2008

Measuring integration in adults with chronic non-malignant pain (CNP)

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MEASURING INTEGRATION IN ADULTS WITH CHRONIC NON-MALIGNANT PAIN (CNP)

by

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A Thesis
Submitted to the Faculty of Graduate Studies
through the Faculty of Nursing
in Partial Fulfillment of the Requirements for the
Degree of Master of Science at the
University of Windsor

Windsor, Ontario, Canada

2008

Your file Votre référence
ISBN: 978-0-494-47016-9
Our file Notre référence
ISBN: 978-0-494-47016-9

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Abstract

Despite advances in understanding pain processes, chronic non-malignant pain (CNP) remains a complex and challenging condition which affects all aspects of the sufferer's life. Integration is defined as an ongoing process in which the person with CNP evolves, becoming a mentally and physically stronger individual and creating a sense of harmony and control in one's life. Facilitation of the integration process may be a key intervention for health care providers working with individuals with CNP. Thus the aim of this study was to develop a tool to measure levels of integration to CNP. The newly-developed tool, the Chronic Pain Impact Questionnaire (CPIQ), demonstrated content validity, internal consistency reliability, stability, and concurrent validity when correlated with the Hearth Hope Index (Herth, 1992) and the EuroQol (EuroQol Group, 1990). In addition, the two CPIQ subscales, intrapersonal reciprocality and psychoemotional adjustment, demonstrated internal consistency reliability and beginning evidence for construct validity.

Dedication

I would like to dedicate this thesis to my two daughters, Kari and Robyn Deshaies. They are two wonderfully clever, funny, and beautiful individuals and they light up my life each and every day. Through their witnessing of this process, I hope they will come to recognize the importance of lifelong learning. I wish for them love and success in every aspect of their lives.

Acknowledgements

I would first like to thank all the members of my graduate committee. My advisor, Dr. Cheri Hernandez, introduced me to her theory of integration which was a pivotal piece of information that started this research endeavour. Her support and guidance was an essential component of my successful completion. The department reader, Dr. Sharon McMahon, has an eloquent way with words. Her feedback helped me to refine many components of this thesis and she was always present with a comforting word and smile which was reenergizing. The outside reader, Dr. Ken Cramer, provided valuable feedback contributing to research quality. Of most importance was his recommendation to include in the study two established questionnaires. It meant extra work but in the end provided information that proved most valuable.

I also acknowledge Dan Edelstein, the U of W Data Center Manager, who assisted me with computing the necessary statistical analyses. He was always welcoming and helped me to feel more confident when using the statistical software.

Words cannot truly express the love, gratitude, and appreciation I have for my family. My parents, Peg and Stan Soteros, readily gave up their time to read and edit this thesis on many occasions. Their never failing support was expressed and felt daily. My sister, Dr. Christine Soteros, assisted me through many tough times and kept me on track. I don't think I would have made it through the advanced statistics course if it wasn't for her expert knowledge, teaching ability, and support.

Especially, I would like to thank my husband, Mike Deshaies. He has consistently supported my educational aspirations and willingly kept the household functioning whenever I was stressed with a deadline (or just needed to relax). His love and support surrounds me each and every day and I couldn't have done this without him.

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CHAPTER ONE: BACKGROUND AND SIGNIFICANCE

There have been great advances over the years in understanding pain: Despite these advances, pain remains a significant problem (Turk, 2003). This study focuses specifically on one type of pain: chronic non-malignant pain (CNP). In this chapter, the impact of CNP on the individual, family, and society, and the current treatments for CNP are outlined. Lastly, the purpose of the research study and the theory that guided it are discussed.

Chronic non-malignant pain (CNP) is defined as pain that has lasted at least six months in duration, has extended beyond the usual healing time, and is due to non-life-threatening causes (Dunajcik, 1999, p. 471). Other terms used synonymously with CNP are chronic non-cancer pain, persistent pain, and chronic intractable benign pain: The general category of chronic pain includes all types of chronic non-malignant and cancer pain (Dunajcik; Jeffrey & Lubkin, 2002). The pain experienced in CNP can be intermittent or constant and can vary in intensity from mild to excruciating (Dunajcik). The general classification of CNP is comprised of a large number of conditions for which no treatment can cure (Turk, 2004). Examples of some common chronic pain conditions are headache, arthritis, low back pain, and neuropathy (Dunajcik; MacLellan, 2006). Twenty-nine percent of over 2000 adult Canadians (27% men, 31% women) who participated in a 2001 survey had CNP, with the average duration of pain being 10.7 years (Moulin, Clark, Speechley, & Morley-Forster, 2002). Eighty percent reported moderate to severe pain levels, and almost half were unable to attend social and family events.

The reduction of or withdrawal from social, family, or work activities is seen as an end product of the significant impact CNP has on the person's quality of life (Gerstle, All, & Wallace, 2001; MacLellan, 2006; Scharf & Turk, 1998). Pasero, Paice, and McCaffery

(1999) identified the impact of unrelieved CNP on quality of life (QOL) to be significant with effects ranging from decreased physical activity to suicide. The authors further stated that when compared to all the adverse effects of unrelieved pain, decreased QOL represented the greatest harm. In 1994, 204 individuals with CNP responded to a survey in which it was revealed that chronic pain had a high negative affect on QOL (Hitchcock, Ferrell, & McCaffery, 1994). Sixty-nine percent of the respondents reported feeling hopeless and fifty percent of these same respondents reported thoughts of suicide due to feelings of hopelessness. In a study conducted by Albrecht and Devlieger (1999), participants who identified having a poor quality of life related it to the experience and loneliness of having pain. This low quality of life was reported to be due, in part, to the loss of control of mental or body function and having no purpose in life.

Negative perceptions of health are also more evident in individuals with CNP compared to individuals without CNP (Gureje, Von Korff, Simon, & Gates, 1998). Health related quality of life (HRQL) was shown to be significantly reduced in patients with CNP and was equally low or lower than in patients with cardiopulmonary disease or major depression (Becker, Thomsen, Olsen, Sjøgren, Bech, & Eriksen, 1997; Veillette, Dion, Altier, & Choiniere, 2005).

Not only is the individual's quality of life affected, the psychological impact on the individual is reported to be great. Turk (2003) reported that forty to fifty percent of individuals with CNP suffer from depression. Depression is twice as high among people reporting chronic pain as those without chronic pain (Breen, 2002; Marcus, 2000).

The prevalence of anxiety and anger among individuals with CNP is also high (Turk, 2003). This anxiety and anger, along with feelings of helplessness, sadness, and guilt can lead to feelings of despair and hopelessness (Davis, 2000; Roy, 2004; Schofield,

2005). Roy identified sadness, hopelessness, and depression as symptoms of atypical grief in individuals with chronic illnesses (including those with CNP). The focus of the grief was on things lost and promises unfulfilled. Roy identified the grief as atypical in chronic illness since people with a chronic illness will experience ups and downs and would not typically go through stages of grief from disbelief to resolution and acceptance. "The unpredictable nature of many chronic diseases complicates the grieving process" (p. 41). The idea of grief was further echoed again in more recent work by Turk (2004) who stated that the central problem for the person with chronic pain is overcoming grief and finding meaning and acceptance of the loss of function.

CNP also produces significant changes in the welfare and functioning of the family (Roy, 2006; Registered Nurses Association of Ontario [RNAO], 2002; Watt-Watson & Donovan, 1992). In a qualitative study, which examined the lived experiences of women with fibromyalgia, the women expressed a change in relationships with their husbands and children (Soderberg & Lundman, 2001). The women took on a more passive role in the family, and intimate sexual relationships with their spouse were significantly reduced. People with CNP are more likely to experience separation and divorce (Dunajcik, 1999).

In addition to the physical, social, and psychological impact on the individual, CNP has a dramatic impact on societal costs. According to Gordon, Pellino, Miaskowski, McNeill, Paice, Laferrier, and Bookbinder (2002) chronic pain has a major financial impact on our society resulting in lost days at work, plus increased workers' compensation benefit (WCB) expenses, use of sick days, and expenditures on traditional and nontraditional health care treatments (p. 117). The Chronic Pain Association of Canada (CPAC) estimates that chronic pain costs Canadians in excess of 10 billion

dollars annually (Chronic Pain Association of Canada [CPAC], nd, para 4). The proportion of Canadians who have chronic pain or discomfort increases with age (Statistics Canada, 2003). Therefore, as the population of people over 65 increases, it is tempting to project that the proportion of people with CNP will dramatically rise, greatly increasing the costs to the health care system and to society in the future.

Given the negative influences of CNP on the individual and society, various treatment interventions for CNP have been developed as efforts to decrease personal and societal loss and cost (Davis, 2000; McCaffery & Pasero, 1999; Watt-Watson & Donovan, 1992). Numerous clinical trials have provided evidence for the effectiveness of interdisciplinary pain management programs in the treatment of CNP (Lynch, Agre, Powers, & Sherman, 1996; Nielson, Jensen, & Kerns, 2003; Turk, 2003; Vlaeyen & Morley, 2005). Of the treatments provided in these programs, cognitive behavioural therapy (CBT) has been established as the most effective in achieving positive outcomes for the individual suffering with CNP (Lynch et al.; Morley, Eccleston, & Williams, 1999; Naylor, Helzer, Naud, & Keefe, 2002; Turk, 2003; Vlaeyen & Morley). However, the long-term benefits of these interventions have not been consistently evident within the research literature (Dworkin, Turk, Farrar, Haythornthwaite, Jensen, Katz et al., 2005; Lynch et al.). A significant number of individuals, within a few months following discharge from an interdisciplinary program, regress to a state they exhibited prior to admission (Robinson, Bulcourf, Atchison, Berger, Lafayette-Lucy, Hirsh, & Riley, 2004; Naylor et al.). Morley et al. (1999) further reported that CBT was not provided routinely for individuals with CNP. Medical and physical interventions continued to be the sole treatment in many plans of care even though there was less evidence of their effectiveness. Pain care remains inconsistent and inadequate (Gordon et al., 2002).

Lastly, even though CBT has been effective for people with CNP, at least in the short term, there still remain a large number of individuals who do not benefit from treatment (Vlaejen & Morley). Turk (1990) hypothesized that the reason for the large numbers of individuals who did not benefit from pain management treatment was due to the tendency to treat individuals with CNP as a homogeneous group. Individuals were provided 'generic' treatments and had to adhere to treatment recommendations for success to be evident.

In light of these variable findings and inconsistent treatment plans, perhaps a new approach is needed to determine which treatment interventions for specific CNP individuals would be appropriate and successful over the long term. It is imperative that researchers and health care providers focus on strategies which will lead to more sustainable outcomes for people with CNP in order to improve quality of life and decrease the costs to the health care system and society. There has been a recent shift in research to identify specific subgroups of individuals with CNP in order to identify possible tailored interventions (Vlaeyen & Morley, 2005). It is hoped that matching the individual with specific interventions, based on the individual's self-reported characteristics, will result in better outcomes.

A focus by health care professionals on the development of tailored interventions, rather than generic treatments, may prove to be the key to improving the sustainability of treatment outcomes for those who have been unable to achieve success with current pain management interventions. Prior to matching the individual to the intervention, health care professionals need to have some understanding of the person's pain experience (Schofield, 2005; Watt-Watson & Donovan, 1992). In this author's professional experience, people who have CNP are often told by health care professionals that they

must "learn to live with the pain". However, clear efficacy measures are needed to evaluate which interventions will effectively assist the person as they proceed to learn to live or cope with the pain. It can be assumed that understanding the person's own experience with pain is the first step in developing an effective pain management plan. Learning about the personal lived experience from the person with CNP will provide the health care professional with meaningful assessment and guidance for intervention options (Watt-Watson & Donovan).

In recent years, several studies have been conducted examining the concept of acceptance in chronic pain (McCracken, 1998; McCracken & Eccleston, 2005; McCracken, Vowles, & Eccleston, 2004, 2005). McCracken defined acceptance of chronic pain as 'the acknowledgment that one has pain, has given up unproductive attempts to control pain, acts as if pain does not necessarily imply disability, and is able to commit one's efforts toward living a satisfying life despite pain" (p.22). However, it remains unclear if acceptance is a single process or a number of smaller related processes (McCracken et al., 2004). Studies to assess the effectiveness of acceptance-based interventions at completion and at three month follow-up have demonstrated significant improvements in emotional, social, and physical functioning, and health care use (McCracken & Eccleston; McCracken et al., 2004), yet studies examining long term benefits post four months have yet to be conducted.

A concept that has received particular attention over the past few years (and has demonstrated similar outcomes to that of acceptance) has been *integration* (Whittemore, 2005). "The process of integration appears to be a significant phase that occurs between a diagnosis of illness and subsequent physical and emotional healing" (p. 261). Through a concept analysis, Whittemore defined integration 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" (p. 263). The outcomes of the integration process were 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, self-transcendence, and actualization of life potential. In studying individuals living with diabetes, Hernandez (1995) reported that integration should be the focus of diabetes education and treatment resulting in the desired outcome of glycemic control. She defined integration 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. 19).

If decreased QOL is the greatest harm to individuals suffering with CNP (Pasero et al., 1999) and integration results in satisfaction with one's quality of life (Whittemore, 2005), then perhaps the goal of pain management treatment and programs should be the development of individualized treatment plans focusing on enhancing the integration process.

A number of qualitative studies, which have examined the lived experiences of people with a variety of CNP conditions, have identified common themes or phases through which the individuals progress as they adjust to their life with pain (Asbring, 2001; Carson & Mitchell, 1998; Gullacksen & Lidbeck, 2004; Howell, 1994; Paulson, Danielson, & Soderberg, 2002; Schaefer, 1995). The characteristics outlined within the final phases identified in these studies were similar to the characteristics of integration as identified by Hernandez (1995) and Whittemore (2005). These studies provide some

insight into how people adjust and live with CNP. For example, a common theme of grieving was evident within many of the qualitative studies (Asbring; Carson & Mitchell; Gullacksen & Lidbeck; Howell; Paulson et al.; Schaefer). The person grieved for the life they once had. If an individual with CNP is grieving, pain management interventions that do not address the grieving process may be inadequate and lead to failure. One could assume that not all interventions will be effective at one time and for each individual: Understanding the individual's lived experience with CNP could guide the intervention development process.

Themes or phases identified in the qualitative studies reviewed support the need for assessment, intervention, and evaluation strategies, which assist the individual's progress to independently and effectively live his or her life with pain. It is critical that health care professionals conduct comprehensive assessments of the pain experience prior to planning tailored interventions (Watt-Watson & Donovan, 1992). If integration yields outcomes such as healing, recovery, achievement of optimal functioning, satisfaction with one's quality of life, a sense of overall well-being, and renewed life purpose and meaning (Whittemore, 2005), it can be hypothesized that the use of tailored interventions designed to assist the individual to progress toward higher levels of integration to CNP will enhance the effectiveness and sustainability of the outcomes. What health professionals require, as part of the assessment of the individual, is a tool that can be used throughout the professional-client relationship to determine individual progress toward successfully living one's life with pain (i.e., integration). If such a tool demonstrates change over time, the same tool could be used to measure the effectiveness of specific interventions.

Purpose of Study

The primary objective of this study was to design and pilot-test an instrument to measure integration in individuals with CNP. It can be anticipated that assessing how and to what extent a person with CNP has integrated CNP into their life will assist health care professionals to plan tailored interventions as well as effectively evaluate the effects of the treatment interventions. Measuring the degree to which the individual has integrated CNP into his or her life is a necessary addition to the assessment and evaluative process of pain management: based on the principle of best practices and the aspects of wholistic care (Watt-Watson & Donovan, 1992) where care of the whole is more healthful and wellness oriented. Application of a more holistic picture of the individual's CNP experience is expected to assist in planning personalized interventions. It is also expected to provide a more accurate evaluation of the success and sustainability of the pain management interventions that could enhance integration qualities. If health care professionals can assess the individual's level of CNP integration, collaborate with the individual on strategies that focus on physiological and psychosocial outcomes, and assist the person to more fully integrate CNP into their lives, it is anticipated that people with CNP will be able to use this knowledge to effectively manage their pain over the long term.

Theory of Integration

The theory, which guided this research study was the theory of integration developed by Hernandez (1991). Hernandez (1995) defined integration 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).

In this work, the *personal self* is the person as he or she existed prior to the diagnosis of diabetes. The *diabetic self* is the new entity that emerged post diabetes diagnosis. Within the integration theory, clients and health care providers are co-experts in collaborative practice (Hernandez, 1995): The client is the expert in living with diabetes and the healthcare provider provides complementary specialized knowledge about diabetes. The client and the provider collaborate on strategies which focus on physiological and psychosocial outcomes. The client decides on which strategies and outcomes are relevant. The principles of co-expertise will apply to this CNP research activity.

The theory of integration (Hernandez, 1991) involves a three-phase process: (a) *having diabetes*, (b) *the turning point*, and (c) *the science of one*. The *having diabetes phase*, commencing at time of diagnosis, is characterized by a lack of knowledge about the disease, a disinterest in diabetes, and/or varying degrees of commitment and involvement with diabetes management (Hernandez, 1995). The individual focuses on being seen as living a normal life and not appearing different from others. The second phase, *the turning point*, begins when a life event forces the individual to examine his/her life with diabetes. It is characterized by an increased interest and involvement in diabetes and its treatment. Phase three, *the science of one*, is a gradual progression from the second phase and is termed "a personalized science of living with diabetes" (p.19). It is characterized by the individual striving to understand diabetes. The focus is on living one's life with diabetes. In the third phase, integration of the personal self and the diabetic self occurs most fully. In the third phase the person begins to "tune-in" to his or her body cues and uses this knowledge to maintain good glycemic control. The

individual successfully integrates diabetes into his or her life without it becoming the major focus of living, that is, there is integration of the personal and diabetic selves.

In 1995, Hernandez developed and tested an instrument to measure integration to diabetes: The Diabetes Questionnaire (TDQ; see Appendix A). The TDQ is a 15-item questionnaire with known published content, qualitative, and construct validity, as well as internal consistency reliability ($\alpha = 84$) and test-retest reliability ($r = .75$). The two subscales, psychoemotional adjustment and somatic sensitivity, identified through factor analysis demonstrated internal consistency ($\alpha = .77$ and .80 respectively).

Upon reading Hernandez's theory of integration (Hernandez, 1991), and based on five years of experience working with individuals with CNP, the author recognized similarities between the integration of diabetes to characteristics and expressions of those living with CNP. These similarities prompted a comparison between qualitative research (Asbring, 2001; Carson & Mitchell, 1998; Gullacksen & Lidbeck, 2004; Howell, 1994; Paulson, Danielson, & Soderberg, 2002; Schaefer, 1995) which reported characteristics of phases or stages experienced by adults living with CNP and (a) the characteristics identified within the theory of integration, and (b) items on the TDQ (Hernandez, 1995). Additional similarities were discovered through this two-part comparison and provided the evidence to support the further investigation of integration with individuals with CNP and the development of a tool to measure integration to CNP. The analysis is described in more detail in chapter 2 under the heading *CNP and the Theory of Integration.*

CHAPTER TWO: REVIEW OF THE LITERATURE

This chapter has been organized into three parts: (a) a literature review of pain definitions and the current treatments for chronic non-malignant pain, (b) a literature review of qualitative research reporting the lived experiences of adults with CNP (more specifically, those studies which reported the phases or stages experienced by people living with CNP), and (c) a detailed description of the similarities between the qualitative research studies, the characteristics reported in the theory of integration (Hernandez, 1991), and the items on the TDQ (Hernandez, 1995).

Chronic Non-Malignant Pain (CNP) Definition and Treatment

Historically the pain literature has shown that pain is a subjective experience (Davis 2000; McCaffery & Pasero, 1999; Schofield, 2005; Watt-Watson & Donovan, 1992). Pain is what the person says it is, existing whenever the person says it does (McCaffery & Pasero, 1999). The International Association for the Study of Pain (IASP) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (International Association for the Study of Pain [IASP], nd, para 11). The impact of pain is not limited to the actual sensation of pain but includes many negative influences at multiple levels: physically, psychologically, emotionally, and spiritually (MacLellan, 2006; Schofield). Chronic non-malignant pain (CNP) is defined as pain that is at least six months in duration, has extended beyond the usual healing time, and is due to non-life-threatening causes (Dunajcik, 1999).

There have been great advances over the years in understanding the anatomy, physiology and biochemistry of pain including development of a variety of analgesics and technological inventions (Turk, 2003). In spite of these advances, pain has remained a

significant problem. Even the strongest medication is found to reduce chronic pain by only 30 to 40 %. In recent years treatment protocols for acute pain (non-cancer and cancer) have become more consistent compared to treatment protocols for chronic non-malignant pain (Sanders, Harden, Benson, & Vincente, 1999, p. 47). Treatment protocols for CNP remain controversial. The treatment that has received the strongest endorsement and research support for people with CNP has been the use of interdisciplinary or multidisciplinary treatment approaches (Sanders et al., 1999). According to Lynch et al. (1996), interdisciplinary pain management treatments (IPM) focus on sensory, operant behavioural, and cognitive behavioural conceptual models and techniques in order to manage symptoms. The primary focus of IPM has been to help patients cope with pain, reduce dependence on the health care system, improve functional abilities and psychosocial functioning, and reduce psychological distress.

Becker, Sjøgren, Beck, Olsen, and Eriksen (2002) conducted a randomized controlled trial investigating the effect of an outpatient multidisciplinary pain centre treatment (MPT) compared to treatment by a general practitioner (GP) and to a group of patients on a six month waiting list. At referral, after three months, and after six months, 189 participants completed questionnaires evaluating pain intensity, health related quality of life, and use of analgesics. After six months, participants in the MPT group reported a significant decrease in pain intensity ($p < 0.001$), improvement in psychological well being ($p < 0.001$), improvement in quality of sleep ($p < 0.001$), and improvement in physical functioning ($p < 0.05$). No improvements were seen in the GP group in relation to decrease in pain intensity, increase in psychological well-being, quality of sleep, and physical functioning. In the waiting list group a significant deterioration was observed in psychological well-being ($p \leq 0.05$) with no change in pain intensity. In both the MPT

and the GP groups a reduction in the use of short acting opioids (prescription analgesic) was observed ($p < 0.01$). No change in the use of analgesics was seen in the waiting list group.

Morley et al. (1999) performed a systematic review and meta-analysis of 25 randomized controlled trials of CBT and behaviour therapy for adults with chronic pain. The researchers wanted to answer two questions: (a) Is cognitive behavioural therapy an effective treatment for chronic pain? and (b) Is cognitive behavioural therapy more effective than alternative active treatments? The researchers concluded that active psychological treatments based on CBT (including behaviour therapy and biofeedback) were effective relative to waiting list control conditions. CBT produced significant changes in measures of pain experience, mood/affect, cognitive coping and appraisal, pain behaviour and activity level, and social role function.

Research evidence has further supported the use of cognitive behavioural therapy (CBT) specifically in the treatment of CNP (Lynch et al., 1996; Morley et al., 1999; Naylor et al., 2002; Turk, 2003; Vlaeyen & Morley, 2005) in restoring function and mood, and reducing pain and behaviour related to disability. However, according to Turk (2003), there is a considerable variation in individuals' responses to the same treatment. Turk further stated that nothing was known about which treatments would be most effective for specific types of individuals. There was also little research to demonstrate how to best combine psychologically based interventions with medically based interventions such as medications (p. 578). In addition, the longer-term benefits of these interventions have not been consistently evident within the research literature (Dworkin et al., 2005; Lynch et al.). A significant number of individuals, within a few months

following discharge from an interdisciplinary program, were reported to revert to a state/stage they exhibited prior to admission (Robinson et al., 2004; Naylor et al.).

Qualitative Research Review

Problems with current interdisciplinary treatments may be related to the lack of attention that has been paid to the actual lived experiences of people with CNP. Previous qualitative studies did little to describe the life adjustment process in CNP (Gullacksen & Lidbeck, 2004, p. 146). More recently, however, qualitative research on the lived experience of people with CNP has grown. Various studies (Asbring, 2001; Carson & Mitchell, 1998; Gullacksen & Lidbeck, 2004; Howell, 1994; Paulson, Danielson, & Soderberg, 2002; Schaefer, 1995) have identified common themes or phases which reflect how people with CNP adjust and live full lives despite their pain. Many of the characteristics identified within the studies also reflected similarities with the characteristics identified by Hernandez (1991) in her theory of integration.

Through a literature search of CINAHL, Medline, and Pubmed databases, six studies (Asbring, 2001; Carson & Mitchell, 1998; Gullacksen & Lidbeck, 2004; Howell, 1994; Paulson, Danielson, & Soderberg, 2002; Schaefer, 1995) were identified which reported themes or phases experienced by people living with CNP. No study was identified which examined CNP integration or the development or use of a tool to measure CNP integration. A description of each study is provided below (see Appendix B for an outline of each study). Lastly, the similarities between (a) the reported characteristics and statements within the qualitative studies, (b) the characteristics reported in the theory of integration (Hernandez, 1991), and (c) the items on the TDQ (Hernandez, 1995) are provided.

Howell (1994)

Howell (1994) interviewed 19 women living with various CNP syndromes of 1 to 27 years duration. Data were gathered using in-depth interviews, critical incident health diaries, and participant observation at support group meetings and analyzed using the grounded theory method of constant comparison. The researcher identified four major theoretical categories: three of which were represented as healthy phases demonstrating movement from the beginning of a woman's pain experience toward her new life of health with chronic pain. The three phases which identified the women's healthy progression through their experiences of living with chronic pain were: (a) *the pain takes over, (b) filling my life with new hope, and (c) fulfilling my life with pain.* Some of the women did not progress through these healthy phases and instead progressed toward illness. The researcher identified this progression toward illness as the fourth category: *filling my life with pain and despair.*

The *pain takes over*, also identified as healthy phase one, was characterized as focusing on the pain, searching for diagnosis and cure, and counting the losses of the former life. It was the beginning of the women perceiving the pain as chronic. They searched for a cure and tried everything to rid themselves of the pain. As this pain experience continued, the women either made a healthy progression toward phase two and three or progressed toward illness and despair.

In healthy phase two, *filling my life with new hope,* the women began to grieve the losses. The grieving process was facilitated when their chronic pain was validated by the participants themselves and/or others. It was also facilitated when the person would neither blame themselves nor feel blame from others. The women accepted their limitations, cared for themselves, shared the burden with others, took control of their pain

through self-care, and had hope for a new life. One participant stated "...it's not just a matter of taking pills – we have to do that sometimes ... but the pain is more constant and intense when I am not caring for myself physically, mentally, and spiritually" (p. 110). The women recognized that their well-being and pain relief were interactive processes. No one factor was the cause for producing or relieving pain (p. 111). All of the women acknowledged some use of medications and traditional health care, yet they assumed a primary role in promoting their health and pain management through self-care and the use of many nontraditional treatments such as relaxation, aerobic and stretching exercises, massage, yoga, imaging, prayer, medication, music, laughter, and body dialogue. "The women who perceived themselves as healthy were able to fulfill their lives despite the continuing pain" (p. 111).

In healthy phase three, *fulfilling my life with pain,* the women focused on fulfilling their lives despite the pain. They didn't deny pain but did not focus on it. They learned, from their experiences with pain, how to manage the bad days with the good days thereby avoiding despair. The women recognized how the wisdom gained from learning to live with chronic pain gave them special abilities to grow as women and give to others.

The fourth category, *filling my life with pain and despair,* followed phase one in the process. Rather than a healthy progression to living with pain, some of the women progressed towards illness. The women responded negatively to the chronicity of the pain when the pain was doubted, either by themselves or by others. The women were either blamed by others for the non-success of treatment or they blamed themselves. Continual negative responses to pain chronicity led to the women isolating themselves. The women expressed a sense of being trapped and the isolation led to despair. In conclusion, Howell noted that all the themes were not static events, neither were they

mutually exclusive, linear, nor time specific. They were all part of a dynamic process of progression to living one's life with chronic pain.

Schaefer (1995)

Schaefer (1995) examined the experiences of 36 women living with fibromyalgia (a chronic pain condition). A combination of grounded theory and feminist research methods was used to describe how the women lived with fibromyalgia. Through the descriptions, Schaefer identified the basic psychosocial process for the study as *struggling to maintain a balance.* Struggling to maintain a balance was described as "a process of negotiating the pain and discomfort associated with the illness while finding an acceptable way to live with it" (p. 96). The process was characterized by *recalling perceived normality, searching for a diagnosis, finding out,* and *moving on.*

Recalling perceived normality was the process of reflecting and talking about the life the women lived prior to the start of their illness. This reflection of their previous life was used as a basis for how life was now and, for the women, placed their story in a context that had meaning for them (p. 97).

Searching for a diagnosis was the process of "making sense out of ambiguity" (p. 97). If the women could determine what the illness was then it could be treated. Finding out was characterized by the validation of the illness. The women finally had a label for what had been thought of as an 'all in your head' phenomenon. Once the women had a diagnosis, they would make attributions as to how it had happened. For some, attributions made it easy for them to deny their symptoms or explain them as part of the normal aches and pains of living. Schaefer concluded that denial was protection against the fear of loss of control which resulted in the person being immobilized by the pain and fatigue (p.99). The women also made attributions about what aggravated the symptoms

in order to find a way to manage the symptoms. They created a balance between home remedies and medical therapy in order to control their symptoms. "If comfort was achieved the illness began to take a less significant role in their lives" (p. 101).

Moving on was considered to be a "transcending" of the illness that was characterized by *finding meaning*, and *living day by day*. In moving on, the focus of the illness was no longer central to their lives. "...they began to live with a new reality" (p. 99). Finding meaning described how the women were able to find some good as a result of their suffering. For example, some started support groups or consulted others through the disability system. Living day by day was the process of making choices to manage the illness and one's life. Health care providers attempting to impose change at this stage resulted in responses of indignation from the women. They had learned to listen to their bodies and how it reacted to certain situations. They listened to early signals from their bodies and thus were able to predict when they might not feel well and take action to avoid major setbacks.

From the interviews, Schaefer also identified that some of the women relinquished the struggle to maintain a balance. The women described the process of living with the illness as being more than they could handle. The medical treatment itself was viewed as taking over their lives, removing things from the women's own control. However, Schaefer stated perhaps this relinquishing of the struggle was only temporary. Relinquishing the struggle may give the women time to renew the energy they need to manage and maintain the balance in the future (p. 100).

Carson and Mitchell (1998)

Carson and Mitchell (1998) conducted a descriptive exploratory study with 17 people (10 women, 7 men) with persistent pain. The various pain diagnoses were

arthritis, stroke, cancer, fibromyalgia, and rheumatoid arthritis. Three themes were identified from the responses of the participants: (a) *forbearance surfaces with the drain of persistent anguish*, (b) *isolating retreats coexist with comforting engagements*, and (c) *hope for relief clarifies priorities of daily living.*

In theme one, *forbearance surfaces with the drain of persistent anguish*, the participants described how it was difficult living with pain. Pain was described as horrible, relentless, and it changed their lives: however, the participants stated they found the strength to endure the pain.

In theme two, *isolating retreats coexist with comforting engagements*, the participants reflected on how they withdrew from their day-to-day activities yet found ways to participate in comforting activities. Participants described a movement back and forth between avoiding and participating in activities depending on their pain. Medications, non-medical therapies, diversional activities and time with caring family members helped to relieve the pain. This theme was also characterized by the telling and not telling of others about their pain experiences. Participants spoke of being careful not to be seen in pain. They didn't want to worry family or push family away by talking about their pain.

Stage three, *hope for relief clarifies priorities of daily living,* was characterized by the participants describing ways in which they transcended the illness. This transcendence was achieved by remembering, keeping busy with distracting activities, and retreating from others. The participants stated they had hope for some relief from the pain even if it was only for a short time. Thinking about pain-free days or other times and situations was a way of dealing with difficult times, and a way of carrying on with life.

Participants had personal strategies for living with pain by finding ways to get some relief.

Asbring (2001)

Asbring (2001) interviewed 25 women (12 with chronic fatigue syndrome, and 13 with fibromyalgia), using a grounded theory approach, to determine how women create new concepts of identity and come to terms with the new identity following onset of illness. Two themes were identified: (a) *earlier identify partly lost*, and (b) *coming to terms with a new identity.*

In the theme *earlier identity partly lost*, participants described a longing for their past life. The women often expressed grief over the loss of their former self. The new identity was described as being separate from them. The new self had not yet been integrated with the earlier one. Also, identity was often connected with work, and if the women were now unable to work, it resulted in feelings of isolation and low self-esteem. Participants tended to withdraw from social situations. Withdrawal was described as an avoidance strategy. At times, the person avoided social interaction due to fatigue and poor health but also due to demands and expectations from others or when the person was unable to pretend that everything was normal.

Coming to terms with a new identity was characterized by getting to know the body and its limits. It was also characterized by the women finding something positive associated with the illness. It provided them time to reflect and re-evaluate their lives. This often led to changes in attitudes, strategies and habits compared to those exhibited prior to illness. Many of the women stated they had increased self-respect and personal integrity. "Approximately 80% of the women in the study described new insights in terms of illness gains" (p. 317). The women described how they sought alternative

activities to replace earlier activities. Some of the women felt they had attained a deeper understanding of themselves, others and life in general.

Paulson, Danielson, and Soderberg (2002)

Using a phenomenological hermeneutic approach, Paulson et al. (2002) examined the lived experiences of 14 men living with fibromyalgia. They identified three major themes (experiencing the body as an obstruction, being a different man, and striving to endure) which were characterized by sub-themes reflected in the men's reported experiences.

In the first theme, e*xperiencing the body as an obstruction*, the men described their pain and how it affected their body. The sub-themes identified were (a) living with a reluctant body, and (b) living day by day with a body in pain. They were in pain both during movement and when inactive. They could not participate in many of the activities they used to do prior to having pain due to fatigue, weakness, and reduced movement. They also experienced symptoms of restlessness and anxiety. The body pain fluctuated and consisted of both good days (low pain levels) and bad days (high pain levels). It was impossible for them to make plans as their pain could emerge without warning, thus, they lived one day at a time.

The second theme, b*eing a different man*, was characterized by two sub-themes: (a) not being the same man as earlier, and (b) not being really understood. The men described not being a "whole person" as they were before the illness. The researchers described how chronic illness separates the person in the present from the person in the past (p. 246). The men also described becoming angry and being easily irritated, especially when experiencing pain for periods of 24 hours. They felt other people believed they were in pain but did not truly understand. They often imagined that other

people talked about them behind their backs. In these situations, strong feelings of grief were evident (p.244).

The third theme, s*triving to endure*, was characterized by three sub-themes: (a) living as normally as possible, (b) searching for alleviation, and (c) having to nurture hope. The men described how they were reluctant to show people that they felt ill. They would agree to family functions even if they knew it was going to be difficult. They would grieve the losses of various activities, however, felt happy because they felt things could have been worse in their lives. Other qualities of life that were not associated with physical strength were appreciated. The men continued to have goals in life even though they viewed a future of never being without pain. "The men experienced a state of well-being despite being ill" (p. 247). They searched for ways to alleviate the pain but they also showed an awareness of being able to increase their ability to work and participate in activities despite the pain. They described seeing the world through 'new eyes' and having a positive attitude toward themselves which made them feel life was worth living.

Gullacksen and Lidbeck (2004)

Gullacksen and Lidbeck (2004) carried out a qualitative study, using a phenomenological framework, which examined the life adjustment process in chronic non-malignant pain. They interviewed 18 women (11 with myofacial pain syndrome, and 7 with fibromyalgia) who were participating in an outdoor pain management program. The researchers concluded that adjusting to and learning to live with chronic pain involved changes in the relationship between the individual's past, present and future life. They identified three active stages of change in the life of the individual experiencing chronic pain.

Stage one was characterized by (a) prelude (a slow beginning to the process of change due to pain being periodic and regarded as temporary), (b) struggling to restore life, (c) self-deception, (d) confirmation , and (e) acknowledgement of the pain. The women tried to hold on to their former identity and social life. Physical and mental exertions were required to maintain the previous life leading to an increase in everyday stress load. In this stage, denial was the most common coping strategy used by the participants. In order to maintain an outwardly normal appearance participants provided examples of a fast return to work even if no improvement was experienced, hiding the symptoms from others, and 'explaining the symptoms away'. Interviewees provided examples of how they tried to convince themselves and others that they did not feel ill. Receiving a diagnosis for the symptoms facilitated the adjustment process for the women. Specifically, the physician's attitude was important in facilitating personal adaptation in the adjustment process. Also, within this stage was the acknowledgement by the participant that the pain was not temporary. It was necessary for the women to give up the goal to return to life as it had been before their illness. Now the women looked toward the future which gave rise to further anxiety. For some, acknowledgement led to a crisis in their life with feelings of loss and worry about the future. Later in the process, as the women strove to change and adjust, they stopped searching for a miracle treatment and began to trust their own resources.

Stage two was characterized by (a) working through, (b) sorrow and loss, (c) losing oneself, (d) leaving the role of being sick, (e) defining the problem, (f) finding solutions, and (g) picture of the future affects coping. The admission that the pain was not going away was a clear turning point in the life adjustment process. The admission was often followed by feelings of grief. Uncertainty about what the body was capable of

threatened the women's self-image. The women tried to create new patterns and routines to their everyday life in order to re-establish their self-confidence, independence, and a normal life. The focus eventually moved from the pain and the body to important aspects of life such as family, social, and work life as well as leisure time. Once the women gained a new trust in their body, and their self-identity was adjusted, a new picture of the future developed. "This stage was a 'farewell to the past', which we would consider the first step toward a biographical reinforcement" (p. 149).

Stage three was characterized by *establishing the new course of life*. Once the individual made the transition to stage three, maintaining the adjustment was a continuous process. The researcher noted that this transition from the second to the third stage was a gradual process. The women interviewed clearly stated they oscillated between stage two and stage three. In stage three, the person was considered to now be "living with pain". The adjusted self-image allowed a foundation for the creation of new goals and a picture of the future.

Following the three stages of life adjustment, as identified by the researchers, maintaining the adjustment was a continuous process. This maintenance process included characteristics of (a) competence of handling future changes, (b) a new attitude to life, and (c) regular self-care. The women described how life had been normalized despite the pain. The women increasingly learned and became aware of what the body was capable of doing, which led to increased self-knowledge. Adapting to changes in life and their body required that the women balance what the body was capable of with that of their desires in life. For example, many of the women often decided to accept a temporary worsening of the pain to be more socially active. The women also recognized they had to carry out their regular programs of exercise, relaxation and training to avoid a worsening

in their condition (increased pain) yet were secure in knowing that there were measures they could take to control the pain. "By having a choice of their own they were also able to control their situation" (p. 150). Gullacksen and Lidbeck considered the maintenance process of living with pain as a natural part of life, and thus, it was not considered part of the adjustment process. The researchers also commented that, during the transition process and from their own experiences, there was often a reduction of medication use, less depression, and an overall enhanced quality of life.

CNP and the Theory of Integration

The characteristics identified in the six qualitative studies described above parallel the characteristics identified by Hernandez (1995) in her theory of integration (having diabetes, the turning point, and the science of one). These similarities provide further evidence emphasizing the importance of developing a tool to measure integration in individuals with CNP. The similarities are pinpointed in the following paragraphs in which characteristics of Hernandez's phases of diabetes integration are compared to the six CNP research studies previously cited.

Phase One: Having Diabetes

The 'having diabetes phase' of integration, commencing at time of diagnosis, is characterized by a lack of knowledge about the disease, a disinterest in diabetes, and/or varying degrees of commitment and involvement with diabetes management. It is also characterized by denying, minimizing, and normalizing. The focus is on being normal or being the same as one was prior to the diagnosis of diabetes (Hernandez, Antone, & Cornelius, 1999). Telling others about one's diabetes is reserved for specific individuals and situations (Hernandez, 1991).

Within the research literature examined, the lived experiences of individuals with CNP revealed similar characteristics to the having diabetes phase. Telling and not telling others about the pain and continuing in pre-pain activities in order to appear normal (Asbring, 2001; Carson & Mitchell, 1998; Gullacksen & Lidbeck, 2004; Paulson et al., 2002), minimizing the pain (Howell, 1994), and denying pain (Gullacksen & Lidbeck; Howell; Schaefer, 1995), which can be seen as a disinterest and/or described as varying degrees of commitment and involvement with pain management: all were evident in the interviews and found in the theory of integration (Hernandez et al., 1999).

Phase Two: The Turning Point

The turning point occurs when a single event or multiple life events (physiological or psychosocial) forces the individual to examine their life with diabetes and to recognize that diabetes is not going to go away: It is a personal image and health state that they must integrate into the context of their lives. The individual continues to focus on living but not at the expense of their diabetes. This phase is characterized by an increased interest and involvement in diabetes and its treatment. The person self-experiments in order to develop and test a way of diabetes management that works for them and is part of their lives, rather than the diabetes management schedule and duties demanded by others (Hernandez, 1991).

Within the CNP literature, the life event of diagnosis with chronic life-long pain took on what could be described as an emotional crisis more so than an acute physical crisis, as may occur with an individual with diabetes. This life event came with the realization that the pain was not temporary and was to be a permanent fixture in the person's life (Asbring, 2001; Gullacksen & Lidbeck, 2004; Howell, 1994; Schaefer, 1995). Grieving the life the person had before pain was a common characteristic

(Asbring; Gullacksen & Lidbeck; Howell; Schaefer). Compared with those studied by Hernandez (Hernandez, 1991; Hernandez et al., 1999), similarities are noted, almost to the sameness of expressions and phrases used to describe the impact and crises. The participants in many of the CNP studies described re-establishing their self-confidence by creating new patterns and routines in their day-to-day life. The same was found in diabetes. The focus in life was moved from the pain and the body to other important parts of life such as family, social relationships, work, and leisure time. The individual with CNP was occupied with the task of learning to live with their new identity. They assumed a primary role in promoting their pain relief and health through self-care and healing modalities (Gullacksen & Lidbeck; Howell; Schaefer). Those with diabetes expressed similar goals and tasks as they learned to live with diabetes (Hernandez, 1991; Hernandez et al., 1999).

Phase Three: Science of One

The science of one is a gradual progression from the second phase and is termed "a personalized science of living with diabetes" (Hernandez, 1997, p.19). It is characterized by the individual striving to understand his or her diabetes. The focus is on living one's life with diabetes. In the third phase, integration of the personal self and the diabetic self occurs more fully. The personal self is the person prior to the diagnosis of diabetes. The diabetic self is the new person living with diabetes. In the third phase the person begins to "tune-in" to his/her own body cues, develops a deep self-awareness of how his/her body responds in certain situations, and relies on this knowledge to maintain good glycemic control. The individual successfully integrates diabetes into their life without it being the major focus of their life.

The characteristics of the science of one phase were also evident within the CNP studies. In the final phases identified by many of the researchers, participant responses spoke of getting to know the limits of their body and the mind in relation to various activities and they were aware of their pain but it was no longer a focus in their life (Asbring, 2001; Gullacksen & Lidbeck, 2004; Howell, 1994; Schaefer, 1995). Gullacksen and Lidbeck specifically commented how, from their experiences in the field, there was often a reduction of medication use, less depression, and an overall enhanced quality of life for an individual with CNP. This could be compared with the maintenance of good glycemic control in an individual with diabetes. Of particular interest is the reference in three of the six studies specifically to the concept of there being two selves, also identified by Hernandez (1991) in people with diabetes. Several researchers (Asbring, 2001; Gullacksen & Lidbeck; Paulson et al, 2002) made reference to the two aspects of the individual with CNP: the one before pain diagnosis, and the one now living with pain. Asbring in particular identified that adjustment occurred once the 'two selves' were integrated.

Hernandez (1995) developed a questionnaire to measure integration of diabetes (The Diabetes Questionnaire [TDQ]). In light of the similarities between characteristics of diabetes integration and the reported lived experiences of people with CNP outlined above, statements made by people living with CNP were mapped to items on the TDQ (see Appendix C)

Summary

The repeated frequencies, similar patterns, and adaptive responses of those living with CNP when compared to the experiences of people living with diabetes, have provided evidentiary support for an integration process in those who have been diagnosed

with CNP, therefore, warranting the development of a tool to measure integration. The importance of instrument development, not only for integration but also for health in general, is to draw attention to a specific problem and develop interventions which will resolve the problem (McDowell & Newell, 1996, p. 11). According to McDowell and Newell "as societies evolve health problems alter in salience and new health indicators must be chosen to reflect changing health issues"
(p. 11).

The integration tool developed in this study, if shown to be reliable and valid, could have the potential for use in staging future treatment protocols and CNP research, thus promoting the personalization of individually designed treatment and evaluation of treatment outcomes. Strategies that promote the integration process for people with CNP may lead to more positive outcomes of overall life quality, lower CNP-associated illnesses, and the ability to successfully self-manage pain over the long term following increasingly insightful, responsive, and personally paced chronic pain management resources, programs, or interventions.

CHAPTER THREE: METHODOLOGY

There are two overarching purposes of this study: (a) to develop a questionnaire to measure CNP integration, and (b) to assess the new instrument for validity and reliability. This chapter describes the research design, methods of development and instrument testing, and the ethical consideration conducted for this study.

Research Design

According to Norbeck (1985), the results of psychometric testing should include at least one type of content validity, test-retest reliability, internal consistency reliability, and at least one type of criterion-related or construct validity. This study was designed to incorporate each of the required reliability and validity measures identified by Norbeck.

Qualitative strategies (including focus group methodology) were used for instrument development and ensured face and content validity of the final instrument titled the Chronic Pain Integration Questionnaire (CPIQ). The CPIQ was tested on individuals living with CNP to determine the test-retest reliability, internal consistency reliability, criterion-related validity (concurrent validity) and construct validity of the instrument. The following section describes the CPIQ development and testing process.

Questionnaire Development

Construction of the Initial Draft through a Review of the Literature

Questions for a quantitative instrument are often derived from clinical experience, theory, prior research, or qualitative inquiries (Polit & Beck, 2004). Components of each of these practices were incorporated into the development of the CPIQ. On reading Hernandez's theory of integration (Hernandez, 1991), and based on five years of experience working with individuals with CNP, the author recognized similarities between integration of diabetes to characteristics and expressions of those living with

CNP. A review and comparison of qualitative research studies examining the lived experience of CNP to that of the theory of integration (Hernandez, 1991) and The Diabetes Questionnaire (TDQ; Hernandez, 1995) provided further evidence to the concept of integration in adults with CNP as previously outlined in chapter two (see Appendix C). The similarities noted between Hernandez's theory of integration (Hernandez, 1991), the lived experiences of people with CNP, and the TDQ formed the basis of the first draft of the CPIQ.

Even though the items on TDQ ask about the person's life with diabetes, many of the items were linked to similar statements made by people with CNP and findings within the CNP qualitative studies. In light of the similarities many of the items on the TDQ were restructured, using words and phrases identified by participants in the qualitative CNP studies, to form the items that comprised the first draft of the CPIQ. For example, item four on the TDQ was "I work to try and keep my blood sugar in a certain range" (Hernandez, 1995). Item six on the first draft of the CPIQ was "I must take regular care of myself (physically, mentally, spiritually) to manage my pain day-to-day" (see Appendix D). The *work* identified in the TDQ was expressed as *care of the self* by participants in some of the qualitative studies (Gullacksen & Lidbeck, 2004; Howell, 1994).

As CNP and diabetes are two different illnesses, it is likely CNP integration may have different key components than diabetes integration: Words and phrases used by the participants in the qualitative CNP studies were used as a guide by the researcher for additional item development not captured in the TDQ. The first draft of the CPIQ included 23 items (see Appendix D).

Review by Expert CNP Practitioners

The first draft of the CPIQ (see Appendix D) was revised based on a review of experts in the field of CNP. According to Polit and Beck (2004), the substantive content in a first draft of an instrument should be discussed with experts. Distribution to experts in the field of CNP was needed to evaluate the questionnaire and comment on whether the items in the draft CPIQ were consistent with statements expressed by people living well with CNP (i.e. theoretically identifying integration), and if there was a need to add, remove, or revise items.

Twelve expert practitioners in the field of CNP were identified as potential reviewers of the first draft of the CPIQ. An expert in the field of CNP was defined as having worked a minimum of five years with individuals with CNP. A demographic data sheet identifying (a) professional designation (Registered Nurse, Physiotherapist, Occupational therapist, Physician, Psychologist, Social Worker, other) and (b) number of years working with individuals with chronic pain was included with the questionnaire to determine the qualifying criteria of the expert (see Table 1). Each of the potential participants were provided with a letter of information outlining the requirements of the study (see Appendix E). Responses were anonymous. Return of the completed questionnaire reflected consent by the participant (a self-addressed, stamped envelope was provided to facilitate return of the questionnaire to the researcher).

Four experts returned the completed questionnaire; three were the minimum allowable (Polit & Beck, 2004). The experts rated the questionnaire items on a six-point Likert scale identifying the relevancy of the statement on the draft CPIQ to that experienced by people living well with chronic non-malignant pain (one = *strongly disagree* to six = *strongly agree*). An individual living well was characterized as

Table 1

Sample Characteristics

Variable	N (% total)
Professional Designation (Total $N = 4$)	
Registered Nurse	3 (75%)
Occupational Therapist	1 (25%)
Number of Years Working with Individuals with Chronic Pain (Total $N = 4$)	
5 Years	1 (25%)
12 Years	1 (25%)
17 Years	1 (25%)
48 Years	1 (25%)

someone who does not dwell on CNP, does not make CNP the focus of living, has a set routine to manage CNP, has life goals, and has low levels of anxiety and/or depression. Experts were also asked to comment on any additional items that were not captured in the draft version, but would be felt to be important statements made by individuals living well with CNP.

Based on the panel of experts' feedback, items 1, 8, 13, and 18 were revised slightly with the addition of the word *mind* or *thoughts*. For example, item one "living with chronic pain has taught me how to read signals from my body" was changed to "living with chronic pain has taught me how to read signals from my body and mind". Item eight "living with chronic pain teaches me to pay attention to my body" was

changed to "living with chronic pain teaches me to pay attention to my body and thoughts". No specific suggestions were provided for additional items.

According to Norbeck (1985), in psychometric testing at least one type of content validity needs to be analyzed. There is no solely objective method to measure face and content validity of an instrument: It is based on judgment (Polit & Beck, 2004). If an instrument looks as though it is measuring the appropriate construct it is said to have face validity. If the same instrument has an appropriate sample of items for the construct being measured, it is said to have content validity (Polit & Beck).

A common method to evaluate and document the face and content validity of a new instrument is through the use of a panel of experts (Polit & Beck, 2004). Each expert rates the relevancy of the items on the questionnaire to the construct being measured. Likert scales are used for the expert to provide feedback as to the relevancy of the item (For example, one = *not relevant*; four = *very relevant*). Two content validity index (CVI) scores (item-level, I-CVI, and scale-level, S-CVI) are calculated based on the experts' ratings of item relevance (Polit & Beck, 2006). If a 4-point scale is used, the I-CVI score is calculated as the number of experts giving a rating of either three or four for each item divided by the total number of experts. Several methods may be used to determine the S-CVI score (Polit & Beck, 2006). One method (used in this study) is to compute an average of the I-CVI scores (the sum of all I-CVI scores divided by the number of items). According to Polit and Beck (2006) a minimum S-CVI of .80 or better indicates good content validity.

The I-CVI (for this study) was calculated by determining the proportion of each item rated by the experts as five or six on a 6-point Likert scale (one = *strongly disagree*,

six = *strongly agree*). The average of the I-CVI scores was computed to determine the S-CVI score.

Low I-CVI scores would constitute removal of the item from the questionnaire (Polit & Beck, 2006) however, a review of all 23 items by the focus group participants (the true experts in the field) was deemed valuable and necessary before final decisions were made about item inclusion or deletion.

Focus Group with CNP Clients

The purpose of the focus group session was to further refine the CPIQ based on the participants own experiences with CNP and to enhance the content validity. Each participant was encouraged to share his or her opinion about the items on the CPIQ. If two or more participants disagreed about the relevance of an item, the item was removed from the CPIQ. As discussion progresses in a focus group, participants become increasingly aware of their commonalities and easily identify areas in which they both agree or disagree (Morgan, 1998). This assists the researcher in identifying issues that might otherwise have been ignored, as well as providing strength for those issues deemed to be important for inclusion. "Using focus groups to inform questionnaire development enhances the researcher's chances of asking appropriate questions" (Kingry, Tiedje, & Friedman, 1990, p. 125) and contributes to increased questionnaire validity.

Four individuals known to be living well with CNP participated in one focus group session which was led by the researcher. According to Kingry, Tiedje, and Friedman (1990), a group of 4 to 12 individuals is adequate for focus group formation. Kingry et al. also identified homogeneity as the key principle in forming focus groups, which was determined by the purpose of the study (i.e., adults with a CNP diagnosis and living well with CNP).

The participants were recruited with assistance from a Registered Nurse (RN) working in a pain management program. Clients exhibiting characteristics similar to integration (i.e., focus is on living; not the CNP, person tunes-in to body to manage pain, depression is lessened, and quality of life enhanced) were approached in person by the RN and asked if they would be interested in participating. Those individuals who verbalized interest in participating were later contacted by phone by the researcher (all were given a letter of information, including consent, outlining the details of the study [see Appendix E2]). A verbal explanation of the focus group requirements was provided (including audio taping), questions from the participant were answered, and tentative dates were set for the focus group session. The participants were also informed of the voluntary nature of the study and their rights to withdraw from the study at any time with no consequence. Furthermore, it was explained that no remuneration would be given for their time, but an opportunity to voluntarily enter a draw for $25.00 would be available at the completion of the focus group session. At the end of four months, five participants had agreed to participate and a set date had been determined. Two days prior to the date of the focus group session, one participant withdrew from the study due to a conflicting meeting on the same date, leaving a total of four participants.

The focus group session of 2.5 hours was held in an office setting. The office was opened after hours specifically for the focus group session in order to create a quiet atmosphere with no distractions. The room consisted of one couch and four comfortable chairs (arranged in a circle to facilitate the flow of discussion), a flip chart, and a table in the center to hold two recording devices and writing materials (pen and paper).

At the start of the focus group session, participants were given the letter of information outlining the study. A consent form for audio taping (see Appendix E3) was

presented to the participants to review and sign. The voluntary nature of the session and their right to withdraw at anytime was verbally reinforced.

Participant discussion was documented on a flipchart which was visible to each of the four focus group participants. A research assistant was recruited to record participant comments on the flip chart, leaving the researcher available to concentrate on and facilitate the discussion, insuring all thoughts and ideas about integration and the questionnaire items were captured. The participants were provided with pen and paper as needed to write down thoughts, ideas, and suggestions for item development. Voice recording of the session was conducted using two recorders to decrease the chance of loss of data due to machine error.

The focus group recordings were transcribed verbatim by a professional transcriptionist and the transcription was verified by the researcher. The flip-chart, voice recording, and transcription were reviewed by the researcher and compared to the draft CPIQ to insure accurateness, make revisions as required, and to insure all aspects of integration to CNP were captured within the CPIQ.

In addition to providing opinions about items on the CPIQ, the focus group participants developed their own definition of integration: "Integration is an ongoing process in which the person with chronic pain rebuilds oneself/evolves, becoming a mentally and physically stronger individual and creating a sense of harmony and control in one's life.

Following the review by the researcher, the CPIQ was mailed to the focus group participants for completion and additional comments. The focus group participants were also asked to provide feedback regarding comprehensibility (clarity of directions and

readability of items), the format of the questionnaire, and to determine the length of time required to complete the CPIQ.

Once the CPIQ was completed and returned by the focus group participants, six guidelines replicated from Hernandez's (1997) research were used to make decisions regarding the inclusion or exclusion of questionnaire items (see Appendix F). The responses from the panel of experts (item CVI scores) were also used in order to capture all opinions related to the items. Any revisions required, based on the feedback obtained, were completed and the CPIQ was finalized and ready for testing. Feedback related to the clarity of instructions and the wording of items resulted in no changes. Instructions and wording of items were felt to be clear. The final CPIQ consisted of 17 items (see Appendix G). The average length of time for completion was five minutes. Two items on the CPIQ (item 7 and item 13) were negatively stated to avoid response bias (Polit & Beck, 2004).

Lastly, the focus group participants were asked to provide feedback related to the definition of integration developed during the focus group session. The only suggestion by the participants was to remove the words "rebuilds oneself". The agreed on definition is "Integration is 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".

Instrument Testing

The above section has described the development of the 17-item CPIQ along with a discussion of the process of insuring acceptable content validity. In the next section the testing of the newly developed CPIQ for validity (construct and criterion-related) and reliability (internal consistency and stability) will be discussed.

The Questionnaire Package

A final sample of 106 individuals with CNP completed the CPIQ along with two additional instruments: (a) The Herth Hope Index (HHI; Herth, 1992) and (b) The Euroqol Quality of Life Scale (EQ-5D; EuroQol Group, 1990). A copy of each of the questionnaires is available in Appendix H and they are described in detail in this section.

The HHI (Herth, 1992) and the EQ-5D (EuroQol Group, 1990) were chosen in order to measure the relationships between integration, hope, and health-related quality of life. Several authors have reported the impact of CNP on health related quality of life (Becker et al., 1997; Veillette et al., 2005) and hope (Hitchcock et al., 1994). In addition, two outcomes of the integration process, identified by Whittemore (2005), were satisfaction with one's quality of life and renewed life purpose and meaning. It was presumed that there would be a positive relationship between integration, hope, and quality of life. Individuals who have more fully integrated CNP in to their life would express feelings of hope in various aspects of their life and would look positively toward the future (feelings of hopelessness would be diminished). In addition, individuals who have more fully integrated CNP in to their life would identify themselves as healthy despite their pain condition and verbalize a satisfaction in overall life quality.

The Herth Hope Index (Herth, 1992) is a 12-item adapted version of the Herth Hope Scale (HHS) used to measure different levels of hope. Items on the HHI are in Likert-format (one = *strongly disagree*, four = *strongly agree*). Scoring of the HHI consists of summing the ratings for the subscales and for the total scale (only the total scale sum was used in this study). The HHI demonstrated an alpha coefficient of .97, a 2-week test-retest reliability of .91, criterion-related validity when correlated with the HHS

(r = .92) and the Existential Well-Being Scale (r = .84), and divergent validity with the Hopelessness Scale (r = -.73).

The EQ-5D is a generic (disease non-specific) health-related quality of life (QOL) scale, which expresses health status in a single index score (McDowell & Newell, 1996). It is comprised of five questions with three possible answers for each item. In addition, there is a visual analogue scale (VAS) to indicate the general health status with 100 indicating the best health status. Scoring of the EQ-5D consists of using weights. The weights may either use the respondent's own expressed preferences using a 0-to-100 scale (VAS) that indicates overall value of one's current state of health, or established scale values (weights of established scale values were used for this study). Alternatively, a score can be based solely on the respondent's own value placed on the VAS (the VAS scores were also analyzed in this study). Test-retest reliability was reported as .86. It correlated .51 with depression scores and .44 with anxiety scores from the Hospital Anxiety and Depression scale. When used to assess QOL in patients with Parkinson's disease (Schrag, Selai, Jahnshahi, & Quinn, 2000), the EQ-5D correlated with the PDQ-39 (r = -.75, $p < 0.0001$) as well as the physical score of the SF-36 (r = .61, $p < 0.0001$).

The questionnaire package also included a letter of information describing the study and the expectations of the participant (see Appendix E4). Return of the questionnaire implied consent by the participant.

Recruitment and Sample

The questionnaire package (inclusive of the final CPIQ, HHI, EQ-5D) was distributed by hand, post, email, and to five waiting rooms over a three-month period. The inclusion criteria for participation was (a) a diagnosis of a CNP condition, (b) age 18 or older, and (c) ability to read and write English. Participants were excluded if they

identified a pre-existing diagnosis of anxiety and/or depression. Each package included a postage paid return envelope in order to facilitate return of the completed questionnaire to the researcher (except for those distributed by email, as will be discussed later in this chapter).

Demographic data were collected and consisted of age, sex, race, number of years living with CNP, type of diagnosis, location of pain on body, pre-existing anxiety or depression, and identification of anxiety or depression post CNP diagnosis (see Appendix I). Chronic non-malignant pain (CNP) was termed chronic pain in order to simplify the terminology and facilitate understanding (the word *malignant* may be more difficult for participants to understand). Chronic pain was defined using the same definition for CNP outlined in chapter one (pain that has lasted longer than 6 months, has gone beyond the usual healing time, and is due to non life-threatening causes [Dunajcik, 1999, p. 471]).

Some participants were recruited by a Registered Nurse (RN) working in a pain management program. One hundred and fifty questionnaire packages were distributed by mail to former patients of the program. An additional 46 questionnaires were distributed by hand to patients currently in the program. Of the mailed questionnaires, 11 were returned undeliverable.

Twenty-five questionnaires were distributed by the researcher to each of five waiting rooms: three physiotherapy clinics, one chiropractic clinic, and a general practitioner's office ($n = 125$). At the completion of the study, 37 questionnaire packages from the various waiting rooms remained unused. It can be assumed that 88 questionnaire packages were taken and had the potential to be returned to the researcher.

Through these recruitment strategies a total of 89 questionnaires were received. In an attempt to obtain an even larger sample size, a further set of questionnaire packages

were distributed by email to the staff and faculty at two educational institutions in Windsor, Ontario: (a) St. Clair College, South Campus, and (b) The University of Windsor. Available to staff and faculty on the email was the letter of information outlining the requirements for the study and a $25.00 draw ballot. The recipients of the email who were willing to participate were instructed to download, print, and return the completed questionnaire package in an unmarked envelope to the researcher's mailbox (St. Clair College) or to the secretary in the Faculty of Nursing (University of Windsor). The total number of staff who may have CNP at either of these sites is unknown. The number of potential participants that may have received the questionnaire package is also unknown. Twenty-six questionnaire packages were completed and returned through the email recruitment.

In total, through all recruitment efforts (inclusive of the responses from the four focus group participants), 119 completed questionnaire packages were received: Eleven were unable to be used due to the exclusion criteria and two were removed due to missing data (see chapter 4 for a detailed description of data screening). The removal of these 13 questionnaires resulted in a final sample size of 106.

CPIQ Analysis

The final sample size (N = 106) is supported by McDowell and Newell (1996) who stated there should be a minimum of five respondents per item. According to their criteria, a 17-item scale, such as the CPIQ, would require a minimum of 85 respondents. Other authors identified samples of 100 as sufficient (Kline, 1994; Dixon, 2001). In addition, prior to commencing factor analysis, it is appropriate to calculate a measure of sampling adequacy (Dixon; Tabachnick & Fidell, 2001): the Kaiser-Meyer-Olkin measure (KMO). The KMO must be a minimum of .60. The KMO calculated for the

CPIQ was .84 which is well above the .60 minimum. A KMO of .84 provides additional supporting evidence to the adequacy of the sample size ($N = 106$) for the study.

Of all the completed questionnaires returned, a small number ($n = 10$) had less than 5% unanswered items on the demographic page, the CPIQ, or the HHI. Case means were calculated to replace the missing value on the HHI specifically ($n = 1$). Questionnaire packages that had missing values on the CPIQ resulted in removal of the questionnaire package from the study. A complete description of data screening is provided in chapter 4. The procedure for analyzing the validity and reliability of the CPIQ is outlined below.

Validity

Content validity. The methods for ensuring adequate content validity during instrument development have already been discussed earlier in this chapter.

Concurrent validity. According to Norbeck (1985), the results of psychometric testing should include at least one type of criterion-related or construct validity. Criterion-related validity is the determination of the relationship between an instrument and an external criterion (Polit & Beck, 2004). "The instrument is said to be valid if its scores correlate highly with scores on the criterion" (p. 424). Concurrent validity is considered a criterion-oriented validation procedure (Cronbach & Meehl, 1955). Concurrent validity is identified as "an instrument's ability to distinguish individuals who differ on a present criterion (Polit & Beck, p. 425). The scores from the CPIQ (test score) were correlated with the scores from the HHI and the EQ-5D (criterion scores) in order to measure concurrent validity. This method is considered to be concurrent validity as the test scores were determined at the same time; rather than at separate times which would measure predictive validity (Cronbach & Meehl).

Construct validity. According to Cronbach and Meehl (1955), a construct is "some postulated attribute of people, assumed to be reflected in test performance" (p. 283). Construct validity is studied when "the tester has no definite criterion measure of the quality with which he is concerned, and must use indirect measures" (p. 282). The criterion of interest in this study was integration and no known tool to measure integration in adults with CNP had been previously identified.

The procedures providing evidence for construct validity are (a) group differences, (b) correlation matrices and factor analysis, (c) studies of internal structure, and (d) studies of change over occasions (Cronbach & Meehl, 1955). Integration is a new construct in CNP and the CPIQ is a newly developed tool, therefore, factor analysis was conducted in this study. Several sources report the long association between factor analysis and construct validity and support the use of factor analysis as an approach to construct validity (Nieswiadomy, 2008; Tabachnick & Fidell, 2001; Thompson & Daniel, 1996). According to Dixon (2001),

> factor analysis is an important statistical tool for providing validity evidence concerning the structure of instruments....items that form a strong factor in factor analysis generally yield acceptable alpha coefficients when grouped together in a scale, thus providing evidence of internal consistency reliability and supporting beginning evidence of construct validity for a developing scale (p. 307).

Future studies, using the other procedures identified by Cronbach and Meehl (1955), are recommended to build further evidence for the construct validity of the CPIQ. A detailed description of the method of factor analysis is described below.

Factor analysis. Factor analysis is the reduction of data into a smaller number of factors (Dixon, 2001). A factor is defined as a group of items that appear to belong

together. "One assumes that observed covariation between variables is due to some underlying common factors" (p. 250). Some benefits of factor analysis for this study include (a) assisting the researcher to make decisions about which items should be removed from the CPIQ, and (b) determining the justification for the use of summated scales (Dixon, 2001).

The type of factor analysis computed in this study was exploratory factor analysis. The extraction method used was principal component analysis (PCA). According to Dixon (2001), there is potential for differences between extraction methods in factor analysis. Running multiple factor analyses of the same dataset with various extraction methods enables the researcher to identify distinctions and other decision points in the factor analytic process (p. 331).

Within the research literature, the words factor and components are often used interchangeably (Tabachnick & Fidell, 2001). The term component was used in this study since PCA was the extraction method of choice.

Two processes were used to determine the appropriate number of components in this study: (a) an analysis of the scree plot, and (b) an assessment of interpretability by the researcher (Tabachnick & Fidell, 2001). A scree plot is the graphing of the eigenvalues. Eigenvalues may often overestimate the number of components yet, when placed on a graph "...the relative importance of each factor becomes apparent" (Field, 2005). The appropriate number of components can be determined by looking at the characteristic curve of the scree plot (DeVellis, 2003; Field). The first component has a relatively high eigenvalue and is followed by successive components in descending order until there is a leveling off. "The vertical portion of the plot is where the substantial factors are located while the horizontal portion is the scree, or rubble, that should be discarded" (DeVellis, p.

114). After review of the scree plot, alternatives need to be assessed in order to determine the result that is the most interpretable and has the best fit theoretically (Tabachnick & Fidell, 2001). A cutoff point of 0.30 was used for component loading and two rotation methods, orthogonal (Varimax) and oblique (Direct oblimin), were used to determine the solution that could be most meaningfully interpreted (Dixon, 2001).

Reliability

Test-Retest reliability. The first thirty questionnaire packages distributed included a second questionnaire package for retesting. The respondents were asked to complete the questionnaire package and then complete the same questionnaire 7 days later in order to assess the CPIQ's stability over time. The short time period was chosen since the chance of measured attributes changing increases over time (Polit & Beck, 2004). The stability of an instrument is considered to be the extent to which similar results are obtained at two separate time frames: Test-retest reliability procedures are one assessment of an instrument's stability (Polit & Beck, 2004). Of the thirty questionnaires distributed for retesting, 11 were returned. Pearson's r (reliability coefficient) was calculated based on the responses from the 11 participants. Pearson's *r* is a numeric index of the magnitude of the test's reliability: reliability coefficients above .70 are considered satisfactory (Polit & Beck). In addition to a calculation of Pearson's *r*, a paired sample *t*-test was conducted to determine if the pre-test scores were similar or significantly different to the post-test scores.

Internal consistency reliability. According to Polit and Beck (2004), Cronbach's alpha (coefficent alpha) is the most widely used method for evaluating internal consistency. A value greater than .70 was determined to be desirable for this study; higher values reflect a higher internal consistency. Item-total correlations were also

analyzed. Correlations less than .30 would be considered unacceptably low and would be removed in a stepped fashion beginning with the lowest item until all remaining items were above .30.

Ethical Considerations

This study conformed to Tri-Council Standards for the ethical conduct of research and approval was obtained from the Research Ethics Boards of the University of Windsor in Windsor, Ontario. Informed consent was obtained from all study participants (written consent from the focus group participants and implied consent from all other participants). The data were coded and stored in a locked cabinet, and accessible only to the researcher. Questionnaires distributed to participants were coded in numerical sequence from A1 to A(n). No information, leading to identification of a subject, was required for questionnaire completion and there was no available means to match a subject to a specific completed questionnaire.

CHAPTER FOUR: RESULTS

This chapter summarizes the results of the statistical analyses. A description of the data screening process is provided followed by a summary of the sample characteristics. Finally, the statistical analysis associated with each of the required reliability and validity measures for instrument testing is presented. All statistical calculations of the data were completed through the use of the Statistical Package for the Social Sciences (SPSS) version 16 computer program.

Data Screening and Analysis

Screening of the data by the researcher revealed no missing data on the items returned by the panel of experts and the four focus group participants. However, there were missing data in the questionnaire packages used for instrument testing (demographic data sheet, CPIQ, and HHI specifically). Of the 108 questionnaires returned ten had missing data (1%): eight questionnaires were missing one item and two were missing two items. In order to avoid dropping all ten cases, which would result in a reduction in sample size and statistical power (Fox-Waslyshyn & El-Masri, 2005), case mean substitution was used to replace missing values on the HHI specifically (an established questionnaire). Using case means to estimate the missing value is a recognized solution for missing data (Polit & Beck, 2004). Since the amount of missing data was low (less than 5%), the choice of approach to handling missing data should have little impact on the overall statistical results (Polit & Beck; Roth & Switzer, 1995).

Two questionnaire packages had missing data specifically on the CPIQ. Case means substitution would not be appropriate in this case as the CPIQ is not an established questionnaire. The two questionnaire packages were removed from the study reducing the total sample size to 106.

Sample Characteristics

Panel of Experts (Draft Two)

Subjects were recruited by phone, post, or email from within the Windsor, Ontario region (n = 3), and the London, Ontario region (n = 1). Of the four experts, three (75%) were Registered Nurses (RN) and one (25%) was an occupational therapist; fifty percent had between five and twelve years of experience and the other fifty percent had seventeen or more years of experience.

Focus Group Participants (Draft Three)

Focus groups participants (n = 4) were recruited in person with the assistance of an RN working at a pain program. There was an even distribution in relation to sex (two men and two women). The mean age of the sample was 49 years. All participants reported their race as white. The mean length of time living with pain was 12 years (SD ± 8). Two of the participants had completed a pain management program; the other two had not. In addition, each participant had one or more differing CNP diagnoses (spinal stenosis, myofacial pain disorder, headache, low back pain, neuropathy, rheumatoid arthritis, repetitive strain injury).

Instrument Testing (Final CPIQ)

Participants for instrument testing were recruited in person, by post, or by email. Of the 119 returned questionnaires 13 were deemed invalid and were not included in the analysis (N = 106). Of the 13 invalid questionnaires, eleven were removed from the study due to the exclusion criteria: identification of a pre-existing diagnosis of anxiety and/or depression. The two additional questionnaires were removed due to missing data on the CPIQ (as outlined previously). The majority of the participants reported being between the ages of 40 and 49 (37%), were women (64.8%), and reported their race as white

(96.2%). The mean length of time living with chronic non-malignant pain was 7.79 years (SD ± 7.67) and the most common CNP diagnosis was low back pain (38.5%). See Table 2 and 3 for a complete summary of the sample characteristics.

CPIQ Statistical Analysis

Validity

Face and Content Validity

As stated previously in chapter 3, there is no solely objective method to measure content validity of an instrument (Polit & Beck, 2004). Using experts in the field however, has become a common method to evaluate and document content validity of a new instrument. Two separate reviews by experts (using two different expert groups) were used for this study: (a) a group of four clinical experts having worked a minimum of five years with CNP individuals, and (b) a focus group of four participants diagnosed and living well with CNP. The feedback from one or both of the groups, at various points of CPIQ development (drafts 1-3), was used to make decisions about item inclusion/exclusion.

Draft one. The first draft of the CPIQ was distributed to a panel of expert practitioners ($n = 4$). Once the questionnaire was returned to the researcher, the content validity index (CVI), including both item (I-CVI) and scale (S-CVI) scores (Polit & Beck, 2006), was calculated by determining the portion of items rated as five or six on a 6-point Likert scale provided to the experts (one = *strongly disagree*, six = *strongly agree*). See Table 4 for the panel of experts' I-CVI scores.

According to Lynn (1986), all experts must agree on the content validity of an item (I-CVI of 1.00) if the panel consists of five or fewer experts. This standard can be relaxed when there are six or more experts (a minimum I-CVI of .78). Only nine of

Table 2

Sample Characteristics

Variable	*n* (% total)	Variable	*n* (% total)
Age ($N = 106$)		Gender ($N = 105$)[a]	
18-29	3 (2.8%)	Male	37 (35.2%)
30-39	13 (12.3%)	Female	68 (64.8%)
40-49	41 (38.7%)	Years with Pain ($N = 105$)[a]	
50-59	37 (34.9%)	1-5 Years	58 (55.2%)
60-69	7 (6.6%)	6-10 Years	22 (20.9%)
70-79	4 (3.8%)	11-15 Years	14 (13.3%)
80-89	1 (0.9%)	16-24 Years	7 (6.6%)
≥90	0	≥ 25 Years	4 (3.8%)
Ethnicity ($N = 104$)[a]		Anxiety[b] ($N = 106$)	
White	100 (96.2%)	Yes	14 (13.2%)
Black	2 (1.9%)	No	92 (86.8%)
Asian	2 (1.9%)	Depression[b]($N = 106$)	
Hispanic	0	Yes	42 (39.6%)
Other	0	No	64 (60.4%)
Participation in a Chronic Pain Management Program ($N = 105$)[a]			
Currently Enrolled	19 (18.1%)		
Completed Program	38 (36.2%)		
Never Participated	48 (45.7%)		

[a] *N* reduced from 106 due to questionnaires with missing demographic data.
[b] Diagnosed post CNP diagnosis.

Table 3

Sample Characteristics

Variable	*n* (% total)
CNP Conditions ($N = 104$)[a]	
Fibromyalgia	9 (8.7%)
Rheumatoid Arthritis	9 (8.7%)
Sciatica	15 (14.4%)
Low Back Pain	40 (38.5%)
Arthritis	35 (33.7%)
Herniated Disc	24 (23.1%)
Osteoarthritis	16 (15.4%)
Osteoporosis	5 (4.8%)
Reflex Sympathetic Dystrophy (RSD)	5 (4.8%)
Degenerative Disc Disease (DDD)	25 (24.0%)
Neuropathy (nerve pain)	37 (35.6%)
Headache	19 (18.3%)
Other	19 (18.3%)
Number of CNP Conditions per Participant ($N = 104$)[a]	
One Condition	45 (43.3%)
Two Conditions	19 (18.3%)
Three Conditions	11 (10.6%)
Four Conditions	14 (13.5%)
≥ Five Conditions	15 (14.4%)

[a] *N* reduced from 106 due to questionnaires with missing demographic data.

Table 4

Content Validity Index (CVI): Panel of Experts (PE) and Focus Group (FG) Review

Item	I-CVI [a] PE	FG Review	Item	I-CVI [a] PE	FG Review
1	.75	Item deleted	13	.75	Reworded (FG I-CVI=1.00)
2	1.00	Reworded (FG I-CVI = 1.00)	14	.50	Item deleted
3	1.00	I-CVI = 1.00[b]	15	.50	I-CVI = .75[b]
4	.75	Item deleted	16	.75	I-CVI = .88[b]
5	.50	Item deleted	17	1.00	I-CVI = 1.00[b]
6	1.00	I-CVI = .88[b]	18	.75	Item deleted
7	1.00	I-CVI = 1.00[b]	19	.75	Reworded (FG I-CVI=1.00)
8	.75	Reworded (FG I-CVI = 1.00)	20	1.00	I-CVI = 1.00[b]
9	1.00	Reworded (FG I-CVI = 1.00)	21	.25	Item deleted
10	.75	I-CVI = .88[b]	22	1.00	I-CVI = .88[b]
11	1.00	I-CVI = 1.00[b]	23	.50	Reworded (FG I-CVI=1.00)
12	.50	Item deleted			

Scale CVI (S-CVI) [c]

Initial S-CVI = .77 (no items removed)

Final S-CVI = .88 (seven items removed: 1, 4, 5, 12, 14, 18, 21)

[a] Item CVI score (I-CVI) = total number of experts rating item as 5, or 6 on a Likert scale divided by the number of experts (n = 4).

[b] Item CVI scores based on panel of experts and focus group participants (n = 8)

[c] Sum of I-CVI scores divided by the total number of items (PE I-CVI scores only).

the 23 items in the first draft of the CVI had I-CVI scores of 1.00 (items 2, 3, 6, 7, 9, 11, 17, 20, 22). The computed scale CVI (S-CVI) was .77. If following the criteria reported by Lynn (1986), items with an I-CVI less than 1.00 should be deleted, however, as stated in chapter 2 all 23 items were reviewed first by the focus group participants before considering deletion of any item. The process used for item deletion is described in detail in the next section and displayed in Table 4.

Draft two. The second draft of the CPIQ, consisting of the same 23-items as draft one with some rewording, was further refined through feedback from a focus group of individuals living with CNP. Items 1 and 18 were removed as the focus group members felt they were redundant to item three. The panel of experts' I-CVI scores for these same items were .75; supporting the removal of the items. Items 4 and 5 were purposefully worded as contradictions (Item 4: I don't mind telling people I have chronic pain; Item 5: I don't like talking about my pain) since no conclusive information supporting either of these items was reported in the qualitative CNP research literature. It was hoped that introducing both items would facilitate discussion and provide evidence for the item that would most resemble integration to CNP. Following discussion of both items the focus group participants were unable to obtain consensus. Two participants stated they did not mind talking about their CNP while the other two participants stated they were selective about who they spoke to about their CNP. Both items were removed from the draft: The panel of experts' I-CVI scores (.75 and .50 respectively) supported the removal.

Based on feedback from the participants, items 8, 12, 13, 19, and 23 were reworded. The panel of experts' I-CVI scores for items 8, 12, 13, 19, and 23 were .75 or lower suggesting removal of the items, however, the focus group participants felt they were important to CNP integration and required rewording only. Items 2, 3, and 9 were

also reworded based on focus group participant feedback. Following the focus group session 20 items remained. These 20 items plus three additional items suggested from the focus group session comprised the third draft of the CPIQ (see Appendix J).

Draft three. The third CPIQ draft was sent by mail to the focus group participants for completion. Once the questionnaires were returned, criteria developed by Hernandez (1991; see Appendix H) and I-CVI scores from the panel of experts were used to make decisions about item inclusion/exclusion in the final questionnaire. Through this process items 12, 14, and 21 (using draft 2 sequencing) were removed and one of the three newly formed items was retained. This left a total of 17 items which formed the final CPIQ (see Figure 1).

On review of the individual CVI scores computed from the panel of experts, seven of the fourteen items with scores lower than 1.00 were subsequently deleted from the CPIQ. A scale CVI (S-CVI) of the remaining sixteen items was computed resulting in a score of .88: an S-CVI score of .80 or higher indicates good content validity (Polit & Beck, 2006). Items 10, 15, and 16 from draft two had I-CVI scores of .75, .50, and .75 respectively. These same items, when scored by the focus group participants, each received a rating of six on the 6-point Likert scale. Since eight experts rated these specific items (allowing for the criteria of 1.00 to be relaxed to a minimum of .78 [Lynn, 1986]), the recalculated I-CVI scores equated to .88, .75, and .88 respectively. The recalculated I-CVI scores support the retention of items 10 and 16 but not item 15. Item 15 "I don't dwell on having chronic pain – it is part of me", when reviewed by the focus group participants, was felt to be relevant to CNP integration. When completing the questionnaire all four of the focus group participants (the true experts in the field of CNP) gave item 15 a rating of six (strongly agree) on the Likert scale. This meets the criteria

Figure 1. The Chronic Pain Integration Questionnaire (CPIQ).

What is living with chronic pain like? (Chronic pain is defined as pain that has lasted longer than 6 months, has gone beyond the usual healing time, and is due to non life-threatening causes)
Read each statement carefully. Then, **circle** the number that shows the extent to which you agree or disagree with the statement.
Note: Circling number 1 means you strongly disagree with the statement, whereas circling number 6 means you strongly agree with the statement.
(For example: If the statement was "**I get tired more often than before I had chronic pain**", and you **do** get tired more often, then you **agree** with the statement. You would circle one of the numbers on the **agree** (right) side – either 4, 5, or 6. If you **strongly agree** with the statement, you would circle number **6**.)

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1. I know what my body will, or will not, allow me to do.	1	2	3	4	5	6
2. I am able to read signals from my body and mind that tell me my pain may worsen.	1	2	3	4	5	6
3. I must take regular care of myself (physically, mentally, spiritually) to manage my pain day-to-day	1	2	3	4	5	6
4. I know what works best for me when managing my chronic pain.	1	2	3	4	5	6
5. Living with chronic pain teaches me to pay attention to my body and mind	1	2	3	4	5	6
6. I can take specific measures that will allow me to live with chronic pain.	1	2	3	4	5	6
7. I have no choice about the daily activities in my life	1	2	3	4	5	6
8. I have learned new ways to do activities so as not to increase my pain levels	1	2	3	4	5	6
9. I take action based on any signal from my body and mind	1	2	3	4	5	6
10. I don't dwell on having chronic pain – It is part of me	1	2	3	4	5	6
11. I try to learn as much as possible about my chronic pain	1	2	3	4	5	6
12. Trying to control my chronic pain day-to-day is automatic for me.	1	2	3	4	5	6
13. I have found no set routine to help manage my chronic pain	1	2	3	4	5	6
14. Living with chronic pain has taught me a lot about myself	1	2	3	4	5	6
15. I feel I live a generally healthy lifestyle despite my chronic pain	1	2	3	4	5	6
16. Living with chronic pain has taught me about what is important in life	1	2	3	4	5	6
17. I have supportive relationships in my life which help me to live with chronic pain	1	2	3	4	5	6

for an I-CVI of 1.00 when five or fewer experts are in the sample (Lynn, 1986). Due to the high rating by the focus group participants item 15 was retained (see Table 4 for a complete outline of items deleted and retained).

When excluding the six reworded items (items 2, 8, 9, 13, 19, 23), a total of ten items had been reviewed by both the panel of experts and the focus group participants for a total expert sample of $n = 8$. A recalculation of an S-CVI, based on these ten items, resulted in a score of .93; well above the .80 required (Polit & Beck, 2006). The remaining seven items (six items reworded and one item added based on feedback from the focus group) were revised or added after the I-CVI scores were obtained from the panel of experts. Therefore only the I-CVI scores from the focus group participants could be used to calculate an S-CVI score for these seven items. All four of the focus group participants rated each of the seven items as a six on the Likert scale for an S-CVI of 1.00.

An S-CVI of .93 (10 items; $n = 8$), an S-CVI of 1.00 (7 items; $n = 4$), and the use of qualitative strategies for instrument development (focus group methodology and a review of qualitative CNP studies) support the face and content validity of the final 17-item CPIQ.

Concurrent Validity

The total scores of the CPIQ were correlated with the total scores of the HHI (Herth, 1992), and the weighted scores and VAS scores of the EQ-5D (EuroQol Group, 1990) to determine the relationship between the three instruments. A Pearson's r of .63 ($p < .01$) was obtained when the total scores of the CPIQ were correlated with the total scores of the HHI. It appears that when integration scores are high, hope scores are also high. A Pearson's r of .36 ($p < .01$) was obtained when the VAS scores of the CPIQ were

correlated with the total scores of the EQ-5D. A lower correlation ($r = .27$; $p < .01$) existed between the total CPIQ scores and the weighted scores of the EQ-5D. It appears that when integration scores are high, health-related quality of life scores are also high. These positive correlations provide beginning evidence for the concurrent validity of the CPIQ.

Construct Validity

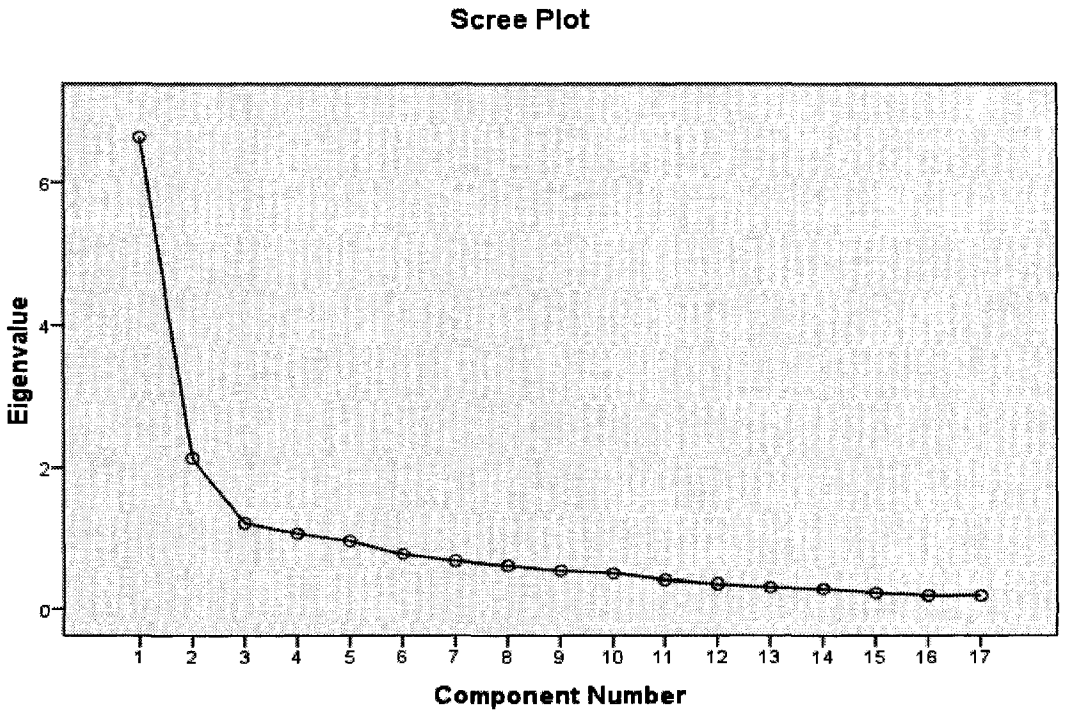
The procedures for measuring construct validity are (a) group differences, (b) correlation matrices and factor analysis, (c) studies of internal structure, and (d) studies of change over occasions (Cronbach & Meehl, 1955). The results from the factor analysis computed in this study are described in detail in the following section.

Factor analysis. Prior to commencing factor analysis, it is appropriate to calculate a measure of sampling adequacy (Dixon, 2001; Tabachnick & Fidell, 2001): the Kaiser-Meyer-Olkin measure (KMO). The KMO must be a minimum of .60. The KMO calculated for the CPIQ was .84 which is well above the .60 minimum. A KMO of .84 provides additional supporting evidence to the adequacy of the sample size ($N = 106$) for the study.

Exploratory factor analysis was used for instrument testing. Varimax (orthogonal) and oblique (Direct oblimin) rotations of the 17-item questionnaire were conducted following principal components analysis. Initially four components were extracted using this method (see Appendix K for the unrotated principal component matrix). Using published guidelines for scree plot interpretation two components were identified (DeVillis, 2003; Field, 2005; Tabachnick & Fidell, 2001) or no more than a three component solution as identified by a third source (Kim & Mueller, 1978). See Figure 2

for the scree plot and Appendix K for the communalities. When the items that loaded on each component were reviewed, the third component was not interpretable. Therefore,

Figure 2. Principal component analysis: Scree plot.



the two component solution was chosen for its simplicity in structure and the components made sense theoretically. The first component accounted for 38.4% of the variance and the second component accounted for 12.9%. Both components accounted for a total of 51.2% of the variance.

When reviewing the results from each of the rotation methods (orthogonal and oblique), the items loaded on the exact same components, however, the component correlation identified from the oblique rotation was .34. Therefore, the orthogonal rotation (Varimax) was chosen as the desired method.

To determine the items that loaded substantially on a component, a cutoff of .30 was established (Dixon, 2001; see Table 5). Eight items (2, 3, 5, 9, 11, 12, 14, and 16) which loaded highest on the first component reflected *intrapersonal reciprocality.* These items measured the following aspects: I am able to read signals from my body and mind that tell me my pain may worsen; I must take regular care of myself (physically, mentally, spiritually) to manage my pain day-to-day; living with chronic pain teaches me to pay attention to my body and mind; I take action based on any signal from my body and mind; I try to learn as much as possible about my chronic pain; trying to control my chronic pain day-to-day is automatic for me; 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 (see Figure 3).

Nine items (1, 4, 6, 7, 8, 10, 13, 15, and 17) which loaded highest on the second component reflected *psychoemotional adjustment.* These items measured the following aspects: I know what my body will, or will not, allow me to do; I know what works best for me when managing my chronic pain; I can take specific measures that will allow me to live with chronic pain; I make choices about the daily activities in my life; I have learned new ways to do activities so as not to increase my pain levels; I don't dwell on having chronic pain – it is part of me; I have settled into a routine when managing my chronic pain; I feel I live a generally healthy lifestyle despite my chronic pain; and, I have supportive relationships in my life which help me to live with chronic pain (items 7 and 13 were negatively stated within the CPIQ; see Figure 3).

Intrapersonal reciprocality and psychoemotional adjustment appear to be aspects of integration. According to Hernandez's 1995 definition, "Integration is an ongoing process in which the two selves (diabetic and personal) more fully merge to create an

Table 5

Varimax Rotation of a Two Component Solution for CPIQ (Chronic Pain Integration Questionnaire)

Items	Component One	Component Two
CPIQ1	.330	**.525**
CPIQ2	**.602**	.399
CPIQ3	**.594**	.211
CPIQ4	.291	**.722**
CPIQ5	**.772**	-.044
CPIQ6	.367	**.718**
CPIQ7R	-.142	**.703**
CPIQ8	.398	**.609**
CPIQ9	**.610**	.545
CPIQ10	.197	**.681**
CPIQ11	**.709**	.085
CPIQ12	**.702**	.244
CPIQ13R	-.065	**.565**
CPIQ14	**.833**	.145
CPIQ15	.108	**.629**
CPIQ16	**.759**	.093
CPIQ17	.288	**.399**

Note. R = items which were reverse scored as they were negatively stated. Item loadings in bold are the items which loaded highest on the component.

Figure 3. Mapping of items to components.

Intrapersonal Reciprocality	*Psychoemotional Adjustment*
I am able to read signals from my body and mind that tell me my pain may worsen	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 day-to-day	I know what works best for me when managing my chronic pain
Living with chronic pain teaches me to pay attention to my body and mind	I can take specific measures that will allow me to live with chronic pain
I take action based on any signal from my body and mind	I make choices about the daily activities in my life
I try to learn as much as possible about my chronic pain	I have learned new ways to do activities so as not to increase my pain levels
Trying 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
Living with chronic pain has taught me a lot about myself	I have settled into a routine when managing my chronic pain
Living with chronic pain has taught me about what is important in life	I feel I live a generally healthy lifestyle despite my chronic pain
	I have supportive relationships in my life which help me to live with chronic pain

individual who is healthy, both mentally (psychoemotional adjustment/ intrapersonal reciprocality) and physically (intrapersonal reciprocality). This unification of the selves is manifested in the person's ways of thinking (psychoemotional adjustment/ intrapersonal reciprocality), being (psychoemotional adjustment/ intrapersonal reciprocality), and acting (psychoemotional adjustment/ intrapersonal reciprocality)..." (p. 18).

These same two components can also be applied to the definition of integration developed by the focus group participants in this study. According to the focus group participants, "Integration is an ongoing process in which the person with chronic pain evolves, becoming a mentally (psychoemotional adjustment/ intrapersonal reciprocality) and physically (intrapersonal reciprocality) stronger individual and creating a sense of

harmony (intrapersonal reciprocality) and control (intrapersonal reciprocality/ psychoemotional adjustment) in one's life".

Reliability

Test-Retest Reliability

Eleven participants completed the study questionnaire package on two occasions. These questionnaire packages were used to compute test-retest reliability. The participants completed each questionnaire one week apart (identified by the documented date at the top of the page). The Pearson's *r* (reliability coefficent) was .99. A Pearson's *r* above .70 demonstrates good test-retest reliability (Polit & Beck, 2004). These findings suggest the CPIQ has demonstrated stability over time. Pearson's *r* calculated for the responses on the HHI and EQ-5D were .96 and .94 respectively (see Table 6).

Table 6

Internal Consistency Reliability and Stability

Variable	Internal Consistency	Stability	
	Cronbach's alpha (N = 106)	Pearson's r (n = 11)	Paired t-test (df = 10)
CPIQ	.88	.99	t = -.33 (p > .05)
HHI	.90	.96	t = -.59 (p > .05)
EQ-5D	.73	.94	t = 1.60 (p > .05)

Note. CPIQ = Chronic Pain Integration Questionnaire, HHI = Herth Hope Index (Herth, 1992), and EQ-5D = The EuroQol (EuroQol group, 1990).

In order to ensure the pre-test and post-test scores were similar, a paired sample *t*-test was conducted. The results from the paired sample *t*-test identified that there was not

a significant difference between the pre-test and the post-test scores (see Table 6 for the *t* values)

Internal Consistency Reliability

Internal consistency reliability of the CPIQ was evaluated through calculation of Cronbach's alpha (coefficient alpha). A Cronbach's alpha of .88 was reported from the analysis (see Table 6). A Cronbach's alpha of .88 demonstrates good internal consistency reliability of the CPIQ: Coefficients greater than .70 are the desirable measure (Polit & Beck, 2004). All item-total correlations were above the .30 cut-off, therefore no items required deletion (see Table 7). Analysis of internal consistency of the HHI and EQ-5D resulted in Cronbach's alphas of .90 and .73 respectively (see Table 6).

Scoring of the CPIQ

The following Cronbach's alphas of the two subscales provide justification for computation and use of subscale scores in future research: .88 (intrapersonal reciprocality) and .82 (psychoemotional adjustment). A total summative score may also be calculated since all item-total correlations were above .30. Therefore, when using the CPIQ, it is possible to use either a total summative score for the instrument and/or total summative subscale scores.

Summary

The CPIQ was proven to be a valid and reliable instrument that was simple to administer. During instrument construction, several strategies for enhancing content validity were employed and resulted in a scale CVI of .93 ($n = 8$) and 1.00 ($n = 4$). Two types of reliability were demonstrated: internal consistency ($\alpha = .88$) and stability (Pearson's $r = .99$). Concurrent validity of the CPIQ, when correlated with the HHI and EQ-5D (VAS scores), was .63 ($p < .01$) and .36 ($p < .01$) respectively. Finally, beginning

Table 7

Item Total Correlation of the CPIQ

Item	Item Total Correlation	Cronbach's Alpha if Item Deleted
1	.52	.87
2	.63	.87
3	.48	.88
4	.65	.87
5	.42	.88
6	.72	.87
8	.65	.87
9	.75	.87
10	.56	.87
11	.47	.88
12	.59	.87
14	.60	.87
15	.47	.88
16	.52	.87
17	.44	.88
7R	.36	.88
13R	.32	.89

Note. R = items which were reverse scored as they were negatively stated.

evidence for construct validity was found using factor analysis. The two subscales, intrapersonal reciprocality and psychoemotional adjustment, identified through exploratory factor analysis, demonstrated internal consistency of .88 and .82 respectively.

CHAPTER FIVE: DISCUSSION

This chapter presents a discussion of the study results. A review of the significant findings and implications for nursing practice and research will be discussed. A summary of the discussion will conclude the chapter.

Significant Findings

The results of this study have provided two significant findings: 1) Integration is an important concept needing further examination in individuals with CNP and 2) qualitative and empirical evidence has provided support for the measurement of integration in the CNP population.

Integration

The qualitative strategies (review of various qualitative CNP research studies, and focus group methodology) executed in this study provided evidence of the integration process in adults with CNP. Multiple phases and stages were identified in the qualitative CNP studies: the characteristics of which were similar to characteristics described by Hernandez (1995) and Whittemore (2005). Through discussion of the integration concept and questionnaire items, the focus group participants validated the stages of integration: All participants were able to identify similarly experienced characteristics. The two components extracted (intrapersonal reciprocality and psychoemotional adjustment) through exploratory factor analysis were easily identifiable as elements of integration when compared to two integration definitions.

Instrument Testing

The development process of the CPIQ promoted content validity while the statistical testing conducted provided evidence of the CPIQ's reliability and validity. The scale content validity index (S-CVI) was .93 ($n = 8$) and 1.00 ($n = 4$), test-retest reliability

(Pearson's *r*) was .99, and the internal consistency reliability (Cronbach's alpha) was .88. Using principal components analysis and varimax rotation, two components were extracted with greater than .4 loadings for each item. The results of these statistical tests provide accumulating evidence of the CPIQ's construct validity.

The CPIQ was positively correlated with both the HHI (Herth, 1992) and the EQ-5D (The EuroQol Group, 1990). The correlations were .63 ($p < .01$) and .36 ($p < .01$) respectively. The correlations provide empirical support of a positive relationship between integration, hope, and health related quality of life.

Implications for Nursing Practice

If integration leads to outcomes of 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 self potential (Whittemore, 2005), it should be of prime importance to nurses. The results of this study lend support for the assessment of integration and development of integration-promoting interventions in the CNP population. The CPIQ was relatively quick and easy to use increasing the feasibility of use by nurses in the field.

According to Turk (2003) "pain must be viewed as a complex phenomenon that incorporates physical, psychosocial, and behavioural factors: Failure to incorporate each of these factors will lead to an incomplete understanding" (p. 578). Individuals with chronic pain (including CNP) need to be given opportunity to discuss how and what they are feeling related to their chronic pain experience (Breen, 2002). Early in the adjustment process to CNP, individuals can feel misunderstood by health care professionals and become frustrated, powerless, and angry resulting in mistrust in the relationship (Gullacksen & Lidbeck, 2004). Understanding how individuals define and live with CNP

can facilitate the nurse-client relationship (Asbring, 2001; Carson & Mitchell, 1998). Nurses could use the CPIQ as a way to elicit part of the pain experience from the CNP sufferer. Ultimately, quality of care increases when nurses listen to and understand the lived experiences of individuals in pain (Carson & Mitchell, 1998).

Several authors (Asbring, 2001; Paulson, Danielson, & Soderberg, 2002; Risdon, Eccleston, Crombez, & McCracken, 2003) made reference to an identity change or transformation occurring in individuals adjusting to life with CNP. This transformation was echoed in Hernandez's 1995 definition of diabetes integration: "...the two selves (diabetic and personal) more fully merge to create an individual who is healthy, both mentally and physically" (p. 19). Asbring recommended that discussion of this identity transformation with the client would bring knowledge to him or her and would assist the client to feel understood resulting in a decrease in the impact of the illness. Having the client complete the CPIQ could facilitate a discussion of integration between the nurse and the client. It could also assist the nurse to focus health teaching on areas of particular concern to the client.

Nurses may use the CPIQ to guide nursing practice in the area of nursing interventions and care plans. For example, having an understanding of the concept of integration might assist nurses to identify priorities when planning client care (Whittemore, 2005). Individualized treatment plans have been proposed by many (Schofield, 2005; Turk, 1990; Watt-Watson & Donovan, 1992) to be important CNP pain management practices. Clients should also be the ones to direct the development of individualized care plans (Carson & Mitchell, 1998) therefore, using the CPIQ, which is based on the clients' experiences, will promote the client-directed treatment plan process. According to Whittemore (2005) an understanding of the integration process, combined

with knowledge of the individual's lived experiences, could potentially improve client focused nursing interventions. In addition, Whittemore stated "facilitating integration as a focus of nursing interventions provides a framework for providing holistic nursing care, a hallmark of the discipline" (p. 266).

Lastly, nurses may use the CPIQ as an evaluative tool at both the individual and program level. Nurses could implement the CPIQ with clients at the start of treatment and then on completion to determine if client-focused interventions were effective at meeting desired outcomes.

Implications for Research

The concurrent validity of the CPIQ was identified by a positive correlation with both the HHI (Herth, 1992) and the EQ-5D (The EuroQol Group, 1990). Future studies examining predictive validity is recommended to further support the validity of the CPIQ. For example, studies could use the CPIQ to predict outcomes such as optimal functioning, quality of life, and well-being.

The findings from this study highlight the need for further research related to CNP integration. An increase in the number of qualitative research studies examining the lived experiences of people with CNP is needed to enhance the health professionals understanding of CNP as well as other important CNP constructs. For example, McCracken and Eccleston (2005) reported that there was work needed to assess the psychological processes that may be involved with acceptance to CNP. Integration may be one of these psychological processes. The CPIQ could be used in studies examining acceptance and integration to CNP promoting further understanding of both constructs.

According to McCracken et al. (2005) it is still not clear which specific psychological and cognitive behaviour therapies (CBT) lead to success for chronic pain

sufferers or address the processes by which clients improve. The findings from this study lend support for the use of the CPIQ in clinical trials attempting to understand which psychological and CBT interventions contribute to integration. The CPIQ could also be used to measure outcomes over time allowing for the determination of the sustainability of CBT and other chronic non-malignant pain intervention therapies. Pre-intervention and post-intervention integration scores from the CPIQ could also be used to assess the effect of newly developed interventions on clients with CNP.

A further research consideration would be to test the CPIQ as a possible diagnostic tool used to differentiate between types of CNP conditions. For example, what is integration like for individuals with rheumatoid arthritis versus fibromyalgia? An identification of differences in integration among various CNP conditions may assist to streamline interventions thereby enhancing efficacy of treatment.

It is recommended that future studies to test the CPIQ are conducted in other countries. Investigation with different cultures and translating the instrument in to different languages would enhance the use of the CPIQ.

Limitations of the Study

The majority of participants in this study were women and reported their race as white. It is not known if people in other cultures would have the same response. Future testing of the CPIQ with other cultures and obtaining information related to education and socioeconomic status would be beneficial.

When distributing the questionnaire for the test-retest measure, the two questionnaires were mailed to the participants within the same envelope. Even though each questionnaire had its own return envelope (encouraging participants to return the first questionnaire on completion followed by the second questionnaire one week later) it

would have been possible for participants to refer to their first questionnaire when completing the second questionnaire one week later. This could have been the reason for the high correlations computed for the test-retest reliability. Future testing of the CPIQ should include further test-retest reliability analysis.

A third possible limitation of the study was the decision to have two negatively worded items instead of (a) no negatively worded items as recommended by DeVellis (2003), or (b) the common rule of using an equal number of positive and negative worded items (DeVellis; Torabi & Ding, 1998).

"The intent of wording items both positively and negatively within the same scale is usually to avoid an acquiescence, affirmation, or agreement bias" (DeVellis, 2003, p. 69). Using an equal number of positive and negative worded items is said to result in a more psychometrically sound instrument (Torabi & Ding, 1998). According to this rule, at least eight of the items on the CPIQ should have been worded negatively. However, according to Torabi and Ding, several researchers have identified problems with this approach. It has been identified that participants have more difficulty responding appropriately to the negative worded items and may become confused when choosing a response (DeVellis; Torabi & Ding). According to DeVellis the disadvantages of negatively worded items outweigh the advantages. If his perspective is followed, none of the items on the CPIQ should have been worded negatively.

Due to the differing opinions outlined above, future testing of the CPIQ should include a further evaluation of the number of negatively worded items versus positively worded items. One recommendation reported by Schmitt and Stuits (1985) was to provide a warning to respondents within the questionnaire instructions identifying that some items will be negatively worded and thus, each item should be read carefully.

Summary

Integration is an important concept in the CNP population. The CPIQ was found to be a valid and reliable tool. The relatively small number of items and its ease in completion enhances its use in nursing practice and research.

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Appendix A

TQD

Case ID 42
Date _____

The Diabetes Questionnaire

What is living with diabetes like? Read each statement, carefully. Then, **circle** the number that shows the extent to which you agree or disagree with the statement.
Note: Circling number 1 means you disagree the most, number 2 the next most and number 3 is least disagreement. Circling number 6 means you agree the most, number 5 is less agreement and number 4 is least agreement.

e.g. Let's say the statement was "**I get tired more often than before diabetes.**" If you do **not** get tired more often, then you **disagree** with the statement. So you would circle one of the numbers on the **disagree** (left) side - either number 1, 2, or 3. For example, if you feel you **strongly disagree** with this statement you would circle number **1.**

	STRONGLY DISAGREE	MODERATELY DISAGREE	SLIGHTLY DISAGREE	SLIGHTLY AGREE	MODERATELY AGREE	STRONGLY AGREE
1. Living with diabetes has taught me a lot about how diabetes affects my body	1	2	3	4	5	6
2. I am aware of cues from my body that tell me about my blood sugar level	1	2	3	4	5	6
3. I don't mind telling people I have diabetes	1	2	3	4	5	6
4. I work to try and keep my blood blood sugar in a certain range	1	2	3	4	5	6
5. I feel confident of what I have to do if my blood sugar is too high or too low	1	2	3	4	5	6
6. Living with diabetes teaches me to pay attention to my body	1	2	3	4	5	6

STRONGLY DISAGREE MODERATELY DISAGREE SLIGHTLY DISAGREE SLIGHTLY AGREE MODERATELY AGREE STRONGLY AGREE

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	STRONGLY DISAGREE	MODERATELY DISAGREE	SLIGHTLY DISAGREE	SLIGHTLY AGREE	MODERATELY AGREE	STRONGLY AGREE
7. Routine to fit most new situations	1	2	3	4	5	6
8. Living with diabetes has become natural for me	1	2	3	4	5	6
9. I take action based on little signals from my body	1	2	3	4	5	6
10. I know more about taking care of my diabetes than anyone	1	2	3	4	5	6
11. I don't dwell on having diabetes - it's part of me	1	2	3	4	5	6
12. I try to learn as much as possible about my diabetes	1	2	3	4	5	6
13. Fitting diabetes into my daily activities is automatic for me	1	2	3	4	5	6
14. I 'tune in' to things that my body is telling me	1	2	3	4	5	6
15. I have settled into a comfortable routine with my diabetes	1	2	3	4	5	6

STRONGLY DISAGREE	MODERATELY DISAGREE	SLIGHTLY DISAGREE	SLIGHTLY AGREE	MODERATELY AGREE	STRONGLY AGREE

Printed with permission, Hernandez, C., May 20, 2008 (see Appendix L)

Appendix B

Six Qualitative CNP Studies

Source	Target Population/Sample Size	StudyDesign, Methods & Instruments	Main Findings/Outcomes
Asbring, P, (2001) Stockholm, Sweden	Population – women with Fibromyalgia and chronic fatigue syndrome (CFS) Sample = 25 women (13 with fibromyalgia, 12 with CFS) – discriminate sampling used	Grounded theory "orientated" approach. Data collection: Semistructured interviews.	Themes: 1)Biographical disruption and its consequences for identity. 2)Strategies of coming to terms with a new identity. (length of time it took to come to terms fluctuated, often it was a case of getting to know the limits of the body and psyche, coming to terms meant a life with the illness 3)Experienced illness gains.
Carson & Mitchell, (1998) Toronto, Canada	Population – People with "persistent" pain (diagnoses range from arthritis, stroke, heart disease, cancer, fibromyalgia, rheumatoid arthritis, and back pain) Sample = 17 (10 women, 7 men aged 54-93)	Descriptive exploratory design. Open-ended questions used. Interviews were taped and transcribed.	Themes: 1)"Forbearance surfaces with the drain of persistent anguish" 2)"Isolating retreats coexist with comforting engagement" 3)"Hope for relief clarifies priorities of daily living" (transcendence, thinking of pain free times)
Gullacksen & Lidbeck, (2004) Malmo, Sweden	Population – women with chronic musculoskeletal pain. Sample = 18 (age 23-55) (length of illness 1-9 years)	Phenomenological framework based on narrative accounts. Interviews transcribed verbatim	Stages: Stage 1: (Prelude, Struggling to restore life, Self-deception, Confirmation, Acknowledgement) Stage 2: (Working through, Sorrow and loss, Losing oneself, Leaving the role of being sick, Defining te problems, Finding solutions, Picture of the future affects coping) Stage 3: (Establishing the new course of life) Maintenance: (Competence of handling future changes, A new attitude of life, Regular self-care)

Howell, (1994) Denver, USA	Population – women with a variety of chronic nonmalignant pain syndromes. Sample = 19 (age 21-76) (length of time with disease 1-27 years)	Grounded theory method of constant comparison from interviews, critical incident health diaries, and participant observation at support group meetings.	4 Theoretical Categories: 1) "The pain takes over" (Getting my attention, Responding to the pain, Perceiving the pain as chronic, Counting the losses) 2) "Filling my life with new hope" (Grieving the losses, Caring for myself, Hope for a new life) 3) "Fulfilling my life with pain" (Transcending the pain, Gaining wisdom) (Categories 1-3 are healthy phases) 4)"Filling my life with pain and despair" (Responding negatively to chronicity of pain, Isolating from self and others, Despairing) (Professing toward illness)
Paulson, Danielson, & Soderberg, (2002) Sweden	Population – adult men with fibromyalgia Sample = 14 men (age 41-56) (length of time with symptoms 4-24 years)	Phenomenological "hermeneutic" method Open-ended interviews were tape-recorded and transcribed verbatim.	3 Themes: 1) "Experiencing the body as an obstruction (Living with a reluctant body, Living day by day with body in pain) 2) "Being a different man" (Not being the same man as earlier, Not being really understood) 3) "Striving to endure" (Living as normally as possible, Searching for alleviation, Having to nurture hope)
Schaefer, (1994) Pennsylvania, USA	Population – women with fibromyalgia Sample = 36 women (ages of women not identified)	Combination of grounded theory and "feminist methods" In-depth interviews were used. Some, but not all interviews were tape-recorded and transcribed, others were recorded from notes. Constant comparative method was used to analyze data.	A process of *struggling to maintain a balance* emerged. Within this process was: 1) Recalling perceived normality 2) Searching for a diagnosis 3) Finding out 4) Moving on (Finding meaning living day by day, creating a safe environment, transcending the illness) 5) Relinquishing the struggle

Appendix C

Mapping of CNP Studies to TDQ: Draft One Creation

The Diabetes Questionnaire (TDQ) (Hernandez, 1995)	CNP Qualitative Studies	Draft 1 : CPIQ
1. Living with diabetes has taught me a lot about how diabetes affects my body 2. I am aware of cues from my body that tell me about my blood sugar level. 9. I take action based on little signals from my body. 14. I 'tune in' to things that my body is telling me.	"For the women it was often a case of getting to know the limits of the body and psyche in relation to varying activities" (Asbring, 2001, p. 316). "..the women learned and increasingly became aware of what the body was capable of ." (Gullacksen & Lidbeck, 2004, p. 150). " The participants spoke of how they were able to read their body (Howell, 1994). "Because these women were able to read their bodies, they could predict when they might not feel well" (Schaefer, 1995, p. 100).	**1. Living with chronic pain has taught me how to read signals from my body.** **2. I know the limits of my body.** **3. I am aware of signals from my body that tell me my pain may worsen.** **13. I take action based on little signals from my body.** **18. I 'tune in' to things that my body is telling me.**
3. I don't mind telling people I have diabetes.	The various studies identified that individuals did not want to tell others about their pain in the phases prior to a healthy adjustment. There was no mention of wanting to tell others once healthy adjustment was achieved.	**4. I don't mind telling people I have chronic pain.** **5. I don't like talking about my pain.**
4. I work to try and keep my blood sugar in a certain range.	"If I skip my training because I don't have the time or the strength, my condition gets worse" (Gullacksen et al, p. 150). "...but the pain is more constant and intense when I am not caring for myself physically, mentally, and spiritually" (Howell, 1994, p. 110).	**6. I must take regular care of myself (physically, mentally, spiritually) to manage my pain day-to-day.**
5. I feel confident of what I have to do if my blood sugar is too high or too low.	"the women...began to trust their own resources" (Gullacksen et al., p. 148). There were measures they could take to handle pain. "The women who were confident in their perceptions of their bodily pains as real described their use of a wide range of modalities that potentiated maximizing their pain relieve and general well-being" (Howell, p. 111).	**7. I know what works best for me when managing my pain.**
6. Living with diabetes teaches me to pay attention to my body.	Asbring, 2001: know limits Gullacksen & Lidbeck, 2004: learned and increasingly became aware of what the body was capable of. Howell, 1994: able to read their body. Schaefer, 1994: able to read their bodies – picked up on signals, know limits	**8. Living with chronic pain teaches me to pay attention to my body.**
7. I can adjust my diabetes routine to fit most new situations.	The participants reported how they carried on activities in a different way (Asbring, 2001). "They described personal choices to rise above the pain, to carry on with the discomfort, and to deal with the pain while living" (Carson & Mitchell, 1998, p. 1245). "Adapting to such changes in the conditions of life required them to balance what the body was capable of against the	**9. I can take specific measures to handle the pain.** **10. I make choices about the daily activities in my life.** **11. I have learned new ways to do activities so as not to increase my pain.**

	desires of the mind" (Gullacksen et al, p. 150). Participants reported accepting a temporary worsening of pain to be more socially active. There were measures they could take to handle pain	
8. Living with diabetes has become natural for me. 13. Fitting diabetes into my daily activities is automatic for me.	"...life had been normalized in spite of the pain." (Gullacksen et al., p. 150). "They discovered a new way of living..." (Paulson, Danielson, & Soderberg, 2002, p. 246). There was a shift to a positive image of normality.	**12. Living with chronic pain has become natural for me.** **17. Managing my pain day-to-day is automatic for me.**
10. I know more about taking care of my diabetes than anyone.	The women made choices to manage the illness and one's life – health care providers attempting to impose change resulted in responses of indignation from the women (Schaefer, p. 100).	**14. I know more about how to manage my pain than anyone.**
11. I don't dwell on having diabetes – it is part of me.	"You have to learn to rise above it, to carry on in spite of it, you have to do the best with what you've got" (Carson & Mitchell, p. 1244). "...the focus...was moved from the pain and the body to important parts of life..." (Gullacksen et al., p. 149) "They characterized their perceptions of the pain as an awareness but not a focus" (Howell, 1994, p.111) Illness was not the central focus (Schaefer, 1994).	**15. I don't dwell on having chronic pain – it is part of me.**
12. I try to learn as much as possible about my diabetes.	"Knowledge regarding the bodily condition played a decisive role in understanding the situation in the context of a new wholeness in life...the attention of the women was directed towards changing, building up a new experience base and repairing their existence" (Gullacksen et al., p. 149)	**16. I try to learn as much as possible about my pain.**
15. I have settled into a comfortable routine with my diabetes.	The participants reported seeing the world with new eyes (Paulson et al., 2004). The participants reported beginning life with a new reality (Schaefer, 1994).	**19. I have settled into a comfortable routine when managing my pain.**
	Priorities: Participants reported other activities took precedent. They had an enhanced sense of what they regard as important in life (Asbring, 2001). The particiapants reported how their priorities changed (Carson & Mitchell, 1998). Participants reported how other qualities of life were appreciated (Paulson et al., 2004) Participants reported how other activities in life took precedence (Schaefer, 1994).	**20. Living with chronic pain has taught me about what is important in life.** **21. My pain does not stop me from enjoying life.**
	Positive Aspects and Meaning: Participants reported an increased self image (Asbring, 2001) Participants reported increased self-image, and found meaning (Gullacksen & Lidbeck, 2004). Participants considered themselves healthy and living satisfying lives, fulfilling life despite pain (Howel, 1994). Participants reported finding meaning, and a strong sense of purpose and responsibility (Schaefer, 1994).	**22. Living with chronic pain has taught me a lot about myself.** **23. I am living a healthy life with pain.**

Appendix D

The Chronic Pain Integration Questionnaire (CPIQ)
Draft One: Panel of Experts (developed February 4, 2007)

Each questionnaire item is to reflect statements that would be made by people **living well** with chronic non-malignant pain (CNP). An individual **living well** with CNP may be defined as someone displaying the following characteristics: would not dwell on having CNP, would not make CNP the focus of living, would have a set daily routine to manage pain, would have life goals, and would have low levels of anxiety and/or depression.

Read each statement carefully. Then, **circle** the number that shows the extent to which you agree or disagree with the relevancy of the statement. Circling number 1 means you strongly disagree with the statement (it **does not** reflect words that would be stated by someone living well with chronic non- malignant pain), whereas circling number 6 means you strongly agree with the statement (it **does** reflect words that would be stated by someone living well with chronic non- malignant pain). If you feel the item should be reworded, please provide an example in the area indicated.

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1. Living with chronic pain has taught me how to read signals from my body.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						
2. I know the limits of my body.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						
3. I am aware of signals from my body that tell me my pain may worsen.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						
4. I don't mind telling people I have chronic pain.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						
5. I don't like talking about my pain.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						
6. I must take regular care of myself (physically, mentally, spiritually) to manage my pain day-to-day.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
7. I know what works best for me when managing my pain	1	2	3	4	5	6
Item should be reworded (please provide example)						
8. Living with chronic pain teaches me to pay attention to my body	1	2	3	4	5	6
Item should be reworded (please provide example)						
9. I can take specific measures to handle the pain	1	2	3	4	5	6
Item should be reworded (please provide example)						
10. I make choices about the daily activities in my life	1	2	3	4	5	6
Item should be reworded (please provide example)						
11. I have learned new ways to do activities so as not to increase my pain	1	2	3	4	5	6
Item should be reworded (please provide example)						
12. Living with chronic pain has become natural for me	1	2	3	4	5	6
Item should be reworded (please provide example)						
13. I take action based on little signals from my body	1	2	3	4	5	6
Item should be reworded (please provide example)						
14. I know more about how to manage my pain than anyone	1	2	3	4	5	6
Item should be reworded (please provide example)						
15. I don't dwell on having chronic pain – it is part of me	1	2	3	4	5	6
Item should be reworded (please provide example)						
16. I try to learn as much as possible about my pain	1	2	3	4	5	6
Item should be reworded (please provide example)						

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
17. Managing my pain day-to-day is automatic for me.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						
18. I 'tune in' to things that my body is telling me.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						
19. I have settled into a comfortable routine when managing my pain.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						
20. Living with chronic pain has taught me about what is important in life.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						
21. My pain does not stop me from enjoying life.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						
22. Living with chronic pain has taught me a lot about myself.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						
23. I am living a healthy life with pain.....	1	2	3	4	5	6
Item should be reworded (please provide example) _____						

Please add below any additional items that have not been identified which you feel may be relevant experiences/expressions of individuals living well with chronic non-malignant pain (CNP).

_____

_____

_____

_____

_____

_____

_____

_____

Appendix E

UNIVERSITY OF WINDSOR

LETTER OF INFORMATION FOR CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Measuring Integration in Adults with Chronic Non-cancer Pain (CNP). (Questionnaire Development, Panel of Experts)

You are asked to participate in a research study conducted by Kathryn Deshaies, Master's student, from the Faculty of Nursing at the University of Windsor. *The results will be contributing to a Master's thesis.*

If you have any questions or concerns about the research, please feel free to contact **Kathryn Deshaies (519-972-2727 ext. 4933), or Dr. C. Hernandez, student supervisor, (519-253-3000 ext. 2263).**

PURPOSE OF THE STUDY

The purpose of this research study is the testing of a newly developed questionnaire which has potential usefulness for understanding individuals' experiences with chronic pain. It may be further useful in future research to develop interventions that have positive health outcomes for individuals with chronic pain.

PROCEDURES

If you volunteer to participate in this study, we would ask you to:

1) Rate and provide additional comments as needed for each item on a newly developed questionnaire titled the Chronic Pain Integration Questionnaire (CPIQ). The purpose is to develop a tool which reflects the experiences of individuals who are living well with CNP.
2) Return the questionnaire in the return-address, stamped envelope.

The review and provision of comments will take approximately one hour of your time. The questionnaire is included with this letter of information. A postage paid return envelope has been provided to you, should you decide to participate. The return envelope will facilitate return of the questionnaire to the researcher.

POTENTIAL RISKS AND DISCOMFORTS

No direct potential risk or discomfort is known.

POTENTIAL BENEFITS TO SUBJECTS:

No direct benefit to rating and providing comments related to the questionnaire is known.

POTENTIAL BENEFITS TO SCIENCE AND SOCIETY:

The ability to measure integration of chronic non-cancer pain is critical for health care providers, especially nurses. It will increase nursing knowledge of the experiences of individuals with CNP and have potential for future research on the development and testing of interventions for CNP.

PAYMENT FOR PARTICIPATION

No payment for participation has been provided.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. No information, linking the study participant to his/her completed questionnaire, will be required or discernible. All returned questionnaires will be kept in a locked cabinet available only to the student researcher. All returned questionnaires will be shredded at the completion of the study.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. Your consent to participate will be implied through your return of the questionnaire to the researcher.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

The results of the study will be made available at www.uwindsor.ca/reb. For those subjects who do not have internet access, they may contact the researcher directly for a copy of the research results. It is estimated the results will be made available by July 1, 2008

SUBSEQUENT USE OF DATA

This data may be used in subsequent studies.

☐ Yes ☐ No

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. This study has been reviewed and received ethics clearance through the University of Windsor Research Ethics Board. If you have questions regarding your rights as a research subject, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4; telephone: 519-253-3000, ext. 3916; e-mail: lbunn@uwindsor.ca.

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

_____ _____

Signature of Investigator Date

Appendix E2

UNIVERSITY OF WINDSOR

CONSENT TO PARTICIPATE IN RESEARCH (Focus Group)

Title of Study: Measuring Integration in Adults with Chronic Non-cancer Pain (CNP).

Subjects: Individuals with chronic non-cancer pain in the Windsor-Essex Region who have attended Encompass Health Systems Inc, Concepts in Pain Management program.

You are asked to participate in a research study conducted by Kathryn Deshaies, Master's student, from the Faculty of Nursing at the University of Windsor. *The results will be contributing to a Master's thesis.*

If you have any questions or concerns about the research, please feel free to contact **Kathryn Deshaies (519-972-2727 ext. 4933), or Dr. C. Hernandez, student supervisor, (519-253-3000 ext. 2263).**

PURPOSE OF THE STUDY

The purpose of this research study is the testing of a newly developed questionnaire which has potential usefulness for understanding individuals' experiences with chronic pain. It may be further useful in future research to develop interventions that have positive health outcomes for individuals with chronic pain.

PROCEDURES

If you volunteer to participate in this study, we would ask you to:

1) Participate in a small focus group of approximately 2 hours in length. The purpose of the focus group will be to analyse, provide input, and suggest revisions of a questionnaire which was developed to measure an individual's level of integration to chronic non-cancer pain. As someone who has been living with CNP, you are the expert and will be able to provide the feedback needed for the researcher to create a questionnaire that is valid. The focus group meeting will be audio-taped to ensure accuracy. All means will be taken to insure confidentiality (see the confidentiality section below).

The focus group will take place at Encompass Health Systems Inc. at 14B-25 Amy Croft, Tecumseh, Ontario.

2) Complete the final revised questionnaire, based on the focus group discussion. You will be contacted in person or by mail to complete the final revised questionnaire. The completion of the questionnaire is estimated to require 15 minutes of your time. A postage paid return envelope will be provided to you to facilitate return of the questionnaire to the researcher.

POTENTIAL RISKS AND DISCOMFORTS

Participants will be involved in a focus group of approximately four individuals. As it is unlikely the other participants will be known to you, you may find it uncomfortable initially. Every effort on the part of the researcher will be made to introduce the group to each other, using code names, in order to decrease the discomfort. You may also find it uncomfortable to be audio-taped. Every step will be taken to ensure confidentiality with the audio-tape (see the confidentiality section below).

POTENTIAL BENEFITS TO SUBJECTS:

Participants in the focus group may find it beneficial to discuss how they have adjusted to or integrated chronic non-cancer pain into their life. Listening to others' pain experiences may also strengthen their own adjustment and or integration. In addition, being involved in the development of a questionnaire which may benefit others may be a positive experience for participants.

POTENTIAL BENEFITS TO SCIENCE AND SOCIETY:

The ability to measure integration to chronic non-cancer pain increases its potential for use in understanding individual experiences of the patient and use in research (evaluation of outcomes post interventions) for health care providers, especially nurses, when determining which treatment plan would best suit the needs of the person with CNP. The same measurement tool could then be used to evaluate which treatment interventions were effective and lead to sustainable outcomes for CNP sufferers. As nurses are key collaborators with clients in facilitating achievement with pain management, the results may enhance and direct nursing practice which will lead to positive client outcomes.

PAYMENT FOR PARTICIPATION

Participants in the focus group will be entered into a draw for $25.00. Following the focus group session, the draw will occur and the winner will be given the $25.00. Only those participants present at the end of the focus group session will be entered into the draw as it will be the participants code name noted on the ballot.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission.

The focus group is a group event. This means that while confidentiality of all the information given by the participants will be protected by the researchers themselves, this information will be heard by all the participants and therefore will not be strictly confidential. Participants in the focus group will be given code names to strengthen confidentiality. Information from the completion of the mailed questionnaire will not be disclosed to anyone outside the research team. All audiotapes will be kept under lock and key and accessible only to the researcher. The audio-tape will be transcribed verbatim. Once the transcription has been completed, the audio-tape will be destroyed. The transcription will remain under lock and key and be available only to the researcher. The results of the study will be compiled into a Master's thesis which will be submitted to a review committee. Publication of the thesis and journal article(s) will be completed. Names of participants will not be used in any written or verbal presentation of the study.
Following completion of the study, the written data will be shredded unless all focus group participants provide consent to the researcher for the data to be used in subsequent research (please see Subsequent use of Data below).

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study.

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

The results of the study will be made available at www.uwindsor.ca/reb. The results will also be available at Encompass Health Systems, or by contacting the researcher directly. It is estimated the results will be made available by December 1, 2007

SUBSEQUENT USE OF DATA

This data may be used in subsequent studies.

☐ Yes ☐ No

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. This study has been reviewed and received ethics clearance through the University of Windsor Research Ethics Board. If you have questions regarding your rights as a research subject, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4; telephone: 519-253-3000, ext. 3916; e-mail: lbunn@uwindsor.ca.

SIGNATURE OF RESEARCH SUBJECT/LEGAL REPRESENTATIVE

I understand the information provided for the study, Measuring Integration in Adults with Chronic Non-cancer Pain, as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

_____
Name of Subject

_____
Signature of Subject Date

SIGNATURE OF INVESTIGATOR
These are the terms under which I will conduct research. _____ Date _____

Appendix E3

UNIVERSITY OF
WINDSOR

CONSENT FOR AUDIO TAPING

Research Subject Name: _____

Title of the Project: Measuring Integration in Adults with Chronic Non-Cancer Pain (CNP)

ID# Number: _____

Birth date: _____

I consent to the audio-taping of the focus group discussions.

I understand these are voluntary procedures and that I am free to withdraw at any time by requesting that the taping be stopped. I also understand that my name will not be revealed to anyone and that taping will be kept confidential. Tapes are filed by number only and stored in a locked cabinet.

I understand that confidentiality will be respected and the reviewing of materials will be for professional use only.

_____ _____

(Research Subject) (Date)

Appendix E4

UNIVERSITY OF WINDSOR

LETTER OF INFORMATION FOR CONSENT TO PARTICIPATE IN RESEARCH

Title of Study: Measuring Integration in Adults with Chronic Non-cancer Pain.
(Instrument Testing)

You are asked to participate in a research study conducted by Kathryn Deshaies, Master's student, from the Faculty of Nursing at the University of Windsor. *The results will be contributing to a Master's thesis.*

If you have any questions or concerns about the research, please feel free to contact **Kathryn Deshaies (519-972-2727 ext. 4933), or Dr. C. Hernandez, student supervisor, (519-253-3000 ext. 2263).**

PURPOSE OF THE STUDY

The purpose of this research study is the testing of a newly developed questionnaire which has potential usefulness for understanding individuals' experiences with chronic pain. It may be further useful in future research to develop interventions that have positive health outcomes for individuals with chronic pain.

PROCEDURES

If you volunteer to participate in this study, we would ask you to:

3) Complete a questionnaire package which includes the Herth Hope Index (a questionnaire developed to measure hope), the EQ-5D (a questionnaire designed to measure health related quality of life) and a new tool, which is the focus of this research study, designed to measure integration to chronic non-cancer pain. The newly developed questionnaire is titled the Chronic Pain Integration Questionnaire (CPIQ).

The completion of the questionnaire package is estimated to require 15 minutes of your time. The questionnaire package is included with this letter of information. A postage paid return envelope has been provided to you, should you decide to participate. The return envelope will facilitate return of the questionnaire to the researcher.

Please return the envelope, with completed questionnaire package, by March 28, 2008.

POTENTIAL RISKS AND DISCOMFORTS

Participants who fill out the questionnaire package may have different thoughts and/or feelings emerge about their chronic pain which may cause the individual some discomfort, however, no other direct potential risk or discomfort is known.

POTENTIAL BENEFITS TO SUBJECTS:

Participants who fill out the questionnaire package may have different thoughts and/or feelings emerge about their chronic non-cancer pain and how they are adjusting to it, however, no direct benefit to filling out the questionnaire may result.

POTENTIAL BENEFITS TO SCIENCE AND SOCIETY:

The ability to measure integration of chronic non-cancer pain is critical for health care providers, especially nurses. It will increase nursing knowledge of the experiences of individuals with CNP and have potential for future research on the development and testing of interventions for CNP.

PAYMENT FOR PARTICIPATION

A draw for $25.00 is open for all participants to enter. If the participant wishes to enter the draw, the mailed questionnaire package will include a separate page (ballot) in which the participant can provide his/her name, address, and phone number in order to be contacted if he/she is the winner. The ballot is to be returned to the researcher in a separate stamped, return-addressed envelope which is provided. The ballot is not to be returned with the questionnaires. Chances of winning are determined by the number of participants who return the ballot to enter the draw. The draw will take place April 4, 2008. **All ballots must be received by midnight April 3, 2008**. All ballots received after April 3, 2008 will be ineligible for the draw.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. All questionnaires will be coded with a number from A(1) to A(n). No information, linking the study participant to his/her completed questionnaire, will be required or discernible. The $25.00 draw ballots are to be returned in a separate envelope included in the package. The ballot and the ballot envelope will not be marked or associated in any way to the questionnaire so as to insure anonymity of questionnaire responses. All returned questionnaires and $25.00 draw ballots will be kept in a locked cabinet available only to the student researcher. All $25.00 ballots will be shredded once the draw has taken place.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. In order to maintain anonymity, if you choose to participate you will not be required to identify yourself on the questionnaire package. Your consent to participate will be implied through your return of the questionnaire package to the researcher. If you decide to participate and enter the $25.00 draw, the researcher will require your name and phone number for contact purposes if your ballot is drawn and you are determined to be the winner. The ballot will be immediately separated from your questionnaire package (see Confidentiality section above).

FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

The results of the study will be made available at www.uwindsor.ca/reb. For those subjects who do not have internet access, they may contact the researcher directly for a copy of the research results. It is estimated the results will be made available by July 30, 2008

SUBSEQUENT USE OF DATA

This data may be used in subsequent studies.

☐ Yes ☐ No

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. This study has been reviewed and received ethics clearance through the University of Windsor Research Ethics Board. If you have questions regarding your rights as a research subject, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4; telephone: 519-253-3000, ext. 3916; e-mail: lbunn@uwindsor.ca.

SIGNATURE OF INVESTIGATOR

These are the terms under which I will conduct research.

_____ _____

Signature of Investigator Date

Appendix F

Decision Rules for Item Inclusion or Revision

Rule 1: An item will be removed from the questionnaire if it does not achieve a score of two (moderately disagree) or less OR five (moderately agree) or more. Rationale: These are all highly integrated individuals, therefore, if they cannot at least moderately agree or disagree with the statement then the item is not discriminating enough or perhaps it is measuring something else besides integration. One possibility is that the item might be measuring individual differences rather than the common concept, integration.

Rule 2: If an item is considered not applicable or is scribbled out by even one person, then it will be removed from the questionnaire. Rationale: Same as number one.

Rule 3: If one or more persons mark an item as strongly agree/moderately agree while the remaining individuals mark the same item as strongly disagree/moderately disagree, then this item will be removed from the questionnaire. Rationale: Same as number one.

Rule 4: If one of the participants rewords an item slightly while the others leave it as it is, the item will remain as is, unless the new wording appears clearer/more concise. If so, participants will be called for approval. Rationale: Enhanced readability will contribute to accuracy of information as well as increased questionnaire reliability.

Rule 5: If more than one person suggests a wording change but the item is considered to be a good one, then the decision to keep or delete the item will be based on three factors: scores on that item, consistency/congruency of the wording changes suggested, and significance of the item on the questionnaire, that is, is the item tapping the same/similar content as another item? Rationale: Content validity is increased when there is a representative sampling of the whole domain of integration.

Rule 6: If one or more persons select a response contrary to that expected, given the integration theory, then this item will be deleted. Rationale: Same as number one.

(Hernandez, 1997, p.63)

Appendix G

The Chronic Pain Integration Questionnaire (CPIQ)

What is living with chronic pain like? (Chronic pain is defined as pain that has lasted longer than 6 months, has gone beyond the usual healing time, and is due to non life-threatening causes)

Read each statement carefully. Then, **circle** the number that shows the extent to which you agree or disagree with the statement.
Note: Circling number 1 means you strongly disagree with the statement, whereas circling number 6 means you strongly agree with the statement.

(For example: If the statement was "**I get tired more often than before I had chronic pain**", and you **do** get tired more often, then you **agree** with the statement. You would circle one of the numbers on the **agree** (right) side – either 4, 5, or 6. If you **strongly agree** with the statement, you would circle number **6**.)

	Strongly Disagree	**Moderately Disagree**	**Slightly Disagree**	**Slightly Agree**	**Moderately Agree**	**Strongly Agree**
1. I know what my body will, or will not, allow me to do.	**1**	**2**	**3**	**4**	**5**	**6**
2. I am able to read signals from my body and mind that tell me my pain may worsen.	**1**	**2**	**3**	**4**	**5**	**6**
3. I must take regular care of myself (physically, mentally, spiritually) to manage my pain day-to-day	**1**	**2**	**3**	**4**	**5**	**6**
4. I know what works best for me when managing my chronic pain	**1**	**2**	**3**	**4**	**5**	**6**
5. Living with chronic pain teaches me to pay attention to my body and mind	**1**	**2**	**3**	**4**	**5**	**6**
6. I can take specific measures that will allow me to live with chronic pain.	**1**	**2**	**3**	**4**	**5**	**6**

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
7. I have no choice about the daily activities in my life.....	1	2	3	4	5	6
8. I have learned new ways to do activities so as not to increase my pain levels	1	2	3	4	5	6
9. I take action based on any signal from my body and mind.	1	2	3	4	5	6
10. I don't dwell on having chronic pain – It is part of me.....	1	2	3	4	5	6
11. I try to learn as much as possible about my chronic pain.....	1	2	3	4	5	6
12. Trying to control my chronic pain day-to-day is automatic for me.	1	2	3	4	5	6
13. I have found no set routine to help manage my chronic pain...	1	2	3	4	5	6
14. Living with chronic pain has taught me a lot about myself.....	1	2	3	4	5	6
15. I feel I live a generally healthy lifestyle despite my chronic pain.	1	2	3	4	5	6
16. Living with chronic pain has taught me about what is important in life	1	2	3	4	5	6
17. I have supportive relationships in my life which help me to live with chronic pain	1	2	3	4	5	6

Appendix H

HERTH HOPE INDEX

Listed below are a number of statements. Read each statement and place an [X] in the box that describes how much you agree with that statement right now.

	Strongly Disagree	**Disagree**	**Agree**	**Strongly Agree**
1. I have a positive outlook toward life.				
2. I have short and/or long range goals.				
3. I feel all alone.				
4. I can see possibilities in the midst of difficulties.				
5. I have a faith that gives me comfort.				
6. I feel scared about my future.				
7. I can recall happy/joyful times.				
8. I have deep inner strength.				
9. I am able to give and receive caring/love.				
10. I have a sense of direction.				
11. I believe that each day has potential.				
12. I feel my life has value and worth.				

EQ - 5D

Health Questionnaire

(Canadian English version)

By placing a check-mark in one box in each group below, please indicate which statements best describe your own state of health today.

Mobility

I have no problems in walking about	❑
I have some problems in walking about	❑
I am confined to bed	❑

Self-Care

I have no problems with self-care	❑
I have some problems washing or dressing myself	❑
I am unable to wash or dress myself	❑

Usual Activities *(e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities	❑
I have some problems with performing my usual activities	❑
I am unable to perform my usual activities	❑

Pain/Discomfort

I have no pain or discomfort	❑
I have moderate pain or discomfort	❑
I have extreme pain or discomfort	❑

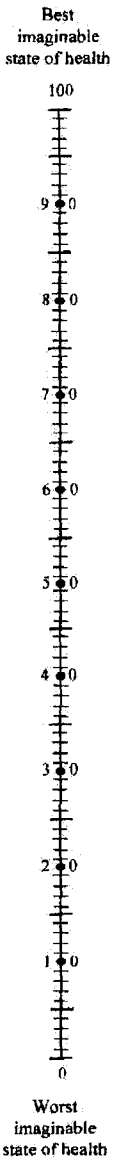
Anxiety/Depression

I am not anxious or depressed	❑
I am moderately anxious or depressed	❑
I am extremely anxious or depressed	❑

To help people say how good or bad their state of health is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your state of health is today.

Your own state of health today



3

Printed with permission, Cheung, K., May 6, 2008. (see Appendix L)

Appendix I

Demographical Data: Place a check in the appropriate box **Date:** _____

1) **Age**:
18-29..... □
30-39..... □
40-49..... □
50-59..... □
60-69..... □
70-79.....□
80-89.....□
90-99.....□
100 or more...□

2) **Sex**: Male.....□ Female.....□

3) **Race**: Black.....□ White.....□ Hispanic.....□ Asian.....□ Other _____ (please print)

4) Have you been diagnosed with a chronic non-cancer pain condition? (Note: Chronic non-cancer pain is pain that has lasted for 6 months or longer and is not related to pain caused from cancer) **Yes**...□ **No**...□

5) How long have you been living with chronic non-cancer pain?
_____ year(s) _____ month(s)

6) If known, which chronic non-cancer diagnosis have you been given? (**check all that apply**)

Fibromyalgia.....□
Rheumatoid Arthritis.....□
Sciatica.....□
Low Back Pain.....□
Arthritis.....□
Herniated Disc.....□
Osteoarthritis.....□
Osteoporosis.....□
Reflex Sympathetic Dystrophy.....□
Degenerative Disc Disease (DDD).....□
Neuropathy (nerve pain).....□
Headache.....□
Other (please print) _____

7) What part(s) of your body has been affected by pain? (please print)

_____

8) Are you now, or have you ever, participated in a chronic pain management program? (**check only one**)

Currently enrolled in a chronic pain management program..... □
Have completed a chronic pain management program..... □
Have never participated in a chronic pain management program..... □

9) Prior to being diagnosed with chronic non-cancer pain (i.e. before you experienced any pain), had you ever been diagnosed with one of the following conditions? (check all that apply)

Anxiety Disorder..... □
Depression..... □

10) Since experiencing chronic non-cancer pain, have you been diagnosed with one of the following? (check all that apply)

Anxiety Disorder..... □
Depression..... □

Appendix J

The Chronic Pain Integration Questionnaire (CPIQ)
Draft Three

What is living with chronic pain like? (Chronic pain is defined as pain that has lasted longer than 6 months, has gone beyond the usual healing time, and is due to non life-threatening causes)

Read each statement carefully. Then, **circle** the number that shows the extent to which you agree or disagree with the statement.
Note: Circling number 1 means you strongly disagree with the statement, whereas circling number 6 means you strongly agree with the statement.

(For example: If the statement was "**I get tired more often than before I had chronic pain**", and you **do** get tired more often, then you **agree** with the statement. You would circle one of the numbers on the **agree** (right) side – either 4, 5, or 6. If you **strongly agree** with the statement, you would circle number **6**.)

	Strongly Disagree	**Moderately Disagree**	**Slightly Disagree**	**Slightly Agree**	**Moderately Agree**	**Strongly Agree**
1. I know what my body..... will, or will not, allow me to do.	1	2	3	4	5	6
2. I am able to read signals from my body and mind that ..... tell me my pain may worsen.	1	2	3	4	5	6
3. I do not tell anyone about my chronic pain.....	1	2	3	4	5	6
4. I must take regular care of myself (physically, mentally, spiritually) to manage my pain day-to-day	1	2	3	4	5	6
5. I know what works best for me when managing my chronic pain	1	2	3	4	5	6
6. Living with chronic pain teaches me to pay attention to my body and mind.	1	2	3	4	5	6

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
7. I can take specific measures that will allow me to live with chronic pain	1	2	3	4	5	6
8. I make choices about the daily activities in my life	1	2	3	4	5	6
9. I have learned new ways to do activities so as not to increase my pain levels	1	2	3	4	5	6
10. I have adapted to living a life with chronic pain	1	2	3	4	5	6
11. I take action based on any signals from my body and mind	1	2	3	4	5	6
12. I know more about how to manage my pain than anyone	1	2	3	4	5	6
13. I don't dwell on having chronic pain – It is part of me	1	2	3	4	5	6
14. I try to learn as much as possible about my chronic pain	1	2	3	4	5	6
15. Trying to control my chronic pain day-to-day is automatic for me	1	2	3	4	5	6
16. I have settled into a routine when managing my chronic pain	1	2	3	4	5	6

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
17. My chronic pain does not stop me from enjoying life.....1	2	3	4	5	6	
18. Living with chronic pain has taught me a lot about myself.....1	2	3	4	5	6	
19. I feel I live a generally healthy lifestyle despite my chronic pain 1	2	3	4	5	6	
20. Living with chronic pain has taught me about what is important in life.....1	2	3	4	5	6	

The Following are some additional questionnaire items based on the focus group discussion. Any feedback you have would be greatly appreciated.

I have more patience when interacting with others day-to-day.....1	2	3	4	5	6

Your comments/changes (if any)
_____

I generally have a positive frame of mind when interacting....1 with others day-to-day.	2	3	4	5	6

Your comments/changes (if any)
_____

I have supportive relationships in my life which help me to live with chronic pain.....1	2	3	4	5	6

Your comments/changes (if any)
_____

Definition of Integration: (using the words you were describing in the focus group session) An ongoing process, in which the person with chronic pain rebuilds oneself/evolves, becoming a mentally and physically stronger individual and creating a sense of harmony and control in one's life.

Your comments/changes (if any) _____
_____
_____
_____

Appendix K

Unrotated Principal Component Analysis: Four Component (Comp) Extraction for the CPIQ (Chronic Pain Integration Questionnaire)

Items	Comp One	Comp Two	Comp Three	Comp Four
CPIQ1	.596	.171	-.006	-.494
CPIQ2	.715	-.104	.263	-.332
CPIQ3	.583	-.239	.068	-.077
CPIQ4	.699	.344	.066	-.292
CPIQ5	.547	-.547	.192	.116
CPIQ6	.752	.290	-.023	.009
CPIQ7R	.363	.618	.155	.235
CPIQ8	.702	.188	.351	.081
CPIQ9	.818	.000	.022	.002
CPIQ10	.601	.377	-.368	-.142
CPIQ11	.585	-.410	-.067	-.035
CPIQ12	.686	-.286	-.030	.009
CPIQ13R	.328	.465	.570	.408
CPIQ14	.718	-.447	.002	.185
CPIQ15	.500	.397	-.556	.040
CPIQ16	.628	-.437	-.173	.229
CPIQ17	.480	.105	-.416	.489

Note. R = items which were reverse scored as they were negatively stated.

Principal Component Analysis: Communalities for the Two Component Solution of the CPIQ (Chronic Pain Integration Questionnaire)

Items	Initial	Extraction
CPIQ1	1	.384
CPIQ2	1	.522
CPIQ3	1	.397
CPIQ4	1	.606
CPIQ5	1	.598
CPIQ6	1	.651
CPIQ7R	1	.514
CPIQ8	1	.529
CPIQ9	1	.669
CPIQ10	1	.503
CPIQ11	1	.511
CPIQ12	1	.552
CPIQ13R	1	.323
CPIQ14	1	.715
CPIQ15	1	.407
CPIQ16	1	.585
CPIQ17	1	.242

Note. R = items which were reverse scored as they were negatively stated.

Appendix L

Permission for Inclusion of TDQ
cherih@uwindsor.ca [cherih@uwindsor.ca]

Sent:May 20, 2008 3:42 PM
To: Kathryn A Deshaies; Kathryn A Deshaies

Hi, Kathy. Yes, I will give you permission to include the TDQ in your thesis, "Measuring Integration in Adults with Chronic Non-Malignant Pain".
-Cheri-

Cheri Ann Hernandez, RN, PhD, CDE
Associate Professor
Faculty of Nursing, University of Windsor
401 Sunset Avenue
Windsor, ON N9B 3P4
Phone: (519) 253-3000, Ext. 2263
Fax: (519) 973-7084
email: cherih@uwindsor.ca

RE: HHI use in Master's Thesis
Herth, Kaye A [kaye.herth@mnsu.edu]

Sent: May 2, 2008 1:14 PM
To: Kathryn A Deshaies

Dear Kathy,

You have my permission to use the HHI in your thesis project and to attach a copy of the HHI to your appendix. Best wishes!

Kaye

Kaye A. Herth, Ph.D., R.N., F.A.A.N.

Dean, College of Allied Health and Nursing

124 Myers Field House

Mankato, MN 56001

507-389-6315

Fax: 507-389-6447

kaye.herth@mnsu.edu

Re: EQ-5D
Kajang Cheung [cheung@bmg.eur.nl]

Sent: May 6, 2008 5:08 AM
To: Kathryn A Deshaies
Cc: rabin@bmg.eur.nl; mandy oemar [oemar@bmg.eur.nl]
Attachments: User guide v1.0 Nov 2007.pdf (643 KB)[Open as Web Page]; canada_englishclin.doc (72 KB)[Open as Web Page]

Dear Kathy,

Thank you for your enquiry and interest in the EQ-5D.

I assume that the study in which you intend to use the EQ-5D is not funded by the pharmaceutical industry or by any other commercial stakeholders. If this is the case, you may use the EQ-5D instrument free of charge and you may provide a copy of the EQ-5D in your thesis. However, if this is not the case, however, please inform us as the EuroQol Group Foundation has a specific policy for studies funded by pharmaceutical industry or by other commercial stakeholders.

Please find attached the English version for Canada of the EQ-5D (word format), as well as a User Guide on EQ-5D use. If you do decide to use the EQ-5D instrument, the EuroQol Group Foundation would greatly appreciate it if you would register your study at our website www.euroqol.org

If you have any further questions, please do not hesitate to contact us.

Kind regards,

Kajang Cheung
Executive Office Assistant
EuroQol Executive Office

VITA AUCTORIS

Name:	Kathryn Deshaies
Place of Birth:	Windsor, Ontario
Year of Birth:	1965
Education	University of Windsor, Ontario
	1984 – 1988, B.Sc.N
	University of Windsor, Ontario
	1997, B.Ed.
	Dalhousie University, Nova Scotia
	1999 – 2001, Dip. Disability Management
	University of Windsor, Ontario
	2003 – 2008, M.Sc.N