically stronger individual; creating a sense of harmony and control in one's life. These positive outcomes of integration necessitate its continued investigation in chronic pain, especially if it may positively affect life quality.

Objective. There were two overarching purposes of this study: (a) to further refine and test the psychometric properties of the Chronic Pain Integration Questionnaire (CPIQ); and (b) to examine four research hypotheses based on the proposed relationships between several constructs.

Method and Results. Utilizing a quantitative, non-experimental design, the CPIQ demonstrated internal consistency reliability, test-retest reliability, and evidence of validity when tested in a sample of 201 adults living with chronic non-cancer pain. All four of the research hypotheses were confirmed and three domains of the CPIQ were identified through exploratory factor analysis: self-management, self-awareness, and intrinsic adjustment. The favourable psychometric results of the CPIQ provide support for its continued use to understand adjustment in chronic pain. Ultimately, the goal of future research with the CPIQ is to identify effective interventions that promote chronic pain integration; leading to improved life quality for the person with chronic pain.

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Thirdly, I would like to thank my family: my parents for their never ending love and support and my siblings who have had to take on extra duties over the last few years to keep our family afloat. I can't even put into words how much I have appreciated what they have done for me. My daughters, Kari and Robyn, were great administrative assistants when I needed them; they have grown into amazing women and I hope I haven't scared them away from pursuing graduate education.

Lastly I would like to thank my husband Mike who never wavered in his support of my educational aspirations even as his own health declined; he has made the largest sacrifice. I owe him a debt of love and gratitude which I know I will never come close to repaying in our remaining time together.

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Declaration of Academic Achievement

This thesis is a compilation of original work that I completed for partial fulfillment of a Doctor in Philosophy of Science in Nursing degree. I am the main contributor to the work that has been described in this thesis. This work was completed between December 2013 and August 2016; however, the development of the research questions and designs began upon beginning my PhD studies in the fall of 2009. The entire thesis process was supported by my supervisor, Dr. Noori Akhtar-Danesh, and my committee members, Dr. Sharon Kaasalainen, and Dr. Jennifer Skelly. As the primary investigator for this project I conducted all aspects of the study: data collection from recruiters, data entry into SPSS software, and data analysis.

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CHAPTER ONE: INTRODUCTION & BACKGROUND

Chronic pain (CP) is a multidimensional condition which negatively affects the individual, the family, and society (Gordon et al., 2002; MacLellan, 2006; McCracken & Zhao-O'Brien, 2010; Schopflocher, Taenzer, & Jovey, 2011; Turk, 2003). Chronic pain has been defined as "pain which persists past the normal time of healing...with non-malignant pain, three months is the most convenient point of division between acute and chronic pain, but for research purposes six months will often be preferred" (International Association for the Study of Pain (IASP), 1994, p. xi)

When compared to people with other chronic conditions, people with CP report the worst quality of life and their risk of suicide is twofold (Choiniere et al., 2010; Tang & Crane, 2006). In Canada alone 18.9% of adults over the age of 18 suffer from CP (Schopflocher et al., 2011). CP conditions such as neuropathic pain and osteoarthritis have been reported to affect one and 3 million Canadians respectively (National Opioid Use Guideline Group [NOUGG], 2010). The most common site of CP is the lower back and arthritis is the most common cause (Schopflocher et al., 2011). Moreover, as the Canadian senior population grows, CP is likely to become an even greater health concern: 38% of institutionalized seniors and 27% of seniors living at home suffer with CP (NOUGG, 2010). The estimated cost of CP in Canada is between 56-60 billion dollars annually (Canadian Pain Society, 2014).

The personal and societal losses attributed to CP are likely the reason for the decades spent on chronic pain research. Unfortunately, funding for pain research in Canada has been lacking (Canadian Pain Society, 2014). In 2009, Lynch, Schopflocher,

Taenzer, and Sinclair compared the amount of research funding provided for cancer research to that of chronic pain funding. Cancer at that time had been calculated to have a direct health care cost of approximately \$2.5 billion per year and the total amount of research funding for cancer in 2008 was \$390 million. In contrast, chronic pain was calculated to have a direct care cost of \$6.02 billion per year and the total amount of research funding for chronic pain was \$89 million (Lynch et al.). When comparing research dollars spent to the direct health care costs, the authors calculated a 41 times greater proportion of research dollars spent for cancer research over that of chronic pain research.

In spite of the lack of funding available for chronic pain research, studies have still been conducted over the years and have yielded alarming findings: evidence for the best treatment has been inconsistent and inadequate (Gordon et al., 2002; Turk, 2003; Vlaeyen & Morley, 2005) and CP sufferers have often been undertreated or mistreated (Butler et al., 2007; Choiniere et al., 2010). It has been recognized that multidisciplinary pain management clinics, especially those that incorporate cognitive behaviour strategies, are the ideal setting for treatment (Nielson, Jensen, & Kerns, 2003; Turk, 2003; Vlaeyen & Morley, 2005). Yet there are limited numbers of multidisciplinary pain management clinics and lengthy wait-times exist; as people wait for initial treatment their condition continues to deteriorate which may make treatment more challenging when it finally starts (Choiniere et al., 2010). Even when patient improvements have been achieved at discharge from a multidisciplinary pain management clinic, the positive outcomes are often not sustainable over time (Dworken et al., 2005; Nielson et al., 2003; Williams, Eccleston, & Morley, 2012).

As far back as 1990, Turk had proposed that the inconsistent outcomes following chronic pain treatment was likely due to treating patients the same, rather than as unique individuals with unique experiences who required individualized treatment plans. One could safely assume that if more individualized, meaningful, and effective treatment plans are needed, then a deeper understanding of how people adjust to or cope with chronic pain is necessary. Similarly, as psychosocial researchers have focused over the years on understanding pain coping, a growing body of evidence has shown that cognitive, behavioural, and emotional coping efforts can influence pain and pain-related outcomes (De Vlieger, Van den Bussche, Eccleston, & Crombez, 2006; Keefe, Somers, & Kothadia, 2009); yet what is known about people with CP today is still not enough in light of the previously reported issues (McCracken, Barker, & Chilcot, 2014).

The psychosocial research has resulted in the development of several pain coping models such as the cognitive behavioural model of pain coping, the problem emotionfocused coping model of pain, and the chronic pain acceptance model (Keefe et al., 2009). These models focus on the coping strategies or skills that people use when attempting to cope with CP. However, researchers have criticized that this focus on coping has left gaps in understanding key aspects of adjustment to CP and the effective therapeutic modalities that promote CP adjustment (McCracken & Eccleston, 2003; McCracken, Eccleston, & Bell, 2005; McCracken, Vowles, & Zhao-O'Brien, 2010; Risdon, Eccleston, Grombez, & McCracken, 2003). Little is known about the

interrelationships between the psychosocial variables that help to explain CP suffering and their importance to adjustment to CP over time (De Vlieger et al., 2006). In this author's opinion, what is missing from these models is the understanding of how people may actually transform themselves from the person who was once living without pain to the person who now lives with chronic pain. This transformation has been termed *integration*. Integration has been defined as "a complex person-environment interaction whereby new life experiences (e.g. transitions, illness) are assimilated into the self and activities of daily living, resulting in overall life balance" (Whittemore, 2005, p. 263).

Over the past two decades, increased investigation of integration has occurred with specific chronic conditions: diabetes, Crohn's Disease, cardiac rehabilitation, and chronic illness in general (Compton, 2002; Hernandez, 1991, 1995; Whittemore, 2005; Whittemore & Dixon, 2008; Whittemore & Roy, 2002). This interest in integration is likely due to its proposed positive outcomes: healing, recovery, achievement of optimal functioning, satisfaction with one's quality of life, a sense of overall well-being, renewed life purpose and meaning, self-transcendence, and actualization of life potential (Whittemore, 2005). Interestingly, Whittemore and Roy (2002) have developed a middlerange nursing theory, adapting to diabetes mellitus, which was a modification of the adaptation to chronic illness model and the Roy adaptation model (RAM; Roy & Andrews, 1991) from which it was derived. Several concepts were identified as having the potential to enhance the theory, one of which was integration.

Similarly to diabetes, CP is a chronic illness and as such it is not surprising that integration has recently been identified as relevant for people living with chronic pain

(Deshaies & Hernandez, 2011). If the effects of integration contribute to positive patient outcomes, it would be paramount to facilitate integration in the chronic pain population especially if it leads to CP sufferers sustaining positive outcomes over the long term and, ultimately, improved quality of life. However, in order to examine integration in the CP population, it would require some tools to measure it; herein is the problem as outlined in the proceeding section.

Statement of the Problem

As highlighted in the previous paragraphs, if integration contributes to positive patient outcomes, it should be investigated in CP due to the negative effects of CP on the individual and his or her quality of life. Currently there are no known tools for which to measure chronic pain integration. Without the ability to measure CP integration, testing its' proposed relationship to chronic pain as well as other relevant CP concepts would be significantly more challenging if not impossible. A CP integration measurement tool with adequate reliability and evidence of validity would be significantly useful for (a) examining the relationship between coping and adjustment in CP, (b) further development and testing of the integration concept within CP coping models and/or middle range theories, and (c) future research into specific interventions that may enhance chronic pain integration; ultimately leading to positive outcomes that are sustainable over the long term. Moreover, the ability to examine patients' responses on a tool that measures chronic pain integration would likely allow health care professionals to gain insight into their specific patients' pain experiences and how these patients are integrating pain into

their life. This usefulness for an instrument to measure CP integration has formed the basis for this study; the aim of which is noted in the following section.

Aim of Study

The aim of this study is twofold: (1) to further refine and examine the psychometric characteristics of a tool designed to measure chronic pain integration titled the Chronic Pain Integration Questionnaire (CPIQ); and (2) to test several hypotheses that have been created based on current knowledge of integration and its possible relationship to other concepts that have been investigated in CP populations. Various demographic and clinical data collected from the participants were also examined to determine the relationship of these variables to CP integration (e.g. gender, age, length of time living with CP, type of CP diagnosis, education level).

Development of the CPIQ was initially started in 2008 as part of a Master's thesis and incorporated qualitative methods (focus group and expert review) in order to ensure evidence of validity based on item content for the CPIQ (Deshaies, 2008). The CPIQ was developed in order to measure how the person with CP has *integrated* the pain into his or her life. The focus group participants who were living with chronic pain defined CP integration as "an ongoing process in which the person with chronic pain evolves, becoming a mentally and physically stronger individual and creating a sense of harmony and control in one's life" (p. 38). The pilot testing of the CPIQ (n = 106) revealed internal consistency reliability ($\alpha = .88$), test-retest reliability (Pearson's r = .99), and a two factor structure: intrapersonal reciprocality ($\alpha = .88$) and psychoemotional adjustment ($\alpha = .82$). These two components extracted through exploratory factor analysis (EFA; principal component extraction with varimax rotation) were easily identifiable as elements of CP integration when compared to two integration definitions. Even though the statistical results of the CPIQ were favourable, the sample sizes for the EFA and testretest reliability were below that commonly recommended (n = 106 and 10 respectively) and thus a full psychometric testing of the CPIQ was necessary. Additionally, wording on some of the items on the CPIQ required revision which subsequently changed the tool from its original 2008 version and thus, warranted a new exploratory factor analysis.

The proceeding chapter outlines the evidence found within the chronic pain literature which provides support for the development of an instrument to measure CP integration. The chapter also includes the theoretical framework which has guided the study.

CHAPTER 2: REVIEW OF LITERATURE & CONCEPTUAL FRAMEWORK Review of Literature

It is the focus of registered nurses, and likely all health care professionals, to support and enable people to make self-care decisions and to achieve their optimal level of health (Canadian Nurses Association, 2007). It is also known that one's health has a significant impact on one's quality of life (Fayers & Machin, 2007; Golics, Khurshid, Basra, Salek, & Finlay, 2013; Streiner, Norman, & Cairney, 2015) and thus, health care professionals need to focus on treatments or interventions that improve quality of life for their patients.

This focus on health and quality of life by health care professionals becomes more challenging when their clients suffer with chronic pain because (a) people respond differently to their pain experiences (Keefe, Rumble, Scipio, Giordano, & Perri, 2004; Mourao, Blyth, & Branco, 2010; Newton-John, Mason, & Hunter, 2014); (b) the best evidence for treatment has been inconsistent and inadequate (Gordon et al., 2002; Turk, 2003; Vlaeyen & Morley, 2005); and (c) CP sufferers have often been undertreated or mistreated (Butler et al., 2007; Choiniere et al., 2010). Additionally, multidisciplinary pain management clinics, especially those that incorporate Cognitive Behaviour Therapy (CBT) strategies, have been identified as the ideal setting for treatment (Nielson, Jensen, & Kerns, 2003; Turk, 2003; Vlaeyen & Morley, 2005); yet there are limited number of facilities and lengthy wait-times which may make treatment more challenging (Choiniere et al., 2010; Lukewich, Mann, VanDenKerkhof, & Tranmer, 2015). Therapist within

similarities and differences between treatment programs and the ability to make generalizations about patient outcomes. For example, in their systematic review, Williams, Eccleston, and Morley (2012) called for an end to examining the usefulness of CBT for chronic pain and to shift the focus to identifying the aspects of CBT treatment or interventions that are most effective. Lastly, even when patient improvements have been achieved from pain management treatment, the positive outcomes are often not sustainable over time (Dworken et al., 2005; Nielson et al., 2003; Williams, Eccleston, & Morley, 2012).

In spite of the challenges of chronic pain treatment, many people do adjust and function psychosocially despite their chronic pain (Jensen, Turner, Romano, & Karoly, 1991; Keefe et al., 2004; Mourao, Blyth, & Branco, 2010; Newton-John, Mason, & Hunter, 2014). It may be for this reason that many CP researchers have focused on the varying degrees to which individuals respond to pain in the hopes of discovering strategies that facilitate adjustment to CP. The aspect of adjustment to chronic pain is the over-arching interest for the research study herein and thus is the focus of the literature review that follows and has been separated into the following themes: (a) Pain Coping and Adjustment; (b) Acceptance of Chronic Pain; and (c) Integration.

Chronic Pain Coping and Adjustment

Coping has been defined as "efforts to deal with stressful situations that are appraised as taxing or exceeding one's individual resources" (Keefe et al., 2009, p. 1); whereas adjustment has been defined as "a person's psychological well-being and ability to carry out normal physical and psychosocial activities" (Geisser, Robinson, & Riley,

1999, p. 161). With these two definitions in mind, and the known negative impact of CP on the person's well-being, it is not surprising that many researchers have focused on coping as a way to understand the differences inherent between CP sufferers and the various coping efforts that have had an impact on short-term and long-term adjustment to CP (Asghari & Nicholas, 2006; Buenaver, Edwards, & Haythornthwaite, 2007; De Vlieger, Van den Bussche, Eccleston, & Crombez, 2006; Keefe, Somers, & Kothadia, 2009; Stroud, Thorn, Jensen, & Boothby, 2000). In fact, pain coping strategies, as a focus of CP adjustment, have seen the most active research over the past 20 years (Keefe et al., 2004; Keefe et al., 2009; McCracken & Eccleston, 2003) and have been seen as essential to understanding adjustment in CP (Peres & Lucchetti, 2010; Tan, Teo, Anderson, & Jensen, 2011).

In 1991, Jensen, Turner, Romano, and Karoly conducted a review of the literature available at that time on coping and adjustment to chronic pain. These authors found that coping with chronic pain was often categorized into two dimensions: active and passive. The categorization of coping with CP into active and passive activities seems to have remained in place over the last twenty-five years as evidenced by recently published literature on coping with CP (Howe, Robinson, & Sullivan, 2015; Tan et al., 2011). As recent as 2016, Turk, Fillingim, Ohrbach, and Patel, in their review of the biopsychosocial perspectives and psychosocial and behavioural factors of CP, identified these same categories of coping in CP.

Active coping responses to CP have been defined as activities which require the person to take some type of action to manage the pain: keeping busy, exercise, obtaining

information (Howe et al., 2015; Jensen et al., 1991; Tan et al., 2011; Turk et al., 2016). Whereas passive coping responses to CP have been defined as activities for which the person avoids actions that might increase pain: rest, guarding, withdrawing from situations, increased dependence on others) or the person gives up control of pain management to something else (e.g. using medications).

Research into the active and passive ways of coping with CP has also produced additional categories of adaptive and maladaptive ways of coping (Howe, Robinson, & Sullivan, 2015; Jensen et al., 1991; Tan et al., 2011). The active ways of coping (e.g. keeping busy, exercising) have been considered to be adaptive and passive ways of coping (e.g. resting, guarding, and to a degree, the use of medications) have been considered maladaptive. Researchers have also identified that the active and adaptive coping responses have demonstrated positive correlations to adjustment to CP (Jensen et al., 1991).

Additionally, research efforts have focused significantly on a select number of psychological factors that are thought to have an impact on adjustment to CP (Keefe et al., 2004):

1. Psychological factors that increase pain, psychological distress, and physical disability: pain catastrophizing, pain-related anxiety and fear, and helplessness.

2. Psychological factors that decrease pain, psychological distress, and physical disability: self-efficacy, pain coping strategies, readiness to change, and acceptance. Again, the psychological factors that increase pain are thought to be maladaptive (Keefe et al., 2004). For example, pain catastrophizing has been defined as an exaggerated focus

by the person on his or her pain and the pain experience (DiNapoli et al., 2016). People who are perceived to have catastrophic thinking about pain tend to avoid activities because of the fear of increased pain. Fear and anxiety about possible increases in pain on its own, without catastrophizing, has been thought to lead to avoidance of activities. This avoidance of activity is thought to contribute to deconditioning and thus, creates a downward spiraling effect of increased pain (DiNapoli et al.).

Furthermore, Keefe et al. (2009) have determined that there are five main pain coping models that have been used in CP research in order to understand coping and adjustment to CP; all of which have been linked to five different pain coping measurement tools:

1. The Cognitive/behavioural model of pain coping (Rosenstiel & Keefe, 1983) provides an overview of the cognitive-behavioural strategies people use to manage pain: making coping self-statements; diverting attention; reinterpreting pain sensations; ignoring pain sensations; praying or hoping; pain catastrophizing; and increasing behavioural activity. These strategies are measured by the Coping Strategies Questionnaire (CSQ) and scores on the CSQ have positively correlated with adjustment to CP.

2. The problem/emotion-focused coping model of pain (Folkman & Lazarus, 1980) is divided between the two types of coping responses: those that are problemfocused (attempts are made to solve the problem: e.g. avoiding pain by having someone else perform an otherwise painful task) or those that are emotion-focused (attempts are made to manage the emotional consequences of the pain experience: e.g. using distraction

to avoid negative feelings and self-blame that may arise because of the pain). These two types of coping are measured by the Ways of Coping Checklist (WCCL) and studies have shown that emotion-focused coping responses are positively correlated with increased depression and disability.

3. The active/passive coping model (Brown & Nicassio, 1987) is divided into those coping responses that are considered passive and thus, maladaptive (e.g. withdrawing from others, avoidance of activities, talking about pain) and those that are considered active and thus, adaptive (engaging in leisure activities, distracting one's attention from pain, exercising). This type of coping has been measured by the Vanderbilt Pain Management Inventory (VPMI) and the reported evidence has shown that frequent use of passive coping responses is positively correlated with increased pain, depression, and disability.

4. The fear avoidance model of pain coping (Vlaeyen & Linton, 2000) is mainly focused on behavioural coping responses that focus on the person avoiding painful activities rather than confronting or working through them as a way to adjust to living with pain. The scale often used to measure this fear avoidance concept is the Tampa Scale of Kinesiophobia (TSK; Kori, Miller, & Todd, 1990). People who have high fear avoidance scores on the TSK tend to report more pain and disability than those with low scores.

5. The acceptance model of pain coping (Geisser, 1992) is based on the idea that trying to control the pain is maladaptive and actually increases pain and emotional distress. A willingness to continue to engage in daily activities of life despite pain is seen

as more adaptive. The Chronic Pain Acceptance Questionnaire (CPAQ; McCracken, 1999) has been designed to measure a person's willingness to experience pain while continuing to engage in activities of living (i.e. acceptance of CP). Significant correlations have been reported between scores on the CPAQ and scores related to quality of life and depression in people with CP. Interestingly, as outlined in the next section, proponents of the CP acceptance 'model' do not consider it a coping construct (McCracken & Eccleston, 2003).

Even though there has been evidence outlining the different pain coping strategies and the possible pain coping models that outline the adaptive and maladaptive ways in which people attempt to adjust to living with CP, as noted previously, several researchers have criticized that focusing solely on coping as the primary behavioural contribution to adjustment to chronic pain has left gaps in understanding key aspects of therapy and has done little to contribute to the discovery of effective treatment protocols (McCracken & Eccleston, 2003; McCracken, Eccleston, & Bell, 2005; McCracken, Vowles, & Zhao-O'Brien, 2010; Risdon, Eccleston, Grombez, & McCracken, 2003). Further investigation into the relationships between the multiple psychosocial variables that are inherent in CP and their impact on adjustment to CP over time has been deemed a necessity (De Vlieger et al., 2006). There has also been some evidence to suggest that attempts to control and reduce maladaptive coping responses and replace these coping responses with adaptive responses may actually increase the occurrence of maladaptive coping responses (Esteve, Ramirez-Maestro, & Lopez-Martines, 2007; Hayes & Gifford, 1997; Keefe et al., 2004; Thompson & McCracken, 2011; Wenzlaff & Wegner 2000).

McCracken and Eccleston (2003) proposed that the narrow focus on coping over the past 20 to 30 years has led researchers astray from examining other potential theories for how people adjust to living with CP. Interestingly, these authors outlined the conceptual problem between CP coping behaviours and that of CP itself: CP is pain that does not go away; yet coping with CP is seen as something one struggles with in order to master or conquer. It is likely this disparity and the continued gaps in understanding CP adjustment that has led to a growing interest in the concept of chronic pain acceptance and how it is actually different from coping and its potential role in adjustment to CP (Esteve et al., 2007; Keefe, Rumble, Scipio, Giordano, & Perri, 2004; McCracken, 1999; Risdon, Eccleston, Crombez, & McCracken, 2003; Thompson & McCracken, 2011).

Acceptance of Chronic Pain

In 1994, Hayes defined a new construct in the field of psychology known as *psychological acceptance* (PA): "experiencing *events* (thoughts, feelings, and body sensations) fully and without defence, as they are and not as what they say they are" (p. 30). Conversely, attempting to reduce, manipulate, or avoid the event was seen as the opposite of PA (i.e. experiential avoidance). It has been theorized that avoiding thoughts, feelings, or sensations may produce short-term symptom relief but over time may produce increased disability and withdrawal from activities of "life satisfaction" (Wicksell, Lekander, Sorjonen, & Olsson, 2010, p. 771.e1).

The concept of PA had emerged from the discipline of Cognitive Behaviour Therapy (CBT; Zettle, 2005). The concept of PA and interventions designed to facilitate PA have been identified as effective when applied in health contexts and known chronic condition such as diabetes and smoking cessation (Ferreira, Eugenicos, Morris, & Gillanders, 2011). One of the largest bodies of work on PA has been in the field of chronic pain (redefined as *acceptance of chronic pain*; Asghari & Nicholas, 2006). It is believed to be central to CP adjustment (Bendayan, Esteve, & Blanca, 2012) and has been associated with decreased pain, distress, disability, health care use, and greater psychological well-being (McCracken & Zhao-O'Brien, 2010).

According to McCracken (1999), acceptance of chronic pain (herein termed CP acceptance) is defined as "a willingness to experience continuing pain without needing to reduce, avoid, or otherwise change it" (p. 93). It is a "disengagement from struggling with pain, a realistic approach to pain and pain-related circumstance, and an engagement in positive everyday activities" (McCracken & Eccleston, 2003, p. 198). It is important to note that CP acceptance does not mean that people in pain are to resign themselves to pain nor is it a linear process (Thompson & McCracken, 2011). Treatments based on acceptance (for example, therapies such as mindfulness) are thought to be useful alternatives when treatments focused on controlling, reducing, and/or eliminating pain and its impact are unsuccessful.

Through the use of the Chronic Pain Acceptance Questionnaire (CPAQ), McCracken and colleagues have been reporting research evidence for the predictability of CP acceptance to not only adaptive coping strategies used by the person with CP but also to adjustment to CP (McCracken & Eccleston, 2003; Peres & Lucchetti, 2010; Risdon et al., 2003).

Specific to coping, CP acceptance has demonstrated a positive influence on functional status and functional impairment in the person with CP whereas coping measures have been shown to have more of an influence on emotional distress (Esteve et al., 2007). Esteve et al. compared CP acceptance to CP coping in predicting adjustment to chronic pain. They found that there was a significant correlation between scores on the CP acceptance measure and functional status compared to that of coping measures; whereas, there was a significant positive correlation between the coping measures and emotional distress. CP acceptance was also found to have little correlation with a person's reported pain intensity which was as expected since CP acceptance is about accepting pain and not trying to control it (Esteve et al.). Alternatively, participants who reported higher levels of pain intensity also reported higher levels of depression and functional impairment. These authors also found that CP acceptance was positively correlated with active coping strategies and negatively correlated with passive coping strategies.

In 2003, McCracken and Eccleston had also compared CP acceptance to multiple coping strategies. They discovered that coping (diverting, reinterpreting sensations, self-statements, ignoring, praying and hoping, and increasing activity) and CP acceptance were not highly correlated or only moderately correlated with each other. This was an interesting discovery because active coping responses, such as exercise, would be considered a positive behaviour in the CP acceptance model. They also ran several regression analyses which revealed that CP acceptance predicted adjustment to CP independent of coping and at a higher percentage of variability than coping (24% and

4.6% respectively). These results led the authors to conclude that CP acceptance may be a better focus over that of coping responses for enhancing understanding of adjustment to CP.

These seemingly contradictory relationships between coping responses and CP acceptance provide further support for continued examination of these relationships along with other possible relationships that may impact adjustment in CP. These contradictions may also lend support for the criticisms that have been reported (Martin, Rott, Poon, Courtenay, & Lehr, 2001; Molton, Jensen, Ehde, Carter, Kraft, & Cardenas, 2008) about categorizing coping into a few select yet broad ways (i.e. active/passive; adaptive/maladaptive). Furthermore, these contradictions also reinforce the multidimensional nature of pain and the differences that are inherent in each individual's experience with pain and thus, the complexity that health care professionals face when seeking effective and long-lasting treatment for their patients.

Outcomes of CP acceptance have been identified as decreased depression and pain-related anxiety, increased engagement with daily activities, motivation, self-efficacy, and overall functioning and well-being (Esteve et al., 2007; McCracken, 1999; McCracken & Eccleston, 2005; McCracken, Spertus, Janeck, Sinclair, & Wetzel, 1999; Viane, Crombez, Eccleston, Devulder, & De Corte, 2004). Through a systematic review and meta-analysis, Veehof, Oskam, Schreurs, and Bohlmeijer (2011) found that acceptance based therapies (mindfulness and Acceptance and Commitment Therapy [ACT]) had small to medium effects on physical and mental health in CP patients; they were deemed just as beneficial as CBT. However, many of the studies that the authors

reviewed were of low quality (only one study met the high quality criteria set by the authors). Therefore, an increase in well-constructed studies examining and comparing acceptance-based interventions to that of CBT is necessary to increase confidence in Veehof et al.'s findings. Further studies that examine the differences between CP acceptance strategies versus coping strategies (i.e. similarities and differences) would also be warranted.

What has been of interest to this author is the similarities between the outcomes of CP acceptance noted previously and that of a new concept to chronic pain: *integration*. Integration has been defined as "a complex person-environment interaction whereby new life experiences (e.g., transitions, illness) are assimilated into the self and activities of daily living, resulting in overall life balance" (Whittemore, 2005, p. 263). The outcomes of integration are decreased psychological distress, engaging in normal life activities, and decreased physical and psychological disability. Whittemore (2005) has also identified that *acceptance* of a specific life event or transition was a facilitator of integration. These similarities between integration and CP acceptance highlight the importance of examining the relationship between the two concepts.

Integration

The creation of a tool to measure integration in the chronic pain population is the main focus of the current study in order to enhance one's ability to examine various CP constructs and their relationships to each other and ultimately to CP adjustment. The following paragraphs outline what is known of integration to date.

The first known concept analysis of integration was conducted by Westra and Rodgers in 1991. From their analysis, the authors defined integration as "a process of combination in which two or more elements are merged into a new entity. Interaction among the elements occurs, leading to the unity of the newly formed entity" (p. 278). The major antecedents to integration were (a) an awareness of the need to change, and (b) the availability of resources. The consequences of integration were related to improved life quality (economic gains, improved social mobility, enhance performance, improved attitudes, and decreased fear and discrimination). Westra and Rodgers felt integration was superior to other concepts such as assimilation, adaptation, and adjustment especially because it aligned nicely with nursing philosophies of holism, optimal functioning, and person-environment interactions. Assimilation, adaptation, and adjustment were seen as focusing on the individual changing to fit the environment rather than a "shared responsibility for change" (p. 281) which was incorporated within the concept of integration. Furthermore, the authors proposed that the concept of integration was significant for evaluating health status and thus was an important outcome focus for nursing practice.

In 2005 a second concept analysis was conducted by Whittemore, using an integrative review approach, in order to update the definition of integration and to determine the commonalities of integration related to healing, health, and nursing. The analysis spanned empirical and theoretical published reports between 1966 and 2004 and focused on integration and its relationship to health or illness. As common themes were identified, the definition of integration emerged: "A complex person-environment

interaction whereby new life experiences (e.g., transitions, illness) are assimilated into the self and activities of daily living, resulting in overall life balance" (Whittemore, 2005, p. 263). Integration was also seen as an iterative, non-linear process with internal (cognitive and emotional) and external (experiential) aspects as the person adjusted to life events, losses, or changes in addition to the requirements needed for self-management. The outcomes of integration were identified as healing, recovery, and the achievement of optimum functioning (Whittemore, 2005). Acceptance (of the life event or transition), optimism, and accessing appropriate resources (including family, friend, community, and spiritual support) were identified as facilitators of integration. Whittemore proposed that integration, viewed as an important process from illness to healing and central to the discipline of nursing, would provide a useful framework for implementing and coordinating holistic nursing care.

The interest in integration has covered a variety of populations: diabetes (Hernandez, 1991, 1995, 2007); CP (Deshaies, 2008; Deshaies & Hernandez, 2011); cardiovascular procedures (Carroll, 2014); chronic illness in general (Whittemore & Dixon, 2008; Audulv, Asplund, & Norbergh, 2012); HIV/AIDS (Baumgartner, 2007; Baumgartner & David, 2009); medical trauma (Salick & Auerbach, 2006); Veterans with spinal cord injury (deRoon-Cassini, de St. Aubin, Valvano, Hastings, & Brasel, 2013); and Crohn's disease (Compton, 2002). Authors have also been developing theories and theoretical models to explain relationships between integration and other concepts: the theory of integration (Hernandez, 1991); The model of integration of illness and self-management in type 2 diabetes (Hornsten, Jutterstrom, Audulv, & Lundman, 2011); the

process of integration in chronic illness (Whittemore & Dixon, 2008); and adapting to diabetes mellitus: a theory synthesis (Whittemore & Roy, 2002).

Two central concepts that have been examined in integration research have been self-management and what is known as a turning-point (Baumgartner, 2007; Hernandez, 1991; Hornsten et al., 2011). Hornsten et al. defined self-management as "the behaviour or activities that people with chronic disease enact to control or reduce the impact of the disease on their life..." (p. 42). Additionally, a turning-point is a life event that causes the person to re-examine his or her life and this examination results in new insights and changes in behaviours or approaches to living one's life. Hernandez (1991; 1995) has identified that it is at this turning point that the person with diabetes begins to learn more about his or her disease and becomes the expert in self-managing the disease; the result of which is better glycemic control and enhanced quality of life. Moreover, Hornsten et al. (2011) discovered that as people reached the turning point in their adjustment to living with diabetes they subsequently accepted that the disease was to remain part of their lives and self-management was a necessary component of that life; both of these concepts seemed to happen in a parallel fashion (one did not precede the other). Hornsten et al. reached this conclusion after interviewing 44 people living with Type 2 diabetes.

As described above, the self-management and turning-point concepts within integration may have links to that of coping, CP acceptance, and adjustment to CP. For example, active and adaptive coping strategies are seen as activities that a person does to manage CP daily and would be similar to those activities categorized under selfmanagement in integration ("the behaviour or activities that people with chronic disease
enact to control or reduce the impact of the disease on their life..."). Interestingly, a focus on self-management for treatment of CP has been recently identified as a priority by the Health Council of Canada (2012; Lukewich, Mann, VanDenKerkhof, & Tranmer, 2015). Also, within the process of integration, it has been described that when a turning-point occurs, it is at this point that the person 'accepts' that the disease is not going away and a focus on self-managing the disease and finding purpose in life is renewed; the focus is no longer on the disease itself. This proposed way of looking at coping and CP acceptance may help to explain why research results may be contradictory when examining coping and CP acceptance together and it may also point to integration as a potential overarching model of adjustment to CP with coping strategies and CP acceptance as key concepts.

In 2011, Deshaies and Hernandez reviewed the qualitative CP literature by examining those studies which reported phases or stages of living with CP. From this review, similarities to the concepts of self-management and turning-point, and to integration overall, were evident in the descriptions provided by the participants in many of the qualitative CP studies. For instance, four separate groups of CP qualitative researchers reported that their participants described a life-event (i.e. turning-point) in which they experienced an emotional crisis brought about by realizing that the pain was not temporary but permanent (Asbring, 2001; Gullacksen & Lidbeck, 2004; Howell, 1994; Schaefer, 1995). The consequence of this life-event for these individuals was the creation of new life patterns and routines and a renewed self-confidence about management of day-to-day life. Chronic pain was no longer the focus for these

individuals (i.e. this might be CP acceptance); focus shifted to aspects of life that were considered important (e.g. family, social relationships, leisure activities). The participants also expressed that they had subsequently taken on the primary role of managing their pain through self-care activities (i.e. self-management) and treatments (Gullacksen & Lidbeck, 2004; Howell, 1994; Schaefer, 1995).

In addition to the self-management and turning-point concepts, the overarching meaning of integration is the notion of the coming together of two different selves inherent in the individual (the one prior to disease and the new person that has emerged post diagnosis of disease). Westra and Rodgers (1991) referred to this as "two or more elements are merged into a new entity" in their definition of integration; Whittemore refers to this merging as an assimilation into the self. Within the review completed by Deshaies and Hernandez (2011), three of the authors reported that their participants with CP described feeling like they were two different people: the one before the pain diagnosis and the one now living with pain (Asbring, 2001; Gullacksen & Lidbeck; Paulson, Danielson, & Soderberg, 2002). Additionally, as stated in Chapter one, a focus group of individuals living with chronic pain developed their own definition of CP integration and described the person who had integrated chronic pain into his or her life as having had evolved which resulted in life balance and a mentally and physically stronger sense of self (Deshaies, 2008).

Similarities between the lived experiences of people living with chronic pain and those described by people living with diabetes (Deshaies & Hernandez, 2011) prompted the use of the theory of integration (Hernandez, 1991; 1995) to form the conceptual

framework for the development of the chronic pain integration questionnaire (CPIQ). The theory of integration has been outlined in the following paragraphs.

Conceptual Framework

The theory which guided the initial development of the CPIQ was the theory of integration developed by Hernandez (1991). The middle-range theory of integration arose from her work with people with diabetes. Diabetes integration was defined as

An ongoing process in which the two selves (*diabetic* and *personal*) more fully merge to create an individual who is healthy, both mentally and physically. This unification of the selves is manifested in the person's ways of thinking, being, and acting (including verbalization) (p. 18).

The *personal self* was defined as the person who existed prior to diabetes diagnosis and the *diabetic self* was the new entity that emerged post diabetes diagnosis.

Within the theory itself, Hernandez (1991) identified a three-phase process: (a) *having diabetes*, (b) *the turning point*, and (c) *the science of one*. The *having diabetes* phase commences at diagnosis and is characterized by a lack of diabetes knowledge, disinterest, varying degrees of commitment to diabetes management, and a focus on living a normal life and not appearing different from others. The *turning point* phase occurs when a specific life event causes the individual to more closely examine his/her life with diabetes. The person develops an increased interest and involvement with diabetes and its treatments. Lastly, a gradual progression occurs from the *turning point* phase to the *science of one* phase which has been identified as "a personalized science of living with diabetes" (Hernandez, 1995, p. 19). The person strives to understand diabetes

and his/her focus shifts to that of living a quality life rather than a focus solely on diabetes. It is at this point that the *personal* and *diabetic self* integrates more fully; the person tunes-in to body cues and uses these cues to maintain good glycemic control. The person is the expert with diabetes self-management and the health care professional provides complementary specialized knowledge and collaborates on strategies to promote and maintain positive health outcomes. Hernandez (2007) has since demonstrated congruency of the major constructs of the theory of integration with those of Imogene King's conceptual system for nursing.

In 2003, and based on five years of experience working with and listening to people living with CP, the author recognized similarities between the characteristics identified within the theory of integration (Hernandez, 1991; 1995) and the experiences voiced by people living with chronic pain. As noted previously, this led to a closer examination of the qualitative CP literature in which researchers had identified phases or stages experienced by people living with CP (Deshaies, 2008). From this examination, a clear parallel was identified between the characteristics within the middle range theory of integration and the experiences of people living with CP (Deshaies & Hernandez, 2011). Examples of these parallels were previously provided and formed the rationale for the development of a tool to measure CP integration (i.e. the CPIQ).

Because middle range theories are a "set of related ideas that are focused on a limited dimension of the reality of nursing (Smith & Liehr, 2003, p. xi) and are the link between practice and research in nursing, it was deemed ideal to base the development of the CP integration measure on a specific middle range theory. The specific items on the

first draft of the CPIQ were developed by comparing the items on the Diabetes Questionnaire (TDQ; Hernandez, 1995) which was developed to measure diabetes integration, to that of statements made by the participants reported in the qualitative CP literature (Deshaies, 2008).

In conclusion, assisting people who suffer with CP to achieve optimal health can be challenging for health care professionals (Keefe, Ruble, Scipio, Giordano, & Perri, 2004; Mourao, Blyth, & Branco, 2010; Newton-John, Mason, & Hunter, 2014). A continued effort is warranted to examine adjustment to CP and the concepts that may have a positive influence on CP adjustment. Some of the potential conceptual relationships identified within the literature have formed the development of the following hypothesis for the study and the relevance of developing a tool to measure CP integration in particular:

1. The similarities between the outcomes of CP acceptance and that of integration (decreased psychological distress, engaging in normal life activities, and decreased physical and psychological disability) warrant an examination of the relationship between these two concepts. Whittemore (2005) has also identified that acceptance of a specific life event or transition was a facilitator of integration. A valid and reliable instrument such as the CPIQ would assist in the examination of these two concepts and has provided the rationale for the formation of the first study hypothesis: Chronic pain acceptance (measured by the Chronic Pain Acceptance Questionnaire [CPAQ]) and psychological acceptance (measured by the Acceptance and Action Questionnaire [AAQ-II]) are correlated to CPIQ such that individuals with higher levels of chronic pain

acceptance/psychological acceptance will have higher levels of CP integration than those with lower levels.

2. In addition to CP acceptance, social support was also identified as an important facilitator of integration (Whittemore, 2005). In 2008, Whittemore and Dixon designed a study to examine how adults with a chronic illness integrate the illness experience into their life. Ongoing resources and support were identified as critical factors for facilitating an individual's shift in focus from illness to wellness. Therefore, the possibility that social support may be a facilitator of integration shaped the development of the second and forth hypotheses for this study: (a) social support (measured with a visual analog scale) is correlated with CP integration (CPIQ) such that individuals with higher levels of social support have higher levels of integration; and (b) social support (visual analog scale) mediates the relationship between chronic pain integration (CPIQ) and health (measured by the SF-12v2).

3. As previously stated, the positive outcomes of integration have been identified as healing, recovery, achievement of optimal functioning, satisfaction with one's quality of life, a sense of overall well-being, renewed life purpose and meaning, selftranscendence, and actualization of life potential (Whittemore, 2005). Based on these outcomes, a measure of the person's overall functional health and well-being (measured by the SF-12v2) was felt to be a variable that would enhance the analysis. It can be presumed that as people more successfully integrate chronic pain into their life, they will identify themselves as being generally healthy. This perspective formed the rationale for the third hypothesis for the study: Physical, mental, and general health (measured by the

SF Health Survey [SF-12v2]) is positively correlated with CP integration (CPIQ) such that individuals with higher levels of physical, mental, and general health will have higher levels of integration.

The proceeding chapter outlines the methods used to refine and test the CPIQ. Overall, it is hoped that the creation of a valid and reliable instrument such as the CPIQ will lead to future research designed to examine the relationships between integration and concepts within current middle-range CP coping models; enhancing the models and ultimately closing the gap between coping, CP acceptance, adjustment, and effective and sustainable CP treatment modalities. Of specific interest would be the examination of integration and acceptance within the middle-range nursing theories of chronic pain deducted from the Roy Adaptation Model (RAM; Roy & Andrews, 1999) such as the middle-range theory of adaptation to chronic pain (Dunn, 2004; 2005) and a theory of chronic pain (Tsai, Tak, Moore, & Palencia, 2003).

CHAPTER 3: DESIGN AND METHODOLOGY

There are two overarching purposes of this study: (a) to refine the previously developed Chronic Pain Integration Questionnaire (CPIQ); and (b) analyze the CPIQ for structure, evidence of reliability, and evidence of validity (i.e. instrument testing). This chapter describes the research design that was established to meet the above stated purposes. The chapter has been divided into three main sections: research design and rationale; instrument development (revising the CPIQ items); and instrument testing. The ethical consideration for the study has been identified at the end of the chapter.

Research Design and Rationale

Over the last several decades, researchers and clinicians in the health disciplines (such as nursing) have realized the significant impact of health on patients' quality of life and efforts since have focused on developing interventions or treatments that will improve quality of life (Streiner et al., 2015). It is not surprising therefore, that CP researchers and clinicians have also examined the significant negative impact that chronic pain has had on a sufferer's quality of life (Choiniere et al., 2010; McCracken & Zhao-O'Brien, 2010; McGuire, 1992; Tang & Crane, 2006). Moreover, one may conclude that health care professionals must focus on understanding how people adapt to living with CP and the effective interventions that may be developed and implemented to promote positive patient outcomes in order to improve quality of life for the CP sufferer.

As identified in Chapter two, the process of integration has been linked to improved quality of life in people with diabetes and other health conditions (Whittemore, 2005; Whittemore & Dixon, 2008; Whittemore & Roy, 2002). Integration has also been

deemed relevant and worthy of further examination in the chronic pain population (Deshaies & Hernandez, 2011). As such, if integration leads to improved life quality, then examining the relationship between CP integration and life quality is paramount due to the significant negative impact CP has on quality of life. If it can be demonstrated that people with high levels of CP integration also perceive their quality of life to be positive or at a high level, then future development of interventions or therapies that enhance CP integration would be warranted. However, before one may begin to examine the relationship between CP integration and quality of life, one must be able to measure CP integration.

The challenge in measuring CP integration lies in the fact that CP integration is subjective in nature and thus, not easily measured (or unmeasurable) by a piece of equipment in a lab for example. CP integration is a type of attribute that is referred to as a "hypothetical construct" (Streiner, 2011, p. 79) and is not directly observable. Additionally, one cannot just write questions down on paper and distribute these questions to CP sufferers in the hopes of collecting information about CP integration. Development of a tool or instrument to measure a hypothetical construct must be based on sound scientific methods in order to ensure that the instrument is measuring what one presumes it is measuring and in order for the results to be reproducible (Gélinas et al., 2008; Houser, 2008; McDowell, 2006; Rattray & Jones, 2007; Streiner et al., 2015; Switzer, Wisniewski, Belle, Dew, & Schultz, 1999). If the instrument is poorly developed, the inferences that are made from the results will be called into question and ultimately may lead to negative consequences for the patient. Therefore, the following sections outline the sound scientific methods used to develop an instrument to measure CP integration. In the context of this study, the use of the term *instrument* has been used to identify a specific type of data collection tool. The instrument is called the Chronic Pain Integration Questionnaire (CPIQ) and has been developed to collect data on people living with CP in order to measure the hypothetical construct known as CP integration.

Instrument Development

As noted above, if the goal of an instrument developer is to measure something that is not directly observable, it is reasonable to expect than that the process of instrument development will be long and complex and involve both qualitative and quantitative types of designs (Murray, 1999; Polit & Beck, 2004; Streiner et al., 2015). Implementing both qualitative and quantitative designs for instrument development and testing purposes assists the developer to build evidence that the instrument is actually measuring the construct of interest. If the relationship between the items on the instrument and the construct of interest is strong, the instrument is seen as a representation of the construct (DeVellis, 2003; 2016). With this in mind, initial development of the CPIQ was conducted by Deshaies in previous work as part of a Master's thesis and included qualitative and quantitative techniques typically recommended for item development: clinical observation, theory base, review of relevant literature, focus group participation, and expert clinician review (Streiner et al., 2015). Even though the development was conducted in 2008, rewording of some items on the CPIQ was completed for this study as noted herein. The design for the current study has been developed using mainly a quantitative non-experimental approach in order to build

on the information gleaned from 2008 and to fully test the psychometric properties of the CPIQ.

Instrument Testing

Testing the psychometric properties of an instrument allows the developer to draw conclusions about the characteristics of the instrument. The desirable characteristics of an instrument are referred to as reliability and validity (Houser, 2008, p. 297) and when the reliability and validity results are within recommended parameters, the developer may draw accurate conclusions and make appropriate decisions based on a person's, or group's response(s) to items on the instrument. Reliability and validity are two necessary ways to accumulate evidence for the value of an instrument (Streiner et al., 2015). In other words, reliability and validity testing of an instrument assists one to determine if the instrument is "performing properly" (Streiner, 2011, p. 81). The characteristics of reliability and validity have been outlined in the following paragraphs.

Reliability

Reliability is a key aspect in instrument development and testing (DeVellis, 2016). In order to demonstrate that an instrument has reliability, it is necessary to provide evidence that its findings are reproducible: what we know about a specific score is the same no matter how or when it was measured (DeVellis, 2016; Tabachnick & Fidell, 2013).

Several common methods used to assess reliability include test-retest reliability, internal consistency reliability, and inter-rater reliability (Streiner et al., 2015). Analyzing an instrument for test-retest reliability allows the researcher to determine the stability of

the instrument over time (Polit & Beck, 2008) and is usually achieved by obtaining data from the same participant at two different time frames; evidence of reliability of the instrument is increased if the scores obtained at the two different time frames are similar to each other. Analyzing inter-rater reliability is concerned with the consistency that is achieved when, for example, two different people rate the items on the instrument; evidence of reliability of the instrument is increased if the two raters obtain the same results. Additionally, internal consistency reliability "reflects the coherence (or redundancy) of the components of a scale" (McCrae, Kurtz, Yamagata, & Terracciano, 2011, p. 1). In other words, it is necessary to examine the relationships between the items on the instrument: are they "logically connected" to each other (DeVellis, 2016, p. 58)? An instrument is considered to be internally consistent if its items demonstrate strong relationships to one another. Cronbach's alpha is the most widely used method for evaluating internal consistency and a value of .70 or greater is desirable when an instrument is relatively new (DeVellis, 2016; Polit & Beck, 2008; Streiner et al., 2015).

Validity

As noted previously, it is important to assess an instrument for validity, as well as reliability. In the past validity was seen as the degree to which an instrument was measuring what it was proclaimed to measure (Nunnally & Bernstein, 1994; Streiner, 2011) and it was divided into several different types: content, criterion, and construct validity (McDowell & Newell, 1996; Streiner, 2011). Over the past few decades validity has evolved to be defined as "the degree of confidence we can place on the inferences we make about people based on their scores from that scale" (Streiner, p. 84); it is a "unitary

concept" (American Educational Research Association [AERA], American Psychological Association [APA], & National Council on Measurement in Education [NCME], 1999, p.11). As with reliability, the emphasis is on the people completing the instrument, the results that are obtained, and the context in which the instrument was used. In other words, it is not the actual property of the instrument that one is interested in, but the ability to identify and interpret information from the participants based on their scores, and compare these interpretations to what is already known and identify new relationships not yet known; thereby increasing knowledge about the construct as a whole. What is significant is that evidence of validity of an instrument is not achieved after the completion of one study. Evidence of validity is gathered from multiple experiments yielding similar results (AERAAPA, & NCME, 1999; Streiner et al., 2015). For example, if a newly developed instrument, measuring a specific hypothetical construct, is hypothesized to have a significant positive relationship with another construct, one could not be convinced of this relationship as it had been measured in only one specific population. It is not until these same or similar results are obtained over repeated studies that one's confidence would be increased regarding the existence of the hypothesized relationship and thus the validity of the instrument.

In order to evaluate the validity of an instrument, the developer may examine a variety of sources of evidence: evidence based on test content, response processes, internal structure, relations to other variables, and/or consequences of testing (AERA, APA, & NCME, 1999). The source of evidence that is used by the instrument developer is dependent on the instrument's proposed use and purpose. The subsequent evidence

that is accumulated is evaluated to determine if it supports this stated meaning and purpose. There are also several strategies that may be used to collect the evidence: (a) evidence based on test content may include an analysis of the items by experts to ensure adequacy of the items to represent the construct of interest; (b) evidence based on response processes might include verbal discussions with the person who completed the instrument in order to determine his or her rationale for answers given and his or her interpretation of item meaning; (c) evidence based on internal structure may involve analysis of sub-components of the instrument and how the sub-components align with the theoretical model or framework from which the instrument was based; (d) evidence based on relations to other variables may include analysis of the construct with other external constructs proposed to be similar or different to the one under study; and (e) evidence based on consequences of testing may include an examination of the anticipated benefits of the testing and if these benefits are "subsequently realized" (AERA, APA, & NCME, 1999, p. 10).

Evidence based on item content was analyzed in 2008 and evidence based on consequences of testing was not relevant for the specific purpose of the CPIQ, and thus, the design of this study was developed to analyze the remaining evidence strategies for validity.

Factor Analysis

Facor analysis was conducted in order to evaluate validity based on the internal structure of the CPIQ. Factor analysis is a complex array of structure-analyzing procedures used to identify the interrelationships among a large set of observed variables

and then, through data reduction, to group a smaller set of these variables into dimensions or *factors* that have common characteristics (Pett, Lackey, & Sullivan, 2002, p. 2).

According to Pett et al. (2002), if one is interested in investigating a construct, and has developed an instrument to measure the construct, factor analysis will assist the researcher to identify interrelationships between the items on the instrument. The discovery of these interrelationships among the items leads to the identification of dimensions of the construct, thereby reducing what one knows about the construct to a more manageable and easily understood form. Subsequently, knowing the dimensions of a construct increases one's ability to examine relationships between the dimensions and other known constructs; facilitating the building of evidence for validity. Moreover, if one is interested in examining CP integration and its relationship to health and quality of life, for example, reducing the construct to smaller more manageable dimensions may facilitate the exploration of these relationships and guide future studies aimed at improving outcomes for the individual with CP.

Factor analysis is typically divided into two common forms (Pett et al., 2002): exploratory factor analysis (EFA) and confirmatory factor analysis (CFA). EFA is usually conducted when little is known about the relationships between the items and how many dimensions are present. The purpose of EFA is to examine the construct for these underlying dimensions. CFA on the other hand is typically conducted in subsequent research on the construct of interest (after EFA and identification of dimensions of the construct has occurred). In CFA, theoretical models are typically hypothesized and then tested to see if the data fits the proposed model. Even though EFA was previously

conducted on the CPIQ (Deshaies, 2008), the sample size was almost half the size of that recommended and revisions had been made to some item wording. According to DeVellis (2016), the result of a factor analysis (i.e. the pattern of factors that emerge from the analysis) is more stable when the sample size is large versus the patterns that are obtained from a small sample size. Larger sample sizes also tend to increase the generalizability of the results. Thus, it was deemed necessary to conduct another EFA, rather than CFA, in order to determine the dimensions of CP integration and increase one's confidence in the results.

In light of the above rationale, this study has been designed to incorporate EFA and the reliability and validity testing that has been recommended when developing and testing a new instrument (i.e. the CPIQ): test-retest reliability; internal consistency reliability; and three of the five previously noted strategies to evaluate validity (AERA, APA, & NCME, 1999; Norbeck, 1985; Streiner et al., 2015). The following section has been divided into two parts in order to outline the testing methods of the study: (a) Instrument development: revisions to the CPIQ; and (b) instrument testing.

Instrument Development: Revisions to the CPIQ

As previously identified, development of the CPIQ was initially started in 2008 by Deshaies as part of a Master's thesis. The first draft of the CPIQ was constructed through the examination of the lived experiences of people with CP reported in the qualitative research literature (Deshaies & Hernandez, 2011) and comparing these reported lived experiences to the theory of integration (Hernandez, 1991) which was developed through the examination of lived experiences of people with diabetes. The first draft of the CPIQ

consisted of 23 items. Additional qualitative methods (expert review through a focus group session of people living with CP and a survey of expert CP clinicians) were used to refine the CPIQ and build validity evidence for item content. Establishing validity of item content is a necessary first step in instrument development as the items that make up the measure need to adequately cover the construct of interest (Polit, Beck, & Owen, 2007; Streiner et al., 2015).

Through the process of expert review by people living with CP and expert clinicians working in the field of CP, the 23-item draft of the CPIQ was refined in 2008 to a final 17-item version. Decisions to delete, retain, or revise items were based on feedback from the experts and the calculation of Content Validity Index (CVI) scores: a common method to evaluate and document validity evidence for item content for a new instrument (Lynn, 1986; Polit & Beck, 2006). The scale CVI score for ten of the items on the CPIQ was .93 and the remaining seven items obtained a scale CVI score of 1.00. These scale CVI scores for the CPIQ were well above the .80 required (Polit & Beck, 2006) and provided evidence for the validity of item content on the CPIQ (see Deshaies, 2008 for a detailed description of the validity process of item content on the 17-item CPIQ).

Additional pilot testing of the CPIQ by Deshaies (2008, n = 106), using quantitative methodology, revealed internal consistency reliability ($\alpha = .88$), test-retest reliability (Pearson's r = .99), and a two domain structure obtained through exploratory factor analysis with acceptable internal consistency scores for each domain ($\alpha = .88$ and α = .82 respectively). These two domains extracted through exploratory factor analysis

were easily identifiable as elements of CP integration when compared to two integration definitions.

Even though the CPIQ had already been developed, further refinement of some of the items had been identified. Specifically, the CPIQ items required evaluation of (a) reading level; (b) need for balance between positive and reversed scored items; and (c) issues with wording of reversed scored items. The specific reading level of the CPIQ had not been assessed previously. The following paragraphs outline the steps that were taken to refine the CPIQ.

Reading Level

It is recommended that a measure should not be higher than an age 12 reading level (Streiner et al., 2015) or at least it should be between a grade five to seven reading level (DeVellis, 2016). Even though people living with chronic pain reviewed the items on the CPIQ in 2008 for content and readability (clarity and understanding), these individuals were not screened for level of education or literacy. The reviewers may have been at a higher reading level than the average individual living with CP, resulting in the wording of the CPIQ at a higher than appropriate reading level.

Several scoring methods have been developed to assess the reading level of a measure (DeVellis, 2016) and many of these methods have been placed into online scoring calculators in order to facilitate ease of use: for example, one online reading level calculator is Readability-Score.com. This online scoring tool calculates an average reading grade level based on the following scoring methods: (a) Flesch-Kincaid Grade Level Formula; (b) Gunning-Fog Score; (c) Coleman-Liau Index; (d) SMOG Formula;

(d) Automated Readability Index; (e) Spache Score; and (f) Dale-Chall Score (see Readability-Score.com for a detailed description of each scoring method). There is no known recommended method for calculating reading level (Streiner et al., 2015) and it is further advised that results be used cautiously; however, in the absence of any other method, these scoring tools provide general information to the instrument developer regarding the reading level of the measure. Incidentally, Readability-Score.com was the tool for reading level evidence recommended from one of the recruitment agencies identified in the study: evidence of an age 12 reading level was part of the agency's research ethics application and thus, this online calculator was used to assess the reading grade level of the CPIQ. Additionally, it was determined that any revisions made to items on the CPIQ as part of the study would require reassessment of reading level.

Response Bias

As mentioned previously, it is recommended that items on a scale have a balance between those items that reflect one end of the trait being measured (i.e., high levels of CP integration) and items that reflect the opposite end of the trait (Crocker & Algina, 1986; DeVellis, 2003; Nunnally & Bernstein, 1994; Sauro & Lewis, 2011; Streiner et al., 2015). This balance is deemed necessary to reduce response bias: "responses that depart systematically from the true values" (McDowell, 2006, p. 24). For example, some participants may have a tendency to give positive responses regardless of what is being asked on the measure. The original 2008 version of the 17-item CPIQ had only two items which were worded to reflect the low end of the CP integration trait. In order to increase the balance between items that reflect the high end of CP integration with those items that

reflect the lower end of CP integration, rewording of some of the items was deemed necessary.

There is no known agreed upon criteria for the percentage of items that should be reversed in an instrument. Steiner and Norman (2008) recommended that one half of the items should be reversed, however, reversing items, while still maintaining a positively worded structure can be a difficult task; while also maintaining the original content reflected in the items. Therefore, a review of the items on the CPIQ was conducted in order to determine which items could be revised to reflect a low level of CP integration; increasing the balance between the two types of items while still maintaining the relevant content of the item as expressed by the original participants in 2008. Additionally, the two items on the original 2008 version of the CPIQ that reflected the low end of CP integration were worded in negative terms. According to Barnette (2000), DeVellis (2003; 2016), and Streiner et al. (2015), items that include words such as 'no', 'not', or 'never' should be avoided for a multitude of reasons: (a) changing the words from positive to negative does not necessarily reverse the meaning of the item; (b) some individuals have difficulty disagreeing with an item in order to indicate a positive answer; (c) participants are more likely to "endorse a negative item rather than reject a positive one" (p. 82); and (d) lower validity scores have been noted with negatively worded items when compared to positively worded items. As such, these potential issues warranted assessment and revision of these two items on the CPIQ. Because wording changes to items on the CPIQ were going to be made, it was deemed appropriate to also reassess any revised items for clarity (i.e. readability). Once revisions are made to items on an

instrument, assessment of these items by external reviewers is recommended (DeVellis, 2016; Streiner et al., 2015). As such, the method used to assess readability for revised items on the CPIQ has been outlined in the following paragraphs.

Readability

Because wording revisions were deemed necessary for some items on the CPIQ, an evaluation for readability of these revised items was required. An attempt was made to recruit five expert reviewers in the hopes of obtaining at least three reviews (i.e. the minimum acceptable; Polit & Beck, 2006; Streiner et al., 2015). The experts were recruited from local agencies in order to review the readability of revised items on the CPIQ. An individual was deemed an expert if he/she had worked in the field of CP for a minimum of five years. The expert reviewers were asked to rate the readability of the revised items on a 5-point Likert scale (ranging from [1] completely disagree to [5] completely agree). Scores ranging from 3 to 5 were deemed acceptable readability scores for the revised items. Items that did not meet the criteria were to be re-evaluated in order to make decisions about revision or removal from the CPIO. According to DeVellis (2016), the ultimate decision for revision and/or removal falls on the developer of the instrument who has to weigh the advice given by an expert, the expert's familiarity with the construct under development, and the expert's knowledge of instrument development as a whole. Expert reviewers were provided with space to add in comments or suggested revisions to an item if required.

Once revisions to any items on the CPIQ had been completed, the CPIQ was ready for testing. The methods used to test the CPIQ have been explained in the next section.

Instrument Testing of the CPIQ

The method for instrument testing in the current study has been developed using a quantitative non-experimental design in order to fully test the psychometric properties of the CPIQ. Even though the statistical results of the pilot testing of the CPIQ in 2008 were favourable, the sample sizes for the exploratory factor analysis and test-retest reliability were below that commonly recommended (n = 106; n = 10 respectively) and thus a full psychometric testing of the CPIQ was deemed necessary. The following section outlines a description of the sample, sample size requirements, sample recruitment strategies, the measurement instruments used in the study, and the data analysis procedures that were conducted at the completion of data collection.

Description of Sample

Adults with chronic (non-cancer) pain, both males and females, were recruited for this study from three pain management programs in Windsor-Essex County, Chatham-Kent County, and Sarnia-Lambton County: Windsor Regional Hospital (WRH) Pain Clinic-Ouellette Campus, the Victorian Order of Nurses (VON) Chronic Pain Management Assessment & Referral Program, and the Windsor-Essex Community Health Centre (WECHC). A convenience sample recruited from CP programs was necessary in order to obtain the required sample size needed to adequately test the CPIQ. The following were the inclusion and exclusion criteria applied to the sample:

- 1. Inclusion criteria: adult (18 and older); diagnosed with a chronic (non-cancer) pain condition; able to read and write English.
- 2. Exclusion criteria: under 18 years of age; not suffering with chronic non-cancer pain.

Sample Size

Traditionally, psychometric testing has not followed the typical protocol of power analysis for determining an adequate sample size as with other research designs (Sapnas & Zeller, 2002); Rules-of-thumb are often used when conducting psychometric testing which typically includes some type of factor analysis, and 10 participants per item on the questionnaire has been the long accepted sample size criteria for instrument testing. Additional rules-of-thumb have ranged from requiring a minimum of 50 participants to 400 participants or participant-to-item ratios of 5:1 to 20:1 (DeVellis, 2016; Furr, 2011; McDowell & Newell, 1996). These discrepancies in sample size recommendations unfortunately highlight the lack of clarity for effective sample size calculations or decisions (Anthoine, Moret, Regnault, Sbille, & Hardouin, 2014; Bartlett, Kotrlik, & Higgins, 2001; Sapnas & Zeller, 2002). According to MacCallum, Widaman, Zhang, and Hong (1999), rules-of-thumb for sample size for factor analysis in particular are not valid or useful because the minimum sample required may change based on the variables under study and the design of the study. A general rule that seems to have gained increased acceptance is that a sample of 200 is adequate when using basic factor analysis techniques with a maximum of 40 items (DeVellis, 2016).

The CPIQ is a 17-item Likert scale and thus, following the 10 participants per item criteria noted previously for factor analysis, the study would require a minimum of 170 participants. However, a more general rule of 200 participants has been accepted as adequate when performing factor analysis for instruments with less than 40 items (DeVellis, 2016). Additionally, in order to examine the CPIQ for validity, analyzing the relationship between the CPIQ scores with that of the scores on other questionnaires was necessary. This was important in order to examine concepts similar to, different from, and/or previously reported to have a relationship with CP integration. Kline (2005) has reported the need for a minimum of 200 participants for adequate analysis of a concept and its relationship to other concepts. Therefore, a minimum of 200 participants was deemed ideal for the study.

It was feasible to obtain 200 participants from the three recruitment sites based on the number of patients treated each year:

- 1. Windsor Regional Hospital (WRH) Pain Clinic-Ouellette Campus: The physician in this clinic treated approximately 1250 to 1500 patients per year.
- Victorian Order of Nurses (VON) Chronic Pain Management Assessment & Referral Program: From April 1, 2012 to March 31, 2013, the program serviced 340 clients in their Erie St. Clair District.
- The Windsor-Essex Community Health Centre (WECHC) enrolled approximately 30 people every 6 weeks into their newly started chronic pain management program for an estimated 259 people per year.

Sample Recruitment Strategies

It was necessary to recruit participants in two different phases for this study. This was done to simplify the process for the recruiters and to reduce any confusion on the part of a participant. The following section provides the details for the two phases of the study.

Phase one. In order to determine test-retest reliability of the CPIQ, a maximum of 50 participants were needed to complete the questionnaire package and then complete the CPIQ itself at a second time frame (approximately 7-15 days apart; see the Test-Retest Reliability section for the rationale for sample size).

- a) Recruiters at the three organizations (WRH, VON, & WECHC) approached current patients to determine if they were interested in participating in this phase of the study (see Appendix A: Script for Recruiters A).
- b) If the patient was interested in participating, the recruiter obtained consent to release his or her contact information to the principal investigator (PI; see Appendix B: Recruiter consent).
- c) Upon receipt of the patient's consent to be contacted, the PI contacted the potential participant by phone to confirm consent to participate in the study and to determine the 1st and 2nd time frame for completion of the questionnaire package and the CPIQ respectively (see Appendix C: Script for Telephone Contact).

Phase two. In addition to the 50 participants recruited for phase one, a remaining 150 people were recruited (total for both phases = 200) to complete the questionnaire

package at one point in time only. Recruiters at all three agencies approached current patients to determine if they would be interested in participating in this phase of the study (see Appendix D; Script for Recruiters B).

- a) When the patient expressed interest to participate, the recruiter provided the patient with the study package and encouraged the patient to read the study information and contact the PI if he or she had any further questions. If the patient decided to participate in the research, he or she completed the questionnaire package on own time and at own convenience.
- b) At the VON site, a support staff person also mailed out the study package to 500 former patients of the program to determine interest in participating in the study. The PI did not have access to names or addresses of the patients, but provided VON with all study packages and postage required (see Appendix E for the Cover Letter which accompanied the mailed study packages and outlined the maintenance of confidentiality for the potential participant; and see Appendices F-J for Letters of Information and Consents provided to participants at phase one or phase two of study).

Instrumentation

As previously reported, in order to accumulate evidence for the validity of a measure it is commonly compared to other measures of the same or similar attribute, or compared to some other attribute of which it has a hypothesized relationship (Streiner et al., 2015). Therefore, in order to conduct validity analysis of the CPIQ, it was necessary to have the participants in the sample complete the CPIQ along with other established

questionnaires. The following is a list of the questionnaires that were used in the study and their reported psychometric properties.

- 1. Chronic Pain Integration Questionnaire (CPIQ; Deshaies, 2008 & Revised version 2013): The CPIQ is a 17-item, self-administered, 6-point Likert scale and measures the degree to which an individual with chronic pain has integrated the pain into his or her life. The higher the total score computed on the CPIQ, the higher the level of chronic pain integration. Through pilot testing, the 2008 version of the CPIQ demonstrated internal consistency reliability (α =.88) and test-retest reliability (Pearson's *r* =.99). Two domains were also identified through exploratory factor analysis (intrapersonal reciprocality and psychoemotional adjustment) and positive correlations between an index of hope (Herth Hope Index, Hearth, 1992) and quality of life (EuroQol, EuroQol Group, 1990) provided support for initial evidence of validity of the CPIQ.
- 2. Acceptance and Action Questionnaire (AAQ-II, Bond et al., 2011): the AAQ-II is a measure of experiential avoidance/psychological inflexibility (the opposite of which is acceptance/psychological flexibility). The higher the score computed on the AAQ-II, the higher the psychological inflexibility (i.e. nonacceptance). The AAQ-II is a 7-item, self-administered, 7-point scale. It has demonstrated internal consistency (α =.84) and 3-month test-retest reliability (*r* =.81). Evidence of validity has been reported due to its ability to "predict a range of outcomes from mental health to work absence rates that are consistent

with its underlying theory" (p. 676). Author permission to use the instrument is not required for research purposes and for use with clients (Association for Contextual Behavioral Science, n.d.).

- 3. Social Support: A visual analog scale (VAS), created by the author, had been utilized in order to measure the individual's current perceived availability of social support. The participant places a mark at a point on a line indicating his/her perceived availability of social support from 0 to 10 ('0' indicating no social support and '10' indicating highest amount of available support). VAS have been used commonly in health research (Couper, Tourangeau, Conrad, & Singer, 2006; Wewers & Lowe, 1990) and have been shown to be a reliable and valid type of measure (Gift, 1989; Miller, Duncan, Browne, Sparks, & Claud, 2003).
- 4. Chronic Pain Acceptance Questionnaire (CPAQ; McCracken, Vowles, & Eccleston, 2004; Vowles, McCracken, McLeod, & Eccleston, 2008): The CPAQ is a measure of chronic pain acceptance with a 2-factor structure (activities engagement and pain willingness). It is a 20-item, self-administered, 6-point scale and has demonstrated internal consistency (2 factors: $\alpha = .82$ and .78) and test-retest reliability (r = .78). Several studies have also been conducted which have built evidence for the validity of the CPAQ (Bernini, Rivas, & Berrocal, 2014; McCracken, Vowles, & Eccleston, 2004; Reneman, Dijkstra, Geertzen, & Dijkstra, 2010; Vowles, McCracken, McLeod, &

Eccleston, 2008; Wicksell, Olsson, & Melin, 2009). Permission was obtained to use the instrument (see Appendix K).

5. SF Health Survey (SF-12v2): The SF-12v2 is a self-administered, 12 item measure of general health status (3-point and 5-point scale). It has demonstrated internal consistency reliability (α =.80) and test-retest reliability (r = .78). Through numerous studies worldwide, the SF-12v2 has demonstrated evidence of validity in a variety of populations (Gandhi, Salmon, Zhao, Lambert, Gore, & Conrad, 2001; Jayasinghe et al., 2009; Kontodimopoulos, Pappa, Niakis, & Tountas, 2007; Maurischat, Herschbach, Peters, & Bullinger, 2008). Permission was obtained to use of the instrument (see Appendix L).

Data Analysis

The following section describes the statistical analyses planned for the study. The section has been divided into the following categories: (a) exploratory factor analysis (b) reliability testing; and (c) validity testing. All statistical calculations of the data were completed through the use of computer software: Statistical Package for Social Science (SPSS), versions 23 and 24 (renewal of the SPSS license occurred during the time frame of the analyses and thus, resulted in the change from version 23 to 24; this change in versions of SPSS had no impact on the methods or results described herein).

Exploratory Factor Analysis

Prior to conducting EFA to explore the dimensions of the CPIQ, it is important to assess the items for significant correlations (Pett et al., 2003; Tabachnick & Fidell, 2013). Several sizeable correlations (i.e. Pearson r > .30) must be present within the correlation

matrix that is generated from the data in order to proceed with EFA; if correlations above .30 do not exist, the data is to be considered not factorable. However, examining the correlation matrix generated from the data for presence of large correlations is not fail proof. For example, a correlation between two variables may be large because of the presence of some other underlying variable(s) and when these other variables are controlled, the correlation between the two original variables is reduced. Therefore, it is recommended that additional tests are used to determine the significance of the correlations within the matrix thereby increasing ones confidence that the data is factorable. Two common tests used to evaluate the items for significant correlation are the Bartlett's test of sphericity and the Kaiser-Meyer-Olkin (KMO) test. A significant Bartlett's test of sphericity ($p \le .05$) and a KMO value of .6 or higher are desirable for good factor analysis (Tabachnich & Fidell, 2007; Meyers, Gamst, & Guarino, 2006; Pett et al., 2003). Both of these tests were analyzed prior to continuing with the EFA in the study.

Once the significant correlations had been established, two factor extraction methods (principal component analysis and principal axis factoring) were examined to determine which method had the best fit and also made the most theoretical sense (Dixon, 2001; Pett et al., 2003). A factor is identifiable by the number of items that "load most heavily on it" (Pett et al., p. 196) and the various extraction methods display these item loadings in an interpretable way. The goal is to reduce the number of factors that have been identified to the lowest number possible while still maximizing the percent of variance explained.

In order to determine the number of initial factors that have been extracted, eigenvalues were assessed and only eigenvalues greater than 1 were accepted (Pett et al., 2003). An eigenvalue is the sum of the squared factor loadings on each specific component (i.e factor or dimension) and represents the amount of variance in the items that can be explained by the factor. A second approach that was used to determine the number of factors extracted was to review the generated scree plot. A scree plot is a type of graph of the extracted factors and their eignevalues plotted in a descending order from highest to lowest (DeVellis, 2016; Field, 2005; Pett et al., 2003; Tabachnick & Fidell, 2013). A visual inspection of the scree plot helps to identify if there is a distinct break in the slope of the eigenvalues. A straight line is typically drawn through the lower values on the plot and the point at which the curve moves above the line is where the cut-off is considered for determining the number of factors.

A third approach for determining the number of factors is to evaluate the cumulative percentage of variance explained by each successive factor that has been extracted (Pett et al., 2003): typically the first factor will have the highest percentage of variance explained and each subsequent factor will decrease in percentage. However, there is no clear consensus for an acceptable cut-off point for explained cumulative percentage of variance (Pett et al., 2003). Also, according to Pett et al., criteria that has been applied to 'natural science' (e.g. 90% explained variance should be achieved) does not apply in the 'less precise social sciences' (p. 118), where the explained variance is likely to be significantly less.

Usually, the unrotated factor matrix that is generated through the extraction method is difficult to interpret and thus, it is also necessary to rotate the factors (Kline, 1994; Pett et al., 2003). There are two main types of rotation: orthogonal and oblique. The goal is to choose the rotation method that has the simplest solution: each item has a high loading (.30 or higher) on only one factor. Orthogonal rotations are typically chosen when one assumes that the extracted factors will be uncorrelated. Oblique rotations are typically chosen if it is assumed that the extracted factors will be correlated. It is proposed herein that there will be correlation between the extracted factors for CP integration, and thus, oblique rotation was conducted. However, both rotation techniques were examined to ensure the best solution was chosen. Ultimately, and most importantly, the number of factors were decided upon by examining the above noted procedures in combination with what made theoretical sense: for example, it may be difficult to discern if there is a three factor structure or a two factor structure. In this instance, looking at these different structures with a theoretical lens will help to choose that which is the most relevant to CP integration.

Test-Retest Reliability

Analyzing a questionnaire for test-retest reliability allows the researcher to determine the stability of the questionnaire over time (Polit & Beck, 2008). In order to obtain test-rest reliability data for the CPIQ, it was necessary for a certain number of participants to complete the CPIQ at two different time frames. As previously indicated in phase one, questionnaire packages were distributed by the recruiters at WRH, VON, and WECHC until a maximum of approximately 50 people volunteered to participate in

completing the full questionnaire package at one point in time and then completing the CPIQ itself at a second point in time (approximately 7-15 days apart). The short time period was chosen since the chance of measured attributes changing increases over time (Polit & Beck, 2008) and time periods of 2-15 days are average (Streiner et al., 2015).

The sample size of 50 was determined based on estimates of sample sizes for reliability testing presented by Walter, Eliasziw, and Donner (1998). For a minimum reliability of .70 and an expected reliability of .90, with 2 observations per subject, the estimated sample size is 18.4 (see Appendix M); for a minimum reliability of 0.80 and an expected reliability of 0.90, the estimated sample size is 45.8. Reliability scores lower than .70 are unacceptable, whereas scores in the .70 to .80 range are acceptable for new instruments in the early stages of research, and scores in the .80 range or higher are acceptable for established instruments (Streiner, 2011). Therefore, because the CPIQ is a new instrument, a minimum sample of 18.4 was required to obtain a minimum reliability of .70, however, a sample size of 50 was strived for in order to reach a more desirable reliability score of .80.

The intraclass correlation coefficient (ICC) has been recommended as the measure of choice when calculating test-retest reliability (McGraw & Wong, 1996; Streiner, 2011; Streiner et al., 2015; Walter et al., 1998). Thus, the ICC was calculated to determine the test-retest reliability of the CPIQ.

Internal Consistency Reliability

Once the necessary amount of data had been obtained from at least 200 participants and the factors were extracted and rotated, the CPIQ was analyzed for

internal consistency reliability. Cronbach's alpha is the most widely used method for evaluating internal consistency (DeVellis, 2016; Polit & Beck, 2008; Streiner, 2011). A value of .80 or greater is desirable, however, as stated previously, values in the .70 range are acceptable for new instruments.

Validity

In order to accumulate evidence for the validity of the CPIQ, it was compared to other measures with similar attributes and compared to some attributes of which it has a hypothesized relationship. These above noted comparisons allow for "assessing the theory and the measure at the same time" (Streiner et al., 2015, p. 259).

The theory that has guided the study was based on current knowledge of integration that has been investigated in diabetes and chronic illness in general (Hernandez, 1991, 1995; Whittemore, 2005; Whittemore & Roy, 2002; Whittemore & Dixon, 2008). The analysis was designed to examine hypothesized relationships between the chosen variables (tools) (see Chapter 2 for a detailed explanation of these hypothesized relationships) and to identify variables that may predict CP integration. More specifically, the study was designed to answer the following hypotheses:

 Chronic pain acceptance (measured by the Chronic Pain Acceptance Questionnaire [CPAQ]) and general acceptance levels (measured by the Acceptance and Action Questionnaire [AAQ-II]) are correlated with the CPIQ such that individuals with higher levels of chronic pain acceptance/general acceptance have higher levels of CP integration than those with lower levels.

- 2. Social support (measured with a visual analog scale) is positively correlated with CP integration (CPIQ) such that individuals with higher levels of social support have higher levels of integration.
- 3. Functional health and well-being (measured by the physical component summary score (PCS), the mental health summary score (MCS), and the general health (GH) score of the SF Health Survey [SF-12v2]) is positively correlated with CP integration (CPIQ) such that individuals with higher levels of PCS, MCS, and GH have higher levels of CP integration.
- 4. Social support (visual analog scale) mediates the relationship between chronic pain integration (CPIQ) and health (SF-12v2).

In order to answer the research hypotheses one through three noted above, Pearson *r* correlations were calculated between the CPIQ and the continuous variables measured in the study (CPAQ; AAQ-II; Social Support; SF-12v2: PCS, MCS, and GH scores). The following paragraphs outline the process used to answer research hypothesis four: Social support (visual analog scale) mediates the relationship between chronic pain integration (CPIQ) and health (SF-12v2).

As outlined in chapter two, a relationship exists between social support and integration (Whittemore & Roy, 2002) and thus, it was presumed that this relationship may exist between social support and CP integration. One may also presume that there is a relationship between health and social support. The question that has been proposed here is that there may be a causal sequence between these three variables; the variable in the middle of the sequence (i.e. social support) is referred to as the mediator (Tabachnick & Fidell, 2013). Does a person's perception of health 'cause' some difference in his or her perceived level of social support which, in turn, may 'cause' some difference in his or her level of CP integration? In order to assess for this mediator effect, the four-step process outlined by Baron and Kenny (1986) was used. According to Baron and Kenny (as cited in Tabachnick & Fidell, 2013, p. 160), a variable is confirmed as a mediator if

- There is a significant relationship between the independent variable (i.e. health measured by the SF-12v2) and the dependent variable (i.e. CP integration measured by the CPIQ).
- 2. There is a significant relationship between the independent variable and the mediator (i.e. social support measured by a VAS).
- 3. The mediator still predicts the dependent variable after controlling for the independent variable.
- 4. The relationship between the independent variable and the dependent variable goes to zero when the mediator is in the equation. This is known as perfect or full mediation (if the relationship is diminished, but not to zero, mediation is said to be partial).

Each of these steps were conducted in order to determine if social support was indeed a mediator between health and CP integration.

In addition to answering the four research hypotheses reported previously, identifying whether or not any one variable in the study could predict CP integration was deemed useful for enhancing one's knowledge about CP integration and to build further evidence for validity. Analysis of variance (ANOVA) and multiple regression analysis
were used to determine if any variables measured in the study (demographic and clinical) were able to predict scores on the CPIQ.

Ethical Considerations

Approval for the study was received from the Hamilton Integrated Research Ethics Board (HIREB) of McMaster University, Hamilton, Ontario. The HIREB operates under the principles of the Tri-Council Standards for ethical conduct of research. Additionally, approval for the study was received from the Research Ethics Boards of Windsor Regional Hospital, Windsor, Ontario, and the Victorian Order of Nurses, Toronto, Ontario (Head Office). Written informed consent was obtained from the Director of the Windsor Essex Community Health Centre as they did not have a research ethics board. Letters of information were provided to participants (see Appendices I to M) and written informed consent was also obtained from all study participants. Paper data was coded (combination of letters and numbers) and stored in a locked cabinet accessible only to the primary investigator. Consent forms were separated from the coded questionnaire packages and stored in a separate locked cupboard in order that participants could not be identified with their specific questionnaire. Electronic data was stored on a password protected computer stored in a locked office and only accessible to the primary investigator.

CHAPTER 4: RESULTS

This chapter summarizes the results of the statistical analyses proposed for the study. It has been divided into the following components: (a) participants; (b) data screening process; (b) characteristics of the sample; (c) revisions of CPIQ (expert panel review); (d) exploratory factor analysis; (e) reliability testing; and (f) validity testing.

Participants

Recruitment for both phases of the study commenced in December, 2013 and was finished in May of 2016 upon achievement of the recommended sample sizes for the analyses (see Table 1). Of the three recruitment agencies, the Victorian Order of Nurses (VON) had the highest degree of challenges with the in-person recruitment strategy and thus, the majority of recruitment from this agency came from mailing the study package to potential participants in phase two. The VON recruiters reported that it was likely their own lengthy process for patient assessment and admission into the VON program (which included completion of several questionnaires) that caused a barrier to patients participating in the study when approached in person. Nonetheless, the combination of the two samples recruited in phase one (n = 35) and phase two (n = 168) resulted in a total sample size of n = 203 which met the overall minimum of 200 that was desired.

Total Response Rate for Phase Two

When combining all recruitment attempts from the three agencies, a total of 832 questionnaire packages were distributed to potential participants for phase two of the

Number of Participants (n) Based on Recruitment Agency and Phase of Recruitment

		Phase One	
Agency	Supplied Consents	Completed Consents	Participants (n)
VON	25	6	4
WRH	42	37	22
WECHC	30	16	9
			Total 35
		Phase Two	
Agency	Supplied Package	Distributed Packages	Participants
VON	800 (mailed)	770 (30 returned unused)	144
WRH	100	41 (59 returned unused)	16
WECHC	50	21 (29 returned unused)	8
			Total 168

Note. VON = Victorian Order of Nurses; WRH = Windsor Regional Hospital-Ouellette Site Pain Clinic; WECHC = Windsor-Essex Community Health Centre Chronic Disease Program

study. The total number of packages returned to the researcher was 170, and thus, the total response rate for the study was 20.4%. The lowest response rate (18.7%) was seen from the mailing recruitment strategy through VON. Sending out reminder notices to people who have not yet responded to a mailed survey has been shown to improve response rates (Brennan, 1992). However, due to financial constraints and workload demands that would have been placed on the recruiter at the agency, reminder notices were not used and this decision may have contributed to the low response rate. The response rates for the in-person recruitment strategies that took place at the remaining two

recruitment agencies were significantly higher than the mailing (39% and 38% respectively). However, the length of time that transpired for the in-person recruitment to yield a sufficient number of participants took longer than expected and contributed to the decision to return to a mailing strategy with VON in early 2016.

Data Screening

Data was collected for three aspects of this study: (a) from a panel of experts who evaluated the readability of eight items on the CPIQ that had undergone wording revisions; (b) from participants who completed the CPIQ at two separate time periods (test-retest analysis); and (c) from participants who completed the CPIQ at one point in time only. Prior to determining if any data were missing, the data were scanned for errors. Scanning of the data revealed two categorical variables (type of CP diagnosis and race) that had one data entry error each (i.e. the participants score was entered incorrectly into the statistical software). These errors were fixed by examining the original questionnaires submitted by the participants. No other errors were noted when scanning the data collected for the continuous variables in the study. Data received from the testretest participants (n = 35) was complete for all of the items on the CPIQ at both time periods. However, there was missing data in some of the questionnaire packages as a whole for both the second and third data collection aspects of the study: data was missing for some of the categorical variables [demographic and clinical] and/or there were missing answers for some items on either the SF-12v2, AAQ-II, or the CPAQ instruments (See Table N1 for the distribution of missing data in the sample). There was also one piece of data missing from one of the participants recruited for an expert panel review (n

= 5) in order to examine the readability (i.e. clarity) of several items on the CPIQ that had been revised.

For the CPIQ specifically, there were two participants who had not answered the questionnaire and were deleted from the analysis. Therefore, the final total sample size of 203 participants was reduced to 201. Because of a small proportion of missing data, no missing data imputation techniques were used.

Characteristics of the Sample

Table 2 and Table 3 present detailed descriptions of the demographic and clinical variables identified by participants as well as a grouping of these variables by gender. The majority of the participants reported being 50 years of age or older (68%; mean age was 57 years [SD = 15.2]), were female (74%), and reported their race as Caucasian/white (95.5%). Most individuals reported that they had been living with chronic pain for ten years or less (57.3%; the mean number of years living with CP was 12.7 [SD = 10.8]); they had been diagnosed with three or more CP diagnoses (65.5%); and their CP was located in three or more body parts (65.8%). Of the 199 participants who answered the question regarding participation in a CP program, the majority (56.3%) identified that they were currently in a CP program (21.1%) or had completed a CP program (35.2%). The differences between gender and the demographic and clinical variables were assessed (see Table 2) and only two variables demonstrated statistical significant differences between the groups: (a) race (p = .03); and (b) number of body parts involved (p = .06; marginally significant).

Distribution of Demographic and Clinical Variables by Gender [n (%)]

YWCP group	Male	Female	Total	<i>p</i> -value
<u>≤10</u>	25 (55.6)	81 (57.9)	106 (57.3)	.87
10-19	7 (15.6)	24 (17.1)	31 (16.8)	
\geq 20	13 (28.9)	35 (25.0)	48 (25.9)	
Age group				
<50	13 (25.5)	51 (34.2)	64 (32.0)	.31
50-59	10 (19.6)	36 (24.2)	46 (23.0)	
60-69	13 (25.5)	35 (23.5)	48 (24.0)	
≥70	15 (29.4)	27 (18.1)	42 (21.0)	
Education Group				
< high school	12 (25.0)	26 (18.1)	38 (19.8)	.36
High school	11 (22.9)	47 (32.6)	58 (30.2)	
College/University*	25 (52.1)	71 (49.3)	96 (50.0)	
Income Group				
< 25,000	14 (28.0)	50 (35.2)	64 (33.3)	.82
25,000-49,999	19 (38.0)	47 (33.1)	66 (34.4)	
50,000-74,999	9 (18.0)	25 (17.6)	34 (17.7)	
\geq 75, 000	8 (16.0)	20 (14.1)	28 (14.6)	
Number of CP Diagnoses				
1	9 (17.6)	29 (19.5)	38 (19.0)	.37
2	5 (9.8)	26 (17.4)	31 (15.5)	
3 or more	37 (72.5)	94 (63.1)	131 (65.5)	
Number of Body Parts In	volved			
1	8 (16.7)	18 (12.4)	26 (13.5)	.06
2	15 (31.3)	25 (17.2)	40 (20.7)	
3 or more	25 (52.1)	102 (70.3)	127 (65.8)	
Participated in CP Progra	am			
In a program	9 (18.0)	33 (22.1)	42 (21.1)	.12
Completed program	13 (26.0)	57 (38.3)	70 (35.2)	
Never in program	28 (56.0)	59 (39.6)	87 (43.7)	
Race				
Caucasian/white	46 (90.2)	145 (97.3)	191 (95.5)	.03
Other#	5 (9.8)	4 (2.7)	9 (4.5)	

Note. YWCP = Number of years living with chronic pain; *may or may not have graduated; CP = chronic pain; #black/African Canadian, First Nations, Asian, and other.

Summary Measures of Age and Years Living with Chronic Pain: Mean (Standard Deviation; SD), Sample Size (n), and p value (t-test)

	Male	Female	Total	n (male/female)	p value
Age	60.8 (13.5)	54.8 (15.5)	57.0 (15.2)	200 (51/149)	.25
YWCP	12.6 (10.3)	12.8 (11.0)	12.7 (10.8)	185 (45/140)	.29

Note. YWCP=Number of years living with chronic pain; SD = standard deviation.

Revising the CPIQ

Reading Level Assessment

The original 2008 version of the CPIQ was assessed to be at an average grade level of 5.9 (see Figure O1 for the Readability-Score.com results). Additionally, the CPIQ underwent some wording revisions for this study and thus, reading level was reassessed and found to be at an average grade level of 6.1 (see Figure O2 for the Readability-Score.com results). Therefore, both versions of the CPIQ, 2008 and 2013 respectively, fell within the recommended grade levels for reading.

Revision of CPIQ Item Wording

Following a review of all 17 items on the CPIQ, a total of 8 items were revised (See Table P1):

- 1. A total of five items were reversed-keyed: items 2, 4, 9, 13, 15 (item 13 was revised in order to eliminate the word 'no').
- 2. Item 8 was revised in order to eliminate the word 'not'.
- 3. Item 7 was originally reversed-keyed in the 2008 version, but because the removal of the word 'no' was required, it was subsequently changed to reflect

the higher end of CP integration as this was an easier task to accomplish in order to maintain evidence of validity based on item content.

4. Item 6 was revised because of feedback provided from a participant in the 2008 study who felt the phrase 'take specific measures' was confusing because of the combination of the words 'take' and 'measure' which may be misinterpreted as taking a measurement with a device (e.g. weight scale; waist measurement etc.). Subsequently, the words in item 6 were simplified in order to increase clarity while maintaining the evidence of validity based on item content expressed by the 2008 focus group participants.

Due to these revisions, it was deemed important to have an expert panel review the revised items for continued clarity (i.e. readability). The following section provides the results of this review.

Expert Panel Review of Readability

Five expert reviewers were sent a copy of the eight revised items from the CPIQ and asked to rate the readability of the items on a 5-point Likert scale (ranging from completely disagree to completely agree). Items ranked between three and five were considered acceptable for readability. All five reviewers responded to the survey and provided feedback: item-CVI scores exceeded the .78 score of acceptability (see Table 4). Even though feedback was sought to determine item clarity (readability), the same process for calculating validity based on item content, (i.e. the content validity index [CVI]) was used because of its simplicity.

Expert Review of Revised Items for Readability and Calculation of Readability Using Content Validity Index (CVI) Scoring Method.

Item	E-1	E-2	E-3	E-4	E-5	I-CVI Scores
2. My chronic pain will increase without any warning from my	5	3	4	4	5	1
4. I follow the advice of others, rather than my own instincts, when deciding what works best for me.	5	4	3	3	5	1
6. I do specific things that will belp me live with chronic pain	5	4	3	5	5	1
7. I make choices about the daily activities in my life	5	4	3	5	5	1
8. I have learned new ways to do activities	5	5	4	5	5	1
9. I wait until my chronic pain is at its worst before trying to do something to make it better.	5	5	5	4	5	1
13. Following a daily routine makes my chronic pain worse	5	3	4	4	5	1
15. I feel I live an unhealthy lifestyle because of my chronic pain.	5	5		5	3	.80

Note. Code: E = expert reviewer; 1 – completely disagree; 2 – generally disagree; 3 – neither agree nor disagree; 4 – generally agree; 5 – completely agree; I-CVI = Item-CVI and it is the number of experts rating 3-5 divided by the total number of experts (ideal = .78 or higher; Polit, Beck, & Owen, 2007)

Exploratory Factor Analysis

Prior to conducting the EFA, the Bartlett's test of Sphericity and the Kaiser-

Meyer-Olkin (KMO) test were used with the following results: (a) Barlett's test of

Sphericity, p-value = < .01; KMO = .79. Both of these results were within the acceptable

guidelines and thus, it was deemed appropriate to proceed with the EFA.

Once the significant correlations had been established, several steps were taken to determine which solution best fit the data and ultimately made theoretical sense (Dixon, 2001; Pett et al., 2003). Firstly, principal component analysis [PCA] and principal axis factoring [PAF] extraction methods were examined to determine if the different extraction methods yielded different factor results. When using PCA or PAF, the total number of factors extracted was five, with a set cut-off point of eigenvalues greater than one (Pett et al., 2003); there were no significant differences between the unrotated structure nor the number of initial factors extracted when using either PCA or PAF (see Table Q1 for the unrotated factor matrix; and Table Q2 for the total variance explained by those factors with eigenvalues greater than one).

Secondly, the scree plot was visualized to determine if there was an identifiable break in the slope created from the plotting of the eigenvalues (DeVellis, 2016; Field, 2005; Pett et al., 2003; Tabachnick & Fidell, 2013). A straight line was drawn through the lower values on the plot and the total number of plotted eigenvalues that were located above the line (i.e. Three were above the line, see Figure 1) were taken into consideration when making a decision about the number of factors present in the structure of the CPIQ.

Thirdly, because the unrotated factor matrix that is generated through the extraction process is difficult to interpret, the factors were rotated. The oblique rotation was chosen as it had been proposed that there would be a correlation between the extracted factors for CP integration. Because five factors were initially extracted, the five factor rotated matrix was examined initially. However, multiple loadings on more than



Figure 1. Scree Plot of Eigenvalues; Red Line Drawn to Depict Change in Slope

one factor was evident when reviewing the structure matrix (items: CPIQ5, CPIQ12, CPIQ14, rCPIQ15; see Table R1).

Because the scree plot was visually depicting a 3-factor structure, the matrix was rotated again by limiting the number of factor extractions to three. The new structure matrix generated for a 3-factor model was greatly improved: all factor loadings were above .40 and there were no multiple loadings of an item on a factor. This provided evidence of a better fit with the 3-factor model (see Table 5 depicting the three components extracted using the oblique rotation method and Table 6 which outlines the correlation matrix of the three components).

Ultimately, however, and most importantly, the final factor structure was decided upon by examining the above noted procedures in combination with what made theoretical sense (DeVellis, 2016; Pett et al., 2003; Kline, 1994). When examining the 3-

EFA of CPIQ Using Principal Component Extraction: Three Components Extracted with Oblique Rotation (Oblimin with Kaiser Normalization): Pattern and Structure Matrices (loadings less than .40 excluded)

	Pattern	Matrix			Structure M	atrix	
CPIQ Items		Component		CPIQ Items	C	omponent	
	1	2	3		1	2	.3
CPIQ1			.582	CPIQ1			.611
rCPIQ2		.462		rCPIQ2		.466	
CPIQ3	.629			CPIQ3	.616		
rCPIQ4		.490		rCPIQ4		.481	
CPIQ5	.684			CPIQ5	.693		
CPIQ6	.829			CPIQ6	.785		
CPIQ7	.651			CPIQ7	.661		
CPIQ8	.635			CPIQ8	.676		
rCPIQ9		.515		rCPIQ9		.515	
CPIQ10			.805	CPIQ10			.806
CPIQ11	.534			CPIQ11	.558		
CPIQ12			.570	CPIQ12	.506		.659
rCPIQ13		.629		rCPIQ13		.629	
CPIQ14	.607			CPIQ14	.670		.403
rCPIQ15		.723		rCPIQ15		.722	
CPIQ16	.482			CPIQ16	.513		
CPIQ17	.412			CPIQ17	.401		

Note. EFA=exploratory factor analysis; CPIQ=chronic pain integration questionnaire

Table 6

Component Correlation Matrix for Three Components of CPIQ; Principle Component Extraction with Oblique Rotation (Oblimin with Kaiser Normalization)

Component	1	2	3
1	1.000	013	.242
2	013	1.000	028
3	.242	028	1.000

Note. CPIQ = chronic pain integration questionnaire

factor structure, the items that loaded on the first factor all seemed to reflect a person's ability to self-manage his or her CP; Items that loaded on the second factor all seemed to reflect a person's self-awareness about his or her pain levels; and lastly, items that loaded on the third factor seemed to reflect the automatic nature of the person's response to CP and how it was an intrinsic part of their being (see Table 7). Also, these three domains that seem to reflect CP integration made theoretical sense when compared to definitions of integration as noted in Chapter 2. Once the domains of the CPIQ were identified, the construct itself was reduced to a more easily understood manner and thus, could be analysed in several ways as outlined in the proceeding sections.

Reliability Testing

The reliability of the CPIQ was tested in two ways: (a) test-retest reliability; and (b) internal consistency reliability. Thirty-five individuals completed the test-retest protocol and an intraclass correlation coefficient (ICC) of .88 was achieved which demonstrated a high degree of reliability with this current sample (see Table 8).

The internal consistency reliability of the CPIQ achieved acceptable Cronbach's alpha (α) values for a new measure (DeVellis, 2016; Polit & Beck, 2008; Streiner, 1993; 2011): CPIQ total scale $\alpha = 72$; CPIQ dimensions of self-management (SM) $\alpha = .80$; self-awareness (SA) $\alpha = .52$; and intrinsic adjustment (IA) $\alpha = .61$ (see Table 9). The internal consistency reliability for the additional questionnaires used in the study also achieved acceptable scores (see Table 9). Of note, it was not possible to calculate Cronbach's alpha for the SF-12v2 survey results as the scoring software that is required for use, as stipulated by the owners of the tool, does not provide the means to calculate this statistic.

Three Domains of CPIQ Defined by the Items: Self-Management, Self-Awareness, Intrinsic Adjustment (Includes loading score and Cronbach's Alpha [α] for each domain)

Domain 1	Domain 2	Domain 3
Self-Management (SM)	Self-Awareness (SA)	Intrinsic Adjustment
$(\alpha = .80)$	$(\alpha = .52)$	(IA; $\alpha = .61$)
3) I must take regular care of	2) My chronic pain will	1) I know what my body
myself (physically, mentally,	increase without any	will, or will not, allow me
and/or spiritually) to manage	warning from my body.	to do. (.58)
my chronic pain day-to-day.	(.46)	
(.63)		
5) Living with chronic pain	4) I follow the advice of	10) I don't dwell on having
teaches me to pay attention to	others, rather than my own	chronic pain – It is part of
my body and mind. (.68)	instincts, when deciding	me.
	what works best for me.	(.81)
	(.49)	
6) I do specific things that will	9) I wait until my chronic	12) Trying to control my
help me live with chronic	pain is at its worst before	chronic pain day-to-day is
pain. (.83)	trying to do something to	automatic for me. (.57)
	make it better. (.52)	
7) I make choices about the	13) Following a daily	
daily activities in my life.	routine makes my chronic	
(.65)	pain worse. (.63)	
8) I have learned new ways to	15) I feel I live an	
do activities. (.64)	unhealthy lifestyle because	
	of my chronic pain. (.72)	
11) I try to learn as much as		
possible about my chronic		
pain. (.53)		
14) Living with chronic pain		
has taught me a lot about		
myself. (.61)		
16) Living with chronic pain		
has taught me about what is		
important in life. (.48)		
17) I have supportive		
relationships in my life which		
help me to live with chronic		
pain. (.41)		

Note. CPIQ = chronic pain integration questionnaire.

Test-retest Reliability of the CPIQ and its domains

Score N Mean (SD) Mean Time 1: 35 4.6 (.6) 5.1 (.1) Time 2: 35 4.7 (.6) 5.0 (.1)	$\begin{array}{c} (3D) & \text{Mean} (3D) \\ \hline 8) & 3.5 (1.1) \\ \hline 9) & 3.6 (1.1) \end{array}$	5.0 (1.0) 5.1 (.7)
Score N Mean (SD) Mean Time 1: 35 4.6 (.6) 5.1 (.1) Time 2: 35 4.7 (.6) 5.0 (.1)	$\begin{array}{c} (SD) & \text{Mean} (SD) \\ (SD) & 3.5 (1.1) \\ (SD) & 3.6 (1.1) \end{array}$	5.0 (1.0) 5.1 (.7)
Score N Mean (SD) Mean Time 1: 35 4.6 (.6) 5.1 (.4)	$\frac{(5D)}{8} \qquad 3.5 (1.1)$	5.0 (1.0)
Score N Mean (SD) Mean	(SD) Mean (SD)	Wieall (SD)
$\mathbf{O}_{\mathbf{r}}$ $\mathbf{M}_{\mathbf{r}}$ $\mathbf{M}_{\mathbf{r}}$ $\mathbf{M}_{\mathbf{r}}$	(SD) Moon (SD)	Moon (SD)
Total Scale SM	SA	IA

Note. ICC = intraclass correlation coefficient; CPIQ = Chronic Pain Integration Questionnaire; SD = standard deviation; SM = self-management; SA = self-awareness; IA = intrinsic adjustment; CI = confidence interval

Table 9

Tool	Items	Mean (SD)	Cronbach's Alpha	
CPIQ	17	4.5 (.6)	.72	
*SM	9	5.0 (.8)	.80	
*SA	5	3.4 (.9)	.52	
*IA	3	4.9 (1.0)	.61	
AAQII	7	3.9 (1.7)	.93	
CPAQ	20	2.6 (.9)	.88	
*AE	11	3.1 (1.1)	.86	
*PW	9	2.1 (1.1)	.83	
Social Support	1	6.0 (2.9)	NA	

Internal Consistency Reliability: Sample size (n = 201)

Note. CPIQ = Chronic Pain Integration Questionnaire; AAQII = Acceptance and Action Questionnaire II; CPAQ = Chronic Pain Acceptance Questionnaire; SD = standard deviation; * Components of CPIQ based on exploratory factor analysis: SM = selfmanagement; SA = self-awareness; IA = intrinsic adjustment; Components of CPAQ: AE = activities engagement; PW = pain willingness; NA = not applicable

Scoring of the SF-12v2 is based on population weighting and thus, the raw scores for

each item on the tool is not a representation of the final score that is tabulated.

In summary, the CPIQ demonstrated evidence of reliability in the form of an overall ICC score of .88 and Cronbach's alpha of .72 within the current sample of participants. The proceeding section describes the results of the testing that was undertaken to build evidence for validity of the CPIQ.

Validity Testing

In order to examine the relationship between CP integration and other external constructs, four research hypotheses were developed based on proposed relationships between CP integration and acceptance, CP acceptance, health, and social support (see Chapter 2 and 3). The following section has been organized according to the relevant research hypotheses and the relationships that were evident following data analysis. This is followed by an identification of possible predictors of CP integration by the demographic and clinical variables measured in the study.

Research Hypothesis One: Acceptance, CP Acceptance, and the CPIQ

In order to examine the relationships between psychological acceptance, CP acceptance, and integration, correlations between the constructs, as measured by the relevant instruments, were analyzed (see Table 10). All of the correlations were as hypothesized:

 The total mean score of the CPAQ which measures CP acceptance was positively correlated with the total mean score of the CPIQ measuring CP integration (Pearson's r = .36; *p*-value ≤ .01). It appears that when CP acceptance scores are high, CP integration scores are also high.

Correlation (Pearson's r) Between CPIQ (SM, SA, IA) and the CPAQ (AE, PW), AAQII, Social Support, and SF-12v2 (PC, MC, GH)

Questionnaire	CPIQ:	SM	SA	IA	Total
Mean Score					
CPAQ: AE (mean score)		.28**	.35**	.25**	
PW (mean score)		07	.40**	.06	
Total Mean Score		.14*	.44**	.20**	.36**
AAQII (Total Mean Score)		17*	48**	.18**	39**
Social Support		.30**	.25**	.08	.35**
SF-12v2: PC (total score)		07	.19**	18**	01
MC (total score)		.24**	.44**	.27**	.45**
GH (total score)		.08	.36**	.01	.23**

Note. CPIQ = Chronic Pain Integration Questionnaire; SM = self-management; SA = self-awareness; IA = intrinsic adjustment; CPAQ = Chronic Pain Acceptance Questionnaire; AE = activities engagement; PW = pain willingness; AAQII = Acceptance & Action Questionnaire; SF-12v2 = Short-Form 12 Health Survey, Version 2; PC = physical component summary score; MC = mental component summary score; GH = general health score; * = correlation is significant at the 0.05 level (2-tailed); ** = correlation is significant at the 0.01 level (2-tailed)

2. The sub-scales or domains of the CPIQ (SM, SA, and IA) were also examined to identify if correlations exist with the sub-scales of the CPAC. (AE, and PW). Significant (*p*-value ≤ .01) positive correlations were evident between all three domains of the CPIQ and the AE domain of the CPAQ (Pearson's *r* = .28; .35; and .25 respectively). McCracken, Vowles, and Eccleston (2004) have defined the AE domain as "the pursuit of life activities in a normal manner even while pain is being experienced" (p. 164). Therefore, when scores were high in each domain of CP integration, scores were also high on the AE domain of the CP

acceptance. There was also a significant (*p*-value $\leq .01$) positive correlation between the SA domain of the CPIQ and the PW domain of the CPAQ (Pearson's r = .40). McCracken et al. (2004) have identified the PW domain as "the recognition on the part of the patient that avoiding or controlling pain are strategies that are often patently ineffective" (p. 164). Therefore, as SA scores on the CPIQ were high, scores on the PW domain of the CPAQ were also high. Interestingly however, there was no significant correlation between the SM or IA component of the CPIQ and the PW component of the CPAQ. Since the PW domain of the CPAQ relates specifically to avoidance and control, it may be inferred that there would not be a correlation with items on the CPIQ that are defined by self-management activities (SM) or an internal sense that CP is part of the individual (IA). Whereas items on the SA domain of the CPIO reflect aspects such as waiting until my chronic pain is at its worst before trying to do something to make it better' which might be interpreted as avoidance and thus more similar to the PW domain of the CPAQ.

3. The mean total score of the CPIQ was also significantly negatively correlated (p-value $\leq .01$) with the mean total score of the AAQ-II which is a measure of general acceptance (Pearson's r = -.39). Therefore, when scores where high on the CPIQ, scores were actually low on the AAQ-II. This makes intuitive sense because low scores on the AAQ-II actually reflect high levels of acceptance whereas high scores reflect low levels of acceptance and so one would expect the correlation between the two sets of scores to be negative. There was also a

significant negative correlation between the AAQ-II and each of the three domains of the CPIQ (SM = -.17; SA = -.48; IA = -.18).

Research Hypothesis Two: Health and the CPIQ

When examining the results of the correlations between health (as measured by the physical and mental summary scores and general health scores of the SF-12v2) and CP integration (as measured by the CPIQ scores), all correlations were significant (pvalue $\leq .01$) except for the correlations between (a) total mean score of the CPIQ and the PC summary score of the SF-12v2; (b) the SM domain of the CPIQ and the PC summary scores and GH score; and (c) the IA domain of the CPIQ and the GH score of the SF-12v2. The lack of significant correlation between the SM domain of the CPIQ and the PC and GH scores is interesting because the self-management domain of the CPIQ is defined by items that reflect 'doing activities', 'taking regular care of myself' which one would expect to incorporate physical aspects of health. However, the SM component also reflects items such as 'living with chronic pain has taught me a lot about myself', and 'living with chronic pain has taught me about what is important in life' which reflects a more mental health perspective. This is likely the reason why all three domains of the CPIO were significantly and positively correlated with the MC summary scores of the SF-12v2. It leads one to presume that the domains of the CPIQ reflect a more cognitive and emotional aspect of health in CP rather than the physical aspects.

Research Hypothesis Three: Social Support and the CPIQ

When examining the correlation between social support and the mean total score of the CPIQ, the correlation was significant and positive (Pearson's r = .35; *p*-value \le

.01). Therefore, when scores on the CPIQ were high, social support scores were also high. Interestingly, when the correlations between each of the three domains of the CPIQ were examined, only the SM and SA domains were significantly correlated with social support (Pearson's r = .30 and .25 respectively; both had a *p*-value $\le .01$). However, there was not a significant correlation between the IA domain of CPIQ and social support. This makes intuitive sense because the IA domain of the CPIQ is related to intrinsic aspects of CP adjustment rather than outside influences such as social support.

Research Hypothesis Four: Social Support as a Mediator

In order to examine social support beyond just correlation with CP integration, we sought to investigate if a person's perception of health 'caused' some difference in his or her perceived level of social support which, in turn, 'caused' some difference in his or her level of CP integration. In order to assess for this mediator effect, the four-step process outlined by Baron and Kenny (1986) was used (see Figure 2; and Table S1, S2, S3, S4) and the results of the mediation analysis have been detailed in the following section.

Step one and two. All the variables (dependent [CPIQ], independent [SF-12v2 components], and mediator [social support]) were significantly correlated except for the PC summary score of the SF-12v2: PC summary score was not significantly correlated with the CPIQ (p-value = .57; see Table S1; S2; & S3).

Step three. Social support predicted CP integration (CPIQ) after controlling for health (SF-12v2: PC, MC, GH components). The unstandardized coefficient (B) was .07 (*p*-value < .01; see Table S3).





Figure 2. Social Support Mediates the Relationship between Health and Chronic Pain Integration (measured by the Chronic Pain Integration Questionnaire [CPIQ]): The Unmediated and Mediated Models.

Step four. The relationship between health (SF-12v2: PC, MC, GH components) and CP integration (CPIQ) was reduced when social support (the mediator) was in the equation. The original relationship between CPIQ and SF-12v2 was PC (B = .003); MC (B = .021); and GH (B = .005). When social support was added to the equation, the relationship between the CPIQ and SF-12v2 decreased to PC (B = -.002); MC (B = .017); and GH (B = .003). This decrease in the unstandardized coefficient (i.e. B) provides evidence for social support as a mediator between health and CP integration. The significance of the mediation was also examined by conducting a Sobel's test which is testing the difference between the total and direct effects (Tabachnich & Fidell, 2007): *z*-scores are calculated and values >1.96 are considered significant at .05 level (Preacher & Hayes, 2004). The results of the Sobel's test for all three components of the SF-12v2

revealed *z*-scores above 1.96 (PC = 2.3; MC = 2.8; GH = 3.2; See Table S5) which were significant at the .05 level and further confirmed social support as a mediator between health and CP integration. Interestingly, the reduction in the SF-12v2 GH score from .005 (which rounds to .01) to .003 (which rounds to zero) implies a 'perfect mediation' as identified by Baron and Kenny (1986).

Predictors of CP Integration

In order to determine which demographic and clinical variables may be predictors of CP integration, a univariate analysis (i.e. analysis of variance [ANOVA]) was conducted for each variable measured in the study. The significance level for each variable was reviewed and variables with *p*-values \leq .20 were selected for entry into the multiple regression analysis. The significant variables included in the multiple regression were gender, education, income, type of CP diagnosis, and age (see Table 11; 12; 13).

The specific method used to build the regression model was the backward method technique: all significant predictor variables (*p*-value \leq .20) were entered into the regression and then re-evaluated; non-significant predictors were removed one at a time (the least significant variable removed first). The result was a model that included only the following significant predictors: income, gender, and age (see Table 14). People that earned between \$50,000 -\$74,999 in income, were more likely to predict scores on the CPIQ

Analysis of Variance (ANOVA) Between the SM Domain of CPIQ and Seven Demographic or Summary Variables with Greater than Two Groups & Independent-Samples T-test Analysis for Variables with two Groups.

ANOVA: SM	Group 1		Group 2		Group 3		Group 4					
Variable	Mean (SD)), n	Mean (SD), <i>n</i>	Mean (SD)), <i>n</i>	Mean (SD), n	df1, df2	F	р	*Group
YWCP	5.0 (.8)	106	4.9 (.9)	31	5.1 (.8)	48			2, 182	.23	.79	
Age	5.0 (.6)	64	4.8 (1.1)	46	5.2 (.7)	48	5.0 (.7)	42	3, 196	2.38	.07	
Education	4.8 (.9)	38	5.0 (.8)	58	5.1 (.8)	96			2, 189	1.61	.20	
Income	4.8 (.9)	64	5.1 (.8)	66	5.2 (.6)	34	5.0 (.8)	28	3, 188	1.54	.21	
CP Diagnoses	4.9 (.9)	38	5.2 (.7)	31	5.0 (.8)	131			2, 198	1.12	.33	
Body Part	4.9 (.6)	26	5.1 (.7)	40	5.0 (.8)	127			2, 191	.59	.55	
CP Program	4.9 (1.0)	42	5.1 (.7)	70	5.0 (.7)	87			2, 197	.55	.58	

Independent-Samples T-test: SM

	Group 1		Group 2				
Variable	Mean (SD)), n	Mean (SD)	, <i>n</i>	df	t	р
Race	5.2 (.6)	9	5.0 (.8)	191	198	81	.42
Gender	4.7 (.9)	51	5.1 (.7)	149	69.68	-2.83	.01

Note. SM = Self-management component of the CPIQ; CPIQ = Chronic pain integration questionnaire; YWCP = number of years living with chronic pain (CP); SD = standard deviation; n = sample size; df1 = degrees of freedom – numerator; df2 = degrees of freedom – denominator; F = F-value; p = significance value; *For variables with \leq .05 statistical significance, the Tukey Post Hoc Test was used to identify different groups.

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Table 12

Analysis of Variance (ANOVA) Between the SA Domain of CPIQ and Seven Demographic or Summary Variables with Greater than Two Groups & Independent-Samples T-test Analysis for Variables with two Groups.

ANOVA: SA	Group 1		Group 2		Group 3		Group 4					
Variable	Mean (SD)), n	Mean (SD)	, n	Mean (SD),	п	Mean (SD)	, <i>n</i>	df1, df2	F	р	*Group
YWCP	3.4 (1.0)	106	3.5 (.7)	31	3.5 (1.0)	48			2, 182	.08	.92	
Age	3.4 (.8)	64	3.4 (.9)	46	3.5 (1.0)	48	3.4 (1.0)	42	3, 196	.26	.86	
Education	3.4 (1.1)	38	3.3 (1.0)	58	3.5 (.9)	96			2, 189	.66	.52	
Income	3.3 (1.0)	64	3.4 (.8)	66	3.6 (.8)	<i>3</i> 4	3.8 (1.1)	28	3, 188	2.64	.05	1 & 4
CP Diagnoses	3.6 (.8)	38	3.8 (1.0)	31	3.3 (.9)	131			2, 198	4.59	.01	2 & 3
Body Part	3.4 (.8)	26	3.6 (1.0)	40	3.4 (1.0)	127			2, 191	1.30	.27	
CP Program	3.3 (.9)	42	3.5 (.9)	70	3.4 (1.0)	87			2, 197	1.03	.36	

Independent-Samples T-test: SA

	Group 1		Group 2				
Variable	Mean (SD), n	Mean (SD),	n	df	t	р
Race	.4 (7)	9	3.4 (1.0)	191	198	12	.92
Gender	3.4 (.9)	51	3.4 (.9)	149	198	11	.91

Note. SA = Self-awareness component of the CPIQ; CPIQ = chronic pain integration questionnaire; YWCP = number of years living with chronic pain (CP); SD = standard deviation; df1 = degrees of freedom – numerator; df2 = degrees of freedom – denominator; F = F-value; p = level of significance; *For variables with $\leq .05$ statistical significance, the Tukey Post Hoc Test was used to identify different groups.

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Table 13

Analysis of Variance (ANOVA) Between the SI Domain of CPIQ and Seven Demographic or Summary Variables with Greater than Two Groups & Independent-Samples T-test Analysis for Variables with two Groups.

ANOVA: IA	Group 1		Group 2		Group 3		Group 4					
Variable	Mean (SD),	n	Mean (SD),	п	Mean (SD),	п	Mean (SD),	п	df1, df2	F	р	*Group
YWCP	4.8 (1.0)	106	4.7 (1.2)	31	5.2 (.8)	48			2, 182	2.61	.08	
Age	4.7 (.9)	64	4.8 (1.2)	46	5.2 (.8)	48	5.0 (1.0)	42	3, 196	2.38	.05	1&3
Education	4.9 (.9)	38	4.9 (1.1)	58	4.9 (.9)	96			2, 189	1.61	.97	
Income	5.1 (.9)	64	4.7 (1.0)	66	4.9 (1.1)	34	4.8 (.9)	28	3, 188	1.54	.25	
CP Diagnoses	4.9 (1.0)	38	4.9 (.9)	31	4.9 (1.0)	131			2, 198	1.12	.99	
Body Part	4.8 (1.0)	26	4.8 (.9)	40	5.0 (1.0)	127			2, 191	.59	.43	
CP Program	4.9 (1.1)	42	4.9 (1.0)	70	4.9 (.9)	87			2, 197	.55	.92	

Independent-Samples T-test: IA

	Group 1		Group 2				
Variable	Mean (SD),	п	Mean (SD),	n	$d\!f$	t	p
Race	4.7 (.9)	9	4.9 (1.0)	191	198	64	.52
Gender	4.8 (.9)	51	4.9 (1.0)	149	198	22	.83

Note. IA = Intrinsic Adjustment component of the CPIQ; CPIQ = chronic pain integration questionnaire; YWCP = number of years living with chronic pain (CP); SD = standard deviation; df1 = degrees of freedom – numerator; df2 = degrees of freedom – denominator; F = F-value; p = level of significance; *For variables with $\leq .05$ statistical significance, the Tukey Post Hoc Test was used to identify different group.

Multivariable Analysis for Predictors of CPIQ (total mean score) using Multiple Regression (Backward Method): Only Demographic and Summary Variables with Significance Levels $\leq .20$ from Univariable Analysis were Included.

Variable		B (95% CI)	р	
Inco	me			
	< \$25,000	Reference		
	\$25,000-\$49,999	.11 (08, .30)	.26	
	\$50,000-\$74,999	.27 (03, .50)	.03	
	\$75,000 or more	.25 (01, .50)	.06	
Gend	ler			
	Male	Reference		
	Female	.29 (.10, .47)	<.01	
Age				
Ū	< 50 years	Reference		
	50 – 59 years	00 (22, .21)	.97	
	60 – 69 years	.27 (.05, .48)	.02	
	70 or older	.13 (11, .37)	.30	

Note. CPIQ = Chronic Pain Integration Questionnaire; B = unstandardized coefficients; CI = confidence interval; <math>p = significance value; CI = confidence interval.

when compared to people with an income less than \$25,000; women were more likely to predict scores on the CPIQ when compared to men; and people 60 - 69 years of age predicted scores on the CPIQ when compared to people younger than 50 years of age.

The results outlined within this chapter have provided a clear depiction of the reliability and validity of the CPIQ with this current sample of people living with chronic pain. Reliability scores were determined to be within the acceptable range for newly developed instruments: total mean score of CPIQ demonstrated an ICC of .88 (test-retest reliability); and Cronbach's alpha of .72 (internal consistency reliability). Evidence was

also presented for the validity of the CPIQ: all four research hypotheses determined *a priori* were validated. The next and final Chapter has been organized in order to summarize the implications of the results presented herein.

CHAPTER 5: DISCUSSION

The primary aim of this study was twofold: (1) to further refine and examine the psychometric characteristics of the Chronic Pain Integration Questionnaire (CPIQ) in a population of adults living with chronic pain; and (2) to test four hypotheses that were created based on current knowledge of integration and its possible relationship to other chronic pain constructs. From a sample of 201 adults living with chronic pain, the internal consistency reliability of the CPIQ was .72 (Cronbach's alpha) and the test-retest reliability for the total scale was .88 (intraclass correlation coefficient). Both of these reliability scores are acceptable for a newly developed questionnaire (DeVellis, 2016; Polit & Beck, 2008; Streiner, 1993; 2011).

Additionally, as is typically undertaken in questionnaire development and testing, it is necessary to build evidence for the validity of the measure. The results of the validity testing of the CPIQ revealed three domains of chronic pain integration which were easily linked to an existing theoretical definition of integration: self-management (SM), selfawareness (SA), and intrinsic adjustment (IA). The four hypotheses identified *a prior* were also confirmed through correlational analysis. These positive findings provided evidence for the validity of the CPIQ and provided additional support for integration as a relevant concept for the chronic pain population. These results also identify the CPIQ as a relevant and potentially necessary tool to use in the continued exploration of integration and integration promoting interventions that will promote quality of life in people living with chronic pain.

Validity

Through exploratory factor analysis of the CPIQ, three domains of CP integration emerged: (a) self-management, (b) self-awareness, and (c) intrinsic adjustment. These three domains were defined by the items that had the highest loadings on each domain respectively and made theoretical sense when compared to Whittemore's 2005 definition of integration: "a complex person-environment interaction whereby new life experiences (e.g. transitions, illness) are assimilated into the self and activities of daily living, resulting in overall life balance" (p. 263). The items that make up each of the selfmanagement, self-awareness, and intrinsic adjustment domains reflect the assimilation that has occurred (or has not occurred as in the self-awareness domain) for the person who has more fully integrated chronic pain into one's life. The majority of the items in the self-management and self-awareness domains are focused mainly on the assimilation of chronic pain management into the person's activities of daily living with some items reflecting the assimilation of chronic pain into the self. The items that make up the intrinsic adjustment domain are solely focused on assimilation of chronic pain into the self.

Whittemore (2005) also identified that there were self-management requirements, internal (cognitive and emotional) aspects, and external aspects to the integration construct. The self-management domain of the CPIQ had the largest number of item loadings: nine of the 17 CPIQ items loaded on this domain. The internal consistency reliability of this domain was also significant with a Cronbach alpha of .80. Item six had the largest loading (.83) and adequately reflects the naming of the self-management

domain: "I do specific things that will help me live with chronic pain". These findings provide support for Whittemore's identification of self-management as a requirement for integration not only in general but also within the chronic pain population and the assimilation of activities of daily living into the life of the chronic pain sufferer.

There are two items on the CPIQ that may be seen to reflect external aspects of integration as identified by Whittemore (2005): (a) item 17 "I have supportive relationships in my life which help me to live with chronic pain" which loaded on to the self-management domain, and (b) item four "I follow the advice of others, rather than my own instincts, when deciding what works best for me" which loaded on the selfawareness domain. It is interesting that these two seemingly external aspects did not load on the same domain because it could be presumed that along with the support that someone may provide comes also the advice that they may give to someone living with chronic pain. However, the words "help me to live with chronic pain" which is part of item 17 is still referring to the person's ability to self-manage pain and thus, is relevant to the self-management domain of the CPIO. Whereas item four is still referring to the person's own internal perceptions or awareness rather than what might appear to be an external influence and thus, is appropriate for the self-awareness domain. Moreover, the intrinsic adjustment domain contained only items that are internal aspects of CP integration (that which occurs solely within the individual). Item 10 had the highest loading (.81) on the intrinsic adjustment domain and nicely reflects the naming of this domain: "I don't dwell on having chronic pain – It is part of me".

Most importantly however is the linkage between the three domains of the CPIQ (self-management, self-awareness, and intrinsic adjustment) and the three-phase process of integration identified by Hernandez (1991) in her theory of integration: having diabetes, the turning point, and the science of one. The first phase of integration (*having diabetes*) is characterized by a lack of knowledge, disinterest, and varying degrees of commitment to managing diabetes (Hernandez, 1991). These characteristics are similar to the items that form the self-awareness domain of the CPIQ because these items reflect the person's lack of knowledge about chronic pain and how to manage it day-to-day (i.e. listening to the body and anticipating changes in pain levels, and having confidence in one's own ability to manage the pain). One may presume that these characteristics would be seen as occurring prior to the *turning point* phase of integration (Hernandez, 1991) and thus, fit nicely in the *having diabetes* phase (renamed *having chronic pain* for this study population).

At the *turning point* phase of integration, the person becomes more involved in understanding his or her condition and the necessary treatments and strategies to manage life with diabetes (Hernandez, 1991). These similar turning point characteristics are also reflected in the items that are part of the self-management domain of the CPIQ. Item six had the highest loaded item (.83) and reflects these turning point characteristics: "I do specific things that will help me live with chronic pain".

Lastly, the final phase in the theory of integration is the science of one (Hernandez, 1991). The two selves (the one before diabetes and the one now living with diabetes) have more fully integrated and the person's focus has shifted to living life rather than focusing only on diabetes (Hernandez, 1995). The characteristics of the science of one phase are nicely reflected in the items of the intrinsic adjustment domain of the CPIQ and item 10 loaded the highest (.81): "I don't dwell on having chronic pain – it is part of me". This identification of the three domains of the CPIQ and their close link to the three-phase process of the theory of integration (Hernandez, 1991) has provided the most significant evidence for the validity of the CPIQ within this sample population.

CP Integration, **CP** Acceptance, and Psychological Acceptance

The results have confirmed that there is a correlation between three potentially linked constructs and the instruments used to measure them: CP integration, CP acceptance, and psychological acceptance. CP integration (measured by the CPIQ) correlated significantly (*p*-value \leq .01) with both CP acceptance (measured by the CPAQ) and psychological acceptance (measured by the AAQII; .36 and -.39 respectively). What is important to note is that the Pearson's correlations were all below .50. Cohen (1988) identified a frame of reference when examining the size of the correlation since statistical significance itself only informs the researcher that the correlation is significantly different from zero (Meyers, Gamst, & Guarino, 2006). Cohen referred to a correlation of 0.1 as small, 0.3 as moderate, and 0.5 as large; bearing in mind the context for which the correlation was being examined. In this study, high correlations would not be desired since high correlations between two or more of the constructs would lead one to presume that the questionnaires were all measuring the same construct. In this regard, the moderate correlations of .36 and -.39 provide support that the questionnaires are each

measuring discrete constructs, yet significant correlations exist between them as expected theoretically.

These significant correlational findings have provided support for the proposed relationships between acceptance and integration reported by Whittemore (2005) when she identified *acceptance* as a facilitator of integration. If one is to presume that acceptance facilitates integration, then one should see CP integration scores increase as CP acceptance and/or psychological acceptance scores increase. Hornsten et al. (2011) discovered that the 'turning point' in integration was often the impetus for the person adopting improved self-management practice and to accept self-management as a necessary part of living with the disease. It has been proposed herein that the turning point may in fact be the same as or extremely similar to the CP acceptance, and CP integration lend support for this theoretically proposed idea. Interestingly, when examining each of the correlations separately between the three domains of CP integration, CP acceptance, and psychological acceptance, the majority of the significant yet moderate correlations were with the self-awareness domain of the CPIQ.

McCracken (1999) defined CP acceptance as a person's willingness to experience pain while continuing to engage in activities of living. When reflecting on this meaning of CP acceptance, it may be that CP acceptance is linked more closely to a person's own self-awareness of needing to engage in activities of living rather than the actual activities themselves. This is supported in part by Hornsten et al. (2011) in their statement noted previously that part of the turning point for the individual is to accept self-management as

a necessary part of living with the disease. These authors also found that it was the internal negotiations that the person had with him or herself to recognize the importance of self-management and reach the necessary insights that resulted in the occurrence of a turning point for that individual.

CP Integration and Health

Healing, recovery, achievement of optimal functioning, a sense of overall wellbeing, and satisfaction with one's quality of life were some of the outcomes of integration as outlined by Whittemore (2005). These integration outcomes formed the basis for examining the correlation between CP integration and physical, mental, and overall general health as measured by the SF-12v2. The SF-12v2 is a tool designed to measure people's functional health and well-being (Optum, 2016).

CP integration was significantly correlated with both mental health and general health, yet was not significantly correlated with physical health. Even though one might presume that the self-management aspects of integration would involve physical aspects of health, it appears in this case that it is more the internal (cognitive and emotional) aspects rather than the external aspects as identified by Whittemore (2005) that correlate with perceptions of health and well-being for the individual with CP. Furthermore, upon examining the three domains of CP integration separately, there were significant correlations between physical health and the self-awareness domain and the intrinsic adjustment domains of CP integration. As CP integration scores increased in the self-awareness domain, participants also had higher physical health scores. Conversely, as CP integration scores increased in the intrinsic adjustment domain, participants' physical

health scores decreased. These correlations, even though statistically significant, were not that high (.19 and -.18 respectively) and thus do not provide a clear perspective for the relationship between the person's reported physical health and CP integration. Perhaps one's perception about his or her physical health is linked more closely to self-awareness and other intrinsic aspects rather than the physical acts related to self-management. Moreover, it is curious that there was a negative correlation between participants' physical health scores and the intrinsic adjustment domain in CP integration; people that had lower physical health scores actually had higher intrinsic adjustment scores. It may be that people with lower physical health have had to adjust more fully to a different way of functioning with chronic pain when compared to those who have higher levels of physical health; contributing to higher intrinsic adjustment scores. Additionally, they may have engaged in other treatments (e.g. higher doses of pain medication), or have participated in an interdisciplinary pain management program.

These surprising correlations between physical health and integration may be due to the multidimensional nature of both health and CP and the uniqueness for which it is perceived by each individual; making it more difficult to examine in this context. Additional variables that have moderating or mediating effects on health and CP integration need to be examined further. For example, Sturgeon, Dixon, Darnall, and Mackey (2015) analyzed the mediator effects of physical functioning and social satisfaction on rates of pain intensity, anger, and depression in adults living with chronic pain. They found that social satisfaction explained the relationship between physical functioning and anger and depression; when social satisfaction was removed from the

equation, the relationship between physical functioning and anger and depression was not significant. Evers, Kraaimaat, Geenen, Jacobs, and Bijlsma (2003) also found that perceived social support and the size of the social network predicted long-term functional disability and pain in patients with rheumatoid arthritis. Through their longitudinal study of 76 patients with early rheumatoid arthritis, these authors discovered that low levels of perceived social support and small social networks at the time of diagnosis predicted functional disability after one, three, and five years. Therefore, it may be possible that participants in this current study who reported lower physical health, may have had more satisfaction with social aspects of their life, positive perceptions about their social support, and a large social support network; causing the low and negative correlation between the intrinsic adjustment domain of CP integration and physical health.

Additionally, Denton, Prus, and Walters (2004) discovered in their study that social and psychosocial determinants had a strong impact on women's health while behavioural determinants played a major role on men's health. Since the majority of participants in this current study were women, this could further explain the correlation results between the self-management domain of CP integration and the reported physical health perceptions of the participants.

Finally, the location of the pain on the body may have been a factor in the physical health perceptions of the participants in this study. In 2014, van Velzen et al. examined health-related quality of life in 975 patients with complex regional pain syndrome (a chronic pain condition). They discovered that physical health (measured by the physical component summary score on the SF-36) was reported to be lower in
participants who had pain symptoms in their lower extremities when compared to participants who had pain symptoms in their upper extremities. The majority of participants in this study identified having pain in three or more body parts (n = 128); further distinguishing characteristics related to only upper extremities or lower extremities were not collected. However, these authors also reported that it was the participants' attitudes and behaviours towards pain that additionally influenced their physical impairment experiences and this specific finding is supportive of those reported in the previous paragraphs.

It would be important to further examine this specific relationship between physical health, social satisfaction and support, and integration in future research studies to determine if the findings in this study were distinct to this sample population only, are a common characteristic of people living and adjusting to CP, or if gender and pain location have a specific effect on CP integration and health.

CP Integration and Social Support

Aspects of social support have been discussed in the previous section as possible reasons for the physical health perceptions identified by the participants in this study. However, the role of social support and its relationship to CP integration was of key interest herein and was confirmed through correlation and mediation analysis.

Whittemore and Dixon (2008) identified that ongoing resources and support were critical factors for facilitating individuals' ability to integrate chronic disease into their lives. The positive correlations between social support and CP integration identified in

this study have provided additional support for the findings of Whittemore and Dixon. Social support was positively correlated with CP integration: .35 (*p*-value \leq .01).

When examining separately the correlations between social support and each of the three domains of CP integration, social support was significantly correlated with selfmanagement and self-awareness domains (.30 and .25 respectively; p-value \leq .01). However, social support was not correlated with the intrinsic adjustment domain (.08, *p*value > .05). This makes theoretical sense because both the self-management and selfawareness domains include items that refer to external influences in some way: item 17 (I have supportive relationships in my life which help me to live with chronic pain) and item 4 (I follow the advice of others, rather than my own instincts, when deciding what works best for me). Whereas the intrinsic adjustment domain includes only those items that are internal to the individual (see Table 11 in Chapter Four).

In their earlier concept analysis work, Westra and Rogers (1991) also identified that an antecedent to integration was the availability of resources; supportive attitudes from others was included in their definition of these resources. Likewise, Audulv, Asplund, and Norbergh (2012) discovered that social support motivated self-management integration strategies in their participants and they found that individuals used "…inner negotiations to balance self-management and life goals" (p. 341). Furthermore, Holtzman, Newth, and Delongis (2004) in their study examining the effect of social support on individuals with rheumatoid arthritis, specifically discovered that it was the person's satisfaction with social support that demonstrated higher use of cognitive reframing, emotional expression and problem solving coping strategies; further

supporting the correlation between social support and the self-management and selfawareness domains of CP integration.

Because Whittemore and Dixon (2008) felt that ongoing resources and social support, as part of the integration model, facilitated the individuals' shift in focus from illness to wellness, a final hypothesis was developed: social support (measured by a visual analog scale) mediates the relationship between chronic pain integration (measured by CPIQ) and health (measured by the SF-12v2). The results of the mediation analysis revealed social support as a partial mediator between the physical and mental component of health and CP integration. Additionally, social support was a perfect mediator between general health and CP integration: the relationship between CP integration and the general health score reduced to zero. In other words, a high perceived presence of social support needed to exist in the lives of the participants in order for them to self-identify as having a positive perspective on their own health and enhanced integration of chronic pain (based on higher CP integration scores). Other authors have identified the positive association between social support and adaptive ways of coping in chronic disease (Costa & Gouveia, 2013; Holtzman, Newth, & Delongis, 2004; Schreurs & de Ridder, 1997) and the mediation result reported in this study provides additional evidence for the critical role of social support for people with chronic pain as they adjust to living with and integrating CP into their lives. Furthermore, these correlational and mediation findings between CP integration and social support provide additional evidence to the validity of the CPIQ.

Limitations

There are several limitations to the study that should be kept in mind when examining the results. One such limitation was the length of time that transpired for recruitment of a sufficient sample size to adequately test the psychometric properties of the CPIQ. Notably it took approximately 2.5 years to obtain the necessary sample size of 201 participants. Participants were also recruited by means of convenience sampling through chronic pain programs. It may be possible that people who are waiting for admission into a CP program, have been enrolled in a program, or who have been discharged from a CP program may be different from those who have never sought treatment from a chronic pain management program. The majority of the participants also came from one recruitment site; decreasing the heterogeneity of the sample and generalizability of the results.

Additionally, the majority of the participants were female and thus, the results may not be generalized to males with chronic pain. This higher participation rate from women when compared to men is not uncommon (Curtin, Presser, & Singer, 2000; Markanday, Brennan, Gould, & Pasco, 2013; Singer, Van Hoewyk, & Maher, 2000). Also, the majority of the participants were Caucasian. This race distinction, based largely on physical characteristics, excludes many other ethnic and cultural aspects reported to shape a person's perception, response, and adjustment to chronic pain (Campbell & Edwards, 2012; Gagnon, Matsuura, Smith, & Stanos, 2013; Pillay, van Zyl, & Blackbeard, 2014) and further decreases the generalizablity of the results.

Lastly, the visual analog scale (VAS) used to measure social support was developed by the author in order to reduce the number of questions the participants were subjected to in the study package. Use of the author developed VAS, instead of an existing social support instrument may have decreased the strength of evidence for validity in this regard and should be re-examined in future studies. It is important to note however that the social support VAS in this study correlated significantly (r = .61; p =<.01) with item 17 on the CPIQ which also asks about the person's perceptions of social support ("I have supportive relationships in my life which help me to live with chronic pain"). This finding provides evidence for validity of the social support VAS.

Implications for Theory and Research

As iterated in Chapter One, a CP integration measurement tool with adequate reliability and evidence of t validity would be significantly useful for (a) examining the relationship between coping and adjustment in CP, (b) further development and testing of the integration concept within CP coping models and/or middle range theories, and (c) future research into specific interventions that may enhance chronic pain integration; ultimately leading to positive outcomes that are sustainable over the long term. Therefore, the results reported herein have built evidence for the reliability and validity of the CPIQ as a tool to measure integration in adults living with chronic non-cancer pain. The specific testing of the CPIQ undertaken in this study has provided preliminary evidence of several important relationships that are thought to be present in existing models and theories of integration or adjustment and coping in chronic pain: acceptance, health, and social support. As identified by Turk (1990), if more individualized, meaningful, and effective treatment plans are needed, then a deeper understanding of how people adjust to or cope with chronic pain is necessary. Researchers have also criticized that there has been too much of a focus on coping which has left gaps in understanding key aspects of adjustment to CP and the effective therapeutic modalities that promote CP adjustment. The addition and use of the CPIQ may contribute to enhancing our understanding of coping, adaptation, and adjustment to chronic pain and help to bridge the gaps that exist. Future research using the CPIQ can also include examination of the active and adaptive coping responses and how they correlate with CP integration. How these coping responses correlate with the three domains of the CPIQ may shed light on their effect on adjustment.

The addition of the CPIQ may now allow for the examination of integration against current models or theories of chronic pain. A follow-up psychometric study of the CPIQ using confirmatory factor analysis (CFA) would be an important next step because it would provide additional support for the three domains discovered through exploratory factor analysis in this study. If future confirmatory factor analysis reveals the same or similar three domain structure of the CPIQ, relationships that affect CP integration can be explored in more detail. Various models of CP integration could be explored and compared more easily to existing models of chronic pain. Future studies can also be directed at testing relationships between integration and constructs present in current middle-range theories of CP. Westra and Rodgers (1991) proposed that integration was a significant concept for evaluating health status and thus was an important outcome focus for nursing practice. Likewise, Whittemore (2005) proposed

that integration was an important process from illness to health and would provide a useful framework for implementing and coordinating holistic nursing care. Therefore, the development of a middle-range theory for CP integration would further strengthen knowledge about adjustment in chronic pain but ultimately would be a useful framework to inform nursing practice in the area of CP management.

Furthermore, the predictors of CP integration identified through multiple regression analysis in this study (income, gender, and age) require further investigation to gain a more clear understanding of these variables and their relationship to CP integration. For example, participants who had an income of \$50,000-\$74,999 were more likely to have higher CP integration scores when compared to participants in the lowest income category (< \$25,000). One could presume that higher income earners (\$50,000-\$74,999) have higher levels of CP integration because they would be able to afford a variety of self-management strategies. However, participants with an income greater than \$70,000 did not show a significant difference in their CP integration when compared to the lowest income earners. It is also not clear as to why only 60-69 year olds demonstrated higher levels of CP integration when compared to participants younger than 50 years of age; yet participants who were 70 years or older showed no significant difference in their CP integration scores. This finding calls into question the variable of age as a significant factor in the process of CP integration. Also, the differences in gender that were previously reported when comparing CP integration to physical aspects and psychosocial aspects of health have provided a potential rationale for why females have higher levels of CP integration than men; with CP integration having higher

cognitive and emotional aspects rather than physical or external aspects. Repeated studies examining these variables in more detail would need to be conducted to make any substantial conclusions.

Lastly, research needs to focus on the strategies or interventions that will enhance CP integration in the CP sufferer with the focus on improved life quality. We know that cognitive behavioral therapy (CBT) is effective in CP but in the words of Williams et al. (2012), researchers need to shift their focus to examining which specific CBT therapies or interventions are most effective. Future research on CP integration should also focus on specific CBT therapies that might promote integration and thus, improved life quality.

Implications for Practice

In previous work, integration was found to be relevant for people living with chronic pain (Deshaies & Hernandez, 2011). Now, with the addition of a reliable and valid CP integration questionnaire, health care practitioners can use the tool to obtain additional information from their clients to gain an enhanced understanding of their clients' self-management, self-awareness, and internal perceptions of living with chronic pain. If the positive effects of integration contribute to positive patient outcomes, it would be paramount to facilitate integration in the chronic pain population especially if it leads to CP sufferers sustaining positive outcomes over the long term and, ultimately, improved quality of life. The CPIQ is also a short questionnaire, requiring only a short amount of time to complete, which increases its ease of use with clients.

The correlation between CP acceptance, social support, and health identified in this study, may assist health care professionals to focus on self-management approaches

that incorporate activities which enhance these elements. If the 'turning point' phase in the integration process is indeed the impetus for the person adopting improved selfmanagement practices and accepting self-management as a necessary part of living with the disease (Hornsten et al., 2011), health care professionals could examine the clients' answers on the CPIQ to possibly determine if the client has reached this 'turning point'. If a turning point has not been reached, then strategies could be implemented that would facilitate a turning point in the client's perspective on life with CP.

Due-Christensen, Borrild, and Larsen (2006) recommended that health care professions focus on perceptions of illness and the psychosocial aspects of living with diabetes in order to promote integration. The correlation findings from this study appear to confirm the importance of perceptions and psychosocial aspects over physical ones for people with CP as well.

Most importantly, the results from the study identify the significance of social support for facilitating integration in people with CP. It would be key for health care professionals to evaluate their patients' own perceptions of available social supports and resources.

In conclusion, the CPIQ has shown adequate psychometric properties and the results herein have provided evidence for its validity. CP integration has been identified as relevant for the CP population and has potential for increasing understanding of adjustment to CP and thus, positively affecting life quality in individuals with CP. Continued investigation of this construct through the use of the CPIQ is necessary.

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Appendix A



Inspiring Innovation and Discovery

Script for Recruiters A (Phase One)

Title of Research: Development and Testing of the Chronic Pain Integration Questionnaire Kathryn Deshaies, a graduate student in nursing at McMaster University, along with her research team, are examining how people with chronic pain adjust to living with pain day-to-day. They are looking for people with chronic pain to complete a questionnaire package which should take approximately 10 to 15 minutes of time. You would then be required to complete one of the same questionnaires in the package approximately 7 to 14 days later. This should only take 5 minutes of your time.

You are under no obligation to participate in this study. It will have no impact on your current or future treatment plan at Windsor Regional Hospital (WRH; Ouellette site – formerly <u>Hotel Dieu-Grace Hospital; Victorian Order of Nurses (VON); or Windsor-Essex Community Health Clinic (WECHC; correct agency to be inserted).</u>

The care providers at <u>WRH (Ouellette site)</u>; VON; or WECHC (correct agency to be inserted) will have no knowledge of the information you provide if you decide to participate in this research. Would you be interested in participating in this research study? If person identifies interest in participating:

- a) Recruiter to obtain consent from participant (using Recruiter Obtained Consent Statement Form) to release his or her contact information to the principal researcher, Kathryn Deshaies, so that he/she may be contacted to explain research and the process for completing the questionnaire packages at 2 separate time frames.
- b) Recruiter to also give the participant the study package which includes the full details of the study and recruiter is to encourage participant to read the information provided in the package.

If the potential participant is unsure, recruiter may give the study package to the participant to take home and read on own to decide if he/she would like to contact principal researcher to participate in study.

Appendix B



RECRUITER OBTAINED CONSENT STATEMENT (Phase One)

Participant:

I am interested in participating in the research study conducted by the principal investigator, Kathryn Deshaies, through McMaster University.

I give permission to ______(name of organization) to provide my name and contact information to Kathryn Deshaies in order to learn what is required of me as a participant and to ask any questions I may have about the study.

I have been provided with a package which outlines the details of the study. I am also aware that participation in this study is voluntary and I may withdraw from this study at any time.

Name (please prin	t)	Signature	Date
Phone number: _ <u>Recruiter:</u>	()		
Name (please prin	t)	Signature	Date

Name of Organization

*If you have any other questions and wish to contact the principal investigator, Kathryn Deshaies, please feel free to do so at 519-984-8825 or <u>kdeshaies@stclaircollege.ca</u>

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

Appendix C



Inspiring Innovation and Discovery

Title of Research: Development and Testing of the Chronic Pain Integration Questionnaire

PI Telephone Script: Contact with Potential Participant in Phase One

Once obtaining consent from <u>Windsor Regional Hospital (Ouellette site - formerly Hotel Dieu Grace</u> <u>Hospital) or Victorian Order of Nurses (VON)</u> recruiter, I will contact the potential participant by phone per the contact information he/she provided.

Hello ______, I am Kathryn Deshaies and I have received information from (person from VON or HDGH) that you may be interested in participating in my research study, is this correct?

If you would still like to participate, I would need you to fill out the questionnaire package that was given to you by ______, return it in the mail, and then complete it again in 7 to 14 days. Is this something that you feel you are interested in doing?

If he/she is still interested, I will thank the person for participating in this study and ask subsequent questions or provide further information:

Have you had the opportunity to read the information provided in the study package?

Please complete the 2 copies of the consent form located at the end of the Letter of Information – keep one for your records and mail the second one back with the questionnaire package in the enclosed stamped return envelope.

Do you have any additional questions or concerns about this study?

I will reinforce that this study is voluntary; they may withdraw at any time without consequence. I will also reinforce that his/her personal information will be kept confidential – information will be coded and separated from his/her name and contact information. The decision to participate or not participate would also be kept confidential and has no impact on past, current, or future care provided by <u>VON or</u> <u>HDGH.</u>

The two dates for completing the questionnaire package will be determined with the participant. Once the first questionnaire package has been completed and mailed, I will request that the participant contact me by phone so that the second package can be sent to participant for completion. The 5.00 Tim Horton's gift card will also be sent to the participant with the 2nd questionnaire package.

I will remind the participant that he/she will also be entered into a draw for one of three \$50.00 Chapters-Indigo gift cards.
Appendix D



Inspiring Innovation and Discovery

Script for Recruiters B (Phase Two)

Title of Research: Development and Testing of the Chronic Pain Integration Questionnaire Kathryn Deshaies, a graduate student in nursing at McMaster University, along with her research team, are examining how people with chronic pain adjust to living with pain day-to-day. They are looking for people with chronic pain to complete a questionnaire package which should take approximately 10 to 15 minutes of time. This questionnaire package may be taken home and answered at your convenience. You would then return the completed questionnaire package in the stamped return envelope that has been provided.

If you decide to participate, you will have the opportunity to be entered into a draw for one of three \$50.00 Chapters-Indigo gift cards. (odds of winning are dependent upon the number of people who choose to participate).

You are under no obligation to participate in this study. It will have no impact on your current or future treatment plan at Windsor Regional Hospital (WRH; Ouellette site – formerly <u>Hotel Dieu-Grace Hospital; Victorian Order of Nurses (VON); or Windsor-Essex Community Health Clinic (WECHC; correct agency to be inserted).</u>

The care providers at <u>HDGH; VON; or WECHC (correct agency to be inserted)</u> will have no knowledge of the information you provide if you decide to participate in this research. Would you be interested in participating in this research study? If person identifies interest in participating:

Recruiter to give the participant the study package which includes the full details of the study and recruiter is to encourage participant to read the information provided in the package and to contact the principal investigator, Kathryn Deshaies, if he/she has further questions. Contact information is provided in the study package.

Appendix E



Inspiring Innovation and Discovery

Cover Letter

(Date)

Dear Sir or Madam,

My name is Kathryn Deshaies and I am a PhD student in nursing at McMaster University in Hamilton Ontario. As part of the research project for my PhD, my panel and I are looking at how people with chronic pain adjust to living with pain day-to-day. For this reason, we are looking for people with chronic pain to complete a survey package which should take about 10 to 15 minutes of time.

The Victorian Order of Nurses (VON) has kindly agreed to provide the details about this research to past or current patients who are living with chronic pain and who might like to take part in the study. I have had no access to your name or address. I would only have access to your name and address if you decide to take part in the study. Also, if you decide to take part, VON would not be given any details about you or your part in the study and it would have no impact on the care you will or have had.

Full details of the study have been attached and if you have any questions you may contact me at the number below. This study has been approved by McMaster University and VON's research ethics boards. Taking part in the study is strictly your choice and you may refuse to take part at any time.

Thank you for taking the time to think about helping me with this research.

Kathryn Deshaies R.N., MScN PhD (student), McMaster University - School of Nursing 1280 Main Street West Hamilton, ON, L8S 4L8 519-984-8825 kdeshaies@stclaircollege.ca

Appendix F



Inspiring Innovation and Discovery

PARTICIPANT INFORMATION SHEET (Phase One)

Title of Study: Development and Testing of the Chronic Pain Integration Questionnaire **Locally Responsible Investigator:** Dr. Noori Akhtar-Danesh, McMaster University, School of Nursing

Primary Investigator (researcher): Kathryn Deshaies, Registered Nurse, PhD student, McMaster University, School of Nursing

You are being invited to take part in a research study conducted by Kathryn Deshaies because you have been living with chronic pain. This is a PhD student research project supervised by Dr. Noori Akhtar-Danesh. The study will help us learn more about how people cope with chronic pain each day and whether or not we can measure this coping.

In order to decide whether or not you want to be a part of this research study, you should know what will be asked of you and the possible risks and benefits. This form gives detailed information about the research study, if you have more questions please feel free to contact

Kathryn Deshaies at the contact number or email listed at the end of this form. Once you know the details of the study, please sign this form if you wish to take part in the study. Please take your time to make your choice to take part in the study or not. Feel free to discuss it with your friends and family, or your health care worker (e.g. doctor or nurse).

WHY IS THIS RESEARCH BEING DONE?

We would like to know how people living with chronic pain cope with the pain each day. We feel that knowing this process will help us, as health care workers, to provide better care to our clients who have chronic pain.

WHAT IS THE PURPOSE OF THIS STUDY?

We are testing a new questionnaire that measures how people with chronic pain cope with pain each day. If the questionnaire is useful, we hope that health care workers could use it to better know how chronic pain affects their clients each day.

In order to know if this questionnaire is useful, it needs to be filled out by people living with chronic pain and be compared to other questionnaires also found to be useful.

WHAT WILL I HAVE TO DO IF I TAKE PART IN THE STUDY?

If you volunteer to take part in this study, we will ask you to do the following things:

a) Read this Participant Information Sheet and discuss any questions you may have with Kathryn Deshaies when she calls you on the telephone.

- b) After the telephone call with Kathryn Deshaies, please sign the 2 consent forms provided at the end of this information letter. Place one signed consent form in the return envelope along with your completed questionnaire package. Keep the 2nd signed consent form for your records.
- c) Complete all of the forms provided in the package that has been given to you (this should take you about 10 to 15 minutes)
- d) Please complete all the forms on the same day and call Kathryn Deshaies once you have completed the questions to let her know it is done (519-984-8825). A second questionnaire package will then be mailed out to you.
- e) Place the completed questionnaire package in the mail using the stamped return envelope.
- f) When the 2nd questionnaire package arrives complete it 7-14 days after filling in the first set of forms. This package is shorter and should only take about 5 minutes. Please write the date on each form where noted.
- g) Quickly return the completed forms in the stamped return envelope provided in the new package and mail to Kathryn Deshaies.
- h) Inside your second questionnaire package there will be a \$5.00 Tim Horton's gift card to thank you for taking part in the study.
- Also, you will be entered into a draw for one of three \$50.00 Chapters-Indigo Gift Cards (odds of winning depend on the final number of people who take part in the study and you will only be called if you are a winner).

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

- Participants who fill out the questionnaire package may start to have different thoughts or feelings about their chronic pain which may cause some discomfort. No other direct risks or discomfort from taking part in this research study is known.
- If you choose to take part in this study, you will be told about any new information which might affect your consent to continue to take part in this research.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

We hope to recruit at least 50 people for the first phase of the study.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

We cannot promise any personal benefits to you if you take part in this study. However, possible benefits include you having an increased understanding of your own coping with chronic pain. Your participation may help other people with chronic pain in the future as we hope this study will help health care workers better understand their clients and their clients' experiences with living with chronic pain.

There are no specific medical benefits to you if you take part in this study.

IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not wish to fill out the questionnaire package a second time (7 -14 days apart), you do not need to do so. You may throw away the 2nd questionnaire package. There are no other choices available at this time.

*Choosing not to take part in this study will in no way affect your care or treatment.

WHAT INFORMATION WILL BE KEPT PRIVATE?

Your private data (name and address) will not be shared with anyone except with your consent or as required by law. All private data such as your name and address will be removed from the study package and will be replaced with a number. A list linking the number with your name and address will be kept in a locked closet, removed from your answers in the study package until the draw has been completed and the winners have been called. After this time your name and address will be destroyed by shredding. The study package, with your private data removed will be securely stored in a locked closet at St. Clair College, 2000 Talbot Road West, Windsor, Ontario.

If the results of the study are published, your name will not be used and no information that could be linked to you will be released or published.

The information kept from the study package, with your private data removed will be viewed by members of the research team and will be destroyed after 10 years.

CAN PARTICIPATION IN THE STUDY END EARLY?

If you decide to take part in this study, you may withdraw at any time and this will in no way affect the quality of care you receive at any institution. You have the option of removing your information from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study. Kathryn Deshaies may remove you from this research in some situations if it has been decided that doing so is needed.

WILL I BE PAID TO TAKE PART IN THIS STUDY?

You will not be paid for taking part in this study, however if you take part in the study you will be given a \$5.00 Tim Horton's gift card as well as be entered into a draw for a chance to win one of three \$50.00 Chapters-Indigo gift cards.

WILL THERE BE ANY COSTS?

If you take part in this research project, you will not have any extra costs charged to you or your health care insurer.

IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have any questions about the research now or later, please contact Kathryn Deshaies at 519-984-8825 or by email at <u>kdeshaies@stclaircollege.ca</u>; or Dr. Noori Akhtar-Danesh at 905.525.9140 x 22297, daneshn@mcmaster.ca.

RESEARCH RESULTS:

If you would like a summary of the research results when the study has ended, please contact Kathryn Deshaies by email (<u>kdeshaies@stclaircollege.ca</u>) or by phone at 519-984-8825.

CONSENT STATEMENT

Participant:

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name (please print)	Signature	Date
Your address is required for mailing package. Mailing address City: Postal Code:	your \$5.00 Tim Horton's gift carc	and the 2 nd questionnaire

*Participation in this study is voluntary. You may withdraw from this study at any time. If you decide to withdraw from the study, please contact the principal investigator, Kathryn Deshaies, at 519-984-8825 or kdeshaies@stclaircollege.ca.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

*Please sign and date this consent and PLACE IN RETURN ENVELOPE provided

CONSENT STATEMENT

Participant:

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name (please print)	Signature	Date
Your address is required for mailing your \$5.0 package. Mailing address City: Postal Code:	00 Tim Horton's gift 	card and the 2 nd questionnaire

*Participation in this study is voluntary. You may withdraw from this study at any time. If you decide to withdraw from the study, please contact the principal investigator, Kathryn Deshaies, at 519-984-8825 or kdeshaies@stclaircollege.ca.

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*Please sign and date and KEEP THIS COPY of the consent for your records

Appendix G



Inspiring Innovation and Discovery

PARTICIPANT INFORMATION SHEET (WRH Phase One)

Title of Study: Development and Testing of the Chronic Pain Integration Questionnaire **Locally Responsible Investigator:** Dr. Noori Akhtar-Danesh, McMaster University, School of Nursing

Primary Investigator (researcher): Kathryn Deshaies, Registered Nurse, PhD student, McMaster University, School of Nursing

You are being invited to take part in a research study conducted by Kathryn Deshaies because you have been living with chronic pain. This is a PhD student research project supervised by Dr. Noori Akhtar-Danesh. The study will help us learn more about how people cope with chronic pain each day and whether or not we can measure this coping.

In order to decide whether or not you want to be a part of this research study, you should know what will be asked of you and the possible risks and benefits. This form gives detailed information about the research study, if you have more questions please feel free to contact Kathryn Deshaies at the contact number or email listed at the end of this form. Once you know the details of the study, please sign this form if you wish to take part in the study. Please take your time to make your choice to take part in the study or not. Feel free to discuss it with your friends and family, or your health care worker (e.g. doctor or nurse).

WHY IS THIS RESEARCH BEING DONE?

We would like to know how people living with chronic pain cope with the pain each day. We feel that knowing this process will help us, as health care workers, to provide better care to our clients who have chronic pain.

WHAT IS THE PURPOSE OF THIS STUDY?

We are testing a new questionnaire that measures how people with chronic pain cope with pain each day. If the questionnaire is useful, we hope that health care workers could use it to better know how chronic pain affects their clients each day.

In order to know if this questionnaire is useful, it needs to be filled out by people living with chronic pain and be compared to other questionnaires also found to be useful.

WHAT WILL I HAVE TO DO IF I TAKE PART IN THE STUDY?

If you volunteer to take part in this study, we will ask you to do the following things:

j) Read this Participant Information Sheet and discuss any questions you may have with Kathryn Deshaies when she calls you on the telephone.

- k) After the telephone call with Kathryn Deshaies, please sign the 2 consent forms provided at the end of this information letter. Place one signed consent form in the return envelope along with your completed questionnaire package. Keep the 2nd signed consent form for your records.
- I) Complete all of the forms provided in the package that has been given to you (this should take you about 10 to 15 minutes)
- m) Please complete all the forms on the same day and call Kathryn Deshaies once you have completed the questions to let her know it is done (519-984-8825). A second questionnaire package will then be mailed out to you.
- n) Place the completed questionnaire package in the mail using the stamped return envelope.
- O) When the 2nd questionnaire package arrives complete it 7-14 days after filling in the first set of forms. This package is shorter and should only take about 5 minutes. Please write the date on each form where noted.
- p) Quickly return the completed forms in the stamped return envelope provided in the new package and mail to Kathryn Deshaies.
- q) Inside your second questionnaire package there will be a \$5.00 Tim Horton's gift card to thank you for taking part in the study.
- r) Also, you will be entered into a draw for one of three \$50.00 Chapters-Indigo Gift Cards (odds of winning depend on the final number of people who take part in the study and you will only be called if you are a winner).

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

- Participants who fill out the questionnaire package may start to have different thoughts or feelings about their chronic pain which may cause some discomfort. No other direct risks or discomfort from taking part in this research study is known.
- If you choose to take part in this study, you will be told about any new information which might affect your consent to continue to take part in this research.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

We hope to recruit at least 50 people for the first phase of the study.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

We cannot promise any personal benefits to you if you take part in this study. However, possible benefits include you having an increased understanding of your own coping with chronic pain. Your participation may help other people with chronic pain in the future as we hope this study will help health care workers better understand their clients and their clients' experiences with living with chronic pain.

There are no specific medical benefits to you if you take part in this study.

IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not wish to fill out the questionnaire package a second time (7 -14 days apart), you do not need to do so. You may throw away the 2nd questionnaire package. There are no other choices available at this time.

*Choosing not to take part in this study will in no way affect your care or treatment.

WHAT INFORMATION WILL BE KEPT PRIVATE?

Your private data (name and address) will not be shared with anyone except with your consent or as required by law. All private data such as your name and address will be removed from the study package and will be replaced with a number. A list linking the number with your name and address will be kept in a locked closet, removed from your answers in the study package until the draw has been completed and the winners have been called. After this time your name and address will be destroyed by shredding. The study package, with your private data removed will be securely stored in a locked closet at St. Clair College, 2000 Talbot Road West, Windsor, Ontario.

If the results of the study are published, your name will not be used and no information that could be linked to you will be released or published.

The information kept from the study package, with your private data removed will be viewed by members of the research team and will be destroyed after 10 years.

CAN PARTICIPATION IN THE STUDY END EARLY?

If you decide to take part in this study, you may withdraw at any time and this will in no way affect the quality of care you receive at any institution. You have the option of removing your information from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study. Kathryn Deshaies may remove you from this research in some situations if it has been decided that doing so is needed.

WILL I BE PAID TO TAKE PART IN THIS STUDY?

You will not be paid for taking part in this study, however if you take part in the study you will be given a \$5.00 Tim Horton's gift card as well as be entered into a draw for a chance to win one of three \$50.00 Chapters-Indigo gift cards.

WILL THERE BE ANY COSTS?

If you take part in this research project, you will not have any extra costs charged to you or your health care insurer.

IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have any questions about the research now or later, please contact Kathryn Deshaies at 519-984-8825 or by email at <u>kdeshaies@stclaircollege.ca</u>; or Dr. Noori Akhtar-Danesh at 905.525.9140 x 22297, daneshn@mcmaster.ca.

RESEARCH RESULTS:

If you would like a summary of the research results when the study has ended, please contact Kathryn Deshaies by email (<u>kdeshaies@stclaircollege.ca</u>) or by phone at 519-984-8825.

CONSENT STATEMENT

Participant:

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name	(please	print)
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Signature

Date

Your address is required for mailing your \$5.00 Tim Horton's gift card and the 2nd questionnaire package.

Mailing address

City:

Postal Code:

*Participation in this study is voluntary. You may withdraw from this study at any time. If you decide to withdraw from the study, please contact the principal investigator, Kathryn Deshaies, at 519-984-8825 or kdeshaies@stclaircollege.ca.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

*Please sign and date this consent and PLACE IN RETURN ENVELOPE provided

CONSENT STATEMENT

Participant:

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name (please print)	Signature	Date
Your address is required questionnaire package.	for mailing your \$5.00 Tim Horton's gift	card and the 2 nd
City:		
Postal Code:		

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This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

*Please sign and date and <u>KEEP THIS COPY</u> of the consent for your records



Appendix H

Inspiring Innovation and Discovery

PARTICIPANT INFORMATION SHEET (WRH Phase Two)

Title of Study: Development and Testing of the Chronic Pain Integration Questionnaire **Locally Responsible Investigator:** Dr. Noori Akhtar-Danesh, McMaster University, School of Nursing

Primary Investigator (researcher): Kathryn Deshaies, Registered Nurse, PhD student, McMaster University, School of Nursing

You are being invited to take part in a research study conducted by Kathryn Deshaies because you have been living with chronic pain. This is a PhD student research project supervised by Dr. Noori Akhtar-Danesh. The study will help us learn more about how people cope with chronic pain each day and whether or not we can measure this coping.

In order to decide whether or not you want to be a part of this research study, you should know what will be asked of you and the possible risks and benefits. This form gives detailed information about the research study, if you have more questions please feel free to contact Kathryn Deshaies at the contact number or email listed at the end of this form. Once you know the details of the study, please sign this form if you wish to take part in the study. Please take your time to make your choice to take part in the study or not. Feel free to discuss it with your friends and family, or your health care worker (e.g. doctor or nurse).

WHY IS THIS RESEARCH BEING DONE?

We would like to know how people living with chronic pain cope with the pain each day. We feel that knowing this process will help us, as health care workers, to provide better care to our clients who have chronic pain.

WHAT IS THE PURPOSE OF THIS STUDY?

We are testing a new questionnaire that measures how people with chronic pain cope with pain each day. If the questionnaire is useful, we hope that health care workers could use it to better know how chronic pain affects their clients each day.

In order to know if this questionnaire is useful, it needs to be filled out by people living with chronic pain and be compared to other questionnaires also found to be useful.

WHAT WILL I HAVE TO DO IF I TAKE PART IN THE STUDY?

If you volunteer to take part in this study, we will ask you to do the following things:

S) Sign the 2 consent forms provided at the end of this information letter. Place one signed consent form in the return envelope along with your completed questionnaire package. Keep the 2nd signed consent form for your records.

- t) Complete all of the forms provided in the package that has been given to you (this should take you about 10 to 15 minutes)
- u) Complete all the forms in the package on the same day and provide the date on each form where noted.
- v) Once the questionnaire package has been completed, place the completed forms in the stamped return envelope provided and mail back to the research team (along with one of the signed consent forms).
- W) Once your questionnaire package has been received, you will be entered into a draw for a chance to win one of three \$50.00 Chapters-Indigo gift cards. You will be called only if you are a winner of one of the draws (odds of winning depend on the number of people who decide to take part in the study).

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

- Participants who fill out the questionnaire package may start to have different thoughts or feelings about their chronic pain which may cause some discomfort. No other direct risks or discomfort from taking part in this research study is known.
- If you choose to take part in this study, you will be told about any new information which might affect your consent to continue to take part in this research.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

We hope to recruit at least 200 people for this phase of the study.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

We cannot promise any personal benefits to you if you take part in this study. However, possible benefits include you having an increased understanding of your own coping with chronic pain. Your participation may help other people with chronic pain in the future as we hope this study will help health care workers better understand their clients and their clients' experiences with living with chronic pain.

There are no specific medical benefits to you if you take part in this study.

IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to fill out the questionnaire package, there are no other options available at this time. You may simply throw away the package.

*Choosing not to take part in this study will in no way affect your care or treatment. **WHAT INFORMATION WILL BE KEPT PRIVATE?**

Your private data (name and address) will not be shared with anyone except with your consent or as required by law. All private data such as your name and address will be removed from the study package and will be replaced with a number. A list linking the number with your name and address will be kept in a locked closet, removed from your answers in the study package until the draw has been completed and the winners have been called. After this time your name and

be securely stored in a locked closet at St. Clair College, 2000 Talbot Road West, Windsor, Ontario.

If the results of the study are published, your name will not be used and no information that could be linked to you will be released or published.

The information kept from the study package, with your private data removed will be viewed by members of the research team and will be destroyed after 10 years.

CAN PARTICIPATION IN THE STUDY END EARLY?

If you decide to take part in this study, you may withdraw at any time and this will in no way affect the quality of care you receive at any institution. You have the option of removing your information from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study. Kathryn Deshaies may remove you from this research in some situations if it has been decided that doing so is needed.

WILL I BE PAID TO TAKE PART IN THIS STUDY?

You will not be paid for taking part in this study, however if you take part in the study you will be entered into a draw for a chance to win one of three Chapters-Indigo gift cards (\$50.00 value each).

WILL THERE BE ANY COSTS?

If you take part in this research project, you will not have any extra costs charged to you or your health care insurer.

IF I HAVE ANY QUESTIONS OR PROBLEMS. WHOM CAN I CALL?

If you have any questions about the research now or later, please contact Kathryn Deshaies at 519-984-8825 or by email at kdeshaies@stclaircollege.ca; or Dr. Noori Akhtar-Danesh at 905.525.9140 x 22297. daneshn@mcmaster.ca.

RESEARCH RESULTS:

If you would like a summary of the research results when the study has ended, please contact Kathryn Deshaies by email (kdeshaies@stclaircollege.ca) or by phone at 519-984-8825.

CONSENT STATEMENT

Participant:

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name (please print)			ç	Signature				Da	Date							
.,																

Your mailing address is required so that you may be contacted if you are a winner of one of the three \$50.00 Chapters-Indigo gift cards (odds of winning are dependent on the number of participants recruited).

Mailing address	
City:	
Postal Code:	

*Participation in this study is voluntary. You may withdraw from this study at any time. If you decide to withdraw from the study, please contact the principal investigator, Kathryn Deshaies, at 519-984-8825 or kdeshaies@stclaircollege.ca.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

*Please sign and date this consent and PLACE IN RETURN ENVELOPE provided

CONSENT STATEMENT

Participant:

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Name (nlease print)	Signature	Date
Name (please plint)	Signature	Date
Your mailing address is required so that you three \$50.00 Chapters-Indigo gift cards (odd participants recruited). Mailing address	may be contacted if yes of winning are deper	วน are a winner of one of the าdent on the number of

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*Please sign and date and KEEP THIS COPY of the consent for your records

Appendix I



Inspiring Innovation and Discovery

PARTICIPANT INFORMATION SHEET (WECHC Phase One)

Title of Study: Development and Testing of the Chronic Pain Integration Questionnaire **Locally Responsible Investigator:** Dr. Noori Akhtar-Danesh, McMaster University, School of Nursing

Primary Investigator (researcher): Kathryn Deshaies, Registered Nurse, PhD student, McMaster University, School of Nursing

You are being invited to take part in a research study conducted by Kathryn Deshaies because you have been living with chronic pain. This is a PhD student research project supervised by Dr. Noori Akhtar-Danesh. The study will help us learn more about how people cope with chronic pain each day and whether or not we can measure this coping.

In order to decide whether or not you want to be a part of this research study, you should know what will be asked of you and the possible risks and benefits. This form gives detailed information about the research study, if you have more questions please feel free to contact

Kathryn Deshaies at the contact number or email listed at the end of this form. Once you know the details of the study, please sign this form if you wish to take part in the study. Please take your time to make your choice to take part in the study or not. Feel free to discuss it with your friends and family, or your health care worker (e.g. doctor or nurse).

WHY IS THIS RESEARCH BEING DONE?

We would like to know how people living with chronic pain cope with the pain each day. We feel that knowing this process will help us, as health care workers, to provide better care to our clients who have chronic pain.

WHAT IS THE PURPOSE OF THIS STUDY?

We are testing a new questionnaire that measures how people with chronic pain cope with pain each day. If the questionnaire is useful, we hope that health care workers could use it to better know how chronic pain affects their clients each day.

In order to know if this questionnaire is useful, it needs to be filled out by people living with chronic pain and be compared to other questionnaires also found to be useful.

WHAT WILL I HAVE TO DO IF I TAKE PART IN THE STUDY?

If you volunteer to take part in this study, we will ask you to do the following things:

x) Read this Participant Information Sheet and discuss any questions you may have with Kathryn Deshaies when she calls you on the telephone.

- y) After the telephone call with Kathryn Deshaies, please sign the 2 consent forms provided at the end of this information letter. Place one signed consent form in the return envelope along with your completed questionnaire package. Keep the 2nd signed consent form for your records.
- Complete all of the forms provided in the package that has been given to you (this should take you about 10 to 15 minutes)
- aa) Please complete all the forms on the same day and call Kathryn Deshaies once you have completed the questions to let her know it is done (519-984-8825). A second questionnaire package will then be mailed out to you.
- bb) Place the completed questionnaire package in the mail using the stamped return envelope.
- cc) When the 2nd questionnaire package arrives complete it 7-14 days after filling in the first set of forms. This package is shorter and should only take about 5 minutes. Please write the date on each form where noted.
- dd) Quickly return the completed forms in the stamped return envelope provided in the new package and mail to Kathryn Deshaies.
- ee) Inside your second questionnaire package there will be a \$5.00 Tim Horton's gift card to thank you for taking part in the study.
- ff) Also, you will be entered into a draw for one of three \$50.00 Chapters-Indigo Gift Cards (odds of winning depend on the final number of people who take part in the study and you will only be called if you are a winner).

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

- Participants who fill out the questionnaire package may start to have different thoughts or feelings about their chronic pain which may cause some discomfort. No other direct risks or discomfort from taking part in this research study is known.
- If you choose to take part in this study, you will be told about any new information which might affect your consent to continue to take part in this research.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

We hope to recruit at least 50 people for the first phase of the study.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

We cannot promise any personal benefits to you if you take part in this study. However, possible benefits include you having an increased understanding of your own coping with chronic pain. Your participation may help other people with chronic pain in the future as we hope this study will help health care workers better understand their clients and their clients' experiences with living with chronic pain.

There are no specific medical benefits to you if you take part in this study.

IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not wish to fill out the questionnaire package a second time (7 -14 days apart), you do not need to do so. You may throw away the 2nd questionnaire package. There are no other choices available at this time.

*Choosing not to take part in this study will in no way affect your care or treatment.

WHAT INFORMATION WILL BE KEPT PRIVATE?

Your private data (name and address) will not be shared with anyone except with your consent or as required by law. All private data such as your name and address will be removed from the study package and will be replaced with a number. A list linking the number with your name and address will be kept in a locked closet, removed from your answers in the study package until the draw has been completed and the winners have been called. After this time your name and address will be destroyed by shredding. The study package, with your private data removed will be securely stored in a locked closet at St. Clair College, 2000 Talbot Road West, Windsor, Ontario.

If the results of the study are published, your name will not be used and no information that could be linked to you will be released or published.

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CAN PARTICIPATION IN THE STUDY END EARLY?

If you decide to take part in this study, you may withdraw at any time and this will in no way affect the quality of care you receive at any institution. You have the option of removing your information from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study. Kathryn Deshaies may remove you from this research in some situations if it has been decided that doing so is needed.

WILL I BE PAID TO TAKE PART IN THIS STUDY?

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WILL THERE BE ANY COSTS?

If you take part in this research project, you will not have any extra costs charged to you or your health care insurer.

IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have any questions about the research now or later, please contact Kathryn Deshaies at 519-984-8825 or by email at <u>kdeshaies@stclaircollege.ca</u>; or Dr. Noori Akhtar-Danesh at 905.525.9140 x 22297, daneshn@mcmaster.ca.

RESEARCH RESULTS:

If you would like a summary of the research results when the study has ended, please contact Kathryn Deshaies by email (<u>kdeshaies@stclaircollege.ca</u>) or by phone at 519-984-8825.

CONSENT STATEMENT

Participant:

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name (please print)	Signature	Date
Your address is required for mailing your \$5.00 package.	Tim Horton's gift card and the 2	nd questionnaire

Mailing address	
City:	
Postal Code:	

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Name (please print)	Signature	Date
Your address is required for mailing you package.	ır \$5.00 Tim Horton's gift caro	d and the 2 nd questionnaire

Mailing address	
City:	
Postal Code:	

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*Please sign and date and KEEP THIS COPY of the consent for your records



Inspiring Innovation and Discovery

PARTICIPANT INFORMATION SHEET (WECHC Phase Two)

Title of Study: Development and Testing of the Chronic Pain Integration Questionnaire **Locally Responsible Investigator:** Dr. Noori Akhtar-Danesh, McMaster University, School of Nursing

Primary Investigator (researcher): Kathryn Deshaies, Registered Nurse, PhD student, McMaster University, School of Nursing

You are being invited to take part in a research study conducted by Kathryn Deshaies because you have been living with chronic pain. This is a PhD student research project supervised by Dr. Noori Akhtar-Danesh. The study will help us learn more about how people cope with chronic pain each day and whether or not we can measure this coping.

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WHY IS THIS RESEARCH BEING DONE?

We would like to know how people living with chronic pain cope with the pain each day. We feel that knowing this process will help us, as health care workers, to provide better care to our clients who have chronic pain.

WHAT IS THE PURPOSE OF THIS STUDY?

We are testing a new questionnaire that measures how people with chronic pain cope with pain each day. If the questionnaire is useful, we hope that health care workers could use it to better know how chronic pain affects their clients each day.

In order to know if this questionnaire is useful, it needs to be filled out by people living with chronic pain and be compared to other questionnaires also found to be useful.

WHAT WILL I HAVE TO DO IF I TAKE PART IN THE STUDY?

If you volunteer to take part in this study, we will ask you to do the following things:

i) Sign the 2 consent forms provided at the end of this information letter. Place one signed consent form in the return envelope along with your completed questionnaire package. Keep the 2nd signed consent form for your records.

- ii) Complete all of the forms provided in the package that has been given to you (this should take you about 10 to 15 minutes)
- iii) Complete all the forms in the package on the same day and provide the date on each form where noted.
- iv) Once the questionnaire package has been completed, place the completed forms in the stamped return envelope provided and mail back to the research team (along with one of the signed consent forms).
- v) Once your questionnaire package has been received, you will be entered into a draw for a chance to win one of three \$50.00 Chapters-Indigo gift cards. You will be called only if you are a winner of one of the draws (odds of winning depend on the number of people who decide to take part in the study).

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

- Participants who fill out the questionnaire package may start to have different thoughts or feelings about their chronic pain which may cause some discomfort. No other direct risks or discomfort from taking part in this research study is known.
- If you choose to take part in this study, you will be told about any new information which might affect your consent to continue to take part in this research.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

We hope to recruit at least 200 people for this phase of the study.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

We cannot promise any personal benefits to you if you take part in this study. However, possible benefits include you having an increased understanding of your own coping with chronic pain. Your participation may help other people with chronic pain in the future as we hope this study will help health care workers better understand their clients and their clients' experiences with living with chronic pain.

There are no specific medical benefits to you if you take part in this study.

IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to fill out the questionnaire package, there are no other options available at this time. You may simply throw away the package.

*Choosing not to take part in this study will in no way affect your care or treatment. **WHAT INFORMATION WILL BE KEPT PRIVATE?**

Your private data (name and address) will not be shared with anyone except with your consent or as required by law. All private data such as your name and address will be removed from the study package and will be replaced with a number. A list linking the number with your name and address will be kept in a locked closet, removed from your answers in the study package until the draw has been completed and the winners have been called. After this time your name and address will be destroyed by shredding. The study package, with your private data removed will be securely stored in a locked closet at St. Clair College, 2000 Talbot Road West, Windsor, Ontario.

If the results of the study are published, your name will not be used and no information that could be linked to you will be released or published.

The information kept from the study package, with your private data removed will be viewed by members of the research team and will be destroyed after 10 years.

CAN PARTICIPATION IN THE STUDY END EARLY?

If you decide to take part in this study, you may withdraw at any time and this will in no way affect the quality of care you receive at any institution. You have the option of removing your information from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study. Kathryn Deshaies may remove you from this research in some situations if it has been decided that doing so is needed.

WILL I BE PAID TO TAKE PART IN THIS STUDY?

You will not be paid for taking part in this study, however if you take part in the study you will be entered into a draw for a chance to win one of three Chapters-Indigo gift cards (\$50.00 value each).

WILL THERE BE ANY COSTS?

If you take part in this research project, you will not have any extra costs charged to you or your health care insurer.

IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have any questions about the research now or later, please contact Kathryn Deshaies at 519-984-8825 or by email at <u>kdeshaies@stclaircollege.ca</u>; or Dr. Noori Akhtar-Danesh at 905.525.9140 x 22297, daneshn@mcmaster.ca. **RESEARCH RESULTS**:

If you would like a summary of the research results when the study has ended, please contact Kathryn Deshaies by email (kdeshaies@stclaircollege.ca) or by phone at 519-984-8825.

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CONSENT STATEMENT

Participant:

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

if you are a winner of one of the pendent on the number of	
i	f you are a winner of one of the pendent on the number of

Mailing address	
City:	
Postal Code:	

*Participation in this study is voluntary. You may withdraw from this study at any time. If you decide to withdraw from the study, please contact the principal investigator, Kathryn Deshaies, at 519-984-8825 or kdeshaies@stclaircollege.ca.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

*Please sign and date this consent and PLACE IN RETURN ENVELOPE provided

CONSENT STATEMENT

Participant:

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Signature	Date	
u may be contacted if you ds of winning are depend	a are a winner of one of the lent on the number of	
	Signature u may be contacted if you lds of winning are depend	SignatureDateu may be contacted if you are a winner of one of theIds of winning are dependent on the number of

Mailing address	
City:	
Postal Code:	

*Participation in this study is voluntary. You may withdraw from this study at any time. If you decide to withdraw from the study, please contact the principal investigator, Kathryn Deshaies, at 519-984-8825 or kdeshaies@stclaircollege.ca.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

*Please sign and date and KEEP THIS COPY of the consent for your records

Appendix K

Office Outlook Web Access	Type here to search This Folder 💽 🔎 🗓 Address Book 😭 Options 🞯 Log Off
Mail 🔂 🛄 🖭	🚘 Reply 🖓 Reply to All 🚖 Forward 🏝 Move 🗙 Delete 🔯 Junk Close 🔺 👻 🗙
 Deleted Items (19) Drafts [2] Inbox (2) Junk E-Mail Sent Items 	RE: Permission to use CPAQ in PhD research McCracken, Lance [lance.mccracken@kcl.ac.uk] You replied on 04/07/2013 11:03 AM. Sent: July 4, 2013 9:38 AM To: Kathryn A Deshaies
Click to view all folders $ lpha $	Dear Kathryn:
Ist year info Ist year students 2nd year students 4th year info (2) 4th year info (2) Octoral Work (4) Personal (2) Scc misc Tompiting Course	We don't really maintain a formal process of providing permission for the CPAQ. People ask and we grant it most of the time as long as the people asking it are qualified and the application proposed in reasonable. So, for a dissertation you can certainly use it. You might notice that we have increasingly focused on wider processes of psychological flexibility over the years. This has included cognitive defusion, committed action, values, and so forth. This has been better.
Union info	Best wishes and good luck with your work.
Anage Folders	<pre>Lance Lance M McCracken, PhD Professor of Behavioural Medicine Psychology Department, Institute of Psychiatry King's College London Sth Floor Bermondsey Wing Guy's Campus London SE1 9RT T +44 207188 5410 F +44 207188 0184 Lance.McCracken@kcl.ac.uk Lead Psychologist INPUT Pain Management Service Guy's and St Thomas' NHS Foundation Trust From: Kathryn A Deshales [KDeshales@stclaircollege.ca] Sent: 03 July 2013 21:37 To: McCracken, Lance Subject: Permission to use CPAQ in PhD research Dear Dr. McCracken, I am a PhD student in nursing at McMaster University in Hamilton, Ontario, Canada. I am interested in using the CPAQ in a study I am currently developing for my</pre>

Appendix L

OPTUMInsight" NON-COMMERCIAL LICENSE AGREEMENT Office of Grants and Scholarly Research (OGSR) License Number: QM018179 Effective Date: March 18, 2013 Licensee Name: Kathryn Deshaies Licensee Address: McMaster University 2080 Main Street Hamilton, Ontario L8S 4L8 Approved Purpose: Non-commercial academic research and/or thesis - Unfunded Student. Study Name: The Chronic Pain Integration Questionnaire Royalty Fee: None, because this License is granted in support of the non-commercial Approved Purpose Other Definitions: As indicated on Appendix B "License Agreement - Details", including without limitation: Licensed Surveys, Modes, Fees, Administrations, Services, Approved Languages and (if applicable) License

Licensee accepts and agrees to the terms of this Non-Commercial License Agreement (the "Agreement") from the Office of Grants and Scholarly Research (OGSR) of OptumInsight Life Sciences, Inc. (f/k/a QualityMetric Incorporated) ("OptumInsight") as of the Effective Date.

Subject to the terms of this Agreement, including the OptumInsight Non-Commercial License Terms and Conditions attached as Appendix A: OptumInsight grants to Licensee, and Licensee accepts, a non-exclusive, non-transferable, non-assignable, non-sublicensable worldwide license to use, solely for the Approved Purpose and during the License Term, the Licensed Surveys in the authorized Modes and Approved Languages indicated on Appendix B and to administer the Licensed Surveys only up to the approved number of Administrations (and to make up to such number of exact reproductions of the Licensed Surveys necessary to support such Administrations) in any combination of the specific Licensed Surveys and Approved Languages and Modes and to use any related software provided by OptumInsight.

Capitalized terms used in this Agreement shall have the meanings assigned to them above, or in Appendices A and B attached hereto are incorporated into and made a part of this Agreement for all purposes.

EXECUTED, as of the Effective Date, by the duly authorized representatives as set forth below.

OptumInsight Life Sciences, Inc. [OptumInsight]				
Signature:	Muhellulhite			
Name:	Michelle White			
Title:	Director of Consulting Science			
Date:	22 MAR 2013			

Term

Kathryn Deshaies [Licensee]
Signature:
Name: Kathryn Deshaires
Title: PhD student
Date: March 22, 2013

APPENDIX A

Appendix M

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S. WALTER, M. ELIASZIW AND A. DONNER

Table II. Estimates of sample size k, based on $\alpha = 0.05$, $\beta = 0.20$, for various values of ρ_0 , ρ_1 and n

ρ_0					ρ_1				
	0.1	0.2	0.3	0.4	0.5	0.6	0.7	0.8	0.9
n = 2 0 0·1 0·2 0·3 0·4 0·5 0·6 0·7 0·8	615-6	151-9 591-2	70-0 142-8 543-7	35-9 60-6 128-2 476-2	22-0 32-2 53-0 109-0 393-1	14-4 19-1 27-2 43-5 86-6 300-3	9.7 12:0 15:5 21:4 32:9 62:6 205:4	6-6 7-7 9-2 11-4 15-1 22-0 39-1 117-1	4·4 4·8 5·3 6·1 7·1 8·8 11·7 18·4 45·8
n = 3 0 0·1 0·2 0·3 0·4 0·5 0·6 0·7 0·8	225-1	60·2 251·8	28·1 64·8 261·1	16·4 29·2 64·8 251·8	10-7 16-4 28-1 60-2 225-1	7-4 10-2 15-1 25-1 51-5 183-9	5-3 6-8 9-0 12-8 20-3 39-6 133-1	3-8 4-6 5-6 7-1 9-6 14-4 26-1 79-7	2.7 3.0 3.4 4.0 4.7 5.9 8.0 12.8 32.5
n = 4 0 0·1 0·2 0·3 0·4 0·5 0·6 0·7 0·8	122-9	35-3 156-7	17·5 42·4 177·8	10-8 20-0 45-9 183-3	7-4 11-7 20-6 45-2 172-4	5-4 7-6 11-5 19-4 40-4 146-6	4.0 5.3 7.1 10.2 16.4 32.3 109.7	3·1 3·7 4·6 5·9 8·0 12·0 21·9 67·5	2.3 2.6 2.9 3.4 4.1 5.1 6.9 11.1 28.3
n = 5 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	80-2	24-5 114-5	12-8 32-2 139-4	8-2 15-7 37-0 150-8	5-8 9-5 17-1 38-0 147-0	4·4 6·4 9·7 16·6 35·1 128·4	3-4 4-5 6-2 9-0 14-4 28-7 98-1	2.7 3.3 4.1 5.3 7.2 10.8 19.9 61.5	$2 \cdot 1 \\ 2 \cdot 3 \\ 2 \cdot 7 \\ 3 \cdot 1 \\ 3 \cdot 8 \\ 4 \cdot 7 \\ 6 \cdot 4 \\ 10 \cdot 3 \\ 26 \cdot 1 $

Appendix N

Table N1

Summary of Missing Data: Total Number of Participants (n) who Provided a Complete Data Set for Each Variable.

Variable	Total (<i>n</i>)	Percent Missing (%)	
CP Dx	201	0	
YWCP	185	8	
Type CP	201	0	
Body Part	200	.5	
CP Program	200	.5	
Age	200	.5	
Gender	200	.5	
Race	200	.5	
Education	192	4.5	
Income	192	4.5	
AAQ-II	199	1	
CPAQ	197	2	
Social Support	200	.5	
SF-12v2	197	2	

Note. CP Dx = person identified that he/she has been diagnosed with CP; YWCP = number of years the person has been living with CP; Type CP = the type of CP diagnosis that the person has been given; Body Part = the number of body parts affected by CP; CP program = identification if the person has never participated, participated, or currently in a CP management program; AAQ-II = Acceptance and Action Questionnaire; CPAQ = Chronic Pain Acceptance Questionnaire; SF-12v2 = Short Form Health Survey 12, version 2.

Ph.D. Thesis - K. Deshaies; McMaster University - Nursing

Appendix O

Text To Score	Reading Ease	i
Enter Your Text Below Then Click Measure Readability	Readability Formula	Score
	Flesch-Kincaid Reading Ease	77.4
I am able to read signals from my body and mind that tell me my pain may worsen.		
I know what works best for me when managing my chronic pain.	Grade Levels	i
I know what my body will, or will not, allow me to do.		
I must take regular care of myself (physically, mentally, spiritually) to manage my pain	Readability Formula	Grade
day-to-day.	Elosch, Kincaid Crado Lovel	5.8
Living with chronic pain teaches me to pay attention to my body and mind.	Flescii-Kilicalu Grade Level	5.6
I can take specific measures that will allow me to live with chronic pain.	Gunning-Fog Score	8.2
I take action based on any signal from my body and mind.		
I try to learn as much as possible about my chronic pain.	Coleman-Liau Index	7.8
I have no choice about the daily activities in my life.		
I have learned new ways to do activities so as not to increase my pain levels.	SMOG Index	8.8
I rying to control my chronic pain day-to-day is automatic for me.		
I don't dwell on having chronic pain - it is part of me.	Automated Readability Index	4.1
Living with chronic pain has taught me a lot about myself.		
I have found no set routine to help manage my chronic pain.	Spache Score	3.7
Living with chronic pain has taught me about what is important in life.	Dala Chall Sanna	2.2
I feel I live a generally nealthy lifestyle despite my chronic pain.	Dale-Chail Score	3.2
I have supportive relationships in my life which help me to live with chronic pain.	Average Grade Level	5.9

Figure O1. Reading Level Results of the Original 2008 Version of the CPIQ (www.Readability-Score.com).

Enter Your Text Below Then Click Measure Readability	Readability Formula	Score
	Flesch-Kincaid Reading Ease	75.8
I know what my body will, or will not, allow me to do.		
My chronic pain will increase without any warning from my body.	Grade Levels	i
I must take regular care of myself		
(physically, mentally, and/or spiritually) to manage my chronic pain day-to-day.	Readability Formula	Grade
I follow the advice of others, rather than my own instincts, when deciding what works best for me.	Flesch-Kincaid Grade Level	5.8
Living with chronic pain teaches me to pay attention to my body and mind. I do specific things that will help me live with chronic pain.	Gunning-Fog Score	8.2
I make choices about the daily activities in my life.	Coleman-Liau Index	8.8
I have learned new ways to do activities. I wait until my chronic pain is at its worst before trying to do something to make it better. I don't dwell on having chronic pain - It is part of me.	SMOG Index	9
I try to learn as much as possible about my chronic pain.	Automated Readability Index	4.4
Following a daily routine makes my chronic pain worse.	Spache Score	3.6
Living with chronic pain has taught me a lot about myself. I feel I live an unhealthy lifestyle because of my chronic pain.	Dale-Chall Score	3.1
Living with chronic pain has taught me about what is important in life.		
I have supportive relationships in my life which help me to live with chronic pain.	Average Grade Level	6.1

Figure O2. Reading Level Results of the Revised 2013 Version of the CPIQ (www.Readability-Score.com).

Appendix P

Table P1

Revision of select items from 2008 17-item CPIQ original version to 2013 17-item CPIQ: Increase number of reversed-keyed items, revised wording of two previously reversed-keyed items, and improved reading level of two items.

Item: 2008	Item: 2013
2. I am able to read signals from my body	2. My chronic pain will increase without
and mind that tell me my pain may	any warning from my body. (*changed to
worsen.	reflect lower end of concept)
4. I know what works best for me when	4. I follow the advice of others, rather
managing my chronic pain.	than my own instincts, when deciding
	what works best for me.
	(*changed to reflect lower end of
	concept)
6. I can take specific measures that will	6. I do specific things that will help me
allow me to live with chronic pain	live with chronic pain (*changed
	wording to increase clarity)
7. I have no choice about the daily	7. I make choices about the daily
activities in my life.	activities in my life.
	(changed to reflect lower end of concept)
8. I have learned new ways to do activities	8. I have learned new ways to do
so as not to increase my pain levels.	activities
	(*removal of 'not' phrase for clarity)
9. I take action based on any signal from	9. I wait until my chronic pain is at its
my body and mind.	worst before trying to do something to
	make it better.
	(*changed to reflect lower end of
	concept)
13. I have found no set routine to help	13. Following a daily routine makes my
manage my chronic pain.	chronic pain worse. (*reworded so
	word 'no' removed)
15. I feel I live a generally healthy	15. I feel I live an unhealthy lifestyle
lifestyle despite my chronic pain.	because of my chronic pain. (*changed
	to reflect lower end of concept)

Note. CPIQ=Chronic Pain Integration Questionnaire; *identification of how item was revised

Appendix Q

Table Q1

EFA of CPIQ Using Principal Component Extraction: Unrotated Matrix; Extraction of 5 Components with Eigenvalues Greater than 1 (loadings less than .40 excluded)

CPIQ Items	Component					
	1	2	3	4	5	
CPIQ1			.463			
rCPIQ2		.455				
CPIQ3	.576					
rCPIQ4		.479			563	
CPIQ5	.672					
CPIQ6	.708					
CPIQ7	.644			469		
CPIQ8	.699					
rCPIQ9		.523			412	
CPIQ10	.410		.706			
CPIQ11	.562			.460		
CPIQ12	.629		.403			
rCPIQ13		.615				
CPIQ14	.706					
rCPIQ15		.726				
CPIQ16	.526			.514		
CPIQ17						

Note. CPIQ = Chronic Pain Integration Questionnaire

Table Q2

EFA of CPIQ Using Principal Component Extraction: Total Variance Explained by First Five Components (only eigenvalues greater than one included)

Component	Initial Eigenvalues					
	Total	% of Variance	Cumulative %			
1	4.263	25.077	25.077			
2	1.836	10.801	35.877			
3	1.326	7.802	43.680			
4	1.159	6.818	50.498			
5	1.048	6.166	56.664			

Note. EFA = exploratory factor analysis; CPIQ = Chronic Pain Integration Questionnaire

Appendix R

Table R1

EFA of CPIQ Using Principal Component Extraction: Five Components Extracted with Oblique Rotation (Oblimin with Kaiser Normalization): Pattern and Structure Matrices (loadings less than .40 excluded)

Pattern Matrix					Structure Matrix Q						
CPIQ	Components			CPIQ	Components						
Items	1	2	3	4	5	Items	1	2	3	4	5
1			.710			1			.712		
2				-543		2				-531	
3	.672					3	.668				
4					-793	4					-778
5	.543					5	.635			.439	
6	.773					6	.792				
7	.810					7	.779				
8	.576					8	.672				
9					-	9					576
					.540						
10			.812			10			.801		
11				.582		11				.632	
12			.553			12	.472		.650		
13		.624				13		.634			
14				.561		14	.530			.682	
15		.531				15		.601			473
16				.754		16				.754	
17		.716				17		.692			

Note. EFA = exploratory factor analysis; CPIQ = chronic pain integration questionnaire; bolded areas display multiple loadings of same item on different factors.

Appendix S

Table S1

Mediation Analysis **Step One** (**Path c**)[^]: Correlation (Pearson's r) and Regression of Health (SF-12v2: PC, MC, GH) on CP Integration (CPIQ)

	Correlation	Regression
Variable	CPIQ	B p
Path a: SF-12v2: PC (total score)	01	.00 .57
MC (total score)	.45**	.02 <.01
GH (total score)	.23**	.01 <.01

Note. PC = physical component summary score of the SF12v2; MC = mental component summary score of the SF12v2; GH = general health scores of the SF12v2; CPIQ = chronic pain integration questionnaire; **correlation is significant at the 0.01 level (2-tailed); B = unstandardized coefficient; p = significance value; ^Mediation steps from Baron & Kenny (1986).

Table S2

Mediation Analysis **Step Two (Path a)**[^]: Correlation (Pearson's r) and Regression of Health (SF-12v2: PC, MC, GH) on Social Support (Mediator).

Variable		Correlation Social Support	Regression B p		
SF-12v2:	PC (total score)	.18*	.06 .01		
	MC (total score)	.32**	.08 <.01		
	GH (total score)	.31**	.03 <.01		

Note. PC = physical component summary score of the SF12v2; MC = mental component summary score of the SF12v2; GH = general health scores of the SF12v2; CPIQ = chronic pain integration questionnaire; *correlation is significant at the 0.05 level (2-tailed); **correlation is significant at the 0.01 level (2-tailed); B = unstandardized coefficient; p = significance value; [^]Mediation steps from Baron & Kenny (1986).
Appendix S (cont'd)

Table S3

Mediation Analysis Step Three (Path b)[^]: Correlation (Pearson's r) and Regression of Social Support (Mediator) on CP Integration (CPIQ)

	Correlation	Regression	
Variable	CPIQ	В р	
Social Support	.35**	.07 <.01	

Note. CPIQ = chronic pain integration questionnaire; **correlation is significant at the 0.01 level (2-tailed); B = unstandardized coefficient; p = significance value; [^]Mediation steps from Baron & Kenny (1986).

Table S4

Mediation Analysis **Step Four** (**Path** c¹)[^]: Regression of Health (Independent Variable; SF-12v2: PC, MC, GH) and Social Support (Mediator) on CP Integration (Dependent Variable; CPIQ)

Variable	В	р
SF-12v2: PC	00	.61
Social Support	.07	<.01
SF-12v2: MC	.02	<.01
Social Support	.05	<.01
SF-12v2: GH	.00	<.00
Social Support	.06	.04

Note. PC = physical component summary score of the SF12v2; MC = mental component summary score of the SF12v2; GH = general health scores of the SF12v2; CPIQ = chronic pain integration questionnaire; B = unstandardized coefficient; p = significance value; [^]Mediation steps from Baron & Kenny (1986).

Appendix S (cont'd)

Table S5

Sobel's Test: Determination of the Indirect Effect (i.e. Amount of Mediation)

Variable	а	b	s _a	s _b	z-value
SF-12v2: PC	.064	.071	.025	.013	2.3*
SF-12v2: MC	.075	.046	.016	.013	2.8*
SF-12v2: GH	.033	.061	.007	.014	3.2*

Note. Formula for Sobel's test: *z*-value = $a \ge b/(b^2 \ge s_a^2 + a^2 \ge s_b^2)^{1/2}$; a = unstandardized coefficient (B) value for regression of independent variable and mediator; s_a = standard error associated with a; b = unstandardized coefficient (B) value for regression of mediator and dependent variable with independent variable in the equation; s_b = standard error associated with b; **z*-values >1.96 are significant at .05 level.