GUIDED INTERNET-BASED COGNITIVE BEHAVIOURAL SELF-MANAGEMENT INTERVENTION FOR INDIVIDUALS WITH CHRONIC PAIN: A FEASIBILITY STUDY

by

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Abstract

Background: The “gold standard” in chronic pain treatment is multidisciplinary care. With long wait times to receive appropriate care, there is a need for improved access to non-pharmacological treatments in the time gap between primary and specialist care. The Internet is emerging as a tool for delivery of healthcare information and intervention. Using this format to offer access to chronic pain therapies prior to specialist intervention may improve outcomes.

Objective: To develop and test a guided Internet-based intervention for individuals with chronic pain waiting for specialty care.

Method: A novel, Internet-based chronic pain intervention (ICPI) was developed, using evidence-based concepts proven effective in face-to-face interventions. This study was designed to assess feasibility of conducting larger-scale research and usability of the ICPI, and to collect preliminary data on effectiveness of the intervention. Data were collected at baseline, after each of the six intervention modules and 12 weeks after completion of the intervention.

Results: Participants with chronic pain (n=41) reported satisfaction with the structure of the intervention, and ease of use at and away from their computers. Use of the Internet as a recruitment strategy aided in accrual of participants, making further large-scale study of the ICPI feasible. Preliminary data showed that the ICPI was effective in improving emotional function, had no demonstrable effect on physical function and produced a small but significant decrease in average and current pain intensity and pain interference. Most participants felt they benefited at least minimally overall as a result of using the ICPI.
**Conclusion:** The newly-developed ICPI was well-received by participants and demonstrated some positive outcomes in this preliminary study. Further research with more participants is feasible and necessary, to fully assess the effect of this intervention.
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<tbody>
<tr>
<td>BPI</td>
<td>Brief Pain Inventory</td>
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<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
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<td>CDSM</td>
<td>Chronic Disease Self-Management</td>
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<td>CDSMP</td>
<td>Chronic Disease Self-Management Program</td>
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<td>HRQOL</td>
<td>Health-Related Quality of Life</td>
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<tr>
<td>HSREB</td>
<td>Health Sciences Research Ethics Board</td>
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<tr>
<td>ICPI</td>
<td>Internet Chronic Pain Intervention</td>
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<tr>
<td>IMMPACT</td>
<td>Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials</td>
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<tr>
<td>M</td>
<td>Mean</td>
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<tr>
<td>MCS</td>
<td>Mental Component Score</td>
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<td>Number</td>
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<tr>
<td>NRS</td>
<td>Numerical Rating Scale</td>
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<td>PCS</td>
<td>Physical Component Score</td>
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<td>PGIC</td>
<td>Patients' Global Impression of Change Scale</td>
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<tr>
<td>PTSD</td>
<td>Post-Traumatic Stress Disorder</td>
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<tr>
<td>QWI</td>
<td>Quality Website Index</td>
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<tr>
<td>RCT</td>
<td>Randomized Controlled Trial</td>
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<tr>
<td>RMANOVA</td>
<td>Repeated Measures Analysis of Variance</td>
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<tr>
<td>SD</td>
<td>Standard Deviation</td>
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<tr>
<td>SF-12</td>
<td>Medical Outcomes Study Short Form 12</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Package for Social Sciences</td>
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<td>US</td>
<td>United States</td>
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Chapter 1

Introduction

Background

Pain is a highly individualized subjective experience influenced by personal and environmental factors (Fillingim, 2005; International Association for the Study of Pain Task Force on Taxonomy, 1994; McCaffery & Beebe, 1989; Melzack & Wall, 1988; Watt-Watson, 2003). Pain affects individuals from all demographics, through its influence on biological, psychological and social processes (Fillingim, 2005; Tan, Jensen, Thornby & Sloan, 2008; Turk & Okifuji, 2002). Chronic pain can result in loss of productivity and eventual disability (Kronborg, Handberg & Axelson, 2009), causing physical, emotional and financial burden to not only the sufferers, but their social supports as well, and ultimately economic burden to the healthcare system and society (Boulanger, Clark, Squire, Cui & Horbay, 2007; Choiniere et al., 2010; Guerriere et al., 2010; Kronborg et al., 2009; Shipton & Tait, 2005). In the United States (US), healthcare costs associated with pain reach more than $500 billion per year (American Academy of Pain Medicine, 2011), including medical costs of care and economic costs related to sick days, lost wages and decreased productivity (Institute of Medicine, 2011). In Canada, the estimated annual cost of chronic pain is more than $55 billion (Canadian Pain Society, 2011).

Problem and Significance

One in five Canadians suffer with chronic pain and the prevalence of chronic pain increases with age (Moulin, Clark, Speechley & Morley-Forster, 2002; Ospina &
Harstall, 2002; Reitsma, Tranmer, Buchanan & VanDenKerkhof, 2011; Reitsma, Tranmer, Buchanan & VanDenKerkhof, 2012; Statistics Canada, 2002; Statistics Canada, 2006). The median wait-time for chronic pain specialty consultation in Canada is six months, with over one third of publicly funded programs in Canada reporting wait times from 12 months up to five years, and vast areas of the country have no access to appropriate care (Amadeo & Sutherland, 2010; Lynch et al., 2008; Peng, et al., 2007; Roy, 2008). Many individuals who might benefit from consultation may never see a specialist due to lack of access related to scarcity of resources, worsening health while waiting or distance to travel to a clinic with specialty services (Bromberg et al., 2012; LeFort, Gray-Donald, Rowat & Jeans, 1998; McCracken, MacKichan & Eccleston, 2007; Morley-Forster, 2005; Peng et al., 2007). Although the exact time point at which health begins to decline is unknown, individuals waiting longer than three to six months for chronic pain care experience deterioration in health status, particularly in health-related quality of life and psychological status (Choiniere et al., 2010; Lynch et al, 2008).

Evidence-Based Treatment of Chronic Pain

Multidisciplinary treatment, the “gold standard” for chronic pain care, includes pharmacological and non-pharmacological modalities, delivered with attention to function across physical, psychological and social domains (Jeffery et al., 2011; Roy, 2008; Scascighini, Toma, Dober-Spielmann & Sprott, 2008; Stanos & Houle, 2006; Turk, Wilson & Cahana, 2011). While pharmacological interventions may be initiated at a primary care level, prior to referral to a pain specialist, it is possible that these individuals may not have had opportunity to benefit from psychosocial intervention for many reasons, including geographical and financial barriers (Lyckholm, Hackney & Smith,
demand for this service exceeding the availability of therapists (Baer, Greist & Marks, 2007; Bromberg et al., 2012), difficulty with scheduling due to family and work commitments (Peng et al., 2007), long wait lists (Lynch et al, 2008; Peng et al., 2007) and perceived stigma associated with accessing psychological support (Jeffery et al., 2011; Kaltenthaler, Parry & Beverley, 2004; Vogel, Wade & Haake, 2006).

With an increasing number of people accessing the Internet, self-management websites and peer support via Internet forums are becoming more common (Ancker et al., 2009; Ybarra & Eaton, 2005). Use of computers to deliver interventions incorporating elements of cognitive behavioural therapy (CBT), self-management and education has not been studied in depth in individuals with chronic pain, although this is an area that is currently receiving more interest. While research has established the effectiveness of these therapies, delivered via traditional face-to-face methods to those with chronic pain (Hoffman, Papas, Chatkoff & Kerns, 2007; LeFort et al., 1998; McCracken et al., 2007; Nicholas et al, 2010; Reid et al., 2008; Sveinsdottir, Eriksen & Reme, 2012), early studies documenting delivery of this type of therapy via computer had been confined to individuals with depression, anxiety and other social and mood disorders (Andersson, 2006; Andersson, Bergstrom, Carlbring et al., 2005; Anderson, Bergstrom, Hollandaire et al., 2005; Kaldo et al., 2008) and other chronic diseases (Andersson & Kaldo, 2004; Ghahari, Packer & Passmore, 2009; Kerr et al, 2010; Lorig, Ritter, Laurent & Plant, 2006). In particular, the effect of a guided Internet-based non-pharmacologic therapeutic intervention, on health-related quality of life, for individuals awaiting consultation with
chronic pain specialty services had not been studied prior to initiation of this research project.

**Purpose**

The purpose of this project was to develop and test a guided Internet-based intervention for individuals with chronic pain waiting for specialty care. Feasibility testing assessed considerations and potential barriers to conducting a larger study in the population of interest. Specifically, cost and rate of recruitment, attrition, and ability to appeal to a representative sample of the total group on a chronic pain clinic wait list, was explored. Usability testing of the intervention was done to assess the usefulness of the content and delivery method, and overall satisfaction with the intervention. In addition, an exploratory assessment of the effectiveness of the intervention on emotional functioning, physical functioning, pain severity and pain interference, and to document participant perception of the effectiveness of treatment was completed.

**Conceptual Framework**

The Wilson and Cleary (1995) health outcomes model, which proposes that symptom status, functional status and health perception affect overall health-related quality of life, provided the conceptual framework for this study (Appendix A). The model posits optimally effective clinical interventions affect not only physical functioning, but also mental and social functioning and well-being as components of health-related quality of life. Bi-directional relationships among aspects of health and their influencing factors form the basis of the Wilson and Cleary conceptual framework. Measures of health exist on a continuum of increasing biological, social and
psychological complexity (Wilson & Cleary, 1995). Characteristics of the individual and of the environment have an impact along the continuum, leading to overall quality of life.

The five health outcome components of the Wilson and Cleary model include biological and psychological factors, symptoms, functioning, general health perceptions and overall quality of life. Moving from left to right in the model correlates with shifting focus from the cellular level, through the individual level to the “interaction of the individual as a member of society” (Wilson & Cleary, 1995, p. 63). Characteristics of the individual, and environmental influences such as psychological supports, affect symptom status. Personality and motivation, and social and economic supports all have an effect on functional status. General health perceptions and overall quality of life are affected by individual values and preferences as well as social and psychological supports in the individual’s environment.

Although the entire model is valuable when understanding the complexities of chronic pain, the segment of the Wilson and Cleary’s (1995) health outcome continuum that encompasses symptom status through to health-related quality of life is particularly relevant to the structuring of the intervention used in this research, and to the exploratory research questions within this study. These outcomes are affected by personality, motivation, values and preferences at the individual level and social, economic and psychological supports in the environment of the individual. Using Wilson and Cleary’s conceptual model, by working through interventions that build on the positive aspects of an individual’s character and support system, it may be possible to enhance symptom status, functional status and overall quality of life.
Thesis Format

Chapter one is a broad overview of the significance of the problem and its relation to the Wilson and Cleary Conceptual Framework, followed by an overview of the format of the thesis.

Chapter two of this thesis is a review of the literature, outlining evidence-based treatment strategies for chronic pain. Psychological management of chronic pain, treatment goals and availability of resources are discussed, as well as the role of the Internet in chronic pain treatment at the time of intervention development. It should be noted that this literature review was completed for the purpose of design and testing of a novel intervention delivered via computer to those with chronic pain. The intervention was developed and tested between 2009 and 2011, and since then, new research has been published evaluating the use of the Internet in chronic pain treatment. An update of the literature, including new research published from 2009-2012, is included in chapter six, as part of the discussion.

Chapter three of the thesis focuses on the development of the intervention for this study. It begins by describing interventions available in 2010 and outlines the rationale for development of a novel guided Internet-based intervention. The Wilson and Cleary model provided a framework for selection of components for inclusion in the new intervention. Sequence of delivery and presentation style were modeled on existing face-to-face interventions and computer-based interventions in chronic disease and chronic pain.

Chapter four describes the methodology for assessing the newly developed intervention of this thesis. This chapter describes the design of the study, setting, sample,
instruments and procedures. Data collection was divided into three areas: feasibility, usability, and exploratory assessment of the effectiveness of the intervention. A plan for data collection and analysis is outlined.

Chapter five presents the research results of this thesis. Feasibility data were outlined through calculation of cost and time to recruit the sample, and rate of attrition. Usability data were analyzed using descriptive statistics. In addition, demographic and pain description data pertaining to the study sample were analyzed and compared to data from the overall Wait List group. This chapter also presents exploratory analyses assessing the effect of the guided Internet-based intervention on emotional functioning, physical functioning, pain severity and pain interference and participant perception of change in health-related quality of life.

The final chapter of this thesis is an interpretation of study results (chapter six). Trial limitations are discussed, along with validity and generalizability of the study. Similar studies involving computer-based interventions published since the inception of this study are also described, in the form of a second literature review. Finally, this thesis work is summarized, noting implications for practice and future research.

**Contributions to Knowledge**

This thesis contributes to the body of knowledge in the area of chronic pain management. Therapies for chronic pain have potential to be effective only when they are accessible geographically and financially, and when they are readily available and become part of an individual’s day-to-day life without scheduling conflicts. While research in chronic pain has focused on specific non-pharmacological treatments, such as individual session cognitive behavioural and other psychotherapy, self-management
group programs and education about nutrition, pain, relaxation and exercise, not everyone has access to these in-person treatments. The knowledge gap lies in the question of whether effective treatments which are usually delivered face-to-face, can be adapted for delivery through other means, specifically via computer and Internet, and whether this delivery method is effective. Little research has been done to date in delivery of computer-based therapies for individuals with chronic pain. This thesis outlines the development of a guided Internet-based intervention, based on principles of effective chronic pain therapies and framed by the Wilson and Cleary model. It presents data documenting feasibility of conducting a larger scale study, and participants’ perception of usability of the intervention. In addition, preliminary data is presented to explore the effectiveness of this intervention for individuals with chronic pain.

Summary

Chronic pain is a significant issue at both individual and societal levels. Access to evidence-based and timely care continues to be a challenge for individuals with chronic pain. There is a need to find innovative ways to deliver effective therapies to a broader range of people, in a timely fashion, in an easily-accessible way and with little or no cost to the individuals who may already be struggling financially due to the economic burden of chronic pain. The Internet is a resource that has not yet been fully explored to deliver therapy to those with chronic pain. Through delivery of guided Internet-based cognitive behavioural and self-management interventions targeting functional health and general health perception, overall quality of life for individuals with chronic pain may be improved.
Chapter 2

Literature Review

This chapter is an overview of the literature describing the current status of treatment of chronic pain. Prevalence and incidence, as well as characteristics of individuals with chronic pain are reviewed. Non-pharmacological evidence-based treatment of chronic pain is described, with a focus on psychological modalities. In order to understand the unique challenges encountered by those with chronic pain, a description of barriers to treatment, and demographic and pain characteristics of those referred for chronic pain specialty care is discussed. Finally, use of the Internet in healthcare, quality of healthcare websites, and overall use of the Internet in chronic pain is presented.

Introduction

Chronic pain, defined in terms of both duration and healing, is pain persisting after initial injury, and beyond usual recovery time of a similar injury, without apparent biological value, and regardless of presence of demonstrable pathology [International Association for the Study of Pain (IASP) Task Force on Taxonomy, 1994; IASP 2009]. Further, chronic pain is not associated with a chronic medical disease or neoplasm, and has a negative impact on function and well-being of an individual (American Society of Anesthesiologists, 2010). When time points are used in research to define criteria for chronic pain, the period between three to six months has been the accepted transition point from acute to chronic pain, as this is where prognosis starts to deteriorate (Marcus, 2002; Novy, 2004; Tunks, Crook & Weir, 2008).

In their Gate Control Theory, Melzack and Wall (1965) proposed that the cells of the substantia gelatinosa in the dorsal horn of the spinal cord modulate the transmission
of afferent sensory impulses moving from the peripheral nervous system to the brain and the transmission of descending impulses to the periphery, by acting as an open or closed neural gate in response to activity from large and small fibers. Psychological factors, previously viewed as merely reactions to pain, were finally recognized as a part of pain processing, through sensory-discriminative, motivational-affective, and evaluative processes (Melzack, 1996; Melzack & Casey, 1968). Chronic pain, while often initially triggered by injury, illness or an event, persists and may be exacerbated by stress, environmental factors or individual emotional responses (Loeser & Melzack, 1999). The nervous system may not be able to recover and restore normal function (Loeser & Melzack, 1999), and through the process of central sensitization due to neuronal plasticity, individuals with chronic pain may become hypersensitive to even mild sensory input (Latremoliere & Woolf, 2009; Reichling & Levine, 2009). While therapies targeting chronic pain at a biological level may provide transient relief, they do not have a lasting effect on the pathophysiological process underlying the pain, if one can be identified (Loeser & Melzack, 1999).

Chronic pain places physical as well as psychosocial stress on an individual, which may be beyond the capacity of their usual coping responses (Loeser & Melzack, 1999; Vlaeyen & Linton, 2000). Although physical manifestations of chronic pain are often the focus of medical treatment, there are psychosocial comorbidities. Those experiencing chronic pain may start to become depressed and socially withdraw (Gallagher, 2008; Mailis-Gagnon et al., 2007; McWilliams, Cox & Enns, 200; Tunzun, 2007). Whether pain is intermittent or constant, an individual’s health-related quality of life and ultimately overall quality of life deteriorates. Health-related quality of life
(HRQOL) is a concept reflective of the physical, emotional and social effect of an individual’s disease process and its related treatments on wellbeing (Centers for Disease Control and Prevention, 2000; Guyatt, Feeny & Patrick, 1993; The WHOQOL Group, 1998). Chronic pain, with its physical and emotional challenges including its treatments, had a profound and sustained negative effect on HRQOL; however HRQOL is only one domain of overall quality of life. Ongoing pain can affect many other domains of quality of life, through its effect on the ability to work, to provide financial security, to maintain housing and educational obligations (Breivik, Collers, Ventafridda, Cohen & Gallacher, 2006; McWilliams et al., 2003; Tunzun, 2007).

It is generally reported that the psychological factors coexisting with chronic pain are modifiable within pain management interventions (Ferrans, Zerwic, Wilbur, & Larson, 2005; Jeffery et al., 2011; Kerns, Sellinger, Goodin, 2011). These interventions should target physical symptoms associated with the chronic pain, and the social, role and psychological functioning of the person to improve an overall sense of wellbeing (Wilson & Cleary, 1995). When planning interventions, the demographic and psychosocial characteristics of those with chronic pain should be considered.

**Population with Chronic Pain**

There is currently a paucity of good quality descriptive studies about individuals with chronic pain in the general population. The methods used in examining chronic pain have produced inconsistent results on prevalence and incidence, and there has not been consistent use of validated measurement tools making it difficult to compare results from different studies. Most studies describing those with chronic pain are prevalence studies, which do not identify risk factors for chronic pain. In fact, accurately reporting incidence
of chronic pain is further hindered by problems associated with recall; the first occurrence of an individual’s pain may have been in childhood or there may have been several episodes prior to the “chronic” diagnosis (McBeth & Jones, 2007).

**Prevalence and Incidence**

Worldwide, the prevalence of chronic pain has been reported to range from 19-51% (Andersson, Ejlertsson, Leden & Rosenberg, 1993; Azevedo, Costa-Pereira, Mendonca, Dias & Castro-Lopes, 2012; Blyth et al., 2001; Bowsher, Rigge & Sopp, 1991; Breivik et al., 2006; Catala et al., 2002; Elliott, Smith, Penny, Smith & Chambers, 1999; Johannes, Le, Zhou, Johnston & Dworkin, 2010). In Canada, chronic pain prevalence ranges from 11-44% in the general population (Birse & Lander, 1998; Boulanger et al., 2007; Crook, Rideout & Browne, 1984; Millar, 1996; Moulin et al., 2002; Tripp, VanDenKerkhof & McAlister, 2006; Reitsma et al., 2012; VanDenKerkhof, Hopman, Towheed, Anadstassiades & Goldstein, 2003; van Hecke, Torrance & Smith, 2013). Although chronic pain affects all demographics, it has been shown to be consistently higher in females, and in populations with low income, low education, and increasing age (McBeth & Jones, 2007; Rashiq & Dick, 2009; Reitsma et al., 2012). The American Academy of Pain Medicine (2011) compared statistics on the prevalence of pain compared to other chronic diseases; 100 million Americans suffered from chronic pain, more individuals than those with diabetes (25.8 million), coronary heart disease (16.3 million), stroke (7.0 million) and cancer (11.9 million) combined.

Reitsma et al. (2012) calculated the incidence of chronic pain in Canada to be 35.6% over a 12 year time period (1994-2007) using National Population Health Survey data, indicating a large number of newly identified cases each year. A search for similar
statistics reported for other countries, using keywords “incidence” and “chronic pain”, revealed that although data is available for specific types of chronic pain, and incidence of chronic pain after various surgeries, procedures and treatments, there is little compiled information available about the broad incidence of chronic pain in general population studies. The few prospective international studies available were from 2004 and earlier, and reported varied results. A 6-year incidence of 10.7% was reported in Denmark (Ericksen, Ekholm, Sjogren & Rasmussen, 2004), an 8-year incidence of 19% in the United States (Magni et al., 1993) and a 4-year incidence of 33.3% in the United Kingdom (Elliott et al., 2002).

**Gender and Age**

More women than men report chronic pain (McBeth & Jones, 2007; Reitsma et al., 2011), although the ratio of women to men reporting chronic pain in community populations is smaller than in clinic samples (McBeth & Jones, 2007). For both men and women, the incidence (McBeth & Jones, 2007; Reitsma et al., 2012; Statistics Canada, 2002) and prevalence (Moulin et al., 2002; Reitsma et al., 2011; van Hecke et al., 2013) of chronic pain increases with age. Despite this increase in chronic pain with age, the elderly may not be fully or appropriately assessed for pain (Hadjistavropoulos et al., 2007; Kerns et al., 2011), and their pain may be undertreated (Cavalieri, 2002; Kerns et al., 2011). In addition, the increasing incidence of chronic pain with age has been reported to level out or even decrease in the elderly (McBeth & Jones, 2007). This may be due to life changes such as decreased workload or retirement (McBeth & Jones, 2007). Younger and middle-aged people rated their quality of life with chronic pain poorer than similarly afflicted older people (Rustoen et al., 2004; Moulin et al., 2002; Boulanger et
al., 2007), potentially due to the elderly assuming that pain goes along with aging, and that younger people were more affected by pain interfering with work-related activities (Rustoen et al., 2004).

**Socioeconomic Status**

A wide range but inconsistent set of characteristics have been identified as potential risk factors for chronic pain. A recent Canadian incidence study using data from the National Population Health Study (Reitsma et al., 2012) reported that in the development of chronic pain, the risk factors for women were lower education and being widowed, separated or divorced. No sociodemographic risk factors for development of chronic pain were identified specifically for men in this study. Studies conducted in Sweden, the United Kingdom, the United States and Canada all found that decreasing socioeconomic status (education, employment, income) is associated with higher prevalence of chronic pain (Bergman et al., 2001; McBeth & Jones, 2007; Portenoy, Ugarte, Fuller & Haas, 2004; Roth, Punch & Bachman, 2001; Tripp et al., 2006). Higher socioeconomic status has been predictive of more positive outcomes in studies evaluating health, physical functioning and lifespan (Feinstein, 1993; Hanley, Miner, Rockswold & Biros, 2011; Pappas, Queen, Hadden & Fisher, 1993; Rios & Zautra, 2011). For those with chronic pain, the presence of financial stressors was associated with daily pain (Rios & Zautra, 2011), and poorer emotional and physical health (Soares, Sundin & Grossi, 2003). Research also indicates that difficulty with sleep (Nittera, Pripp & Forsetha, 2012), having little control in employment (Elliott et al., 1999) and family, employer and employee response and reaction to pain (van Hecke et al., 2013) are associated with ongoing pain.
Population Referred to Pain Clinics

While studies have attempted to quantify the prevalence of chronic pain in regional populations (Breivik et al., 2006; Johannes et al., 2010; Ospina & Harstall, 2002; Speechley, Moulin, Clark & Morley-Forster, 2002; Tripp et al., 2006; VanDenKerkhof et al., 2003), and describe characteristics of those with chronic pain in national populations (Elliott et al., 1999; Reitsma et al., 2011; Rustoen et al., 2004; Statistics Canada, 2008; Tripp et al., 2006; Tunks et al., 2008), few studies have examined the characteristics of those with chronic pain referred for specialty care. With long wait lists for multidisciplinary treatment for chronic pain (Amadeo & Sutherland, 2010; Guerriere et al., 2010; Lynch et al., 2008; Peng et al., 2007), the group referred to specialty clinics, the group that remains on the wait list, and the group that is eventually seen, may not be representative of the larger population of individuals suffering chronic pain. Many factors influence whether individuals remain on the wait list, whether they attend their initial appointment, and what the individuals’ physical and mental status might be. Individuals with chronic pain may become surgical candidates, find medication and therapy regimens that increase their quality of life, move from the region where the clinic is located, change contact information without informing the clinic, become residents of hospitals or long-term care homes as a result of worsening condition or other comorbid conditions, or die. As such, the group referred to chronic pain multidisciplinary clinics might be very different from the general chronic pain population, and from the group who is eventually treated at the clinics to which they were referred (Jeffery et al., 2011).

In an early study, Crook, Weir and Tunks (1989) compared characteristics of individuals with chronic pain in a family practice clinic to those being seen in a
multidisciplinary pain clinic in Ontario Canada using interview survey methodology with a two-year follow-up. Although demographics and pain location and duration were similar, the authors reported that those in the family practice group reported that their pain, continuous pain, psychological distress, pain on activity, psychosocial complications and use of healthcare resources were lower on initial data collection and in follow-up two years later than that reported by the pain clinic group (Crooks et al., 1989, p. 58).

More recently, Mailis-Gagnon et al. (2007) described pain characteristics and demographics of patients (n=1242) attending a pain clinic in Toronto Canada. Patients had a mean (M) age of 48.5 (±14.2 SD) years, with the majority being female, married, not employed, and likely to have a psychological comorbidity. Mean duration of pain was 7.8 years. While the information provided in this study provides a very specific and comprehensive description of a specialty clinic pain population treated between 2001 and 2004, it is not known whether other individuals were offered appointments but did not attend and why, or whether some individuals referred were not in the queue for appointments and what criteria were used to determine who was offered an appointment.

Choiniere et al. (2010) reviewed data from individuals on the 2004-2007 wait lists of eight multidisciplinary treatment facilities. These individuals had a mean age of 50.8 (±12.6 SD) years, with the majority being female, with a duration of pain of 2 years or more, and likely to have psychological comorbidities. A majority of these individuals were not employed, although there were slightly more employed individuals on these wait lists than there were in the Mailis-Gagnon (2007) clinic study. Table 1 presents a comparison of these two studies.
Table 1. Comparison of Toronto Pain Clinic and Canadian Wait List

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Toronto Clinic (Mailis-Gagnon et al., 2007) (n=1242)</th>
<th>Canadian Wait Lists (Choiniere et al., 2010) (n=728)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age</td>
<td>48.5±14.2</td>
<td>50.8±12.6</td>
</tr>
<tr>
<td>Female</td>
<td>57%</td>
<td>61%</td>
</tr>
<tr>
<td>Most affected age group</td>
<td>35-49 years</td>
<td>40-60 years</td>
</tr>
<tr>
<td>Married</td>
<td>58%</td>
<td>No data</td>
</tr>
<tr>
<td>Employed</td>
<td>19.8%</td>
<td>32.8%</td>
</tr>
<tr>
<td>Duration of pain</td>
<td>Mean 7.8 years</td>
<td>2 years or more (88.7%)</td>
</tr>
<tr>
<td>Psychological comorbidity</td>
<td>75%</td>
<td>82%</td>
</tr>
</tbody>
</table>

In their literature review exploring neglected factors in chronic pain treatment outcome studies, Turk and Rudy (1990) propose that individuals referred for treatment could have different characteristics from those being treated in chronic pain specialty clinics due to exclusion criteria present when screening individuals to see who might benefit most from care offered in the clinic. While exclusion criteria vary, and may range from minimal to extensive, often clinics offer treatment to those most likely to benefit from the specific type of treatment provided. Turk and Rudy (1990) categorized clinic exclusion criteria into six main areas: biomedical status, demographics, psychopathology, medicolegal, apparent lack of motivation, and conceptual (i.e. pain not interfering with life, patient unwilling to return to work, patient not able to identify specific goals). Indeed those groups referred to a chronic pain clinic might be quite different from
individuals seen in primary practice, and those who receive treatment in a specialty clinic.

**Evidence-Based Management**

Intervention studies have shown that effective evidence-based treatment strategies for the management of chronic pain involve a multidisciplinary approach, with attention to medical (pharmacological and interventional), psychological and physical/rehabilitative modalities (Flor, Fydrich & Turk, 1992; Jeffery et al., 2011; Jovey, 2008; Novy, 2004; Ospina & Harstall, 2003). Multidisciplinary treatment may not lead to complete resolution of pain, but rather to optimization of pain control and physical function, and adoption of behavioural strategies to more effectively cope with residual pain (Jeffery et al., 2011; Kerns et al., 2011; Novy, 2004; Robinson, 2007). An evidence-based treatment plan for chronic pain should flow in a logical progression, through recommended primary strategies and then on to those therapies with less evidence available, incorporating not only pharmacologic modalities, but also with consideration of physical, psychological and interventional therapies (American Society of Anesthesiologists, 2010; Winnipeg Regional Health Authority, 2012). Individuals with chronic pain are encouraged to become engaged in their own care, defining attainable treatment goals (Winnipeg Regional Health Authority, 2012; LeFort et al., 1998). In most cases, the objectives when treating chronic pain are not geared toward “curing” or totally relieving the pain, but rather they revolve around improvement of function, tolerance of pain and attaining maximal improvement (American Society of Anesthesiologists, 2010; Robinson, 2007; Sanders, Harden & Vicente, 2005).
Cognitive Behavioural Therapy, Behaviour Therapy and Stress Reduction

Cognitive behavioural therapy (CBT) is a treatment approach that can be used to assist people with pain to realize that they can have an active role in managing their pain and its associated problems. CBT for pain management teaches people to identify maladaptive patterns of thinking that are associated with feelings of being overwhelmed by the demands placed upon their coping resources (Fordyce, 1976; Novy, 2004; Turk, Swanson & Tunks, 2008). This therapy also helps individuals with chronic pain to respond more effectively to stressors by learning and applying new behavioural responses to pain, and to use these new skills to ease the stress of current and future issues (Novy, 2004). Basic therapy components of CBT include education, skills acquisition, cognitive and behavioural rehearsal and generalization, and maintenance (Gatchel & Rollings, 2008; Kerns et al., 2011; Novy, 2004, p. 284). The multidisciplinary approaches to chronic pain management that include CBT appear to be effective regardless of type and location of pain (Eccleston, Morley & Williams, 2013; Gatchel & Okifuji, 2006; Hoffman et al., 2007; Jensen, Turner & Romano, 1994; Keefe et al., 1990; Kerns et al., 2011; Williams, Eccleston & Morley, 1999).

A meta-analysis of 22 randomized controlled trials (RCTs) (N=1627) evaluating the effectiveness of psychological interventions for chronic low back pain found that these therapies had a statistically significant positive effect on health-related quality of life (p<0.05, d=0.42), pain intensity (p<0.01, d=0.50) and pain-related interference (p<0.10, 95% CI= -0.02, 0.88) (Hoffman et al., 2007) when treatment groups were contrasted against wait list control conditions at post-treatment. CBT and self-management treatments were especially effective within a multidisciplinary program.
Similarly, Sveinsdottir et al. (2012) found CBT to be beneficial in treating back pain, and specifically in outcomes related to functional limitations/activity, pain intensity, general health and quality of life, as compared to other treatments such as exercise, surgery, biofeedback, relaxation and usual care, in a review that included data from 46 RCTs. A systematic review of 42 RCTs of good quality (M 15.8/26, with quality improving in the newer publications) (N=4,788) found CBT had a small positive effect on mood, disability and improving pain as compared to treatment as usual and small positive effect on disability when compared to active control (Williams, Eccleston & Morley, 2012).

Henschke et al. (2010) concluded, from their systematic review of 30 RCTs of moderate quality studying behavioural treatment for chronic low-back pain (N=3,438), that behavioural therapy was more effective for short-term pain control when compared to usual care. In the longer term, there was little difference between behavioural treatment and other active therapy such as group exercise, for pain control or improving depressed mood.

Mindfulness-based stress reduction, a present-focused awareness therapy developed by Jon Kabat-Zinn, has also been offered in chronic pain programs (Gardner-Nix, 2009; Kabat-Zinn, Lipworth & Burney, 1985). Goals for mindfulness meditation include attaining a state of relaxation, and working toward a greater focus of attention (Kerns et al., 2011). The mindfulness technique teaches the individual to separate the pain sensation from reactions to the experience such as worry and anxiety, leading to development and incorporation of new coping skills, which often correspond with an increased ability to “live with the pain” (Bishop et al., 2004; Kerns et al., 2011). A systematic review of mindfulness-based interventions in treatment of chronic pain
(N=951) did not find enough evidence to recommend the inclusion of mindfulness therapy in a multimodal treatment plan for chronic pain; limitations of the studies reviewed included small sample size, no randomization and difficulty separating the effect of the mindfulness intervention from nonspecific effects associated with being on a wait list for care (Chiesa & Serretti, 2011). Despite limitations, there was evidence to suggest some improvements in depressive symptoms, pain symptoms and coping in this population, and further well-structured research is warranted (Chiesa & Serretti, 2011).

Relaxation techniques are often taught and used within a structured multimodal chronic pain treatment plan, although specific positive effects of relaxation on the chronic pain experience is not well supported by research. A systematic review of 9 RCTs that used relaxation techniques to manage chronic pain (N=414) found little evidence to support using these techniques for chronic pain relief (Carroll & Seeers, 1998), although results were interpreted cautiously in view of methodological weaknesses within the studies. A subsequent systematic review of 12 studies of various relaxation techniques used in the treatment of chronic musculoskeletal pain (N=980) documented some positive results in pain intensity, mood and healthcare cost, but also advised that recommendations could not be made based on the review results due to similar methodological issues as previous studies in this area (Persson, Veenhuizen, Zachrison, & Gard, 2008).

**Self-Management**

Chronic disease self-management empowers the individual to become a partner in choosing a path moving toward optimal health, and in making decisions about healthcare both in day-to-day activities and with a view to long-term health (Lorig & Holman,
Core self-management skills include “problem-solving, decision-making, resource utilization, formation of patient-provider partnerships and adoption of actions to manage the health condition” (Lorig & Holman, 2003, p. 1). Education and behavioural strategies are part of the process of delivering self-management skills (Lorig & Holman, 2003; Mann, LeFort & VanDenKerkhof, 2013; Reid et al., 2008). Research assessing effectiveness of self-management strategies has been primarily focused on chronic disease in general. Self-management research specific to chronic pain is still relatively scarce.

The critical role of patient motivation in self-management has been documented; however, which motivational techniques enhance active participation in self-management programs is less clear (Jensen, Nielson & Kerns, 2003). Mahomed, Patterson and St. John (2008) conducted face-to-face interviews of individuals (n=19) living with chronic diseases from three general practice offices in Australia in order to document factors which influenced participation in chronic disease self-management (CDSM) courses. Analysis of data revealed that participants felt these courses would provide an opportunity to gain support from those in a similar situation and to gain understanding and information about illness (Mahomed et al., 2008). Those who felt they would not participate described the perception that CDSM was indicated only if the individual’s condition deteriorated, skepticism about benefits of the course and thoughts that the medical practitioner should be the one managing the condition. Time, transport, cost, mobility, scheduling and location were all themes identified in the category of perceived control associated with attending or not attending. From the study, recommendations to improve participation in CDSM courses were formulated, including emphasizing
preventive aim of the course, clarifying that the course assists individual management of conditions, physician endorsement and recommendation, and consideration of venue, transport, cost and promotion (Mahomed et al., 2008).

Pre- and post-test analyses and RCTs have documented that in both the short-term and long-term (up to 2 years post-intervention), individuals with chronic pain who participate in self-management programs report improved function, decreased pain and increased self-efficacy (Farrell, Wicks & Martin, 2004; Hanada, 2003; Redondo et. al, 2004; Reid et al., 2008). In a randomized controlled trial of a community-based psychoeducation program for chronic pain self-management (n=110), the treatment group demonstrated short-term improvements in pain, dependency, vitality, role functioning, life satisfaction, self-efficacy and resourcefulness as compared to wait list controls (p<0.05) (LeFort et al., 1998). Authors of a systematic review of 17 trials in adults with chronic conditions (N=7442) concluded that lay-led self-management programs for this population may lead to a small, short-term increase in self-efficacy, self-rated health and cognitive symptom management (Foster, Taylor, Eldridge, Ramsay & Griffiths, 2007). In a RCT studying individuals with chronic illness, recruited from a primary care network in California, researchers found that those who had more depressive symptoms seemed more likely to increase self-efficacy with chronic illness self-management training than those with less depressive symptoms (Jerant, Kravitz, Moore-Hill & Franks, 2008). A systematic review and meta-analysis of research published about self-management programs for those with chronic musculoskeletal pain (N=7305) compiling data from seven countries, found there was a small reduction in pain and disability for participants (Du et al., 2011). These findings, however, must be interpreted cautiously as outcome
measures in the included studies were not always consistent, and meta-analysis could only be performed on subgroups. Nonetheless, encouraging individuals to take an active role in their own treatment is an effective process in treating those with chronic pain (Smith & Elliott, 2005).

**Education**

Patient education has been included as part of cognitive behavioural interventions and self-management programs (Berman, Iris, Bode & Drengenberg, 2009; Chiauzzi et al., 2010; Gremeaux & Coudeyre, 2010; Jeffery et al., 2011; LeFort et al., 1998; Morlion, Kempke, Luyten, Coppens & Van Wambeke, 2011; Williams et al., 2010), and also studied independently in chronic pain research (Brox et al., 2008; Clarke, Ryan & Martin, 2011; Meeus, Nijs, Van Oosterwijck, Van Alsenoy & Truijen, 2010; Van Oosterwijck et al., 2011). A systematic review of brief education in chronic back pain (N=3,583) found moderate evidence that education had a positive impact in reducing sick leave and short-term disability as compared to usual care (Brox et al., 2008). When pain biology education was studied alone and paired with exercise classes in a pilot study in individuals with chronic low back pain, Ryan, Gray, Newton and Granat (2010) found that those who were randomized to education alone had more improvement in pain and pain self-efficacy (n=38). Educating those with chronic low back pain (Clarke et al., 2011), whiplash (Van Oosterwijck et al., 2011) and chronic fatigue syndrome (Meeus et al., 2010) about pain neurophysiology has produced small but positive results in pain and pain beliefs, even as compared with pacing and self-management education (Meeus et al., 2010), but these results must be interpreted cautiously due again to small sample sizes (Meeus et al., 2010), including a pilot study (Van Oosterwijck et al., 2011) and minimal
number of studies included (n=2) in a systematic review (Clarke et al., 2011). More often, education is woven through behavioural interventions and is more specifically labeled “psychoeducation” (LeFort et al., 1998; McGillion et al., 2008; Morlion et al., 2011), thus the specific effect of the education alone is difficult to discern in the midst of the positive effects of the total intervention.

**Barriers in Management**

While multidisciplinary treatment has been established as the standard for treating those with chronic pain, there are barriers to provision of and access to these programs (LeFort et al., 1998; Lynch et al., 2008; Peng et al., 2007). In addition to long wait list times and too few programs for the populations they serve (Lynch et al., 2008; Peng et al., 2007; Veillette, Dion, Altier & Choiniere, 2005), additional concerns include financial resources, access issues such as geographical distance and transportation, childcare, and time required to be off work to attend programs (Kerns et al., 2011; Sturgis, Schaefer & Sikora, 1984; Turk & Okifuji, 2002; Ybarra & Eaton, 2005). Weir, Browne, Tunks, Gafni and Roberts (1992) compared the group referred to a pain clinic in Ontario Canada, to those who went on to use the clinic. One of the best predictors of non-use of the clinic was geographic location; those who did not use the clinic lived farther away from the clinic, or had referring physicians whose practices were located geographically distant from the clinic, as compared to those who became patients.

**Availability of Psychological Resources**

Psychological interventions for chronic pain management have been described as not readily available at a primary care level, and often not even within chronic pain specialty programs, due to funding, time constraints, and the lack of adequately trained
staff (Eccleston, 2001; Jeffery et al., 2011). Physician training paradigms, specifically the use of a biomedical model, preclude incorporation of full psychosocial assessment and intervention into practice. As individuals with chronic pain require more time per office visit (LeFort et al., 1998), little time is left for education and non-pharmacological interventions (Jeffery et al., 2011). Indeed, provision of CBT would require additional time at a primary care level, resulting in a decreased number of patient visits per day and corresponding potential for loss of revenue to the physicians, and leading to longer wait times for all patients.

When psychological resources are available, they may be more readily accessed in urban centres, leaving some individuals with chronic pain a long distance to travel (Burnham, Day & Dudley, 2010; Lyckholm et al., 2001; Tollefson & Usher, 2006; Turk & Rudy, 1990; Weir et al., 1992), potentially exacerbating their pain along the way. Availability of alternative strategies to educate individuals with chronic pain in self-management and CBT techniques could potentially engage more individuals prior to, and while waiting for, assessment by pain specialists.

The Internet as a Management Tool

Use of the Internet by Individuals with Chronic Pain

As access to the Internet becomes faster and more widely available both at home and in public places, there is increasing opportunity for those with chronic pain to search and download information specific to their diseases, especially potential treatments that are evidence-based and/or those supported by little or no evidence (Kaicker, Debono, Dang, Buckley & Thabane, 2010). One of the components taught in patient self-management courses involves the learning of strategies for increasing productive
communication with health care providers. Individuals may research and print information gathered from the Internet in order to use it as a starting point for discussion with their providers (Corcoran, Haigh, Seabrook & Schug, 2010; Larner, 2005). Without direction, they may not be able to adequately assess the validity of the information they gather (Corcoran, Haigh, Seabrook & Schug, 2009; Larner, 2005).

In a postal survey (n=122) conducted in Australia in 2007, Corcoran et al. (2009) reported that the top four topics that individuals with chronic pain researched on the Internet were exercise, depression, physiotherapy and surgery. The authors found that it was a relatively small proportion of one clinic’s individuals with chronic pain (23.8%) that accessed the Internet for this purpose. Results might be different, however, even five years later, as the Internet has become faster and more accessible both financially and geographically (International Telecommunication Union, 2013; Statistics Canada, 2010). Of the people who obtained chronic pain information from the Internet, 41.4% believed their information was of good quality. Despite this, only 6.9% planned to discuss the information with their physician (Corcoran et al., 2009).

A questionnaire was distributed to 89 individuals between November 2006 through February 2007 in the United States at the time of their appointments with pain-management providers, in order to identify demographic characteristics, satisfaction regarding pain-related information on the Internet and pain-related Internet search characteristics of individuals with chronic pain (Shinchuk, Chiou, Czarnowski & Meleger, 2010). The authors’ affiliation was to a rehabilitation hospital in Boston Massachusetts, and although not specifically addressed, it appears the study sample was taken from that geographic area. Of the 89 participants, eighty (90%) had Internet
Sixty-three percent of the individuals with Internet access reported using the Internet to access pain-related medical information. More than half of those reported that they believed the information they reviewed was credible and useful. Almost all current Internet pain information searchers, and over half of those who did not currently seek medical information on the Internet planned to use the Internet in the future to research pain-related information. Only half of those who had already found information had shared that information with their healthcare providers. Overall, the group who used the Internet to research pain was similar to the group who did not. The typical Internet pain information seeker was aged 47.1 (±10.2 SD) years, and of white non-Hispanic ethnicity (91%). These individuals were employed full time (25%) or on disability (52%), with mean pain duration of 9.3 (±6.9 SD) years and on opioid therapy (80%), and more were female (61%). The only difference between groups was in education status; 58% of those who did not use the Internet for pain information had not attended any post-secondary education as compared to only 20% of those who did seek Internet pain-related information (p<0.01). It is unclear whether this sample was representative of the geographic area as a whole, but descriptive data were similar to previous research done in the Netherlands by de Boer, Versteegen and van Wijhe (2007).

In a more recent study, two hundred and sixty questionnaires were handed out at a University pain centre in France from May to July 2011. Of those who responded (n=245), two-thirds reported using the Internet to find pain-related information, and further, the Internet was often the first source of information for the individuals, even before consulting their healthcare provider (Dousset, Roussel, Giorgi, Peragut & Leveque, 2012). Again, only a minority of individuals (35%) used the information in
discussions with their healthcare provider. Similar to those who did not use the Internet, those using the Internet for pain-related information were more likely to be female (79%) and married/common-law (67%). While a number of those using the Internet were employed (39%) or retired (18%), the proportions of each were slightly different in those not using the Internet (29% employed, 43% retired). The mean age of those with Internet access who researched pain information was 47.5 (±12.6 SD) years, whereas the mean age of those who did not research this information was 55.5 (±14.7 SD) years. The participants reported that the short time it took to search and receive information via the Internet was the most compelling factor in their preferential use of the Internet for pain-related information. They assessed the information to be of fair to good quality, and were inclined to make changes to their treatment regimen based on information found.

**Quality of Information about Chronic Pain on the Internet**

With an increasing number of people accessing the Internet for health-related information (Washington, Fanciullo, Sorensen & Baird, 2008), it is important to assess quality of the information that is available. This has proven to be a difficult task, as website content is constantly subject to change, search engines produce variable results, and tools for evaluation of websites have not been consistently validated (Corcoran et al., 2009).

Washington et al. (2008) evaluated 240 websites discovered using search terms related to chronic pain. The authors selected sites from links displayed on the first two pages of each of three major search engines. The websites were assessed for quality using the Quality Website Index (QWI), a tool that evaluated chronic pain subject material such as etiology, diagnosis, goals of treatment, treatment options and substance
abuse. The sites were also reviewed for presence of professional authorship, commercial gain, website standards, readability, language and video. Overall, the quality of sites was poor; on a QWI scale of -16 (poorest) to +16 (best), the mean score was 2.2 (±3.3 SD). Despite the overall poor quality, the authors did find several sites that were evaluated to be excellent. In addition, those websites found by the search engines and appearing on the first page of results had significantly higher quality scores than those websites that were in the sponsored section of the page. Based on this data, the authors recommend that clinicians suggest websites with high QWI scores to their patients.

Corcoran et al. (2009) studied websites in terms of quality, which they defined as including disclosure and presenting current information, and in terms of technical score, which included accuracy of content. The term “chronic pain” was used in five search engines, and ten sites were retrieved from each. After excluding duplicates, twenty-seven websites were scored. Only two websites were scored as “very good” or “excellent”, with a Wikipedia® site receiving the best score. Common problems with websites retrieved were lack of statement of purpose, lack of references, and selective mention of therapies (i.e. no non-pharmaceutical therapies mentioned).

Kaiker et al. (2010) evaluated 161 chronic pain websites accessed via search terms through Google, MSN and Yahoo search engines, using a tool to assess quality and readability. Overall quality of websites was reported as “moderate”, with some discrepancies; some of the high-scoring websites provided commercial solutions for pain issues, and those sites with low readability, which had an impact on quality scores, provided other options such as interactive media.
Most recently, Bailey et al. (2013) evaluated the quality of online chronic pain health-related information. Of the 408 unique websites identified and accessed, the overall quality rating (by professionals and consumers) was 2.8 (on a 1-5 scale). Only 13% were rated as high quality. Based on findings, the authors recommend that consumers, professionals and researchers thoroughly evaluate website quality using a validated tool, such as the DISCERN used in this study, use websites that provide references, and avoid websites providing direct services or selling products (Bailey et al., 2013).

**Internet-Based Treatment of Chronic Pain**

While Internet-based interventions exist and have been studied for the treatment of depression, anxiety and other mood disorders (Andersson et al., 2005; Christensen, Griffiths & Jorm, 2004; Ghahari et al., 2009), chronic disease in general (Cudney & Weinert, 2012; Lorig, Ritterk, Laurent & Plant, 2006) and other specific chronic diseases such as coronary artery disease (Kerr et al., 2010; Vandelanotte, Dwyer, Van Itallie, Hanley & Mummery, 2010) and epilepsy (Dilorio et al., 2009), no online chronic pain intervention was found. In 2009, at the time of submission of the research proposal for this study, the only available computer-based interventions that included components such as cognitive behavioural therapy, self-management and education were not specific to chronic pain. These intervention websites will be discussed further in Chapter 3. It is important to note that the disease processes targeted by the available interventions have elements similar to those that present in the trajectory of chronic pain, such as depression, psychosocial issues, and role responsibilities; however chronic pain has its own unique
An online version of a chronic pain self-management program, via the Stanford Chronic Disease Self-Management model (Lorig, 2006; Lorig, 2008), was in clinical trials at the time of development of the intervention for this study. It was hypothesized that adaptation of the chronic disease program for the chronic pain population would demonstrate effectiveness similar to the program developed for those suffering from other chronic diseases, but it was expected that the program would be offered at a cost. Other computer-based interventions developed for those with chronic pain have since been studied as well, and this information is captured in greater depth in Chapter 6 of this thesis.

**Summary**

Chronic pain is a condition that affects a wide range of people, across all domains of functioning. As duration of pain increases, those who are afflicted face issues related to employment, role and relationships, finances, and quality of life. Current goals in chronic pain treatment have moved away from “total cure”, toward improving function and quality of life. It seems that the most effective treatments for those with chronic pain incorporate cognitive behaviour therapy principles and self-management education. There is a need to broaden reach to provide for increased access to programs offering these therapies.

Research in the area of interventions delivered in guided Internet-based formats to improve health is still not comprehensive. In addition, although information about chronic pain is available on the Internet, and those with chronic pain are searching
information regarding their disease process at no cost other than their personal Internet 
(or work Internet) connectivity fees, often the consumer is unable to assess quality and 
veracity of the information without guidance. Suggesting appropriate high quality 
websites, which incorporate evidence-based cognitive behavioural and self-management 
principles, in a structured format where sequential access to sites builds on each piece of 
newly acquired knowledge, could provide valuable information and stimulate the 
beginnings of thought and potentially action toward improving health-related quality of 
life for these individuals.
Chapter 3

Design of a Guided Internet-based Intervention for Chronic Pain

As access to the Internet continues to grow (Statistics Canada, 2011a), and users search websites for healthcare information related to their disease processes (Statistics Canada, 2011b), there is opportunity to use the Internet as a tool to educate individuals with chronic pain about components of their illness, and potential treatment modalities. Adaptation of evidence-based treatment modalities, such as cognitive behavioural therapy and self-management, for delivery via the Internet or in a computer-based format is in its infancy, and current research is determining the effectiveness of using this approach (Chiauzzi et al., 2010; Christenson et al., 2004; Lorig et al., 2006; Schulz, Rubinelli, Mariotti & Keller, 2009; Stanford School of Medicine, para. 1, 2013; Sveinsdottir et al., 2012). When considering the barriers to treatment in those with chronic pain, it is necessary to structure an intervention that has flexible timing, has an asynchronous delivery method (i.e., there is no requirement to be online at a specific time in order to receive the intervention), is available at little or no cost, and requires no geographic considerations (i.e. is accessible from the participant’s home). In addition, in light of the long wait for specialty treatment in chronic pain, there is potential benefit for these individuals if they are able to access evidence-based therapy while they are otherwise at a treatment standstill, having received primary care interventions but before seeing a specialist. In particular, interventions that could teach them about their pain and how to maximize their involvement in the treatment process through use of cognitive behavioural strategies and self-management principles, would be especially relevant to help define expectations and goals prior to their opportunity to see the specialist.
In order to appeal to and engage individuals with chronic pain who had not yet established care with a clinic, it was important to find interventions that did not require payment, travel or specific timelines, but were structured enough that they had access to relevant evidence-based material in a logical easy-to-follow flow, without having to search for it, or build on knowledge not yet acquired. As discussed in Chapter 2, there were no computer-based program in existence in 2009 that met all criteria appropriate to address the characteristics of this particular group of individuals. There was a need for a therapeutic intervention specifically designed for those who had exhausted primary care interventions but remained on a wait list prior to establishing care with a specialist. With a view to bridging this time and treatment gap, a self-directed intervention within a structured delivery format was designed to facilitate access to good quality information without requiring involvement of a clinician who had not yet established care.

**Rationale for Design of Novel Intervention for Individuals with Chronic Pain**

A small number of evidence-based computer-delivered programs that included cognitive behavioural, educational or self-management components, were available at the time of development of the intervention. Although these programs were developed for other disease processes, such as depression and anxiety, the research documenting their design and testing will be discussed as part of the design of this intervention. When considering individuals with chronic pain, there were few web-based cognitive behavioural, educational or self-management interventions developed for use by this group; the few programs identified targeted specific types of chronic pain such as headache or low back pain. More specifically, when considering barriers to treatment, there was no one existing program that met the following criteria designed to address
barriers and provide relevant, evidence-based chronic pain-specific content to individuals awaiting chronic pain specialist assessment:

1. Flexible access to address conflicting issues related to scheduling, home/work responsibilities;
2. Financially accessible;
3. Individual structured delivery and pace, with no requirement for on-site attendance or group sessions; and,
4. Reasonable program length to address the impact of time commitment and reduce attrition.

At the time of development of the intervention to be studied (2010), there were only two studies (Berman et al., 2009; Devineni & Blanchard, 2005) assessing interventions for those with chronic pain, that did not employ staff and/or therapists to play a role in the intervention in the form of moderating message boards, regularly responding to individual personal participant emails and questions, and advising or assessing participants via telephone.

Existing Interventions

A search for existing web-based disease management programs was conducted prior to development of the study Internet Chronic Pain Intervention (ICPI). Peer-reviewed literature was searched using combinations of broad terms such as “Internet”, “computer-based”, “CBT”, “pain” and “chronic disease”. In addition, similar terms were used in search engines such as Google, and medical websites such as WebMD. Most computer-based programs discovered using the selected terms were not yet in the public domain, or required fees and/or registration to access the site. Of those that were
accessible, materials were targeted to populations with chronic disease in general, or specific components of chronic disease, rather than the population of interest in this research: those with chronic pain and more specifically, those awaiting specialty consultation. Documentation of pre-existing web-based disease management and education programs including MoodGYM (Centre for Mental Health Research, 2004), ONESELF (Schulz, Rubinelli, Zufferey & Hartung, 2010) and painACTION (Chiauzzi et al., 2010) were reviewed and the websites themselves were accessed when possible.

**Description of existing web-based programs.**

*MoodGYM.* MoodGYM is a computer-based interactive program to prevent depression, developed at the University of Australia by researchers affiliated with the Centre for Mental Health Research (2004). It consists of five modules, which utilize CBT principles. MoodGYM is self-paced with no requirement to be online at a specific time, offered at no cost, and there is no requirement to engage in group chats or forums. Christenson et al. (2004) conducted a randomized controlled trial of MoodGYM compared to a web-based psychoeducation program and no computerized intervention in individuals (n=525) with symptoms of depression. After intervention, the percentage of participants scoring >16 on the depression scale of the Center For Epidemiologic Studies on Depression instrument dropped to 54% (decrease of 25%) for the MoodGYM CBT group, to 50% (decrease of 20%) for the psychoeducation group and to 61% (decrease of 8%) for the control group; however it is important to note that the sample was recruited from a community rather than a medical practice and therefore may have had different characteristics than a chronic pain wait list group.

In terms of fit with a chronic pain intervention, the program is associated with a mental health organization. As such, components could have been useful to link to in the
new ICPI, but because it specifically targets depression, and more specifically preventing depression, rather than the whole spectrum of chronic pain and associated issues, the program in its entirety was not a good fit. Upon further review of the site, it would have been difficult to link applicable components into the ICPI, as there was a requirement for registration and therefore it was not possible to directly link to any appropriate individual webpages without accessing the entire MoodGYM program.

**ONESELF.** ONESELF is an interactive website designed by Schulz, Rubinelli and Hartung (2007) and tested in Switzerland in a group with chronic low back pain. At the time of structuring the ICPI, ONESELF was only available in Italian, and was still in clinical trials, thus components were not considered for inclusion in the chronic pain intervention. The process of building ONESELF was reviewed in order to assess components and rationale for pieces of the program. The purpose of the website was to provide information and support to individuals self-managing their pain. ONESELF was structured to provide educational information about chronic low back pain, in the form of audio, video and text (Schulz et al., 2009). Educational content was based on physicians’ reports of the most frequent questions by individuals with chronic pain. Information about back pain, anatomy and physiology, treatment options and exercise was included. In addition, there was a forum where participants could post questions, and a chat room where participants could interact with each other and various health professionals (one of five rheumatologists and three physiotherapists who monitor the website) (Schulz et al., 2009). Rather than being delivered in modules, the program was presented as a whole website, and users could navigate through the various sections they were interested in at their own pace. In the five months of pilot testing, users (n=20) accessed the site an
average of 11.5 times, and reported the program to be useful and of very good quality (Schulz et al., 2007). Neither ONESELF nor any component of the program was available to the public for use in 2009, which precluded linking to any components when structuring the new ICPI.

**PainACTION.** PainACTION, a self-management website, was designed by a group of psychologists, physicians and health educators in the USA, for use by those with chronic back pain (Inflexxion Incorporated, 2010). With the definition of Internet-based therapeutic interventions evolving to include cognitive behavioural components presented in varying multimedia formats, and with interactivity and feedback (Barak, Klein, & Proudfoot, 2009), Chiauzzi et al. (2010) designed painACTION to deliver concepts related to chronic back pain in a therapeutic intervention format. When tested in those with chronic back pain (n=209), using outcome measures recommended by the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) (Turk et al., 2003), those randomized to painACTION experienced improvement in pain, depression and anxiety, and reported global improvement. There was no requirement for users to be online at scheduled times. Access to information on the painACTION website could be done via open self-directed navigation, or via registration and computer-generated customization using the individual’s back pain characteristics and other information (Inflexxion Incorporated, 2010), all at no cost. Authorship was clear and included healthcare professionals, and funding was received from the National Institute of Health, although the authors also disclose that additional funding was received from a pharmaceutical company. While some of the open content was specific to back pain, individual web pages were well presented, easy to navigate, and had core concepts that
were relevant to those with other types of chronic pain. It was possible to link directly to these particular pages, without adding technical complexity (registration, password) for the user. The full painACTION website was not appropriate for the entire wait list group, as content was geared toward treatment of back pain, however because it was accessible to all at no cost, with evidence-based information, links to relevant painACTION web pages were used in the final version of the ICPI.

Other websites. The Stanford Chronic Disease Self-Management program (CDSMP), an evidence-based program, has been offered in many community settings across Canada and the US (Stanford School of Medicine, para. 1, 2013). In addition, an Internet-based chronic disease self-management program had been developed and was in long-term clinical trials (Lorig et al., 2006) at the time this ICPI was being developed. Neither of the CDSMP programs was accessible for the purpose of evaluating content firsthand; the community program required registration, payment and attendance, and the Internet program was not yet released. An Internet-based self-management program for individuals with arthritis and fibromyalgia had been developed and was also in clinical trials, and this program was expected to be eventually offered at a fee to participants (Lorig, Ritter, Laurent & Plant, 2008; Stanford School of Medicine, para. 1, 2013). While the content in these programs was based on effective face-to-face treatments, at the time of development of the ICPI, neither the Internet-based program, nor any individual component was available, and upon release it was expected to be offered at a cost; thus links to this CDSMP were not included in the ICPI.

In addition to the comprehensive programs listed above, individual components of another comprehensive program were available as stand-alone interventions. Carol
Vivyan, a cognitive behavioural psychotherapist based in the United Kingdom developed an online self-help course in cognitive behavior therapy (Vivyan, 2009). Her resource worksheets incorporate concepts of CBT and self-management and provide structure so participants can record goals, activities and behaviours as they work through the behavioural strategies. While these documents were very basic visually, they were very clear and easily accessible without restriction on use. The complete self-help course in cognitive behavioural therapy was very broad and involved text with a few simple illustrations and charts. Overall the course was not geared to or ultimately appropriate for the group to be studied, but the information was reviewed, and specifically the order and complexity of concepts presented was noted in preparation for designing a novel intervention. Relevant components were included in the ICPI, in the form of hyperlinks to the appropriate web page.

**Conceptual Framework and Intervention Design**

**Building on Previous Research**

Once it had been determined that a new intervention would have to be constructed in order to provide adequate information to those with chronic pain waiting for specialty care, studies documenting interventions in pain or chronic disease (Appendix B), and Internet-based interventions in pain or chronic disease (Appendix C) were reviewed to determine structure, order and key components. In addition, articles discussing the development of Internet interventions were identified. Ritterband et al. (2003) recommended orderly progression toward designing and operationalizing a guided Internet-based intervention, which was achieved using the Wilson and Cleary model, situating components of the intervention within the framework. The intervention would
be structured and self-guided, using established and empirically-supported treatment techniques (Ritterband et al., 2003). Ghahari et al. (2009) engaged focus groups to determine technical requirements in the design of a computer-based chronic fatigue self-management intervention. Recommendations included easy access, clear and easy navigation to assist those with minimal computer experience, asynchronous participation, and no more than two to three hours weekly required for participation (Ghahari et al., 2009). Use of multimedia components was suggested in order to maintain interest, as accessing pages without audio, graphics, video and/or animation, was viewed as only minimally different from reading a book (Ritterband et al., 2003). Effective computer-based interventions to date were designed based on format and evidence-based content that was shown to be effective in traditional face-to-face interventions (Ghahari et al., 2009; Lorig et al., 2006; Ritterband et al., 2003).

When considering dosage of intervention in both face-to-face and computer-based interventions, the number and duration of sessions and number of weeks in total were examined for existing evidence-based chronic pain and/or internet-based health interventions. As noted in Appendices B and C, when there was an attendance requirement, most of the interventions consisted of one 90-120 minute session weekly for six to ten weeks. With Internet-based interventions (no attendance requirement), the number of sessions and duration of sessions required was less clear, but participation usually lasted less than 10 weeks.

**Sequence of Information**

In order to build the intervention with sequence of information that was evidence-based and consistent with those used by other programs, the literature was reviewed for
description of content and sequence. Trudeau et al. (2010) interviewed 32 individuals
with arthritis, and 12 healthcare providers to ascertain what concepts and components
these stakeholders identified as desirable to include in an online self-management
program. Through content analysis of responses, a concept map was generated. The six
clusters that emerged as common themes were disease and pain education, daily living,
physical activity and diet, tools to manage pain, communication and support, and future
of arthritis pain (Trudeau et al., 2010).

Many existing interventions used the chronic disease self-management program
model, developed through Stanford School of Medicine in 1996, and studied by Lorig et
al. (2001) as a foundation for basic sequence (Detaille, van der Gulden, Engels, Heerkens
& van Dijk, 2010; LeFort et al., 1998; Schreurs, Colland, Kuijer, de Ridder, & van
Elderen, 2003). Information was delivered in six weekly sessions, each approximately
two hours. Basic descriptions of the sequence and content were available in some of the
study descriptions, but the actual intervention and/or detailed description of content was
unavailable. Most interventions were structured with a specific focus each week, and
with broader concepts such as problem-solving and goal-setting woven through the entire
intervention. Topics commonly found in these interventions included exercise,
deression, nutrition, communication (with family and with healthcare providers),
evaluating treatment modalities, rest/sleep and medications (Carnes et al., 2012; Dilorio
et al., 2009; LeFort et al., 1998; Schreurs et al., 2003), consistent with what was
identified as important in the Trudeau et al. (2010) research.

Given this information, a concept map (Appendix D) was built to provide a basic
structure for selecting and organizing components of the new intervention. This
intervention design included all of the topics identified by Trudeau et al. (2010) and commonly found in other interventions, in a sequence that moved from basic to more detailed, building on previous knowledge.

Overview of Conceptual Framework

While many of the programs described above used self-efficacy frameworks to build and evaluate interventions, when IMMPACT guidelines (Dworkin et al., 2008; Turk et al., 2003) were considered, a broader framework was chosen. The Wilson and Cleary (1995) framework for health outcomes was used to guide structure and identify essential components. This framework offered opportunity to address physical and psychological issues and outcomes in the setting of chronic pain. Outcomes of interest, with a view to documenting components of health-related quality of life, included assessment of symptom status, functional status and general health perceptions of the participants (Figure 1). All of these concepts have an impact on overall health-related quality of life, a quality of life affected by general health, function, and perception.

![Figure 1. Wilson and Cleary’s Model of Health-Related Quality of Life (1995)](image-url)
Biological and Physiological Variables

Biological variables identified through laboratory and tissue analysis, and measured in the course of assessment and diagnosis, not only affect symptom status, but also affect treatment offered. Similarly, physiological variables evident in tests such as Magnetic Resonance Imaging or Computerized Axial Tomography, in conjunction with findings from physical examination by healthcare providers, can guide treatment provided by medical and allied health personnel. The initial biological and physiological data combined with adherence, or even non-adherence, to a physical or pharmacologic treatment regimen, affects symptom status, functional status, health perception and overall quality of life. At a biological level, pain intensity and other related symptoms, such as loss of motion and function, may be the stimulus to access care; however, as in the case of chronic pain, biological and physiological factors are not necessarily congruent with patient-reported symptoms (Loeser & Melzack, 1999; Wilson & Cleary, 1995).

Symptom Status

Symptom status, defined as the perception of a sensation and the assignment of meaning to that sensation (Wilson & Cleary, 1995), is affected by pathophysiology, but also by characteristics of the individual, such as coping mechanisms, mood and emotion, which may amplify perception of symptoms (Loeser & Melzack, 1999). Characteristics of the environment, such as presence of psychological supports, also have an impact on symptom status leading to health-related quality of life (Wilson & Cleary, 1995).
Functional Status

The next level in increasing complexity moving toward health-related quality of life in the Wilson & Cleary model involves assessment of functional status, the ability to perform a task. While symptom status affects physical and mental function, the other domains that must be considered are social function, role function and psychological function (Wilson & Cleary, 1995). Functioning within this level is affected by personality and motivation, and by social and economic supports.

General Health Perceptions

An individual’s health perception has an impact on general health and quality of life (Wilson & Cleary, 1995) and should be considered when gathering and interpreting health data. Health perception is a subjective concept, affected by values and preferences of the individual, and by availability of social and psychological support. General health perceptions are influenced by symptom status and functional status, although poor symptom control and low functional status do not consistently correlate with poor quality of life (Wilson & Cleary, 1995). Instead, health perceptions involve integration of all of the preceding levels of function in the Wilson & Cleary model, moderated by the individual’s interaction with environmental supports and shaped by the individual’s characteristics (Wilson & Cleary, 1995). These perceptions lead to an overall subjective sense of satisfaction, well-being, or quality of life, as the final level in the model.

Adaptation of the Wilson and Cleary Model: Intervention Development

The Wilson and Cleary framework was further refined for the purpose of this study, in order to identify essential components of the intervention and to ensure those
components lead to a positive change moving toward improving health-related quality of life (Figure 2).

**Figure 2. Adaptation of Wilson & Cleary Framework: Guided Internet-based Intervention**

While the core components of the Wilson & Cleary model remained unchanged, the guided Internet-based intervention was situated within the adapted model to ensure that components selected for the intervention would have an effect on some portion of the continuum leading to health-related quality of life. As the treatment was a non-pharmacological, behavioural intervention, the biological and physiological component was not specifically targeted in the adapted model. Characteristics of the individual, including those acquired such as education, finances and computer literacy, not only
influenced symptom status, functional status, health perceptions and quality of life, but they also influenced selection of intervention components. Similarly, characteristics of the environment, including those previously identified as barriers to treatment, affected not only the continuum leading to quality of life, but also design of the intervention. The guided Internet-based intervention components considered the larger concepts such as symptom status and functional status. In addition, the effects of periodic symptom amplification, motivation, personality, values and preferences, which all have an impact on the larger concepts, were addressed in the selection of components for the intervention. Through this process, the intervention design, using information gleaned from application of the Wilson & Cleary model, also addressed previously identified barriers to treatment:

1. Flexible access:
   a. Components should work well independently as well as within the intervention as a whole;
   b. Modules should be flexible time wise (i.e., there should be no requirement to complete the module in its entirety in one sitting);

2. Financially accessible: hyperlinks included should lead to high quality websites offering information at no cost;

3. Individual structured delivery and pace with no requirement for onsite attendance or group sessions: different types of file formats (e.g., text, audio, video) of varying complexity should be used to appeal to a wide range of participants’ preferences, interests and personalities; and
4. Reasonable program length to address the impact of time commitment and reduce attrition: there should be a limited number of components to the intervention and overall expected time commitment should be communicated clearly at the onset.

**Selection of Components for Inclusion**

**Characteristics of the individual.** In the Wilson and Cleary (1995) framework, characteristics of the individual affect progress toward satisfactory health-related quality of life through their impact on symptom status, functional status and general health perceptions. In the adapted model, (Figure 2), specific individual characteristics such as age, computer literacy, physical disability, financial ability and emotional health were identified, and the guided Internet-based intervention was designed in consideration of these factors. Demographics of individuals with chronic pain referred to specialty clinics were reviewed in order to ensure age-appropriate material was selected and presented in a format appropriate to the educational status of this group. Specific components of the intervention were presented as hyperlinks to external websites that were of good quality, with clear authorship, supported by research, and available at no cost, as fees were identified as a barrier to participation. Components of the intervention were available in audio, video and text formats throughout, in order to ensure that those with minimal computer literacy skills could participate, and that those who did not have high end computers due to financial circumstances were still able to access websites without upgrading equipment. Selected audio files and videos were short in most cases, to ensure that those who had difficulties with attention and/or physical disabilities due to pain or
pain medications were able to complete that piece in its entirety, and participants were able to print texts for review away from the computer.

**Characteristics of the environment.** The adapted model (Figure 2) identifies the specific characteristics of the environment considered when designing the intervention: geographic location, distance to healthcare providers and home/work responsibilities. Because participants would be accessing the intervention from work or home, and in rural or urban locations, the intervention was designed to be delivered in a format where the participant could use any component independently from the others if time, Internet speed, family interruptions and other responsibilities precluded working on the full modules all in one sitting. Components selected worked together and in sequence, but concepts in each module could also be viewed in short periods of time individually, and then re-accessed or printed for later use. When longer videos were offered, there was always a shorter alternative video or similar information in a different format as well. As distance to healthcare providers was considered a barrier to adequate pain treatment and participation in comprehensive pain programs, information chosen for the intervention included written suggestions for maximizing communication with healthcare providers and links to downloadable worksheets for organizing discussion to get the most benefit from in-person visits.

**Functional status.** With more restful sleep and more positive thoughts potentially leading to improved symptom status, participants were given the tools to formulate goals for improving functional status. Information about gentle exercise, activity pacing, and modifying the work environment was provided, along with
downloadable templates for forming, monitoring and evaluating specific, measureable, attainable, realistic and time-bound (SMART) short- and long-term goals.

**General health perceptions.** Participants were encouraged to continue evaluating their progress toward their goals, and to feel positive when even the small goals were met. The intervention was structured to deliver high quality factual information, so that participants were more informed about their health and what they could do as self-managers to effect change. They were also encouraged to explore other topics of interest on the web pages accessed through the intervention in order to learn as much as they could about effectively coping with their chronic pain.

**Overall quality of life.** In the adapted model (Figure 2), positive developments in symptom status, functional status and general health perceptions lead to an increased quality of life. At each point in the model, quality of available support has an impact on progress. Social, psychological and economical support were reinforced in the intervention through provision of information about maintaining significant relationships despite chronic pain and maintaining current level of functioning even if modifications are required, including work modifications.

**Final Structure of Intervention**

**Content.**

Using a similar format to interventions from previous research, the intervention developed for this study consisted of an introductory module plus six intervention modules. Intervention modules, delivered weekly, provided links to public websites containing information about topics similar to those used in validated community-based self-management programs currently provided in group sessions within the community, including The Arthritis Self-Management Program (Lorig & Fries, 2006) and the Chronic
Pain Self-Management Program (LeFort et al., 1998). Table 2 outlines final content of the intervention.

Table 2. Guided Internet-based Chronic Pain Intervention Content

<table>
<thead>
<tr>
<th>Topic</th>
<th>Supporting Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Brox et al., 2008; Chiauzzi et al., 2010; LeFort et al., 1998; Lorig et al., 2008</td>
</tr>
<tr>
<td>Self-management concepts</td>
<td>Farrell et al., 2004; Foster et al., 2007; Hanada, 2003; LeFort et al., 1998; Lorig et al., 2008; Redondo et al., 2004; Reid et al., 2008</td>
</tr>
<tr>
<td>Cognitive behavioural concepts</td>
<td>Hoffman et al., 2007; Sveinsdottir et al., 2012; Williams et al., 2012</td>
</tr>
<tr>
<td>Exercise, activity, pacing</td>
<td>LeFort et al., 1998; Lorig et al., 2008; McGillion et al., 2008</td>
</tr>
<tr>
<td>Communication</td>
<td>LeFort et al., 1998; McGillion et al., 2008</td>
</tr>
<tr>
<td>Mood and emotion</td>
<td>LeFort et al., 1998; Lorig et al., 2008; McGillion et al., 2008</td>
</tr>
<tr>
<td>Nutrition</td>
<td>LeFort et al., 1998; Lorig et al., 2008; McGillion et al., 2008</td>
</tr>
<tr>
<td>Medication</td>
<td>LeFort et al., 1998; Lorig et al., 2008;</td>
</tr>
<tr>
<td>Goal-setting</td>
<td>LeFort et al., 1998; Lorig et al., 2008;</td>
</tr>
<tr>
<td>Relaxation, mindfulness</td>
<td>Bishop et al., 2004; Kerns et al., 2011; LeFort et al., 1998; Lorig et al., 2008</td>
</tr>
<tr>
<td>Sleep</td>
<td>Lorig et al., 2008; McGillion et al., 2008</td>
</tr>
<tr>
<td>Treatment evaluation</td>
<td>LeFort et al., 1998; Lorig et al., 2008; McGillion et al., 2008</td>
</tr>
</tbody>
</table>

**Intervention structure and delivery.** Intervention materials were delivered via a weekly emailed file with active links to video, audio and text pages readily available on the Internet in the public domain, accessible at no cost, and of high quality (research-based and with references). In addition, educational components in the intervention were set up to reinforce the use of activity pacing, techniques to improve sleep, ways to cope
with medication side effects, use of effective communication strategies and mindfulness and relaxation exercises.

Each intervention module was structured to deliver five components:

1. An overview of the topic material for the week;
2. Education in the week’s topic;
3. Physical activity suggestions and information;
4. Goal-setting exercises; and,
5. Relaxation exercises;

For simplicity, the modules were constructed in basic black and white text boxes with blue hyperlinks for ease of delivery to the participant and ability to load quickly. The links led to web pages that used text and charts, colourful images and animations, audio and video. Each of the five components was enclosed within its own border, and the long text of each hyperlink included was renamed to a shorter phrase to indicate the type of information contained, i.e. “Communication (audio file)”. There were often several links with the same subject matter, in different formats, in case a participant had difficulty loading a particular type of file, or had a slow Internet connection.

Components were listed in the same order from week to week. Modules were kept to a maximum of two pages and saved as an Adobe™ (.pdf) file, as the reader for this type of document was readily available for download on the Internet at no cost. Full modules with references for hyperlinks in order of occurrence are found in Appendix E.

While there was no opportunity to conduct structured focus groups prior to piloting the intervention due to time constraints and relatively small pool of potential participants, the intervention was shown to three local researchers/clinicians with an
expertise in chronic pain management and CBT, and small cosmetic revisions were made based on their verbal feedback (face validity). The potential for participants to give free text feedback on quality and usability of the intervention, as well as suggestions for improvement, was built in to the feasibility study in lieu of conducting a formal focus group.
Chapter 4

Methods

The purpose of this study was threefold: 1) To test the feasibility of conducting a larger intervention trial; 2) To assess the perceived usability of a newly developed guided Internet-based intervention for chronic pain; and 3) To provide information on the characteristics and outcomes of the sample to be used for development of future intervention studies.

Objectives

Objective 1

To test the feasibility of conducting a larger intervention trial. Data were collected to assess feasibility of conducting a larger scale intervention trial using the newly developed intervention. Specific questions included:

i. Rate of recruitment: How many participants were recruited monthly? What percentage met inclusion criteria and of those what percentage consented to participate?

ii. Study adherence: What percentage of study participants participated in weekly data collection via Internet-based questionnaires? What was the rate of attrition?

iii. Time in intervention: How much interaction time at the computer with the intervention modules did participants report? How much time working on the modules away from the computer did participants report? How many
days per week did participants report doing some work with the
intervention material?

iv. Representative sample: Did those who consented to participate in the
study have similar characteristics to the entire group on the Wait List?

Objective 2

To assess the perceived usability of a newly developed guided Internet-based
intervention for chronic pain. Overall usability of the intervention was studied.

Specific questions included:

i. Were participants satisfied with each module overall?

ii. How did participants rate layout/design, quality of content, and ease of
navigation, usefulness of information in each module?

iii. Were text, audio and/or video files useful styles of information delivery in
each module?

iv. How did participants rate individual components of the intervention
(introduction, education, activity, goal-setting and relaxation) in each
module?

Objective 3

To provide information on the characteristics and outcomes of the sample to
be used for development of future intervention studies. Recommendations for
selecting outcomes in chronic pain research, outlined by IMMPACT investigators, were
reviewed prior to forming exploratory research questions. Through the use of focus
groups, the IMMPACT investigators generated a pool of significant outcomes in chronic
pain (Turk et al., 2008). When validated with a larger population, the investigators found
that from a patient perspective, it is important to assess quality of life indicators, rather than only measuring pain outcomes. In line with the biological and physiological variables, symptom status and functional levels of the Wilson and Cleary model (1995), those with chronic pain consider increased functioning, reduction in feelings of fatigue and weakness, and improved sleep as positive outcomes (Turk et al., 2008). IMMPACT recommends six core outcome domains for consideration when designing clinical trials in chronic pain (Turk et al., 2003). The domains relevant to this type of intervention include emotional functioning, physical functioning, pain (intensity and interference), participant perception of effectiveness of treatment, and adverse events. Research was structured to address these outcomes. The following domains and exploratory research questions were addressed:

i. *Emotional functioning.* Did use of the guided Internet-based self-management intervention produce a change in the mental health component of health-related quality of life as compared to pre-intervention?

ii. *Physical functioning, pain.* Did use of the guided Internet-based self-management intervention produce a change in the physical component of health-related quality of life, pain intensity, or pain-related interference with activity as compared to pre-intervention?

iii. *Participant perception of effectiveness of treatment.* What was the participant’s global impression of change in health status since beginning the guided Internet-based intervention?

iv. *Adverse events.* Were there any adverse events during the conduct of this study?
Research Design

This feasibility study utilized a one group repeated measures design to assess feasibility and usability of the intervention and to examine potential outcomes for future studies. SurveyMonkey™ was the Internet platform used to design the questionnaire and capture participant responses. Consistent with a one-group design, all participants received the study intervention.

Ethics approval for the research proposal was obtained from St. Mary’s of the Lake Research Review Board, where the chronic pain clinic was located at the time of study initiation, and Queen’s University Health Sciences Research Ethics Board (HSREB). After closure of the chronic pain clinic, ethics approval for an amendment to the protocol, opening the study to any adult with chronic pain, was obtained from Queen’s University HSREB. All ethics approval documents are available in Appendix F.

Participants

Participants were drawn from two sources, a chronic pain clinic wait list and via advertising on the Internet.

Clinic wait list. The wait list recruits were drawn from a convenience sample comprised of all individuals who had documented contact information, and met the eligibility criteria described below, from the wait list of a publicly funded chronic pain clinic. At the time the research proposal was approved, February 2011, the wait list included 400 individuals. As recruitment began in May 2011, the publicly funded chronic pain clinic formally closed, and individuals were no longer accrued to the wait list. The research staff contacted individuals by telephone from May to August 2011, to explain the study, to assess interest in participation and to ensure they met inclusion
criteria for the study. Those who verbally agreed to review information about the study and read the study consent were asked to provide their electronic mail (email) address to receive study documents, or if they preferred, they were supplied with the researcher’s email address in order to send an email expressing interest and requesting information.

**Internet.** The Internet pool was approached via advertising on social media sites including Facebook™, Kijiji™ and the local newspaper community marketplace webpage. Initially, the advertisement on Facebook was set up to be shown within the narrow geographic area similar to that of the clinic wait list cohort in an attempt to recruit individuals with similar characteristics to this cohort. However, as recruitment remained slow, the Facebook™ advertisements were opened up to Ontario. Those who viewed or responded to the advertisements also reposted on websites to which they belonged, and sent the advertisements to friends, widening the geographical area from which the sample was drawn. Potential participants emailed the researcher to indicate interest.

**Recruitment Procedure**

Once email communication was established, potential participants received a letter of information and research consent form via email (Appendix G). Participants were asked to reply to the researcher after reading the documents, in order to discuss participant rights, confidentiality, risks and benefits of participation, or have any questions answered by the investigator either by email or by telephone. Those participants who wished to consent to participation were then assigned a study participant number to maintain confidentiality and emailed a link to the online consent. When participants followed the link, they were directed to give their participant number and
their initials, to read the consent, and to indicate whether they consented to participation by checking ‘yes’ or ‘no’ at the bottom of the secure consent webpage.

**Eligibility Criteria**

Participants were included if they:

1. Were aged 18 or older;
2. (Cohort 1) had been referred to one outpatient chronic pain clinic and were on the wait list for pain specialist consultation at the time of study consent; or (Cohort 2) self-referred to the study after seeing an advertisement or hearing about the study, through social media or word of mouth, and self-identified as experiencing chronic pain;
3. Reported being able to read, speak and understand English;
4. Were able to access the Internet; and,
5. Consented to participate in this study.

Individuals were excluded if they had never accessed the Internet independently, or self-reported lack of proficiency or difficulty navigating the Internet or working with a computer.

**Setting**

The study was conducted in Kingston, Ontario, a southeastern community with an academic health sciences centre and university. Potential participants for Cohort 1 were identified from the wait list at a chronic pain clinic affiliated with St. Mary’s of the Lake Hospital in Kingston, Ontario. Potential participants for Cohort 2 had no geographical restriction.
**Intervention**

The chronic pain intervention (ICPI) is described in Chapter 3 and presented in Appendix E. Participants were asked to review each module at their own pace over the course of one week. There was no suggested or required amount of time to spend on the intervention either at or away from the computer, and as the websites were external to the documents emailed to the participants, there was no ability to track participation. Data were collected online, through self-report, using a multiple-choice format questionnaire.

Participants continued to receive usual care, consisting of treatment outlined by their individual family physicians and those already involved in their care, and in the case of the first cohort, the usual care occurred while they waited for pain specialist consultation. There was no interaction between the Chronic Pain Clinic staff and individuals on the wait list that was therapeutic in nature, nor was there therapeutic communication between the researcher and the participants during the course of the study.

**Data Collection**

**Feasibility Data**

Feasibility data were tracked through calculating the percentage of eligible wait list participants who consented to participate in the study. In addition, data on number of “clicks” (selecting the thumbnail of the advertisement to view a full description) of the social media advertisement was compared to number of participants who elected to participate in the study after learning about it via an online source. As questionnaires were delivered weekly along with the intervention module, and participants were asked to complete the questionnaire when they were finished with the week’s content, weekly
response rate was tracked. The questionnaires also asked for a weekly self-report of days where a portion of time was spent working on module-related content, hours at the computer with the intervention material and hours away from the computer working on module material (Appendix H).

**Usability Data**

In order to collect data about usability of the intervention, a questionnaire was constructed to evaluate participant satisfaction with overall content and individual components of each module (Appendix I). Questions about overall module, layout/design, quality of content, ease of navigation and usefulness of information overall and for individual sections of the module were asked, using a 5 point scale ranging from “poor” or “not satisfied” (1) to “excellent” or “very satisfied” (5). Information delivery styles (text, audio, video) were assessed for usefulness through questions requiring a “yes” or “no” answer.

**Sample Characteristics and Outcomes**

**Characteristics of the sample.** The chronic pain clinic referral form, which was completed by referring physicians, was structured to provide data on demographics, pain location, duration and characteristics, other medical history, and prior and ongoing treatments (Appendix J). Questions asked were in the form of “tick” boxes, yes/no, and short answer. This form was used in determining acuity of individuals on the wait list, and selecting an appropriate healthcare provider from within the clinic, based on interests and subspecialties of the providers. Data from the referral form was entered into a spreadsheet, as the referral form was received, by the clinic manager. Analysis of this data provided a description of characteristics of the overall clinic population. A similar
questionnaire was built to document characteristics of the study sample to determine whether this group was representative of the clinic population (Appendix K). All study participants, including those recruited online instead of from within the clinic, completed this initial questionnaire.

**Emotional functioning.**

**Mental Health Component HRQOL.** As chronic pain is associated with alterations in mood—anxiety, depression, irritability, frustration, anger—assessment of emotional functioning is essential in measuring outcomes in individuals with chronic pain (Turk & Melzack, 2011). Emotional functioning in this case is not related to specific psychiatric illnesses, but rather a reflection on mood and perception of well-being, and overall mental health.

The mental health summary score of the Medical Outcomes Study Short Form 12 (SF-12) (Appendix L) was used to measure emotional functioning in this study. The SF-12 is based on The Medical Outcomes Study 36-Item Short Form Health Study (SF-36), which is a self-administered questionnaire designed to measure health-related quality of life through information gathered about the patient’s perception of health (Ware, 2000). Thirty-six items, divided into subscales of physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role and mental health lead to a mental and physical health summary. This validated tool with internal consistency (0.81 to 0.88) in both general and chronic disease populations (Wittink, Turk, Carr, Sukiennik & Rogers, 2004), takes 5-10 minutes to complete and can be administered in a computerized version to those aged 14 and older (Ware, 2000). Traditionally participants are asked to recall over the past 4 weeks when answering questions, however it can also be used with a 1-week recall period. This tool has been used frequently in chronic
disease studies and more specifically, chronic pain studies, to describe the impact of a
treatment on physical and mental health (Bergman, Jacobsson, Herrstrom & Petersson,
2004; Elliott, Renier & Palcher, 2003; Elliott Smith, Hannaford, Smith & Chambers,
2002; Schlenk et al., 1997; Torrance et al., 2009). Although the SF-36 is reliable and
valid, it is often too long for inclusion in some research situations (Ware, Kosinski &
Keller, 1996), including those which require frequent administration of multiple
questionnaires. In these cases, the SF-12 is a reasonable alternative.

The SF-12 is a 12-item short-form questionnaire, which uses a subset of the
questions from the SF-36. In a comparison of summary scores from 12 items of the SF-
36 in the general US population (n=2,333), the 12 items (SF-12) produced mental and
physical component summary scores (PCS and MCS respectively) which closely
corresponded to those calculated using the SF-36 (Ware et al., 1996). This correlation
has been documented in chronic disease research (Maurischat, Ehlebracht-Konig, Kuhn
& Bullinger, 2006; Muller-Nordhorn, Roll & Willich, 2004; Osthus et al., 2012). The
reduction in number of questions, while maintaining accuracy of measurement, decreases
participants’ time involvement in the questionnaire to two minutes or less (Ware et al.,
1996).

A MCS score of 50 is considered the norm in general population studies, with 10
representing one standard deviation (Norman, Sloan & Wyrwich, 2003; Ware et al.,
2000). One-half of a standard deviation (5, in this instrument) has been identified as the
minimal clinically significant difference in health intervention studies (Norman, Sloan &
Wyrwich, 2003; Copay et al., 2007).
Physical functioning.

**Physical component HRQOL.** The measurement of physical functioning includes strength and endurance as well as ability to carry out activities of daily living (Turk et al., 2003). The physical health summary score of the SF-12 (Appendix L), documenting physical function, role, bodily pain and general health, was used to document the physical component of HRQOL in this study. Scoring and norms are similar to the MCS, and minimal clinically significant difference is a change of 5 in this subscale (Norman, Sloan & Wyrwich, 2003; Copay et al., 2007).

Pain.

**Pain Intensity and Pain-related Interference.** Dimensions of pain include intensity, location and quality (Turk et al., 2003). IMMPACT guidelines advise documenting pain history at baseline, in order to assess change in pain with intervention (Turk et al., 2003). As chronic pain has been associated with physical and emotional sequelae, there is a tendency to assume that reduction in pain will lead to improved physical function and emotional status. Turk et al. (2003) note that this may not necessarily be true. In fact, as this is a CBT and self-management intervention, there is no direct action on biology of pain as with pharmacologic interventions, and therefore by targeting physical function and emotional status, there may be an effect on pain intensity and pain-related interference. Reduction in pain in chronic pain studies is typically a primary outcome, and it should be assessed with other outcomes including physical and emotional functioning.

The Brief Pain Inventory (BPI) (Cleeland, 1991) (Appendix M) was used to document pain intensity and pain-related interference with activity. The twenty-item questionnaire records pain intensity at the time of questionnaire completion and as an
average over time using a numerical rating scale (NRS) with participants assigning a number from 0 (no pain) to 10 (worst imaginable pain) to describe their perception of pain either at present or at a given point in their recent history. Overall, the NRS has been a standard instrument in chronic pain studies, due in part to availability and ease of administration (Farrar, Pritchett, Robinson, Prakash & Chappell, 2010; Farrar, Young, LaMoreaux, Werth & Poole, 2001; Hawker, Mian, Kendzerska & French, 2011; Krebs, Carey & Weinberger, 2007; Mannion, Balague, Pellise & Cedraschi, 2007). Minimally significant change with the NRS is defined as -1.39 to -2 points, or a decrease of 30% from baseline (Dworkin et al., 2008; Farrar et al., 2001; Kendrick & Strout, 2005; Salaffi, Stancati, Silvestri, Ciapetti & Grassi, 2004). In data generated from 10 pregabalin studies in the treatment of chronic pain, Farrar et al. (2001) found that the NRS change scores over time during treatment demonstrated a close association with Patient Global Impression of Change (PGIC) scores. The BPI also assesses six areas where pain could potentially interfere (mood, walking and physical activity, work, social activity, relations with others, and sleep); these are also each rated on a 0-10 NRS, with the mean score indicating overall level of pain interference (McDowell & Newell, 1996). While the BPI was originally developed by Charles Cleeland in 1982 for use with individuals with cancer, to measure intensity of pain and functional limitations due to pain (McDowell & Newell, 1996), it has since found use in chronic noncancer pain as well. In research testing the validity of the BPI in documenting chronic noncancer pain outcomes in individuals with arthritis or low back pain, Keller et al. (2004) reported reliability comparable to that reported in individuals with cancer (coefficient alphas greater than 0.70). The authors concluded that the BPI was sensitive to change in pain status over
time. In individuals with osteoarthritis, the pain-related functional interference subscale had excellent internal consistency (0.82-0.89) and good test-retest reliability with an intraclass correlation of 0.81 (Williams, Smith and Fehnel, 2006).

**Participant perception of effectiveness of treatment.**

**Participant Impression of Change.** Response to treatment and clinical outcome is affected by an individual’s expectations and treatment goals (Turk et al., 2003). Importance of treatment milestones may differ depending on perspective for the individual experiencing chronic pain and the health care provider offering treatment. Risk-benefit discussions may elicit differing views in clinic, and the individual may wish to either discontinue or proceed with the treatment regimen after evaluating alternatives. This engagement and responsibility in his own health care plan may affect an individual’s satisfaction with treatment, thereby affecting clinical outcome (Turk et al., 2003). Participant perception of effectiveness of treatment is a subjective evaluation of whether there has been a change in health status as a result of the treatment.

Patients’ Global Impression of Change Scale (PGIC) (Appendix N), a self-report tool documenting an individual’s perspective about effectiveness of treatment, was used to document global improvement from a participant’s perspective. Seven descriptors of change in treatment, from “no change” to “very much improved” are listed and the participant is asked to select the one which best describes his situation. PGIC has been used to validate minimal clinical significance of pain score changes in research using other instruments (Dworkin et al., 2008; Farrar et al., 2001). When used in a chronic pain rehabilitation program, Ferguson and Scheman (2009) found that PGIC scores were affected by pain intensity, mood and depression (p<0.05). Further, “pain intensity alone accounted for 23.8% of the variance in PGIC, (function) for 5.9%, and depression for
1.7% of the variance” (Ferguson & Scheman, 2009, p. S73). The authors suggested that other variables involved might be diagnosis, duration of pain, and presence of other psychosocial factors. IMMPACT criteria identifies a response of $\geq 3$ indicative of minimally significant change (Dworkin et al., 2008).

**Adverse events.** IMMPACT investigators have identified the recording of symptoms and adverse events, and participant disposition as important considerations in the evaluation of chronic pain treatment effectiveness (Turk et al., 2003). While the reporting of adverse events for this purpose occurs normally in the context of pharmaceutical therapy, participants were asked to report any adverse events attributable to study participation to the researcher, and any concerns about study conduct to the Research Ethics Board. Participants were given the email address of the researcher in order to ask questions or to report problems. They were also provided contact information for the Queen’s Research Ethics Board, and, in Cohort 1, the Providence Care Research Ethics Board. After each module, participants were asked about changes in medication and treatments, as well as whether they had seen other healthcare providers (Appendix O). There were also areas in the questionnaire where the participant could provide free-text comments.

**Timing**

Baseline, weekly post-module, and 12-week post-intervention data were collected, similar to many of the studies reviewed in design of the intervention (Appendices B and C). The questionnaire administration schedule is detailed in Table 3. Weekly time points for questionnaire administration in this study were structured so that if replicated in a larger sample, data analysis might reveal which modules had the most
significant impact on study participants. As this was a feasibility study, number of participants was insufficient to assess this, but the process along with free-text comments provided insight into acceptability of this schedule of questionnaire administration.

Table 3. Questionnaire Administration Schedule

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>Week 1</th>
<th>Week 2</th>
<th>Week 3</th>
<th>Week 4</th>
<th>Week 5</th>
<th>Week 6</th>
<th>12 weeks post</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Usability</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>SF-12</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>BPI</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>PGIC</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Treatment Changes</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
</tbody>
</table>

The initial questionnaire package consisted of a demographic questionnaire, the SF-12 (physical and mental functioning, pain), and the BPI (pain severity and interference). After obtaining informed consent, these questionnaires were administered in a computer-based format. At the completion of each module of the intervention, and again at 12 weeks post-completion, the participants completed a follow-up questionnaire package consisting of the SF-12, BPI, and PGIC (participant perception of effectiveness of treatment) in addition to questions related to usability, such as ease of navigation through intervention and satisfaction with content, and recall of how many minutes they spent working through the intervention in the past week, both on the computer and away from the computer in “homework”. Individual participation was intended to last approximately 20 weeks—2 weeks from initial contact to delivery of first intervention module, 6 weeks of study participation, then 12 weeks until final post-intervention measurement (Appendix P).
Sample Size

Given this was a feasibility study, a formal sample size and power analysis was not conducted. For the purpose of ascertaining whether further study in the form of a randomized controlled study would be indicated, this feasibility study set out to accrue 50 participants, slightly more than previous feasibility studies in chronic pain, including a CCBT Internet intervention in adolescents with chronic pain (n=46) (Stinson et al., 2010a) and a DVD-based educational intervention in individuals with cancer pain (n=25) (Capewell, Gregory, Closs & Bennett, 2010). It was initially felt that recruiting 50 participants would be a reasonable goal given the clinic referral status at the time of research proposal submission.

Procedure

Once the researcher received information via SurveyMonkey™ that a participant had consented, the pre-intervention demographic data questionnaire was emailed. If there were no difficulties with ability to access the Internet and provide basic demographic data, participants were sent the introductory module, and then subsequent intervention modules in accordance with the study timelines (Appendix P). If the demographic questionnaire was not completed, the participants were considered lost to follow-up pre-intervention. However, once they received the introductory module, subsequent modules were sent regardless of whether they completed the questionnaires for prior modules, unless they requested to be withdrawn from the study. With the delivery of each module was a general reminder to complete the associated questionnaire; due to the large volume of emails, there were no additional reminders to those participants who did not complete questionnaires.
Confidentiality and Data Management

Contact information, including email addresses for participants, were kept in a locked cabinet separate from study data. Mass group emails of the intervention had the list of recipients hidden [i.e., blind carbon copy (BCC)]. Participants were assigned a participant number for use in the secure online questionnaire site, and were instructed to use initials only, in combination with this number, to identify themselves. As such, all data was anonymized. Only the study investigator and the research supervisor had access to any identifying information. The unique study identifier and matching personal information were stored separately from the anonymized database. All files were encrypted.

All data were entered directly by the participants into the online questionnaires. At the end of the study, the questionnaire data were downloaded by the researcher from the secure SurveyMonkey™ website in the form of spreadsheets, and the online questionnaires were closed to participants. Data were checked for accuracy (participant number corresponding correctly to participant initials). The final spreadsheets were password-protected and stored on a computer which was password-protected and available only to the researcher. Duplicate copies of the spreadsheets were stored on a second computer which was password-protected, in a locked office and only accessible to the researcher.

Statistical Analysis

As this was a feasibility study, the analysis consisted of descriptive statistics, rather than formal testing of hypotheses, although preliminary data was collected and analyzed. Data distribution of all variables was assessed for normality, using the
Shapiro-Wilk test, and variables were recoded and categorized as necessary. Descriptive statistics included mean [± standard deviation (SD)] on normally distributed data, and frequency and percent on categorical data. When data were not normally distributed, median and interquartile range was calculated along with the mean for comparison. When calculated medians were similar to means, data were analyzed, using the means for parametric statistical analysis. In this way, study results could be compared to findings in other similar research literature. All participants who entered the study, including those who chose to withdraw early, were included in the analysis where possible.

Feasibility data were assessed through calculating rate of recruitment, documenting the amount of time necessary to accrue enough participants to conduct the study, and calculating cost of advertising relative to number of participants recruited from advertisements. Attrition rates and cost were also compared to attrition rates and costs reported in other chronic pain studies, and other computer-based studies. Descriptive analysis was conducted on baseline demographic and pain characteristics, stratified by total Wait List group vs. the group who agreed to participate in the study. Chi-square tests were used to assess the relationship between categorical variables. Usability data were assessed for normalcy and reported using descriptive statistics.

Exploratory outcomes were assessed through analyzing mean (SD) changes in MCS, PCS, pain intensity and pain interference, and PGIC over time. For all pain outcome data, Repeated Measures Analysis of Variance (RMANOVA) was used to compare means over time, and paired t-tests were used to compare pre- and post-intervention (Baseline and Week 6) data. Statistical Package for Social Sciences (SPSS) software, version 21, was used for the analysis.
Chapter 5

Results

This chapter presents the results of the three primary objectives of this study:

1. *To test the feasibility of conducting a larger intervention trial using a newly developed guided Internet-based intervention for chronic pain.*

   Feasibility of conducting a larger scale RCT was assessed through description of participant flow, and analysis of rate of recruitment and associated cost, and attrition. In addition, participant demographic and pain characteristic data were compared to the overall wait list group to assess whether the recruitment process resulted in a representative sample.

2. *To assess the perceived usability of this newly developed intervention in individuals with chronic pain.*

   Data were collected on participants’ perception of usability of the intervention, including evaluation of each intervention module overall, each module’s individual components and style of delivery. Participants provided information on dosage of the intervention through self-report of number of days and time per day at the computer and away from the computer working on information provided in the modules.

3. *To provide information on the characteristics and outcomes of the sample to be used for development of future intervention studies.*

   Exploratory analyses provided preliminary results of outcomes identified by IMMPACT (Turk et al., 2003): emotional functioning, physical functioning, pain, participant perception of effectiveness of treatment and adverse events.
Objective 1: Feasibility of Conducting a Larger Scale RCT

i. Rate of recruitment: How many participants were recruited? What percentage met inclusion criteria, and of those what percentage consented to participate?

Participant flow.

Figure 3 maps out total participant flow, with individual cohort information in parentheses.

Total (Cohort 1 + Cohort 2)

- Assessed for Eligibility: 479 (411+68)
- Included: 50 (20+30)
- Excluded: 429 (391+38)
- Reasons for Exclusion: See detailed participant flow information (Appendix Q)
- Completed Demographic Data baseline questionnaire: 43 (17+26)\(^a\)
- Received Intervention: 41 (16+25)
- Completed Module 6 questionnaire: 15 (7+8)
- Completed 12-week Post-Intervention questionnaire: 14 (8+6)
- Lost to follow-up (LTF): 28 (10+18)
- Analyzed: 14 (8+6)
- Reasons for LTF: See detailed participant flow information (Appendix Q)

\(^a\) 2 participants (1 from each cohort) did not respond to request for demographic data, and therefore were lost to follow-up pre-intervention.

Figure 3. Participant Flow
**Cohort 1 (Pain Clinic Wait List):** The wait list for one publicly-funded chronic pain clinic was examined (April 2011) to assess for eligible participants for this study (n=411). After excluding those who had received appointments and/or had seen other pain specialists (n=119), those for whom participation posed logistical concerns (inmate n=1), duplicate names on the list (n=8), those under 18 years of age (n=4), and one deceased person, there were 278 potential participants to contact (Figure 4). Cohort 1 recruitment was completed in one block, with all individuals contacted by telephone within a 4-month period from May 2011 to August 2011. Out of the initial 278 potentially eligible individuals, 127 could not be contacted, and 3 were deemed ineligible (one was a prisoner, and two were deceased). Ninety-three (33.5%) indicated interest in receiving more information about the study.

After the information sheet and consent were emailed to the 93 potential participants, 20 (7.2% of those eligible to participate; 21.5% of those receiving the consent) agreed to electronically sign (e-sign) the secure online consent. Of those 20 potential participants, 17 went on to e-sign the consent; overall, only six percent (n=17) out of the Wait List individuals, (or 11.5% of the 148 individuals contacted) elected to participate in the study and electronically signed the consent. Sixteen individuals went on to provide demographic data, and received the intervention. Appendix Q provides a detailed list of reasons for non-response and non-participation.

**Cohort 2 (Online Recruitment):** Due to low recruitment from the wait list cohort (Cohort 1), a decision was made to add an amendment allowing additional recruitment in the broader community. As this was a guided Internet-based study, and one of the eligibility requirements was computer proficiency, the researcher decided to conduct the
advertising online, primarily through the social media platform Facebook using a small advertising budget, and on other websites where the study announcement could be posted at no cost to the researcher. It should be noted that although Facebook charged a fee to the researcher to show the advertisement, membership was free and there was no charge to members to view the advertisement. The other websites where the advertisement was posted were also free to view, although they were based more locally so individuals from outside of southern Ontario were less likely to see the posted advertisements.

Advertising for participants for Cohort 2 began on September 7, 2011 and continued through mid-December 2011, with the last participant enrolling on December 22, 2011. The researcher initially set the Facebook advertising parameter to target those 18 years of age or older, with accounts based in Ontario Canada. After one month, the advertising was opened up to all of Canada. A daily advertising budget was set in order to ensure an adequate time period to recruit, and so that a wider audience could be reached. Parameters were set so that no more than $10 per day was spent in showing the study advertisements, except during the last two weeks of October, when the budget was increased to $15 per week in order to maximize the number of participants who would complete the study before the holiday season. It was felt that if participation in the study was ongoing during the holiday season, attrition could potentially increase. The daily advertising budget maximum was reached every day.

The number of times the advertisement was shown was dependent upon how many people “clicked” the link to view it. For the 4 months the advertisement was active on Facebook, it appeared as a small box on the right margin of users’ Facebook screens 5,931 to 95,334 times daily, and was “clicked on” between 3 and 16 times daily.
Clicking on the link took the social media user to a full page advertisement with details about the study and how to become involved (Appendix R). In total, the advertisement was shown 2,321,479 times, receiving 575 “clicks” for a total cost of $686.03. Of the 575 clicks, 68 indicated interest in the study, resulting in an average cost of $10.08 per potential participant. If average cost is calculated, instead, on the basis of actual participants who consented, provided demographic data and were included in analysis, the total advertising cost divided across the 25 participants was $27.44 each. More detailed information about daily “clicks”, cost and demographic data of advertisement viewers is presented in Appendix R.

In the four months of active advertising, 68 people emailed the researcher to request information about the study, which was subsequently emailed to them along with the study consent (Figure 3). Thirty potential participants (44%) expressed interest in consenting to participate in the study, were assigned a participant number and given the link to the secure online consent. Of those, 26 (87%) e-signed the consent and were emailed the link to the demographic data questionnaire. Twenty-five completed the demographic questionnaire and were emailed the Introductory Module and Module 1.

ii. Study adherence: What percentage of study participants took part in weekly data collection via computer-based questionnaires? What was the rate of attrition?

Weekly retention rates. While 41 participants (Cohorts 1 and 2) returned demographic data and received weekly modules, only 32 participants completed the Module 1 questionnaire (78%). Subsequent weekly module response rates were as follows:
Module 2 – 25 participants (61%)
Module 3 – 19 participants (46%)
Module 4 – 18 participants (44%)
Module 5 – 15 participants (37%)
Module 6 – 15 participants (37%)

Attrition. Forty-one participants in total (Cohorts 1 and 2) consented to participate in the study and provided demographic data. One participant from Cohort 1 only provided partial demographic information and accessed and partially answered the questionnaire for Module 1; as such, this participant was included in item analysis when answers were provided. Of the original 41 participants, 11 participants (26.8%) formally requested to be withdrawn from the study (Appendix Q). Another 15 participants (37%) stopped providing questionnaire data by the end of the study. At 12 weeks post intervention, only 14 participants (34%) provided data.

Although the numbers in the two groups were small, those recruited from the clinic Wait List (Cohort 1) had a different attrition rate from the self-referred group (Cohort 2). Through the course of the 6 week intervention, 8 participants in Cohort 1 either withdrew (n=5) or stopped submitting the post-module questionnaires (n=3). If participants did not formally request to withdraw from the study, they continued to receive the weekly modules and links to the post-module questionnaires. In Cohort 1, at the 12-week post-intervention data collection point, questionnaires were completed by 8 participants (50% of those who received the initial module). In Cohort 2, 6 participants formally withdrew and 13 participants did not complete the final questionnaire, leaving only 6 participants (24%) with full data provided. The total number enrolled in the study
and in each cohort was small, so a larger sample would be needed to determine if the response rate to questionnaires differs between those who are recruited from a wait list and those who self-refer. Table 4 provides a summary of participation by cohort.

Table 4. Participation Summary, Cohorts 1 and 2

<table>
<thead>
<tr>
<th>Time</th>
<th>Participants</th>
<th>Cohort 1 n (%)</th>
<th>Cohort 2 n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-study</td>
<td>Participants Eligible</td>
<td>278</td>
<td>unknown</td>
</tr>
<tr>
<td>Pre-study</td>
<td>Participants Interested in Receiving Information</td>
<td>93 (34)</td>
<td>68 (ND)</td>
</tr>
<tr>
<td>Pre-study</td>
<td>Participants Consented</td>
<td>17 (6)</td>
<td>26 (ND)</td>
</tr>
<tr>
<td>Study</td>
<td>Participants Receiving Modules</td>
<td>16</td>
<td>25</td>
</tr>
<tr>
<td>Study</td>
<td>Withdrew</td>
<td>5 (31)</td>
<td>6 (24)</td>
</tr>
<tr>
<td>Study</td>
<td>Retention: Week 6 responses</td>
<td>7 (44)</td>
<td>8 (32)</td>
</tr>
<tr>
<td>Study</td>
<td>Retention: 12 Week Post-Intervention responses</td>
<td>8 (50)</td>
<td>6 (24)</td>
</tr>
<tr>
<td>Study</td>
<td>Attrition: Missing data Week 6</td>
<td>4 (25)</td>
<td>11 (44)</td>
</tr>
<tr>
<td>Study</td>
<td>Attrition: Missing data 12 Week Post-Intervention</td>
<td>3 (19)</td>
<td>13 (52)</td>
</tr>
</tbody>
</table>

ND=no denominator

iii. Time in intervention: How much interaction time at the computer with the intervention modules did participants report? How much time working on the modules away from the computer did participants report? How many days per week did participants report doing some work with the intervention material?

Study participants were asked to report their time spent at the computer and away from the computer working on material learned in the weekly modules. Overall,
participants typically spent less than three days per week working on material from the intervention at and away from the computer combined. The mean (M) number of total days was relatively constant over time, with lowest interaction time during Week 1 (M 2.4 days) and highest at Week 5 (M 3.3 days). Time spent at the computer working on intervention material was constant as well, with more than 50% of participants reporting a mean of 2-4 hours weekly. More than 65% of participants spent less than four hours weekly on the intervention material away from the computer.

iv. Representative sample: Did those who consented to participate in the study have similar characteristics to the entire group on the Wait List?

Description of Clinic Wait List and Study Participant Groups. For the clinic wait list, demographic and pain characteristic data were documented on referral forms (Appendix J). Completed referral forms were received for 400 unique individuals dating from early 2010 to March 2011. Below is a description of the total clinic wait list population including the 16 study participants drawn from the wait list, compared to 41 study participants (Cohorts 1 and 2).

Demographic data. The mean (±standard deviation) age was 51 (±15 SD) years for individuals referred to the Clinic Wait List and 54 (±12 SD) for the 40 study participants who provided information on age (t=-1.33, p=0.18). Study participants were more likely to be female (73% vs. 61%), married (72% vs. 59%), and not currently employed (67% vs. 55%). The study group was also more likely to report longer duration of pain and more anatomical areas of chronic pain. Most individuals in both groups reported their pain as “severe” (57% and 58%). Compared to the wait list group, the study group reported higher rates of difficulty with sleep (93% vs. 80%), fatigue (98% vs.
77%), depressed mood (76% vs. 61%) and anxious mood (68% vs. 46%). While some of these differences were not statistically significant, they may be considered clinically relevant as the study was not powered to detect these differences.

**Additional Study Participant Characteristics.** While some information was not captured on the Clinic Wait List referral form, there was opportunity to collect data about education, treatments, and habits such as smoking, alcohol and drug use, when administering the demographic questionnaire to Study Participants. This information is presented in Table 5.

**Table 5. Study Participants: Additional Demographic and Pain Data**

<table>
<thead>
<tr>
<th>Data</th>
<th>Study Participants n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post-secondary education</td>
<td>35 (88)</td>
</tr>
<tr>
<td>Current smoker</td>
<td>8 (20)</td>
</tr>
<tr>
<td>2 or fewer drinks/week</td>
<td>33 (83)</td>
</tr>
<tr>
<td>Current marijuana</td>
<td>5 (12)</td>
</tr>
<tr>
<td>Current “street” drugs</td>
<td>0 (0)</td>
</tr>
<tr>
<td>History of:</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>32 (82)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>31 (78)</td>
</tr>
<tr>
<td>Post-traumatic Stress Disorder</td>
<td>9 (25)</td>
</tr>
<tr>
<td>Addiction</td>
<td>9 (25)</td>
</tr>
<tr>
<td>Treatments tried:</td>
<td></td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>33 (83)</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>16 (42)</td>
</tr>
<tr>
<td>Psychology/Psychiatry</td>
<td>19 (49)</td>
</tr>
<tr>
<td>Acupuncture</td>
<td>29 (73)</td>
</tr>
<tr>
<td>Chiropractic</td>
<td>25 (66)</td>
</tr>
<tr>
<td>Massage</td>
<td>28 (70)</td>
</tr>
<tr>
<td>Other</td>
<td>14 (34)</td>
</tr>
<tr>
<td>Related surgery</td>
<td>11 (28)</td>
</tr>
<tr>
<td>Two or more specialists</td>
<td>25 (61)</td>
</tr>
<tr>
<td>2 or more current pain medications</td>
<td>27 (68)</td>
</tr>
</tbody>
</table>

Minor variability in sample size for each question. Percentages calculated using actual number answering the question.
Most Study Participants (88%) reported having some college or university education, with 23% of these continuing to post-graduate studies. The majority of Study Participants were nonsmokers, drank little or no alcohol, and did not use marijuana or “street” drugs. Most reported past or current depression and/or anxiety disorder. One-quarter of participants reported a history of PTSD and/or addiction.

Most of the Study Participant group had tried physical therapy, acupuncture, massage and chiropractic and consulted 2 or more specialists in the treatment of their chronic pain. Some participants had also tried psychology/psychiatry and occupational therapy as well as other treatments not specified, or had surgery related to their pain. Including non-prescription medications, most Study Participants took two or more medications to treat their pain.
Objective 2: Usability of Intervention

i. Were participants satisfied with each module overall?

Satisfaction with modules ranged from “very dissatisfied (1)” to “very satisfied (5)”. The percentage of participants “somewhat satisfied” or “very satisfied” with each module is depicted in Figure 4.

![Satisfaction with Weekly Modules](image)

**Figure 4. Ratings of Overall Satisfaction with Weekly Modules**

More than half (52%) of participants were either somewhat or very satisfied with Module 1. At Module 4, the proportion had increased to 71%, and at Module 6, it was 67%. Scores for each module were higher for those who completed all modules (“Completers”), however the difference in scores between Completers and non-completers was not statistically significant in any of the modules. A Repeated Measures Analysis of Variance (RMANOVA) revealed no significant change in overall satisfaction scores over time (Module 1 to Module 6) \[F(5, 50)=1.060, p=0.39\], although these findings must be interpreted with caution because only 11 individuals participated in
rating all 6 modules. Paired t-test comparing Module 1 and 6 scores for the 14 who completed these two modules was also not statistically significant, indicating no significant change in satisfaction over time \[t(13)=0.62, p=0.55\].

ii. **How did participants rate layout/design, quality of content, ease of navigation and usefulness of information?**

Participants were asked to evaluate layout, quality of content, ease of navigation and usefulness of information. Responses were recorded on a 5-point scale (1-5) ranging from “poor” to “excellent”. Median scores remained consistently at 4 with interquartile range of 2 throughout all modules, indicating that the majority of participants rated these factors as above average or excellent. Of note, no participants completing the Module 6 evaluation ranked the delivery of the intervention as “poor”.

iii. **Were text, audio and/or video files useful styles of information delivery in each module?**

For many components within the module, participants could choose whether to access a text file instead of, or in addition to other formats, depending on Internet connection and technical capabilities of the computer. Participants were asked whether text files, audio files and video links were useful to them, by indicating “yes” or “no” for each type of file. Of the three delivery styles, a smaller proportion of participants found the audio files useful most weeks, but the majority reported that all styles were useful overall. Figure 5 displays the percentage of participants rating each of the delivery styles as useful.
iv. How did participants rate individual components of the intervention (introduction, education, activity, goal-setting and relaxation) in each module?

Participants were asked to rate the individual components of each module (introduction, education, activity, goal-setting and relaxation) on a scale of 1 (poor) to 5 (excellent). Results were consistent across all modules, with most participants rating components “above average” or “excellent”. The Week 6 module had the highest rating overall. Relaxation and education components usually received the highest scores week to week. The introduction received the lowest scores week to week, but there were some technical difficulties with the introduction external webpage later in the study which could have contributed to this finding. In the later modules, while approximately 60% of participants found goal-setting above-average or excellent, 70% or more found the education, activity and relaxation in that range.

v. Participants’ Comments related to Usability of the Module

Participants were given an opportunity to provide free text comments at the end of each usability question. Of those who responded to weekly questionnaires,
approximately 65% of participants each week elected to submit free text comments on some component of the questionnaire. The comments covered a wide variety of issues, and due to the small number of respondents, it was not possible to generate general themes. Individuals pointed out links that they could not access, reported success with various components including the relaxation pieces, issues related to mood, and thoughts about quantity of information, in addition to a variety of other personal and module-related comments. All comments are presented in unedited form in Appendix T.
Objective 3: Exploratory Research Questions

i. Emotional functioning.

Does use of the guided Internet-based self-management intervention produce a change in the mental health component of health-related quality of life by Week 6 as compared to pre-intervention?

The mental health component of health-related quality of life was measured using the MCS subscale of the SF-12. Mean scores were calculated weekly and increased from M 40.3 (SD 11.4) at baseline to M 53.4 (SD 6.6) at week 6. This change was maintained at 12 weeks post-intervention (M 54.8, SD 7.1).

Figure 6 shows mean MCS scores for study completers as compared to the whole participant group.

![Mean MCS score](image)

**Figure 6. Mean MCS Scores: Participants and Completers**
RMANOVA for change in MCS from baseline to 12 weeks post-intervention was not significant \[F(7, 28) = 1.380, p=0.25\], however, the total number in that sample was only 5. Study completers \((n=13)\) started out somewhat higher at baseline \((M 47.8, SD 8.5)\) and increased to \(M 53.4 \text{ (SD 6.6)}\) at week 6. This represented a change of \(9.8 \text{ (SD 13.3)}\) \([t(12)=-2.65, p=0.02]\). Individual change ranged from -9.1 to +35.2. Only three out of the thirteen participants who provided data at both time points experienced negative change in MCS, with the other ten reporting positive change. Minimal positive change reported was +2.6. Overall, the improvement in MCS was maintained at 12 weeks post-intervention and the improvements in MCS were clinically significant (an improvement of 5 points for this tool) (Norman, Sloan & Wyrwich, 2003).

ii. Physical Functioning.

Does use of the guided Internet-based self-management intervention produce a change in physical component of health-related quality of life, pain intensity, or pain-related interference with activity by Week 6 as compared to pre-intervention?

*Physical component health-related quality of life.* The PCS subscale of the SF-12 was used to measure the physical component of health-related quality of life. Overall PCS scores remained stable throughout the course of the study. The mean PCS score at baseline was 29.4 (SD 8.2). By week 6, the mean PCS was 30.5 (SD 11.0), which did not represent a clinically significant difference. Similarly, the 13 completers reported no significant mean change in PCS from baseline \((M 29.9 \text{ SD 6.8})\) to week 6 \((M 30.5 \text{ SD 11.0})\) (Figure 7). Individual change scores ranged from -11.3 to +8.6, with seven participants experiencing a decrease in score, and six participants experiencing an increase in PCS. While some of the individual scores could be considered minimum
clinically important differences, as a group the change was not significant (Clement, MacDonald & Burnett, 2013; Norman, Sloan & Wyrwich, 2003; Parker, Godil, Shau, Mendenhall & McGirt, 2013; Riddle, Lee & Stratford, 2001; Schmitt & Di Fabio, 2004).

Figure 7. Mean PCS scores: Participants and Completers

**Pain intensity.** Pain intensity was measured using the BPI. Worst, least, average and current pain scores are reported in Table 6. It should be noted that for most measurements, the data was not normally distributed. Median and interquartile range was calculated for this data, and was closely aligned with means, thus the mean was used for comparison, consistent with what is reported in current pain research literature. The pain intensity summary scores, however, which are the average of the four measures (worst, least, average, current), were normally distributed. RMANOVA using data from Baseline to Week 6, revealed no significant changes in any pain intensity scores over
time, including the mean pain intensity score \([F(6, 36)=1.20, p=0.33]\). Paired t-tests using the Baseline and Week 6 time point measurement did not demonstrate significant change for worst pain or least pain (Table 6). Change in average pain decreased from M 5.4 (SD 1.6) to M 3.5 (SD 2.7) \((p<0.01)\) and current pain decreased from M 5.1 (SD 2.0) at baseline to M 3.3 (SD 2.6) at Week 6 \((p=0.05)\), both statistically and minimally clinically significant changes (defined as -1.39 to -2 points on NRS, or decrease of 30% from baseline) (Dworkin et al., 2008; Farrar et al., 2001; Kendrick & Strout, 2005; Salaffi, Stancati, Silvestri, Ciapetti & Grassi, 2004). Similarly, the change in mean pain intensity over time was meaningful, although there was much variation in the data, especially at the 12-week post-intervention data point.

**Table 6. Pain intensity**

<table>
<thead>
<tr>
<th>Time point</th>
<th>Worst pain M(SD)</th>
<th>Least pain M(SD)</th>
<th>Average pain M(SD)</th>
<th>Current pain M(SD)</th>
<th>Mean intensity M(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline n=40</td>
<td>6.6 (1.8)</td>
<td>3.7 (2.1)</td>
<td>5.4 (1.6)</td>
<td>5.1 (2.0)</td>
<td>5.1 (1.5)</td>
</tr>
<tr>
<td>Week 1 n=29</td>
<td>5.6 (2.4)</td>
<td>2.9 (1.9)</td>
<td>4.6 (2.1)</td>
<td>4.5 (2.1)</td>
<td>4.4 (2.1)</td>
</tr>
<tr>
<td>Week 2 n=22</td>
<td>4.9 (3.1)</td>
<td>2.8 (2.15)</td>
<td>3.8 (2.4)</td>
<td>3.8 (2.7)</td>
<td>4.2 (2.3)</td>
</tr>
<tr>
<td>Week 3 n=19</td>
<td>5.5 (3.0)</td>
<td>2.4 (2.0)</td>
<td>3.8 (2.2)</td>
<td>3.4 (2.6)</td>
<td>3.8 (2.2)</td>
</tr>
<tr>
<td>Week 4 n=17</td>
<td>5.6 (2.4)</td>
<td>2.8 (1.8)</td>
<td>4.0 (1.9)</td>
<td>3.8 (2.5)</td>
<td>4.0 (1.9)</td>
</tr>
<tr>
<td>Week 5 n=15</td>
<td>5.4 (2.2)</td>
<td>3.1 (1.7)</td>
<td>4.2 (2.1)</td>
<td>4.1 (2.3)</td>
<td>4.2 (1.9)</td>
</tr>
<tr>
<td>Week 6 n=15</td>
<td>4.8 (3.3)</td>
<td>2.6 (2.3)</td>
<td>3.5 (2.7)</td>
<td>3.3 (2.6)</td>
<td>3.5 (2.6)</td>
</tr>
<tr>
<td>12 weeks post n=13</td>
<td>4.2 (3.7)</td>
<td>2.1 (2.7)</td>
<td>2.8 (2.7)</td>
<td>3.5 (3.5)</td>
<td>3.1 (3.0)</td>
</tr>
<tr>
<td>Paired t-test Baseline and Week 6 (n=15)</td>
<td>t(13)=1.65, p=0.12</td>
<td>t(14)=1.55, p=0.14</td>
<td>t(14)=3.36, p&lt;0.01</td>
<td>t(14)=2.18, p=0.05</td>
<td>t(13) = 2.09, p=0.06</td>
</tr>
</tbody>
</table>
**Pain-related interference with activity.** Pain interference was measured using the pain interference subscale of the BPI. Pain interference scores were not normally distributed, with the exception of the summary score. However, parametric statistics were performed on these data for the purpose of comparison to other relevant literature, and to demonstrate process in anticipation of a larger scale study. For individual interference scores, median and interquartile ranges were calculated, and in most cases, were similar to the mean. Table 7 presents pain interference data.

**Table 7. Pain Interference**

<table>
<thead>
<tr>
<th></th>
<th>Activity M (SD)</th>
<th>Mood M (SD)</th>
<th>Walking M (SD)</th>
<th>Work M (SD)</th>
<th>Relations M (SD)</th>
<th>Sleep M (SD)</th>
<th>Enjoyment M (SD)</th>
<th>Mean Interference M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline n=40</td>
<td>6.1 (2.5)</td>
<td>4.8 (3.0)</td>
<td>5.1 (3.1)</td>
<td>6.4 (2.9)</td>
<td>4.7 (3.4)</td>
<td>5.7 (3.0)</td>
<td>6.3 (2.9)</td>
<td>5.4 (2.6)</td>
</tr>
<tr>
<td>Week 1 n=29</td>
<td>5.2 (3.1)</td>
<td>4.5 (3.6)</td>
<td>4.6 (3.7)</td>
<td>6.0 (3.0)</td>
<td>4.2 (3.5)</td>
<td>5.1 (3.4)</td>
<td>5.5 (3.0)</td>
<td>5.0 (2.8)</td>
</tr>
<tr>
<td>Week 2 n=22</td>
<td>5.0 (3.1)</td>
<td>4.2 (3.6)</td>
<td>4.3 (3.7)</td>
<td>4.9 (3.4)</td>
<td>3.7 (3.6)</td>
<td>5.1 (3.5)</td>
<td>5.0 (3.4)</td>
<td>4.2 (3.1)</td>
</tr>
<tr>
<td>Week 3 n=19</td>
<td>4.4 (3.0)</td>
<td>3.3 (3.1)</td>
<td>3.8 (3.5)</td>
<td>4.6 (3.3)</td>
<td>3.2 (3.0)</td>
<td>4.5 (3.6)</td>
<td>4.0 (2.8)</td>
<td>4.0 (2.9)</td>
</tr>
<tr>
<td>Week 4 n=17</td>
<td>4.6 (2.9)</td>
<td>4.7 (3.8)</td>
<td>3.9 (3.5)</td>
<td>5.2 (3.1)</td>
<td>3.8 (3.9)</td>
<td>4.8 (3.8)</td>
<td>4.8 (3.6)</td>
<td>4.3 (3.1)</td>
</tr>
<tr>
<td>Week 5 n=15</td>
<td>4.5 (2.6)</td>
<td>3.6 (3.4)</td>
<td>3.1 (2.8)</td>
<td>5.3 (3.0)</td>
<td>3.5 (3.3)</td>
<td>5.6 (3.4)</td>
<td>4.9 (3.0)</td>
<td>4.3 (2.5)</td>
</tr>
<tr>
<td>Week 6 n=15</td>
<td>3.9 (3.2)</td>
<td>2.1 (2.3)</td>
<td>3.2 (3.2)</td>
<td>3.7 (3.0)</td>
<td>1.7 (2.5)</td>
<td>4.7 (3.5)</td>
<td>3.5 (3.0)</td>
<td>3.3 (2.5)</td>
</tr>
<tr>
<td>12 wks post n=13</td>
<td>3.7 (3.4)</td>
<td>2.1 (3.2)</td>
<td>2.9 (3.6)</td>
<td>3.8 (3.6)</td>
<td>1.9 (3.0)</td>
<td>3.6 (3.6)</td>
<td>3.3 (3.5)</td>
<td>3.0 (3.1)</td>
</tr>
<tr>
<td>Paired t-test</td>
<td>t(14)</td>
<td>t(14)</td>
<td>t(14)</td>
<td>t(14)</td>
<td>t(14)</td>
<td>t(14)</td>
<td>t(14)</td>
<td>t(14)</td>
</tr>
<tr>
<td>Baseline/Week 6</td>
<td>=2.06, p=0.06</td>
<td>=2.05, p=0.06</td>
<td>=2.51, p=0.03</td>
<td>=2.20, p=0.05</td>
<td>=2.79, p=0.02</td>
<td>=0.62, p=0.54</td>
<td>=2.65, p=0.02</td>
<td>=2.42, p=0.03</td>
</tr>
</tbody>
</table>

Paired t-tests using the Baseline and Week 6 data (n=15) demonstrate clinically and statistically significant improvement for pain interference with walking, working, relations with others and enjoyment of life (Table 7) and clinically meaningful change for activity and mood. Mean pain interference summary score, using the average of the
seven interference items (0-10 scale), decreased over the course of the study from M 5.4 (SD 2.6) at baseline to M 3.3 (SD 2.5) at the week 6 time point (p=0.03), a change of M - 1.98 (SD 3.17). This difference represents a statistically and clinically significant improvement (Dworkin et al., 2008).

RMANOVA, using data from Baseline to Week 6, revealed a significant change in pain interference over time for walking [F(6, 42)=2.469, p=0.04), working [F(6, 42)=3.113, p=0.01] and enjoyment of life [F(6, 42)=2.279, p=0.05] scores. Upon post hoc comparison, walking ability changed from baseline at the Weeks 3 and 6 measurements. Normal work changed from baseline at 2 and 3 weeks, but no significant changes occurred after Week 4. Significant change in enjoyment of life occurred toward the end of the intervention. Significant comparisons are presented in Table 8.

Table 8. Significant changes in pain interference

<table>
<thead>
<tr>
<th>Pain Interference Item</th>
<th>Comparison</th>
<th>Mean Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking Ability</td>
<td>(Baseline, Week 3)</td>
<td>3.00 (p=0.03)</td>
</tr>
<tr>
<td></td>
<td>(Baseline, Week 6)</td>
<td>3.25 (p=0.02)</td>
</tr>
<tr>
<td>Normal Work</td>
<td>(Baseline, Week 2)</td>
<td>3.88 (p=0.03)</td>
</tr>
<tr>
<td></td>
<td>(Baseline, Week 3)</td>
<td>3.38 (p=0.05)</td>
</tr>
<tr>
<td></td>
<td>(Baseline, Week 4)</td>
<td>1.00 (p=0.05)</td>
</tr>
<tr>
<td></td>
<td>(Week 1, Week 2)</td>
<td>2.13 (p=0.04)</td>
</tr>
<tr>
<td></td>
<td>(Week 1, Week 3)</td>
<td>1.63 (p=0.05)</td>
</tr>
<tr>
<td>Enjoyment of Life</td>
<td>(Baseline, Week 6)</td>
<td>3.75 (p=0.04)</td>
</tr>
</tbody>
</table>


What is the participant’s global impression of change (PGIC) since beginning the guided Internet-based intervention?
Overall change in health status from the participants’ perspective since beginning the intervention was captured using the PGIC. PGIC data was provided by participants weekly. In the first few weeks, most participants did not report a positive change, but by the end of the sixth week, most participants had noticed at least minimal improvement. IMMPACT guidelines (Dworkin et al., 2008) advise reporting PGIC by presenting the percentage of participants responding to each of the seven options. Table 9 summarizes the participants’ responses after the Week 6 module (the end of the intervention). Using the IMMPACT criteria for minimally important change (response ≥3), 73.3% of treatment completers were at least minimally improved. Further, 26.7% reported a moderately important improvement in health status (response ≥5).

Table 9. Week 6 PGIC Scores: Study Participants

<table>
<thead>
<tr>
<th>Response Option</th>
<th>Result n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. No change, or condition has gotten worse.</td>
<td>2 (13.3)</td>
</tr>
<tr>
<td>2. Almost the same, hardly any change at all.</td>
<td>2 (13.3)</td>
</tr>
<tr>
<td>3. A little better, but no noticeable change.</td>
<td>4 (26.7)</td>
</tr>
<tr>
<td>4. Somewhat better, but the change has not made any real difference.</td>
<td>3 (20.0)</td>
</tr>
<tr>
<td>5. Moderately better, and a slight but noticeable change.</td>
<td>2 (13.3)</td>
</tr>
<tr>
<td>6. Better, and a definite improvement that has made a real and worthwhile difference.</td>
<td>1 (6.7)</td>
</tr>
<tr>
<td>7. A great deal better, and a considerable improvement that has made all the difference.</td>
<td>1 (6.7)</td>
</tr>
</tbody>
</table>

Mean PGIC scores were calculated in order to compare time points. Table 10 summarizes the participants’ mean impression of change since beginning treatment at the consecutive study time points. Data was normally distributed, with the exception of Week 1; median and interquartile range were also calculated for this data point and aligned with the mean. The mean PGIC score at week 6 for those who completed the
intervention (n=15) was 3.5 (SD 1.7). This represents the range between “A little better but no noticeable change” and “Somewhat better, but the change has not made any real difference”. RMANOVA on all time points determined that mean PGIC differed significantly between measurements \([F(6, 48)=3.46, p<0.01]\). Post hoc tests using the Bonferroni correction revealed that a statistically significant improvement occurred between weeks 1 and 2 (p=0.03), but not between other individual time points. However, paired t-tests including only Week 1 and Week 6 revealed a statistically significant improvement in overall mean PGIC score (p<0.01).

**Table 10. Mean PGIC: Study Participants**

<table>
<thead>
<tr>
<th>Time point (n)</th>
<th>PGIC M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Week 1 (29)</td>
<td>2.0 (1.2)</td>
</tr>
<tr>
<td>Week 2 (24)</td>
<td>3.2 (1.6)</td>
</tr>
<tr>
<td>Week 3 (18)</td>
<td>3.0 (1.6)</td>
</tr>
<tr>
<td>Week 4 (16)</td>
<td>3.1 (1.5)</td>
</tr>
<tr>
<td>Week 5 (15)</td>
<td>3.3 (1.5)</td>
</tr>
<tr>
<td>Week 6 (15)</td>
<td>3.5 (1.7)</td>
</tr>
<tr>
<td>12 weeks post (13)</td>
<td>3.6 (2.1)</td>
</tr>
<tr>
<td>Paired t-test Week 1 and Week 6 n=14</td>
<td>(t(13)= -4.16, p&lt;0.01)</td>
</tr>
</tbody>
</table>

**iv. Adverse Events.**

No adverse events were reported during the conduct of the study. The researcher did not receive any telephone or email communications from participants expressing concern about participation or the effect of the intervention on their health. Free text comments were reviewed for presence of adverse events (Appendix T) and there were no apparent concerns expressed. Most comments were positive, and the few times the
participants did use the free text area to report an increase in pain, they also added a reason, such as babysitting grandchildren for the week or extra personal stress triggers such as communicating with the “Ministry” and relationship issues. At the end of each module, participants were asked to report medication changes or first-time visits to pain specialists or other healthcare services such as physiotherapy, chiropractic care, etc.

Each week, 17% or fewer had changes in medication (starting or stopping medication, or increasing or decreasing dosage). Through the course of the study and post-intervention follow-up, five participants reported seeing a pain specialist for the first time. New consultation with other healthcare services (physiotherapy, occupational therapy, psychology, chiropractic, acupuncture and massage) was minimal, with the exception of physiotherapy, which was reported by 13 in week 1, 8 in week 2 and 14 at 12 weeks post-intervention.
Chapter 6

Discussion

Chronic pain is a long-term condition, posing great physical and emotional challenges to those affected, and incurring cost to society in the form of loss of productivity and economic impact of treatment (Boulanger et al., 2007; Guerriere et al., 2010; Kronberg et al., 2009). Evidence-based treatment of chronic pain involves a wide variety of therapeutic interventions, delivered in various formats, with attention to individualization of treatment. Initial treatment of chronic pain can effectively be started at the primary care level, but individuals, including those with multiple comorbidities may progress to needing more complex treatment (Peng et al., 2007; Scascighini et al., 2008). With long wait lists for specialty care (Amadeo & Sutherland, 2010; Lynch et al., 2008; Peng et al., 2007) there is a need to bridge the treatment gap that may occur after primary care while waiting for more advanced options. Non-pharmacological strategies, such as education, CBT and self-management, are available, effective, and could potentially even help to prepare the individual for further multidisciplinary chronic pain care (Eccleston et al., 2009; Gatchel & Rollings, 2008; Turk et al., 2008; Williams et al., 2010).

This work was undertaken to explore web-based options for self-management of chronic pain while on the wait list for chronic pain care. Based on strategies used in face-to-face interventions that have been effective in treating those with chronic pain, a novel guided Internet-based CBT and self-management chronic pain intervention (ICPI) incorporating education was designed using the Wilson and Cleary (1995) conceptual model as a framework. The Internet-based intervention was delivered to a cohort of
individuals with chronic pain, and information was collected about the feasibility of conducting a larger trial, the usability of the intervention, and the potential effectiveness of the intervention on various outcomes.

At the time of the development of the Internet-based intervention for chronic pain, no similar intervention was available or in use. However, given the rapid pace of development of Internet-based interventions, seven studies describing similar interventions were published while this study was underway or completed. Therefore, this chapter will present a discussion and interpretation of the results of this study and compare the findings to the current literature (See Appendix U for the search strategy details). Topics covered in this chapter include:

- A description of the total wait list group as compared to other chronic pain wait list groups, and a description of the study sample;
- Assessment of the feasibility of conducting a larger intervention trial;
- Assessment of the usability of the intervention;
- Exploratory research outcomes;
- Study strengths and limitations;
- Implications for nursing
- Recommendations for future research.

**Description of Chronic Pain Samples**

While many studies have described the population with chronic pain in particular geographic areas (Andersson et al., 1993; Bergman et al., 2001; Reitsma, et al., 2011; Reitsma et al., 2012; Tripp et al., 2006), or even upon being seen in a pain clinic (Mailis-Gagnon et al., 2007; Weir et al., 1992), this study provided a description of a chronic pain
wait list group. Through construction of a demographic and pain characteristic questionnaire that was similar in content to the chronic pain clinic referral form, there was opportunity to compare the group of ICPI study participants to those on the clinic wait list. In addition, there was opportunity to analyze the wait list data from this clinic, and compare it to that of other pain clinics in Canada.

**Total wait list sample compared to samples described in the literature.** Table 1 in the first chapter of this thesis presented information about the demographics of those waiting for specialty care in Canada. The demographic characteristics of those on the clinic wait list used for recruitment to this study (Kingston Clinic Wait List) is now added to that chart and presented in Table 11.

**Table 11. Comparison of Toronto Pain Clinic, Canadian Wait List and Clinic Wait List**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Toronto Clinic (Mailis-Gagnon et al., 2007) (n=1242)</th>
<th>Canadian Wait Lists (Choiniere et al., 2010) (n=728)</th>
<th>Kingston Clinic Wait List (current study) (n=400)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (sd)</td>
<td>48.5 (14.2)</td>
<td>50.8 (12.6)</td>
<td>50.8 (14.7)</td>
</tr>
<tr>
<td>Female</td>
<td>57%</td>
<td>61%</td>
<td>61%</td>
</tr>
<tr>
<td>Most affected</td>
<td>35-49 years</td>
<td>40-60 years</td>
<td>41-50 years</td>
</tr>
<tr>
<td>Married</td>
<td>58%</td>
<td>ND</td>
<td>59%</td>
</tr>
<tr>
<td>Employed</td>
<td>19.8%</td>
<td>32.8%</td>
<td>44.6%</td>
</tr>
<tr>
<td>Duration of pain</td>
<td>Mean 7.8 years</td>
<td>2 years or more (88.7%)</td>
<td>2 years or more (63.7%)</td>
</tr>
<tr>
<td>Psychological comorbidity</td>
<td>75%</td>
<td>82%</td>
<td>69%</td>
</tr>
</tbody>
</table>

Comparison of data collected by researchers at a chronic pain clinic in Toronto Ontario (Mailis-Gagnon et al., 2007) from 2001-2004, data collected by researchers who studied individuals on the wait list of eight multidisciplinary pain treatment facilities
across Canada from 2004-2007 (Choiniere et al., 2010), and Kingston clinic wait list data (2009-2011) revealed that groups were similar in demographics, although some reported characteristics were categorized differently (Table 11). The most obvious difference between the groups was that at the time of consultation with the Toronto clinic, 19.8% were employed, whereas on the Canadian Wait Lists, 32.8% and on the Kingston Wait List, 44.6% were employed either full- or part-time. Education information was not collected on the Kingston Wait List group, but given the difference in employment status while age remained similar, it would have been interesting to have that data to compare, as 46% of the Toronto group and 53.7% of the Canadian Wait List group had some college or university education.

**Study participant sample.** The typical ICPI study participant was married, female, aged early 50’s, a nonsmoker, and rare drinker with post-secondary education. Participants were less likely to be currently employed, had a history of depression and anxiety, and had tried several types of treatments, including physiotherapy, acupuncture and massage, prior to being placed on the wait list for specialty care. In addition, these participants were likely to be taking two or more pain medications, and to have seen at least two other specialists (i.e. psychiatrist, neurologist, orthopedic physician). Characteristics of the ICPI study sample were similar to wait list data from the Kingston clinic and other clinics described in the literature (Berman et al., 2009; Bromberg et al., 2012; Carpenter, Stoner, Mundt & Stroelb, 2012; Chiauzzi et al., 2010; Ruehlman, Karoly & Enders, 2012; Williams et al., 2010).
Feasibility

Rate of accrual. Overall, the rate of accrual to this study was slow. Interest in the study might have been dampened by the time of year; participants were contacted starting in the summer, and offered a study intervention which lasted six weeks. This could have interfered with vacation plans, although this was not substantiated in the few free text comments that were submitted by participants. In addition, telephone contact to initiate the process of providing an email address to the researcher, or receiving the researcher’s email address could have resulted in some errors, accounting for those who did not respond to initial email; the researcher could have sent email to the wrong address, or the participant might have misheard the researcher’s email address in the telephone conversation. Mail contact to request Internet response could have been more effective (Dillman, Reips & Matzat, 2010; Messer & Dillman, 2011) for those with a physical address on the wait list, but at an added cost. Other larger healthcare and epidemiological studies that used the Internet to recruit participants report enrolment rates, calculated as number of participants out of total number of individuals identified to be potentially eligible, as 0.2-16.9% (Glasgow et al., 2010; Koo & Skinner, 2005; Stopponi et al., 2009). The enrolment rate for this study falls within that range, as 2% (n=16) of those deemed eligible on the Wait List went on to e-sign consent and provide demographic data.

For those recruited online, there is no way of estimating the total number of potentially eligible participants who saw the advertisement, but of the 68 individuals who emailed to request more information, 37% (n=25) went on to consent and provide data. Using click-through data for those who self-referred in this study, the social media site
delivered 2,321,479 impressions, which were “clicked on” 575 times for a click-through rate of 2.5%. This rate is higher than that reported in a study that noted click-through rates documented a rate of 0.06% for social media advertisements of an online HIV-prevention intervention (Bull, Vallejos, Levine & Ortiz, 2008).

Cost for Internet advertising per recruited participant in the Bull et al. study (2008) was $5.14, lower than the $23.66 per participant for this study. Because their research assessed an intervention promoting disease prevention, their target population was younger (aged 18-24) and their intervention was less involved than this ICPI; this might be a factor in the decreased cost per participant. In addition, they advertised on Yahoo, Black Planet and Mi Gente, whereas cost per participant with chronic pain in this study was calculated based on Facebook advertising. Nonetheless, Webtrends, a digital marketing company, compared twenty categories of web advertising on Facebook, and found that healthcare advertisements had the lowest click-through rate (0.011%) and the highest cost per click ($1.27) (Webtrends, 2011). Due to the large amount of time taken to recruit a minimal number of participants for this study, more widespread advertising would be indicated in order to conduct a larger scale RCT.

**Study adherence and attrition rate.** Study adherence and attrition rate have been studied separately in the literature describing web-based healthcare interventions. Some web-based healthcare interventions have calculated adherence based on website use, reported by tracking software built into the intervention. Adherence rates in these RCTs ranged from 19% to 90% (Christensen, Griffiths & Farrer, 2009; Neve, Collins & Morgan, 2010; Nicholas et al., 2010; Postel et al., 2011; Wangberg, Bergmo & Johnsen, 2008). In this feasibility study, adherence was measured indirectly, by reporting the
percentage of participants responding to the post-module questionnaire, and by participant self-report of time in intervention. By the end of the final module for this study, only 36.5% responded to the associated questionnaire, an adherence rate similar to what has been reported by others. In examining the free-text comments, the process of filling out the same questionnaires weekly might have detracted from the study experience for some participants. In a recent study of individuals (n=2107) with anxiety and/or depression, non-completers of an internet-based cognitive behavioural program derived benefit before dropping out (Hilvert-Bruce et al., 2012). In this study it was not possible to know whether those who stopped completing questionnaires, but did not withdraw, still used or benefitted from the intervention they continued to receive weekly.

Attrition, calculated in this study as the number of participants who officially withdrew, was 27%. This is consistent with attrition rates in other computer-based chronic pain interventions, which have ranged from 10.2-38.1% (Berman et al., 2009; Bromberg et al., 2012; Carpenter et al., 2012; Chiauzzi et al., 2010; Devineni & Blanchard, 2005; Ruehlman et al., 2012; Williams et al., 2010). When considering recruitment and attrition data in chronic pain and non-pharmacologic interventions, it is also important to consider readiness to change and to adopt self-management and CBT strategies (Kerns & Habib, 2004; Prochaska & Clemente, 1982). Information about the nature of the intervention was presented to individuals prior to obtaining their consent to participate. Individuals might not have progressed past the precontemplation or contemplation stages (Prochaska & Velicer, 1997), and therefore were not quite ready to take on the “action” work of self-management (Kerns & Habib, 2004), resulting in the decision to not participate, or to abandon the program before finishing. This was not
assessed prior to baseline data collection in the ICPI, but could have given insight into adherence, attrition, time in intervention and even outcomes.

**Time in intervention.** The majority of participants spent 4 hours or less working at the computer on material from the modules, and 4 hours or less working away from the computer on the intervention. This time was generally spread over 1 to 3 days. Time in intervention in a computer-based platform is difficult to document without tracking software, which was not appropriate for this intervention as the modules directed the participants to external websites. Record of time spent was done via participant self-report (recall). Most computer-based interventions for chronic pain did not document time in intervention. Chiauzzi et al. (2010) reported that participants had 8 sessions that were at least 20 minutes in length, delivered twice-weekly. Using data from participant self-reports, Carpenter et al. (2012) reported that 87% of participants (n=141) use the intervention for 6 or more hours weekly. Other authors were unable to report or provided less clear data (Berman et al., 2009; Bromberg et al., 2012; Devineni & Blanchard, 2005; Ruehlman et al., 2012; Williams et al., 2010). Table 12 outlines the dosage of interventions for studies similar to the current ICPI.

**Table 12. Dosage of Interventions**

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th># Sessions</th>
<th>Duration sessions</th>
<th>Frequency</th>
<th>Duration of intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berman et al.</td>
<td>2009</td>
<td>6</td>
<td>variable</td>
<td>once weekly</td>
<td>6 weeks</td>
</tr>
<tr>
<td>Bromberg et. al.</td>
<td>2012</td>
<td>not clear</td>
<td>not clear</td>
<td>not clear</td>
<td>12 weeks(a)</td>
</tr>
<tr>
<td>Carpenter, et al.</td>
<td>2012</td>
<td>not clear</td>
<td>variable</td>
<td>variable</td>
<td>6 weeks</td>
</tr>
<tr>
<td>Chiauzzi et al.</td>
<td>2010</td>
<td>8</td>
<td>at least 20 min</td>
<td>twice weekly</td>
<td>4 weeks(a)</td>
</tr>
<tr>
<td>Devineni &amp; Blanchard</td>
<td>2005</td>
<td>not clear</td>
<td>variable</td>
<td>variable</td>
<td>4 weeks</td>
</tr>
<tr>
<td>Ruehlman, et al.</td>
<td>2012</td>
<td>not clear</td>
<td>variable</td>
<td>variable</td>
<td>6 weeks</td>
</tr>
<tr>
<td>Williams et al.</td>
<td>2010</td>
<td>not clear</td>
<td>variable</td>
<td>variable</td>
<td>6 months</td>
</tr>
<tr>
<td>Perry (current ICPI)</td>
<td>2013</td>
<td>6 modules</td>
<td>variable</td>
<td>Emailed weekly</td>
<td>6 weeks</td>
</tr>
</tbody>
</table>

\(a\)These studies used the same website, painACTION, as the intervention.
**Usability**

Overall, participants were satisfied with the modules. Those who completed the whole intervention had higher satisfaction scores than those who did not complete the modules even at the early time points. These findings are consistent with other non-computer-based medical and psychotherapy studies (Eugster & Wampold, 1996; Lipton & Stewart, 1999) that also report that those who indicated satisfaction with treatment experienced more positive outcomes. In addition, personality traits (extraversion, openness to experience, agreeableness) and emotional characteristics (catastrophizing, neuroticism) can affect satisfaction with treatment (Green, Hadjistavropoulos & Sharpe, 2008). In requesting that participants report their satisfaction with modules weekly, the participants could have been prompted to formally recognize their own satisfaction, or lack of satisfaction, with treatment which then could have led to a conscious decision to either continue or abandon treatment. Those who were more open to the “work” of increasing their health-related quality of life through non-pharmacologic measures could have been the ones who were satisfied with content, layout and overall usability of the intervention.

Participant rating scores for quality, usefulness, ease of use and look of the modules were consistently “good”. This is similar to findings from other computer-based healthcare interventions that reported “good” usability scores (Bossen, Veenhof, Dekker & de Bakker, 2013), and “very/somewhat helpful” (Berman et al., 2009; Patten et al., 2012) and other descriptors in the range between moderately and strongly positive (Carpenter et al., 2012; Williams et al., 2010).
Exploratory Research Outcomes

While conducting feasibility and usability testing on the ICPI, several preliminary research questions were explored. The results must be interpreted with caution due to small sample size with 41 participants at baseline and 15 at week 6 (completers). The analyses were conducted to inform future research and cannot be generalized to larger populations. Similar outcomes have been explored by others since the development of the ICPI; however, the outcome measures used were varied, and the follow-up intervals were not comparable. Although only two of the studies (Chiauzzi et al., 2010; Bromberg et al., 2012) specifically note that they considered IMMPACT recommendations (pain intensity, physical and emotional functioning, participants’ impression of change) (Turk et al., 2006) when setting up outcome measurements, the other studies included similar primary and secondary outcomes.

Overall, results from the ICPI study were similar in all areas to research conducted on computer-based CBT interventions, including those emerging concurrently with ICPI data collection and analysis. Table 13 presents an overview of studies using computer-based CBT interventions, including those published since the development of the ICPI as well as data collected on the ICPI.
Table 13. Comparison of Computer-based CBT Intervention Studies

<table>
<thead>
<tr>
<th>Author</th>
<th>Total n randomized</th>
<th>% female</th>
<th>Mean age</th>
<th>Intervention Components</th>
<th>Duration of intervention</th>
<th>Attrition</th>
<th>Pain intensity</th>
<th>Physical /Emotional function</th>
<th>PGIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berman et al. (2009)</td>
<td>78</td>
<td>88</td>
<td>66</td>
<td>CBT</td>
<td>6 weeks</td>
<td>12.0%</td>
<td>No change(^a)</td>
<td>No change / No change</td>
<td>ND</td>
</tr>
<tr>
<td>Bromberg et al (2012)</td>
<td>185</td>
<td>89</td>
<td>43</td>
<td>CBT, E. SM</td>
<td>12 weeks</td>
<td>37.5%</td>
<td>ND</td>
<td>No change / Impr.</td>
<td>Impr.</td>
</tr>
<tr>
<td>Carpenter et al. (2012)</td>
<td>141</td>
<td>83</td>
<td>43</td>
<td>CBT, E</td>
<td>6 weeks</td>
<td>19.5%</td>
<td>No change</td>
<td>Impr / ND</td>
<td>ND</td>
</tr>
<tr>
<td>Chiauzzi et al. (2010)</td>
<td>199</td>
<td>68</td>
<td>46</td>
<td>CBT, E, SM</td>
<td>4 weeks</td>
<td>25.8%</td>
<td>Impr</td>
<td>No change / Impr.</td>
<td>Impr.</td>
</tr>
<tr>
<td>Devineni &amp; Blanchard (2005)</td>
<td>139</td>
<td>79</td>
<td>ND</td>
<td>CBT</td>
<td>4 weeks</td>
<td>38.1%</td>
<td>Impr</td>
<td>Unclear(^e) / Unclear(^e)</td>
<td>ND</td>
</tr>
<tr>
<td>Ruehman et al. (2012)</td>
<td>305</td>
<td>64</td>
<td>45</td>
<td>CBT, E, SM</td>
<td>6 weeks</td>
<td>31.8%</td>
<td>Impr</td>
<td>Unclear(^d) / Impr.</td>
<td>ND</td>
</tr>
<tr>
<td>Williams et al. (2010)</td>
<td>118</td>
<td>95</td>
<td>50</td>
<td>CBT, E, SM</td>
<td>6 months</td>
<td>10.2%</td>
<td>Impr</td>
<td>Impr./ No change</td>
<td>Impr.</td>
</tr>
<tr>
<td>ICPI Research: Perry (2013)</td>
<td>41 (feasibility)</td>
<td>71</td>
<td>54</td>
<td>CBT, E, SM</td>
<td>6 weeks</td>
<td>36.6%</td>
<td>Impr</td>
<td>Unclear(^f) / Impr.</td>
<td>Impr.</td>
</tr>
</tbody>
</table>

CBT= Cognitive behavioural therapy, E=Education, SM-= Self-management, ND= no data, Impr. = Improvement
\(^a\)improvement in both treatment and control group
\(^b\)incomplete data set
\(^c\)decrease in pain-related disability; did not discriminate between physical and emotional
\(^d\)decrease in pain-related interference in some functional tasks
\(^e\)No change in PCS, but decrease in pain-related interference in some functional tasks
**Emotional functioning.** Mean MCS scores improved from below population norms at baseline (40.3, SD 11.4) to above norms at week 6 to 53.4 (SD 6.6), resulting in a statistically and clinically significant improvement in mental HRQOL. This change was maintained at 12 weeks post-intervention (M 54.8, SD 7.1) and was supported by the PGIC score (which will be discussed in more depth later in this section), which indicated that participants perceived at least minimal improvement. The improvement in emotional functioning and health related quality of life is consistent with findings from other studies which used CBT in the treatment of chronic pain, delivered in either face-to-face traditional intervention or via the computer (Hoffman et al., 2007; Williams, Eccleston & Morley, 2012). In the seven studies reviewed post ICPI data analysis, six reported results that aligned with emotional functioning. Of these, three (Bromberg et al., 2012; Chiauzzi et al., 2010; Ruehlman et al., 2012) reported improvements in emotional functioning as compared to the group exposed to the computer-based CBT intervention. Devineni and Blanchard had results that were less clear regarding emotional function, but positive; there was a decrease in headache-related disability in the treatment group. Emotional function in the ICPI improved over the course of the intervention and was maintained 12 weeks post-intervention.

**Physical functioning.** Overall, mean PCS scores were lower than population norms (Ware et al., 2000) from baseline to week 6 (consistently PCS=30). The PCS score ranged from 13-55 at baseline and 13-56 at Week 6, indicating that even some of those with the worst physical HRQOL remained in the study. While some components of the intervention focused on gentle exercises, pacing activity and setting priorities for accomplishing tasks, it is possible that a gradual exercise program without supervision
did not affect physical functioning in the short 6-week period of time that the participants received modules. At the 12-week post-intervention time point, it is possible that without continued encouragement and without demonstrable change in physical function at week 6, participants may have abandoned exercise programs, thus there was no opportunity to see the effect of physical conditioning over a longer period of time. Further research would be necessary to ascertain which factors influenced lack of change in physical function with this intervention. Nonetheless, minimal or lack of improvement in physical functioning is not unusual in chronic pain clinical research that has tested the effect of CBT, education and/or self-management (Eccleston, Williams and Morley, 2009). Of the seven RCTs in the literature review that assessed physical function, two (Carpenter et al., 2012; Williams et al., 2010) reported improvement in the intervention group, one (Devineni & Blanchard, 2005) reported a decrease in headache-related disability and one (Ruehlman et al., 2012) reported an improvement in some pain-related interference measures.

**Pain intensity/interference.** From baseline to week 6, participants in the ICPI study reported no statistically or clinically significant change in worst or least pain intensity (a 30% change in NRS) (Dworkin et al., 2008), but had a significant decrease in average, current, and calculated mean pain. Mean pain interference, as well as pain interference with specific individual components such as walking, normal work and enjoyment of activities, decreased over time but there was high variability in the scores. It should be noted that while pain intensity and pain interference decreased in a small but meaningful way, this reduction was not mirrored in the PCS score, the physical component of health related quality of life. In addition question about pain interference
with normal work, present in both surveys, the PCS score also reflects limitations due to pain in moderate activity such as using a vacuum cleaner or bowling. It may be that participants were less limited in normal or light activity, but decompensated with more intense activity. Also, the pain interference score is affected by a few mood items as well as the physical items, whereas the SF-12 PCS subscale is able to tally physical effort alone.

In four of six RCTs that provided data on pain intensity, exposure to the intervention produced an improvement (Chiauzzi et al., 2010; Devineni & Blanchard, 2005; Ruehlman et al., 2012; Williams et al., 2010). In the studies where improvement was noted in pain intensity, the effect size was small, the improvement met the criteria of “minimally clinically significant”, the improvement was only in one or two categories (i.e. “worst” or “current” pain) or the improvement was only significant in a subgroup of participants enrolled that study (i.e. those recruited online). In pain research, including the ICPI, pain, physical function and emotional function are not all proportionally linked together. The relationships among these outcomes are more complex and reduction in pain does not necessarily lead to improved physical status and mental function (Turk et al., 2003).

**Participant perception of effectiveness of treatment.** After completing the ICPI, most study participants felt they were “a little” or “somewhat” better as a result of using the intervention, as reported on the PGIC. This is considered a minimally significant change (Dworkin et al., 2003). As the MCS, and pain intensity and interference scores improved, it is possible that those components of HRQOL affected the PGIC positively. The PCS (a reflection of physical function, role, bodily pain and
general health) did not change throughout the course of the study; it is possible that the lack of improvement in physical HRQOL tempered the amount of improvement participants reported in the PGIC. Participant’s Global Impression of Change in health status after study participation was only documented in three of the studies in the post-analysis review. Although all of these studies reported improvement in the treatment group, one study was not able to collect data from more than 40% of participants. Bromberg et al. (2012) reported at mean post-intervention PGIC of 3.56 and Chiauzzi et al., (2010) reported 3.76. The mean post-intervention PGIC for the ICPI was 3.50, consistent with these other studies. In addition, Williams et al. (2010) reported that 57% of those who answered the PGIC question in their study experienced “improvement”. In the analysis of the ICPI data, 73% of participants felt they improved from pre-intervention.

**Strengths and Limitations**

One of the strengths of this feasibility study is that the study sample was similar to those on the local chronic pain wait list and to Canadian samples described in the literature. The sample included those who were thought to be maximally treated at a family practice level, awaiting specialty consultation, as well as those who self-referred who may have had active and ongoing titration of therapy and new consultations with providers for other treatment modalities such as physiotherapy. This study also provides evidence that some of the assumed barriers to use of an online intervention may not exist to the extent initially proposed. These include availability and proficiency with computer use, and availability and speed of Internet connection related to geographic location of rural participants, however the study sample may be biased if individuals who were not
computer proficient or were without adequate internet connections refused to participate in the study. Exploratory research findings from this study are consistent with recent adequately powered randomized controlled studies using computer-based interventions, indicating that the intervention and the preliminary findings are consistent with the current and future direction of this work.

There were several limitations to this study. Rate of enrollment was slow and low and eventually the decision to end recruitment, due to time constraints and cost, came before the proposed 50 participants had been accrued. Due to difficulty with recruitment from the wait list group, recruitment was expanded to the general population using social media. The feasibility, usability and outcomes may differ for these two groups if, for example, the wait list is comprised of individuals with higher levels of pain intensity and interference than the Internet-recruited group. Although testing revealed that there were no initial differences in these measurements between groups, the number included in each group was small. In addition, the online group self-reported chronic pain; there was no verification of a formal diagnosis. Although this could have had an impact on study results if these participants did not fully understand the definition before verifying that they had chronic pain, only one person in this group (as compared to no one in the wait list group) reported duration of pain less than six months. Self-report of chronic pain is common in survey research on chronic pain, and this is likely to be the case with future research conducted via the Internet, although there could be an additional step added to define chronic pain for the purpose of the study and have the participant verify each piece of the definition before formal study entry. In future studies, it would be beneficial for recruitment to open the study up to all individuals with chronic pain and to institute the
advertising from the beginning of recruitment. Future researchers would benefit from consulting with experts in marketing and recruiting using social media. Similarly, expertise in monitoring website traffic to identify which online pages that carry advertising would be accessed most frequently by those with chronic pain could enhance recruitment (Danaher & Seeley, 2009). In recruiting wait list participants, all clinics in the area should be approached, if it were clear that “duplicates” could be identified in order to accurately assess the proportion of participants who enroll or decline participation. In this way, a larger study sample could be accrued in a short period of time and it would be more representative of individuals with chronic pain. By using active wait lists affiliated with clinics, it is possible that enrolment would be enhanced as participants may feel a connection to the clinic when participating, and could look forward to eventually being seen for their appointment.

There were some limitations in the design of the study intervention. The intervention was used shortly after development, having had only minimal revision after clinician review. It would have been valuable to conduct qualitative research, such as a focus group, to assess use of the intervention and provide comments and suggestions before using it for the feasibility study. This could address issues such as content that was too repetitive, too sophisticated, or irrelevant, which in turn could have prevented some attrition, if those who stopped answering questionnaires did so for content-related reasons. However, in this study, the addition of a focus group would have diminished the number of participants available to test the intervention because the chronic pain clinic was closing, therefore the decision was made to forego the qualitative component of the study. Instead, the study was set up as a feasibility study and a free text box was added to
the usability questionnaires so that participants could make suggestions and comment on the intervention. Although the amount of information provided in the free text area was not sufficient to organize into themes, individual comments were helpful in pointing out details and considerations for fine-tuning the ICPI before conducting a larger scale study, specifically which links did not consistently work, and adaptations to reach a broader portion of the group (i.e. providing alternatives for those who cannot do some of the exercises).

Another intervention design limitation involved lack of researcher control and potential unreliability of external content. The intervention was composed of links to external websites in the public domain. This approach was taken partially due to lack of available funding and the time required to generate new webpages for the intervention; but also because in reality if this intervention were to be part of formal chronic pain care, it would have to be developed with little or no funding, given the general lack of funding for new healthcare ventures. This became problematic part way through the study, when a webpage used in the introduction of each module was taken down. Overall, the problem was minor, as links to websites used for content remained functional, but it is not known whether this had an impact on participant frustration with modules, attrition and loss to follow up. In future, it would be beneficial to find or develop a tool, such as the Quality Website Index (Washington et al., 2008) discussed in chapter two, for assessing the quality of chronic pain websites, and then fitting these websites into the Concept Map (Appendix D) used in the design of this ICPI. In this way, it would be possible to substitute quality links with similar content, quickly and with minimal effort in the event that a link became inactive or was not well-understood by individuals.
Through use of the Concept Map, clinicians could adjust the intervention as necessary to maximize ease and effectiveness. Alternately, with funding, independent webpages could be created for use as the intervention, using the Concept Map as a basic structure.

While there were high attrition rates in this study, the rates were similar to those reported in the literature. Implementation of strategies to improve retention, such as telephone follow-up, text messages and email reminders (Andersson, Lundstrom, & Strom, 2003; Bull et al., 2008; Buhrman, Faltenhad, Strom, & Andersson, 2004) might have led to more study completers; however, the initial concept for the study involved providing an intervention to fill the gap between primary care and specialty care. In practice, prior to establishing care at a specialty clinic, there would be no staff member to offer therapeutic contact, oversee components of the modules or track participation and therefore it was constructed as a stand-alone intervention. With adequate funding, the intervention could be adapted to be overseen in a family practice setting, with telephone or email reminders to encourage ongoing participation (Andersson et al., 2003; Bossen et al., 2013; Buhrman et al., 2004; Christensen et al., 2004; Neve et al., 2010; Nicholas et al., 2010).

It has been established that increasing age and low socioeconomic and educational status are associated with chronic noncancer pain in Canada (Rashiq & Dick, 2009; Reitsma et al., 2011; Reitsma et al., 2012). Opportunity to enroll in this study either did not reach or did not appeal to that demographic. In fact, based on the Kingston clinic wait list demographics, and in comparison with other wait lists, those on wait lists in Canada demonstrate different characteristics from those with chronic pain in the general population. By offering enrolment only to those who are actually referred to a specialty
Further study is warranted, drawing from both waitlists and the general population, in order to ensure all demographics are reached, and to evaluate for characteristics that are associated with follow through and success with the intervention. Additional effort, in the form of recruitment posters in rural clinics and churches, and other strategies designed to include the most affected demographic, should be undertaken in future research in order to ensure opportunity to evaluate this intervention reached those most affected.

Finally, while the demographic characteristics of the study sample were comparable to other chronic pain study samples, because the study sample was small, it is not possible to say with confidence that findings from this feasibility study are generalizable to other chronic pain waitlist groups. Because of the single group design, it is not possible to say with certainty that improvements demonstrated post-intervention were attributable to the intervention itself. In fact, potential presence of the Hawthorne effect could have skewed results, and use of self-report questionnaires could have led to overestimation of positive results in the absence of formal objective testing.

**Implications for Nursing**

In looking at the status of accessibility to chronic pain specialty care, a need was identified: individuals should have an opportunity to continue to move forward in treatment even while they are at a standstill waiting for specialty consultation, the next level of care. The Wilson and Cleary model (1995) provided a framework with which to conceptualize and develop an intervention for use by individuals with chronic pain. The model posits that health exists on a continuum which is influenced by internal and external factors. These factors, such as demographics, environment, supports and
symptoms, affect response to the chronic disease process. Taking these factors into consideration, and building on previous research, a cognitive behavioural intervention which incorporated education and self-management principles was constructed.

Evaluation of the intervention consisted of examination of each factor on the continuum toward overall quality of life in the Wilson and Cleary conceptual framework, including symptom status, functional status, and health perception. This framework underpinning the ICPI provided opportunity to measure domains of function prioritized in the IMMPACT statement (Turk et al., 2003), and in doing so, enhanced relevance in applying this ICPI to clinical practice.

Individuals on a wait list are often simply waiting. Their primary care providers may have exhausted resources available at that level of care, and wait for specialty care can be long or non-existent. Staff of chronic pain clinics have not yet established care with those on the wait list, but they often field many phone calls as the wait with chronic pain is, at the least, unproductive, and at the worst, depressing. This is an opportunity to provide good quality information in a self-directed format. Although findings from this study are preliminary, and at present there is no one internet-based intervention that is accessible and affordable to all, clinic staff could identify and recommend web-based resources for those with chronic pain so that individuals are prepared for the “work” of chronic pain multidisciplinary care when the opportunity to attend finally arises. Primary care practices can refer to clinics with pre-intake resources available, or even construct their own resources. Clinic nurses can be proactive, providing evidence-based information, and revising modules as new data emerges, prior to these individuals attending a pain clinic. Interventions that incorporate cognitive behavioural strategies
may assist individuals to start conceptualizing their treatment plan as a collaborative effort, requiring their own input on treatments and evaluation. Individuals may arrive at the clinic knowing what to expect and feeling positive, having had small improvements prior to even beginning specialty treatment. Computer-based interventions, such as the one developed in this research project, can be an asset to clinics as they require minimal effort and staffing to deliver, are cost-effective (personnel and equipment) and they introduce topics that clinics can fully explore and build on when they finally see the patient in consultation.

**Recommendations for Future Research**

While this feasibility study was a good starting point, there is much work to be done to fully assess the effect of the guided Internet-based intervention. As done in this study, further research should incorporate use of the IMMPACT recommendations to clearly evaluate all clinically important domains, and to allow comparison to other chronic pain research. In order to identify particular attributes of those for whom the intervention is especially effective, assessment of other concepts not addressed in IMMPACT guidelines but relevant to pain research and psychological intervention, such as self-efficacy, catastrophizing and readiness to change, should also be done. In this way, it may be possible to identify characteristics of those who benefit most from the intervention. A larger scale randomized controlled trial would give more power to the studies, and the effect of the intervention would be made clearer with good supporting evidence. In addition, longer follow-up would facilitate insight into whether concepts learned in the intervention are carried forward and used by participants after the intervention is over, or whether continued contact or maintenance is necessary to effect
lasting change. Consideration of individual components of the intervention would be possible with a larger sample size; patterns around which components work for which participants could become clearer. If possible, “dosage” of the intervention should be reported more objectively, rather than relying on participant recall. If the stand-alone intervention is found to be effective for individuals with chronic pain, the next step would be to evaluate whether some cost-effective contact, such as a moderated discussion forum, would enhance effectiveness. Finally, with some minor revision of content, it could be possible to use the intervention for other chronic diseases, and study the effect of participation in individuals with other chronic health challenges.

**Conclusion**

This feasibility study demonstrates that individuals with chronic pain found the guided Internet-based intervention, developed for use while waiting for specialist consultation, easy to use and to navigate, and that information provided was useful overall. While the intervention was tested in a small sample in this study, through use of the Internet in the recruitment phase, it should be possible to reach more potential participants and recruit enough participants for a strongly powered randomized controlled trial. Preliminary results indicate that the intervention is effective in the domains of emotional functioning overall, and in pain intensity and interference, and that participants generally felt that use of the intervention had at least a minimally positive effect on overall wellbeing. Further large-scale research is feasible and necessary, including comparison to a control group, to fully evaluate the potential effectiveness of a guided Internet-based cognitive behavioural self-management intervention, and to identify characteristics of those who would benefit most from receiving it.
References


Statistics Canada (2002). *Health Indicators*. 82-221-XIE.


Statistics Canada (2010). Intensity of Internet use in Canada: understanding different types of users. Retrieved from:

http://www.statcan.gc.ca/pub/88f0006x/88f0006x2010002-eng.htm


Appendix A

Wilson and Cleary – Conceptual Model of Quality of Life (1995)
## Appendix B

Non-Computer-based Interventions for Chronic Disease

<table>
<thead>
<tr>
<th>Study Authors</th>
<th>Population</th>
<th>Intervention</th>
<th>Total n (age)</th>
<th>#Sessions</th>
<th>#Weeks</th>
<th>Duration of session</th>
<th>Data points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ersek et al. (2007)</td>
<td>CNCP</td>
<td>SM group vs. education</td>
<td>256 (m81.8)</td>
<td>7</td>
<td>7</td>
<td>90min</td>
<td>B, P, 6moP, 12moP</td>
</tr>
<tr>
<td>Farrell, Wicks &amp; Martin (2004)</td>
<td>chronic disease</td>
<td>peer-led CDSM</td>
<td>48 (m59.7)</td>
<td>6</td>
<td>6</td>
<td>150min</td>
<td>B, P</td>
</tr>
<tr>
<td>Green et al. (2009)</td>
<td>chronic pain</td>
<td>CBT</td>
<td>95 (a75)</td>
<td>10</td>
<td>10</td>
<td>60min</td>
<td>B, P, 3moP</td>
</tr>
<tr>
<td>Jerant et al., (2008)</td>
<td>chronic disease</td>
<td>peer-led CDSM</td>
<td>415 (m60)</td>
<td>6</td>
<td>6</td>
<td></td>
<td>B, P</td>
</tr>
<tr>
<td>Kabat-Zinn, Lipworth &amp; Burney (1985)</td>
<td>CNCP</td>
<td>mindfulness meditation</td>
<td>90 (m44)</td>
<td>10</td>
<td>10</td>
<td>120min</td>
<td>B, P, up to 15moP</td>
</tr>
<tr>
<td>King-VanVlack et al., (2007)</td>
<td>CNCP</td>
<td>education and exercise program</td>
<td>10 (m45.6)</td>
<td>24</td>
<td>12</td>
<td>90min</td>
<td>B, P, 3moP</td>
</tr>
<tr>
<td>LeFort et al. (1998)</td>
<td>CNCP</td>
<td>group psychoeducation program</td>
<td>110 (m40)</td>
<td>6</td>
<td>6</td>
<td>120min</td>
<td>B, 3moP</td>
</tr>
<tr>
<td>Puder (1988)</td>
<td>CNCP</td>
<td>group CBT</td>
<td>69 (m52.7)</td>
<td>10</td>
<td>10</td>
<td>120min</td>
<td>B, thru, P, 1moP, 6moP</td>
</tr>
<tr>
<td>Sagula &amp; Rice (2004)</td>
<td>chronic pain</td>
<td>mindfulness meditation</td>
<td>71 (nd)</td>
<td>8</td>
<td>8</td>
<td>90 min</td>
<td>B, P</td>
</tr>
<tr>
<td>Schreurs et al. 2003)</td>
<td>Chronic disease</td>
<td>SM</td>
<td>nd</td>
<td>5</td>
<td>12</td>
<td>120min</td>
<td>B, P</td>
</tr>
<tr>
<td>Strom, Petterson &amp; Andersson (2000)</td>
<td>headache</td>
<td>relaxation &amp; problem-solving</td>
<td>102 (m41.5)</td>
<td>nd</td>
<td>6</td>
<td>nd</td>
<td>B, P</td>
</tr>
<tr>
<td>Subramanian (1991)</td>
<td>CNCP</td>
<td>group CBT</td>
<td>39 (nd)</td>
<td>8</td>
<td>8</td>
<td>120min</td>
<td>B, P, 6moP</td>
</tr>
</tbody>
</table>

SM=self-management, CNCP=Chronic noncancer pain, CDSM=Chronic disease self-management, B=baseline, P=post-intervention, 3moP=3 months post-intervention, 6moP=6 months post-intervention, 12moP=12 months post-intervention, 15moP=15 months post-intervention, nd=no data
## Appendix C

### Computer-Based Interventions

<table>
<thead>
<tr>
<th>Study Authors</th>
<th>Population</th>
<th>Intervention</th>
<th>Total n (age)</th>
<th>#Sessions</th>
<th>#Weeks</th>
<th>Duration</th>
<th>Data points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anderssen et al., (2002)</td>
<td>tinnitus</td>
<td>CCBT</td>
<td>117 (48)</td>
<td>na</td>
<td>6</td>
<td>na</td>
<td>B, P, 1yrP</td>
</tr>
<tr>
<td>Brattberg (2006)</td>
<td>chronic pain</td>
<td>CCBT</td>
<td>60 (m47)</td>
<td>na</td>
<td>20</td>
<td>na</td>
<td>B, P, 1yrP</td>
</tr>
<tr>
<td>Buhrman et al. (2004)</td>
<td>chronic LBP</td>
<td>CCBT with telephone support</td>
<td>51 (m45)</td>
<td>na</td>
<td>6</td>
<td>na</td>
<td>B, P, 3moP</td>
</tr>
<tr>
<td>Carlbring et al. (2009)</td>
<td>social phobia</td>
<td>CCBT</td>
<td>57 nd)</td>
<td>na</td>
<td>9</td>
<td>na</td>
<td>30month P</td>
</tr>
<tr>
<td>Christensen et al. (2006)</td>
<td>depression</td>
<td>CCBT</td>
<td>2794 (median 35-44)</td>
<td>5 modules</td>
<td>nd</td>
<td>20-40min modules</td>
<td>B, Pre and P-each module, P</td>
</tr>
<tr>
<td>Devineni &amp; Blanchard (2005)</td>
<td>headache</td>
<td>CCBT</td>
<td>139 (m41)</td>
<td>na</td>
<td>4</td>
<td>na</td>
<td>B, P, 2moP</td>
</tr>
<tr>
<td>Hicks et al. (2006)</td>
<td>pediatric headache</td>
<td>CCBT</td>
<td>47 (m12)</td>
<td>na</td>
<td>7</td>
<td>na</td>
<td>B, P, 3moP</td>
</tr>
<tr>
<td>Hunt, Moshier &amp; Milonova (2009)</td>
<td>IBS</td>
<td>CCBT</td>
<td>54 (m39)</td>
<td>6</td>
<td>5</td>
<td>na</td>
<td>B, P, 3moP</td>
</tr>
<tr>
<td>Kaltenthaler et al. (2008)</td>
<td>depression</td>
<td>CCBT</td>
<td></td>
<td></td>
<td></td>
<td>systematic review</td>
<td></td>
</tr>
<tr>
<td>Kenardy et al. (2003)</td>
<td>panic disorder</td>
<td>CCBT vs CBT</td>
<td>186 (nd)</td>
<td>6 or 12</td>
<td>6 or 12</td>
<td>60min</td>
<td>B, P, 6moP</td>
</tr>
<tr>
<td>Lorig et al (2006)</td>
<td>chronic disease</td>
<td>CCBT</td>
<td>958 (m57)</td>
<td>na</td>
<td>6</td>
<td>na</td>
<td>B, P, 1yrP</td>
</tr>
<tr>
<td>Palermo et al. (2009)</td>
<td>pediatric chronic pain</td>
<td>CCBT / family</td>
<td>48 (11-17)</td>
<td>8</td>
<td>8</td>
<td>30min</td>
<td>B, P, 3moP</td>
</tr>
<tr>
<td>Spek et al. (2008)</td>
<td>depression</td>
<td>CCBT</td>
<td>301 (m55)</td>
<td>na</td>
<td>10</td>
<td>na</td>
<td>B, P</td>
</tr>
<tr>
<td>Stinson et al. (2010b)</td>
<td>adolescent arthritis</td>
<td>CCBT</td>
<td>46 (teens)</td>
<td>12 modules</td>
<td>avg 14.7 (SD 2.1)</td>
<td>B, P</td>
<td></td>
</tr>
<tr>
<td>Strom et al. (2004)</td>
<td>insomnia</td>
<td>CCBT</td>
<td>109 (m44)</td>
<td>na</td>
<td>5</td>
<td>na</td>
<td>B, P</td>
</tr>
<tr>
<td>Zetterqvist et al. (2003)</td>
<td>general</td>
<td>computerized stress management</td>
<td>63 (am39)</td>
<td>intro +6modules</td>
<td>na</td>
<td>na</td>
<td>B, P</td>
</tr>
</tbody>
</table>

SM=self-management, CNCP=Chronic noncancer pain, CDSM=Chronic disease self-management, B=baseline, P=post-intervention, 3moP=3 months post-intervention, 6moP=6 months post-intervention, 12moP=12 months post-intervention, 15moP=15 months post-intervention, na=not available
Appendix D

Intervention Concept Map

**Introduction**
- 1. Moving from patient to person
- 2. Emotions, activity plan
- 3. Gentle exercise, difficult emotions, sleep
- 4. Communication, nutrition
- 5. Medications, sadness, positive thinking
- 6. Evaluating treatment, communicating with providers

**Education**
- 1. Overview of SM, CBT, pain cycle
- 2. CBT step 2
- 3. CBT step 3, sleep
- 4. CBT step 4, nutrition
- 5. CBT step 5, medications
- 6. CBT step 6, making decisions, significant relationships

**Relaxation**
- 1. Learning to relax
- 2. Relaxation tools, guided imagery
- 3. Sleep diary, positive affirmations
- 4. Mindfulness
- 5. Positive frame of mind, relaxation response
- 6. Additional resources, relaxation treatment evaluation

**Activity**
- 1. Activity pacing
- 2. Developing an exercise program
- 3. Household chores, beginner yoga
- 4. Balancing your week, activity diary
- 5. Adjusting work activities
- 6. Reviewing exercise goals

**Goal Setting**
- 1. SMART goals and building an action plan
- 2. Review SMART goals
- 3. Evaluate short term goals. Obtain input and revise
- 4. Review and revise goals
- 5. Evaluate progress toward goals
- 6. Evaluate, set new goals

**Additional Resources**
- 1. Learning to relax
- 2. Relaxation tools, guided imagery
- 3. Sleep diary, positive affirmations
- 4. Mindfulness
- 5. Positive frame of mind, relaxation response
- 6. Additional resources, relaxation treatment evaluation
Appendix E
Study Intervention

Modules, including module references in order of occurrence:

Introductory Module

Module 1
Module 2
Module 3
Module 4
Module 5
Module 6
Introduction to Chronic Pain Management

Chronic pain facts: Canada. Fact sheet

Click on the following video link for an overview of some of the things we’ll be discovering in the next 6 weeks. Chronic Pain self-management program Introduction (3min)

Education

Is there life with pain? Click on the following link to see people with chronic pain, talking about the positives in their lives. Chronic pain patients (3 minute video)

What is chronic pain self-management, and why bother? Chronic Pain self-management (reading material)

Activity

Pain can be a reason that we stop doing activities that we have previously enjoyed. Less participation in activity could lead to trouble sleeping, less time with family and friends, and even feeling “down” or “depressed”. Here’s an overview of the benefits of getting back into activities. Increasing Activity (reading material)

Activity pacing is a way to balance your activity during the day, to accomplish more without making your pain worse. Over the next 6 weeks we will learn techniques for gradually increasing activity. Have a look at this overview of how to make the most of your activity time during the day. Pace and Plan (reading material)

Goal-setting / Homework

Each week, you’ll be asked to look at what you want to accomplish in the near future, and also where you’d like to see yourself physically, emotionally and in your relationships in years to come. It’s best to try to see yourself clearly as you are right now, and set some realistic, achievable goals. You might find that discussing some of these ideas with your family and friends, and your family doctor, might help you to choose goals that you have a good chance of reaching. The following link leads to instructions on how to set goals – the example they use is migraine headache, but it can be adapted in any type of pain. Goal-setting Lesson (web lesson)

Here is the SMART goal worksheet we will use throughout the next six weeks. SMART goals (worksheet) Start thinking now about the kinds of things you’d like to accomplish in the next few months.

Relaxation Exercises

Finding a way to relax that works for you is important! By decreasing stress, and learning new ways to cope with the events of the day, we can feel better about ourselves, have more energy and even move toward better sleep patterns. This link will take you to a webpage that discusses the benefits of relaxation, and the ways to use your mind to relax your body. Relaxation overview (reading material) Print it out and try some of the exercises away from the computer!
Introductory Module Links (in order of occurrence)

Canadian Pain Fact Sheet, (Canadian Pain Resource Centre), Canadian Pain Society

http://www.medschoolforyou.com/videoplayer/default.aspx?contentFile=/Programs/ChronicPainSelfMan/patient00/video.xml&id=patient
Partners: Canadian Pain Society, Canadian Pain Coalition, Chronic Pain Canada, Association Quebecoise de la Douleur Chronique and Painexplained.ca

American Chronic Pain Association, Is there life with pain?

http://prc.canadianpaincoalition.ca/en/self_management.html
Canadian Pain Society, Self-management, Dr. Martha Butler

http://www.getselfhelp.co.uk/docs/IncreasingActivity.pdf
Increasing Activity. Vivyan, Carol. 2010

http://www.getselfhelp.co.uk/docs/PACE.pdf
Pace and Plan, Vivyan C and Ayres M. 2010


http://www.getselfhelp.co.uk/docs/SMARThgoals.pdf

http://www.getselfhelp.co.uk/docs/Relaxation.pdf
Module 1 -- Chronic Pain Management

- Topics: Background. What is chronic pain? Overview of self-management

The Chronic Pain Self-Management Program, by Sandra LeFort and Lisa Cardas, has been effective when delivered in community group settings. Watch Lisa Cardas give an overview of module 1 of their program. We will be working on similar concepts through our internet work.

Self-management module 1 (video: 7min)

Background:

The American Pain Association outlines 10 steps to move from patient to person. Click on this link to see an overview of these steps. We'll be working on these things throughout the following 6 modules.

Moving from Patient to Person (introduction video, 1 min)
Patient to Person Brochure (printable pain brochure)

In fact, the American Chronic Pain Association has put together a list of your rights to help empower you to deal with your pain.

Your Basic Rights (printable page)

Education

What is chronic pain? View this video to learn more about chronic pain.

What is Chronic Pain? (2 min video)

Overview of self-management

Chronic Pain Self-management Lesson (audio, video, text)

The Chronic Pain cycle shows us that how we experience and react to our pain can have an effect on how we cope with our pain, and how our symptoms present themselves. If we learn new ways to think about and manage our pain, fatigue and activity, we can make positive changes in our lives. One of the processes of learning new patterns of thinking and reading is called “Cognitive Behavioural Therapy” or CBT. The following link leads to an overview of the pain cycle and how CBT can help. It may seem a bit overwhelming because there is a lot of information on these pages. If you can, print it out, and read it over several times throughout the week.

Pain, Fatigue and CBT (printable pages)

Start to open your mind to different ways of looking at the situations you find yourself in due to your pain, and try to brainstorm different ways to think about and react to these situations. Specifically, think about what kind of positive advice you’d give a friend who had similar challenges.

Homework:

As you move through this week, and you start to understand the material in this section, have a look at this additional information about CBT.

CBT information
CBT: Step 1
Activity
Why exercise? [Benefits of exercise](text)

It's important to pace activity, slowly increasing your exercise routine, but also scheduling rest breaks. This article is about building an exercise program. It talks a bit about back pain, but the ideas in the article apply to any type of pain. [Activity pacing](text)

You may have already worked out an exercise routine with the help of a physiotherapist. Or, you may be doing pool-based exercises already. Whatever level of activity you’ve achieved up to this point is great! It’s time to slowly build on what you’ve done, to maintain or even increase the amount you do every day. The following link contains beginning back strengthening exercises. Have a look – talk to your doctor or physiotherapist about whether these exercises may be right for you, or ask them to suggest some new movements you can do to build strength. [Building an exercise program](Exercise lesson with audio/video)

Goal-setting / Homework
Starting to build an Action Plan
It’s time to set goals for the next few weeks, and also to name one long-term goal that might take a few months or even years to reach. Look at the following link to find some guidelines and examples. [Building an Action Plan](audio, video, text)

Here is a page outlining things to consider when moving toward feeling well. These topics might give you some ideas for your goal-setting. [Positive Steps to Wellbeing](text)

Let’s look at the SMART goal worksheet. Print this out and fill in the columns [SMART goals](worksheet)

Have your family and friends look at your goals with you and help you decide whether they’re realistic and achievable. Bring your goals to your next doctor’s appointment to discuss. Keep your goals handy; we’ll be working through them and adjusting them as necessary through the next 6 weeks.

Relaxation Exercises
Let’s start this week’s relaxation exercise by learning about Mind-Body medicine. [Learning how to relax](text lesson with audio exercise)

Here is a relaxation video. You can play this at the computer, or record it for use when you’re away from the computer. You could also print out the text and have a family member or friend read it to you. [Relaxation video](5 min)

If you prefer relaxation exercises that you’ve previously used, that’s fine! Or write your own relaxing text to read. Use whatever works best for you!
Module 1 Links (in order of occurrence)


Partners: Canadian Pain Society, Canadian Pain Coalition, Chronic Pain Canada, Association Quebecoise de la Douleur Chronique and Painexplained.ca


Moving from Patient to Person. American Chronic Pain Association


Ten Steps from Patient to Person. American Chronic Pain Association


Your Basic Rights. American Chronic Pain Association


What is Chronic Pain? American Chronic Pain Association


http://www.getselfhelp.co.uk/docs/Pain&Fatigue.pdf

Pain and Fatigue. Vivyan, C. 2009

http://www.getselfhelp.co.uk/cbt.htm


http://www.getselfhelp.co.uk/cbtstep1.htm


Zeis, J. 2008. How to develop a safe exercise program 1. Inflexxion Inc. (Corsini, E., Schwartz, A., Zeis, J., Patterson, E.)

Zeis, J. 2011. How to set realistic goals when you have chronic pain. Inflexxion Inc. (Corsini, E., Schwartz, A., Zeis, J., Patterson, E.)


Relaxation Guide. American Chronic Pain Association
Module 2 -- Chronic Pain Management

- Topics: Activity, exercise, breathing.

The Chronic Pain Self-Management Program, by Sandra LeFort and Lisa Cardas, has been effective when delivered in community group settings. Lisa Cardas gives an overview of module 2 of their program. We will be working on similar concepts this week.

Module 2 (8 min)

As discussed, through their groupwork, the participants provide support for each other. By involving your family or a friend in your chronic pain modules, working toward your goals and finding the positives in your daily routines, you may find support and encouragement through these relationships. In turn, they may feel good about themselves too, because they are there for you.

Education

When you’ve lived with chronic pain long enough, you might be finding that the process of coping with everyday life has gotten a bit more difficult. You may find that situations that would have been no problem before, now have you reacting in a very different way. You may experience frustration, anxiety, anger or even depression. Click on this link and read through the information for an overview of the link between thoughts, feelings and behaviours.

[CBT Step 2](#)

Start to open your mind to different ways of looking at the situations you find yourself in due to your pain, and try to brainstorm different ways to think about and react to these situations. Specifically, think about what kind of positive advice you’d give a friend who had similar challenges.

Homework:

As you move through this week, and you start to understand the material in this section, have a look at these links to start identifying some of your thoughts and feelings, and to learn new ways to look at them.

- [Depression](#) (text)
- [Anxiety](#) (text)
- [Anger](#) (text)

Activity

**Why exercise?** (text)

Continue to build on your exercise program this week. How?

[Gradually increasing exercise](#) (text)

Remember, continue to pace your activity and find new ways of doing things that you enjoy.

[Pacing activity](#) (text)

Continue to work out your exercise routine. Ask your health care provider for suggestions, then gradually build on those. The following link has further suggestions for building a back exercise program, but the ideas presented apply to all exercise programs.

[Developing an exercise program](#) (Exercise lesson with audio/video)
Goal-setting / Homework

Let’s look at your SMART goal worksheet. Are you still on track? Are you getting close to meeting some of your short-term goals? If so, take the time to enjoy the feeling of accomplishment. If you’re finding that your goals are still way off in the distance, maybe they need to be broken down into smaller pieces. If necessary, print out the goals worksheet, and rework some of the columns, breaking a big goal down into smaller achievable bits.

SMART goals (worksheet)

Have your family and friends look at your goals with you and help you decide whether they’re realistic and achievable, and whether you’re making progress. Bring your goals to your next doctor’s appointment to discuss. Keep your goals handy, we’ll be working through them and adjusting them as necessary through the next few weeks.

Relaxation Exercises

By this week, you might have found a relaxation exercise that really works well for you. If so, continue to use it, every day if possible, to bring your mind and body into a relaxed state.

Here are some relaxation techniques you could consider.

Relaxation techniques (text)

Let’s try some guided imagery this week.

Guided imagery tool (video—choice of three guided imagery scenarios)

You could make up your own guided imagery scenes and record them for yourself, or have a friend read them for you. Experiment with different relaxation techniques!
Module 2 Links (in order of occurrence)


Partners: Canadian Pain Society, Canadian Pain Coalition, Chronic Pain Canada, Association Quebecoise de la Douleur Chronique and Painexplained.ca

http://www.getselfhelp.co.uk/cbtstep2.htm
Understanding links between thoughts, feelings and behaviours. Vivyan, C. 2010

http://www.getselfhelp.co.uk/depression.htm
Depression. Vivyan, C. 2010

http://www.getselfhelp.co.uk/docs/AnxietySelfHelp.pdf
Anxiety. Vivyan, C. 2010

http://www.getselfhelp.co.uk/docs/anger.pdf
Anger. Vivyan, C. 2010

http://prc.canadianpaincoalition.ca/en/exercise_engaging_in_regular_physical_activity.html
LaChapelle, D. Exercise: Engaging in regular physical activity.

http://prc.canadianpaincoalition.ca/en/the_rule_for_increasing_your_activity_level.html
LaChapelle, D. The 10% rule for increasing your activity level.

http://prc.canadianpaincoalition.ca/en/the_five_ps_of_pain_management.html
LaChapelle, D. The five p’s of pain management.


http://www.getselfhelp.co.uk/docs/SMARTgoals.pdf
SMART goals. Vivyan, C. 2010

http://prc.canadianpaincoalition.ca/en/relaxation_techniques.html
Relaxation techniques. LaChapelle, D.

Guided Imagery Tool. painACTION team, 2008. Inflexxion Inc. (Corsini, E., Schwartz, A., Zeis, J., Patterson, E.)
Module 3 -- Chronic Pain Management

- Topics:  Gentle exercise, difficult emotions, fatigue and sleep.

The Chronic Pain Self-Management Program, by Sandra LeFort and Lisa Cardas, has been effective when delivered in community group settings. Lisa Cardas gives an overview of module 3 of their program. We will be working on similar concepts this week.

Module 3 -- (7 min. video)

As discussed in the video, it's important to start with gentle exercise and build strength. By now, you may have talked to a health care provider to learn about gentle exercises, and you may be well on your way to increasing activity. If not, there's still time! Remember, fatigue and lack of sleep contribute to the cycle of worsening pain, so find a pre-sleep routine that works for you in order to tackle your next day's exercise with energy!

Education

Let's continue to work through ways to make changes in our behaviour through learning new ways to deal with difficult emotions.

CBT Step 2 (text)

Sleep / Insomnia

Fatigue and lack of sleep can be another challenge to effectively dealing with pain. The following link will take you to a webpage on the University of Maryland Medical Center website. Dr. Steven Sharf, the Director of the Sleep Disorders Center talks about Sleep and Insomnia. He gives some advice about 'sleep hygiene', or preparing yourself to get a good night's sleep.

Dr. Steven Sharf, MD -- Insomnia (12 min video)

Look at the right side of the screen, at the small video player. Click on the blue bar labeled "Sleep and Insomnia 2/2", just under the picture of Dr. Sharf.

For more detailed information about the physical processes involved in sleep and the various stages of sleep, click on "Sleep and Insomnia 1/2" on the same webpage.

Sleep hygiene is the process of preparing your body to fall asleep. The following links will give you some of the information you need to get yourself into good sleep habits.

Sleep Hygiene (text) Sleep self-help (text)

Homework:

As you move through this week, and you start to understand the material in this section, click on the CBT Step 3 webpage above again. There are many links on that page that can lead you to explore the concepts that pertain most to you. For instance, if you really can't figure out why sometimes you're exhausted and other times you're not, try printing out the Activity Diary and fill it in for a few days to see if there's a pattern. The ACE Log might help you to identify the things that really bring you enjoyment while enhancing your relationships with those close to you. Explore the links on the CBT Step 3 page to discover more about yourself and your pain! As always, you could discuss what you're learning about yourself with family or a close friend.
Activity

Continue to work out your exercise routine. You may be finding that you can stretch farther, or keep moving longer than you could a couple of weeks ago. Consider trying some yoga techniques this week. Here are some beginner yoga exercises:

- Beginner Yoga

Even common chores can require more energy than you think you have. If you modify the chores a bit or break them down into smaller pieces, you may find that your capacity for doing things around the house is increasing! The following link gives advice about modifying household tasks if you suffer from back pain. Take some of these ideas, no matter what type of pain you have, and use them to think about how to complete the things you want to do around the house.

- Household chores (text)

Goal-setting

Let’s look at your SMART goal worksheet. Are you still on track? Are you getting close to meeting some of your short-term goals? If so, take the time to enjoy the feeling of accomplishment. If you’re finding that your goals are still way off in the distance, maybe you need to think about how to make the goals more manageable. Have a look at this link to help shape your goals.

- Setting goals (text)

If necessary, print out the goals worksheet, and rework some of the columns, making sure that you have a few goals that are achievable in the very near future, as well as one or two that may take a while.

- SMART goals (worksheet)

Have your family and friends look at your goals with you and help you decide whether they’re realistic and achievable, and whether you’re making progress. Bring your goals to your next doctor’s appointment to discuss. Keep your goals handy; we’ll be working through them and adjusting them as necessary.

Relaxation Exercises

By this week, you might have found a relaxation exercise that really works well for you. If so, continue to use it, every day if possible, to bring your mind and body into a relaxed state.

You’ve visited this site already earlier in this module. On the left side of this webpage, there are some relaxation exercises, such as deep breathing, toe tensing and guided imagery, that you can print out and work on when you’re away from the computer. This builds on some of the relaxation exercises we’ve worked on in previous modules.

- Relaxation techniques (text)

Identifying the barriers to sleep and relaxation might help you to structure your time at the end of the day to help with relaxation. Have a look at this sleep diary. Are there any patterns that could be hurting your chance of getting a restful sleep?

- Sleep Diary (worksheet)

Try one of these positive affirmations to put your mind in a positive state before beginning your relaxation exercises.

- Positive Affirmations (text)
Module 3 Links (in order of occurrence)

http://www.medschoolforyou.com/videoplayer/default.aspx?contentFile=/Programs/ChronicPainSelMan/patient03/video.xml&id=patient
Partners: Canadian Pain Society, Canadian Pain Coalition, Chronic Pain Canada, Association Quebecoise de la Douleur Chronique and Painexplained.ca

http://www.getselfhelp.co.uk/cbtstep3.htm
Making changes – behaviours. Vivyan, C. 2010

http://www.umm.edu/sleep/relax_tech.htm
Sleep Insomnia. Sharf, S. University of Maryland Medical Center, 2011.

http://www.umm.edu/sleep/sleep_hyg.htm
Sleep hygiene: helpful hints to help you sleep. University of Maryland Medical Center, 2010.

http://www.getselfhelp.co.uk/docs/Sleep.pdf


http://www.getselfhelp.co.uk/docs/SMARTgoals.pdf
SMART goals. Vivyan, C. 2010

http://www.umm.edu/sleep/relax_tech.htm
Relaxation techniques. University of Maryland Medical Center, 2010.

http://www.getselfhelp.co.uk/docs/SleepDiary.pdf
Sleep Diary. Vivyan, C.

http://www.getselfhelp.co.uk/docs/PositiveAffirmations.pdf

**Module 4 -- Chronic Pain Management**

**Topics:** Communication, nutrition.

The Chronic Pain Self-Management Program, by Sandra LeFort and Lisa Cardas, has been effective when delivered in community group settings. Lisa Cardas gives an overview of module 4 of their program. We will be working on similar concepts this week.  
**Module 4** (6 min video)

It is so important to communicate well, in order to maintain those important relationships in our lives. We all need support and encouragement. By keeping the lines of communication open, and by communicating the positives we are more likely to be able to count on our significant relationships when we need help with the negatives.

**Education**

Sometimes negative thoughts just occur to us. Learning to deal with these thoughts and finding new ways to be positive can help us to change the way we react to situations. Click on the link below to discover ways to deal with negative thoughts. When you're comfortable with the information presented on the page, explore the other links on the webpage—learn about automatic thoughts, and differentiating fact from opinion.  
**CBT Step 4** (text)

Our method of communicating with others can affect the way they react to us. If we communicate in a passive or aggressive fashion, we may not get the feedback we're looking for. In fact, we may be damaging our relationships with these communication styles. Learn about different communication styles, and how to keep the lines of communication open by being assertive.  
**Communication Styles** (text)  
**Assertiveness** (text)

Chronic pain affects all aspects of someone's life. Healing, in the case of chronic pain, might not mean totally getting rid of pain, but it might mean learning the best ways to physically and mentally cope with all the issues that go along with chronic pain, while learning to maintain or increase function and strength and optimize mood and attitude. Good nutrition is essential for mental and physical healing. Work through this overview of nutrition in chronic pain.  
**Nutrition and pain** (text, audio, video)

Download and review this free brochure about healthy eating as it relates to depression. These concepts hold true for someone dealing with chronic pain too.  
**Healthy Eating and Depression** (text)

**Homework:**

Identifying unhelpful thinking habits can help us to keep those thoughts from affecting our communication patterns and our significant relationships. Work through this page and identify those patterns that you use.  
**Unhelpful Thinking Habits** (text)  
Now find alternative thoughts: **Alternative thoughts** (text)

Keep this pain and fatigue diary handy for a few days, and try filling it in. Are there any patterns? Are there any ways to change what goes through your mind when the pain is bad? If you change your thinking, does that help you cope with the pain a bit better?  
**Pain and Fatigue Diary** (worksheet)
Activity

Continue to work out your exercise routine. You may be finding that you can stretch farther, or keep moving longer than you could a couple of weeks ago. Go back to the yoga website from last week and try a different lesson or pose.

There are things that we do every day that lift our mood. There are also things that increase our stress and tension. Look at this description of nourishing and depleting activities. Can you identify the things in your life that lift your mood?

- Nourishing and Depleting Activities (text)
- Activity Diary (worksheet)
- Now, see if you can plan your day or your week to balance some of the activities that are difficult with the things that lift your mood. Use this worksheet.
- Balancing your week (worksheet)

Goal-setting

Let’s look at your SMART goal worksheet. Are you still on track? Are you making progress?

If necessary, print out the goals worksheet, and rework some of the columns, making sure that you have a few goals that are achievable in the very near future, as well as one or two that may take a while.

- SMART goals (worksheet)

Have your family and friends look at your goals with you and help you decide whether they’re realistic and achievable, and whether you’re making progress. Bring your goals to your next doctor’s appointment to discuss. Keep your goals handy; we’ll be working through them and adjusting them as necessary.

Relaxation Exercises

Continue to use the relaxation exercises that you’ve found helpful so far.

Mindfulness is a technique that some people find helpful to focus attention and filter out distractions. Look at this overview of mindfulness.

- Mindfulness (text)

Here are some mindful meditation audio files. Try them out, and see if they add to the techniques that you’re developing to relax your body.

- Mindful meditation audio files
Module 4 Links (in order of occurrence)

Partners: Canadian Pain Society, Canadian Pain Coalition, Chronic Pain Canada, Association Quebecoise de la Douleur Chronique and Painexplained.ca

http://www.getselfhelp.co.uk/cbtstep4.htm
How can we change our thoughts? Vivyan, C. 2010

http://www.getselfhelp.co.uk/docs/CommunicationStyles.pdf
Communication styles. Vivyan, C., 2009

http://www.getselfhelp.co.uk/docs/Assertiveness.pdf


http://www.mentalhealth.org.uk/publications/?entryid5=43900&q=0%e2%acnutrition%e2%ac
Mental Health Foundation, 2007. Healthy Eating and Depression.

http://www.getselfhelp.co.uk/docs/UnhelpfulThinkingHabits.pdf

http://www.getselfhelp.co.uk/docs/UnhelpfulThinkingHabitsWithAlternatives.pdf
Unhelpful thinking habits with alternatives. Vivyan, C., 2009

http://www.getselfhelp.co.uk/docs/PainDiary.pdf
Pain diary. Vivyan, C.

http://www.getselfhelp.co.uk/docs/NourishingDepleting.pdf
Nourishing and depleting activities. Vivyan, C. 2010

http://www.getselfhelp.co.uk/docs/ActivityDiary.pdf
Activity diary. Vivyan, C.

http://www.getselfhelp.co.uk/docs/WeeklyPlanner.pdf
Weekly Planner. Ayres, M., and Vivyan, C. 2010

http://www.getselfhelp.co.uk/docs/SMARTgoals.pdf
SMART goals. Vivyan, C.

http://www.getselfhelp.co.uk/mindfulness.htm
Mindfulness. Vivyan, C., 2010

http://marc.ucla.edu/body.cfm?id=22
Module 5 – Chronic Pain Management

Topics: Medications, sadness and depression, positive thinking, guided imagery.

The Chronic Pain Self-Management Program, by Sandra LeFort and Lisa Cardas, has been effective when delivered in community group settings. Lisa Cardas gives an overview of module 5 of their program. We will be working on similar concepts this week.

Module 5 (6 min video)

There are many medications used in chronic pain. Some of these medications were originally developed for other illnesses, but have been found to be useful in pain and conditions that go along with it such as depression and insomnia.

Education

We assign meaning to our negative thoughts, and then they affect the way we react to situations. Learn how to challenge these thoughts.

CBT - Step 5 (text)

Chronic Pain Medications

Different types of chronic pain may be treated with different types of medication. In speaking with your doctor, you may have a diagnosis associated with your pain, such as diabetic neuropathy, low back pain, migraine or fibromyalgia. Part of the treatment of these painful conditions may require medications. Click on the following link to find out about your type of pain. Work your way through the menu on the left side of the webpage to get more information about your specific pain type.

Chronic Pain Conditions

There are many classifications of medications used for the treatment of pain. Click on this link to bring you to a medication page on the American Chronic Pain Association website. Click on the links on the webpage to learn about the role of medication and developing realistic expectations.

Medications in Chronic Pain (videos)

Medications for mild to moderate pain

Mild to moderate pain (text)

Medications for severe pain

Severe pain (text)

More about opioids:

Some examples of opioid medications include: Percocet, Oxycontin, Dilaudid (hydromorphone),entanyl or codeine as found in Tylenol #3.

If you are contemplating discussing opioids with your healthcare provider, or if you want to know more about opioid medications, click on this link to view an educational video.

Opioids

(32 minute video - 15 x 2 minute segments)

Other classes of medications:

Other pain medications (text)

Homework:

Work through this patient-doctor communication tool. Decide what you need to discuss with your doctor, including medications, and find out how to make the most of your visit.

Patient-doctor tool (audio, text)
Activity

Continue to work out your exercise routine. You may be finding that you can stretch farther, or keep moving longer than you could a couple of weeks ago. Yoga is a great way to gain tone and flexibility.

Do you need to make adjustments at work, or are you thinking about going back to work in the future? Here are some ideas about maintaining or adjusting your work activity when you have chronic pain. The example here is someone with neuropathic pain, but the ideas will still work well for other kinds of pain.

*Working with Chronic Pain* (text)

Goal-setting

Let’s look at your SMART goal worksheet. How well are you progressing toward your goals?

If necessary, print out the goals worksheet, and make adjustments in some of the columns, making sure that you have a few goals that are achievable in the very near future, as well as one or two that may take a while.

*SMART goals* (worksheet)

Have your family and friends look at your goals with you and help you decide whether they’re realistic and achievable, and whether you're making progress. Bring your goals to your next doctor’s appointment to discuss. Keep your goals handy; we’ll be working through them and adjusting them as necessary.

Relaxation Exercises

Continue to use the relaxation exercises that you’ve found helpful so far.

Maintaining a positive frame of mind is important. The following link will lead you common negative thoughts and ideas to reframe them into positives.

*Positive Frame of Mind* (text)

Remind yourself why you're learning to relax. Click on the relaxation response link. Then move to the guided imagery tool that might be helpful in addition to the other techniques you've been using.

*Relaxation response* (text, audio)  *Guided Imagery tool* (text)
Module 5 Links (in order of occurrence)

http://www.medschoolforyou.com/videoplayer/default.aspx?contentFile=/Programs/ChronicPainSelfMan/patient05/video.xml&id=patient
Partners: Canadian Pain Society, Canadian Pain Coalition, Chronic Pain Canada, Association Quebecoise de la Douleur Chronique and Painexplained.ca

http://www.getselfhelp.co.uk/cbtstep5.htm
Challenging our Thoughts. Vivyan, C., 2010

http://prc.canadianpaincoalition.ca/en/chronic_pain_conditions.html
Chronic Pain Conditions. Canadian Pain Society, Pain Resource Centre

http://www.theacpa.org/medsup/default.aspx
Medications and chronic pain. American Chronic Pain Association

Medicines for Mild to Moderate Pain. Watson, P., and Watt-Watson, J.,

Medicines for Severe Pain. Watson, P., and Watt-Watson, J.,

http://www.theacpa.org/opioids/default.aspx

http://prc.canadianpaincoalition.ca/en/other_medications_for_pain.html
Other Medications for Pain. Watson, P., and Watt-Watson, J.,

How to keep working when you have chronic pain. Corsini, E. 2009.
Inflexxion Inc. (Corsini, E., Schwartz, A., Zeis, J., Patterson, E.)

http://www.getselfhelp.co.uk/docs/SMARTgoals.pdf
SMART Goals. Vivyan, C. 2010


Module 6 – Chronic Pain Management

- Topics: Evaluating treatment options, communicating with your health care providers.

The Chronic Pain Self-Management Program, by Sandra LeFort and Lisa Cardas, has been effective when delivered in community group settings. Lisa Cardas gives an overview of module 6 of their program. We will be working on similar concepts this week.

Module 6 - (6 min video)

Discussing treatment goals and communicating effectively with your health care provider is a positive step toward attaining some of these goals. Supportive relationships with family and friends will help you to stay on track, and keep your mood as positive as it can be.

Education

Learning to distance ourselves from negative thoughts allows us to change the way we would react. Look at these techniques for changing perspective. When you’re comfortable with the ideas presented, go to the CBT summary.

CBT – Step 6 (text)  CBT summary (text)

The American Chronic Pain Association has put together a brief summary of what they have learned over the last 30 years. It nicely sums up some of the themes woven through the 6 modules you have worked on.

What we have learned (text).

Making treatment decisions

As we’ve seen over the past 6 modules, medications are only one aspect of treatment. Other therapies and strategies can help in the treatment of chronic pain. Many of the links in the previous modules have incorporated aspects of complementary medicine, such as physical strategies, cognitive and coping strategies and nutritional strategies. Click on this link to see an overview of complementary treatments.

Complementary treatments (audio, video, text)  More information (text)

Communicating with your health care team is important. For you to make good decisions and take an active role in how your treatment proceeds, learn how to give and receive healthcare information.

Communication (audio file)

Maintaining significant relationships can lead to a more support and less stress. Pain can be isolating. It is important for to keep our friends and family close, informed, and feeling like a valued part of our lives.

Significant relationships (text)

Finding social support, and staying in touch with others can keep us from getting depressed and isolated. In addition to friends and family, there are community resources and support groups we can access to know we are not alone.

Social support (text, audio, video)
Activity

It is important to continue with exercise as often as possible, even after you are finished with the modules. Hopefully your exercise routine has increased from a few minutes a few times weekly to something more structured and frequent. You have likely learned how to increase activity slowly and you may be noticing positive changes in your mood as a result of being able to do more.

Continue to exercise, and take this opportunity to review your exercise goals. What would you like to accomplish next. Now that you're a little more mobile, and maybe more encouraged, look for community resources where you could get out with other people. Or form your own walking group – in bad weather, you could walk in a mall. By including others in activity, you may become more motivated, and you may be able to offer support to someone else!

Goal-setting

Time for a review of your SMART goal worksheet. Have you met any of your goals? Are there still things you want to work on?

Print out a new goals worksheet. Move the goals you're still working on over to the new sheet, and add some new goals. Make sure that you have a few goals that are achievable in the very near future, as well as one or two that may take a while.

SMART goals (worksheet)

Have your family and friends look at your goals with you and help you decide whether they're realistic and achievable, and whether you're making progress. Bring your goals to your next doctor's appointment to discuss. Keep your health care team in the loop! Make sure they realize that you've been working hard and you've had some success, no matter how big or small.

Relaxation Exercises

Revisit the relaxation exercise web sites that we used throughout the program. Your library or the bookstore may have additional tapes and CDs for use or purchase. You likely know by now which types of exercises work best for you.

Explore your community. Perhaps there are self-management classes available where you could work through some of these relaxation exercises in a group. Ask your health care providers whether they have any information or could suggest resources for you to keep developing techniques for relaxation.

Use this tool to evaluate your progress toward reshaping the way you react to pain and negative emotions. Decide what you need to continue to work on.

Treatment Evaluation and Plan (worksheet)
Module 6 Links (in order of occurrence)

Partners: Canadian Pain Society, Canadian Pain Coalition, Chronic Pain Canada, Association Quebecoise de la Douleur Chronique and Painexplained.ca

http://www.getselfhelp.co.uk/cbtstep6.htm
Distancing or defusing from thoughts. Vivyan, C. 2010.

http://www.getselfhelp.co.uk/cbtstep7.htm

http://www.theacpa.org/20/WhatWeHaveLearned.aspx
What we have learned. American Chronic Pain Association.


Corsini, E. 2010. How to safely try complementary and alternative medicine (CAM). Inflexxion Inc. (Corsini, E., Schwartz, A., Zeis, J., Patterson, E.)

Zeis, J. 2009. How to communicate more effectively with your health care provider. Inflexxion Inc. (Corsini, E., Schwartz, A., Zeis, J., Patterson, E.)

Zeis, J. How to increase social support. Inflexxion Inc. (Corsini, E., Schwartz, A., Zeis, J., Patterson, E.)

http://www.getselfhelp.co.uk/docs/SMARTgoals.pdf
SMART Goals. Vivyan, C. 2010

http://www.getselfhelp.co.uk/docs/TreatmentPlan.pdf
Appendix F
Ethics Board Approvals

Queen’s University Research Ethics Board Approval, Cohort 1

February 28, 2011

Ms. Jennifer Perry
School of Nursing
Cataract Building
Queen’s University

Dear Ms. Perry,

Study Title: Computer-Based Self-Management Intervention for Individuals Awaiting Consultation With A Chronic Pain Specialist: A Feasibility Study
Co-Investigators: Dr. Elizabeth VanDeVenKruhof

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol and the consent form for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair’s signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following list of ethics requirements you must fulfill over the course of your study:

- Reporting of Amendments: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. (see http://www.queensu.ca/vpr/reb.htm).

- Reporting of Serious Adverse Events: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information.

- Reporting of Complaints: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.

- Annual Renewal: Prior to the expiration of your approval (which is one year from the date of the Chair’s signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

Chair, Research Ethics Board

[Signature]

March 2, 2011

Date

Study Code: NURS-266-11

Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete.
May 24, 2011

Ms. Jennifer Perry
School of Nursing
Cataraqui Building
Queen’s University

Re: “Computer-Based Self-Management Intervention for Individuals Awaiting Consultation With A Chronic Pain Specialist: A Feasibility Study” NURS-266-11

Dear Ms. Perry,

I am writing to acknowledge receipt of your email dated Tuesday, May 17, 2011 which included the following:

- A copy of the revised information/consent form (Version May 16, 2011)

I have reviewed this revised form and hereby give my approval. Receipt of this will be reported to the Health Sciences Research Ethics Board.

Yours sincerely,

[Signature]

Albert Clark, Ph.D.
Chair
Research Ethics Board

AFC/kr
March 24, 2011

Jennifer Perry, PhD Candidate
School of Nursing, Queen’s University

Re: Computer-based, Self-management Intervention for Individuals Awaiting Consultation with a Chronic Pain Specialist: A Feasibility Study

Dear Ms. Perry

Thank you for your letter of March 21, 2011, which included a revised consent form, proof of Queen’s REB approval and your application for Departmental Assistant Status.

With this added information, I consider that the concerns raised by the Providence Care Research Review Committee have been addressed.

I am therefore pleased, on behalf of the Committee, to approve your proposal as amended.

Yours sincerely

John Farty, M.B., Ch.B., FRCP
Chair, Providence Care Research Review Committee
c: Dr. Stephen Bagg, Head, Department PM&R
Ms. Madeline Halladay, Director Patient Records & Registration
Ms. Maureen McGuire, Administrative Leader, PM&R
Dr. David Ruggles, PM&R
Dr. Elizabeth VanDenKerkhof, Thesis Supervisor
Dr. Susan Wood, Director, Office of Research Studies, Queen’s University
Queen's University Research Ethics Board Approval, Cohort 2

June 30, 2011

Ms. Jennifer Perry
School of Nursing
Queen's University

Re: “Computer-Based Self-Management Intervention for Individuals Awaiting Consultation with a Chronic Pain Specialist: A Feasibility Study”
NURS-266-11

Dear Ms. Perry,

I am writing to acknowledge receipt of your request for some amendments to your study. I have reviewed the following:

- Request to advertise for additional participants
- Remove the restriction limiting the participants to those on the wait-list for chronic pain specialist consultation
- Removal of Providence Care as a source of recruitment
- Revised information/consent form (Version: June 21, 2011)

I have reviewed these amendments and the revised consent form and hereby give my approval. Receipt of these amendments will be reported to the Health Sciences Research Ethics Board.

Yours sincerely,

[Signature]

Albert Clark, Ph.D.
Chair
Research Ethics Board

AFC/kr

think Research
think Queen's
Appendix G

Letters of Information and Consents

Letter of Information, Cohort 1

QUEEN'S UNIVERSITY SCHOOL OF NURSING

LETTER OF INFORMATION RESEARCH STUDY

TITLE OF PROJECT: Computer-based Self-management Intervention for Individuals Awaiting Consultation with a Chronic Pain Specialist: A Feasibility Study

BACKGROUND
If you have been referred to see a chronic pain specialist and are currently on the wait-list; have access to a computer, the Internet, and an email address; are able to use the computer independently; and are able to read, write and understand English; you will be invited to participate in a research study led by Jennifer Perry and overseen by Dr. Elizabeth VanDenKerkhof. The purpose of the study is to evaluate the usefulness of a computer-based self-management program for individuals with chronic pain. This study is being conducted by Jennifer Perry to fulfill the requirements for a Doctorate in Nursing at the School of Nursing, Queen’s University, Kingston, Ontario.

DETAILS OF THE STUDY
If you choose to participate in this study, you will receive 7 weekly emails with links to resources such as educational information, relaxation techniques, and gentle exercise suggestions. You will also be asked to set goals for yourself and to monitor your progress toward these goals. As part of the study, you will be asked to fill out weekly questionnaires through a secure website, in order to evaluate the usefulness of the website information, and whether having access to the information in this format has made a difference in your health and wellbeing. Data collection will take no more than 30 minutes weekly.

OTHER INFORMATION
Regardless of whether you participate in this research, you will remain in place on the Wait List for pain specialist care. You should continue with all other treatments as recommended by your usual health care provider. If your turn comes up to see the pain specialist after you have entered the study, you can see the specialist and continue to participate in the study. You may benefit from accessing the chronic pain websites recommended in this study, however if you do not benefit directly, the information you provide will assist in planning future research into computer-based self-management interventions for individuals with chronic pain.

All information obtained during the course of this study is strictly confidential. Your participation in this study is voluntary; you may withdraw from this study at any time, and your withdrawal will not affect your future medical care at Providence Care or with the pain specialists.
TITLE OF PROJECT: Computer-based Self-management Intervention for Individuals Awaiting Consultation with a Chronic Pain Specialist: A Feasibility Study

BACKGROUND INFORMATION:
You are being invited to participate in a research study led by Jennifer Perry and overseen by Dr. Elizabeth VanDenKerkhof, to evaluate the usefulness of a computer-based self-management intervention in the treatment of chronic pain. Ms. Perry or delegate will contact you by telephone to read through this consent form with you, describe procedures in detail, and answer any questions you may have. This study is being conducted to fulfill the requirements for a Doctorate in Nursing at the School of Nursing, Queen’s University, Kingston, Ontario. This study has been reviewed for ethical compliance by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board, and by the Providence Care Research Review Committee.

DETAILS OF THE STUDY
Aim
The purpose of this study is to assess the feasibility of a computer-based self-management intervention for individuals awaiting consultation with a chronic pain specialist. You will be considered for the study if you have been referred to a chronic pain specialist and are currently on the wait-list; have access to a computer, the Internet, and an email address; are able to use the computer independently; and are able to read, write and understand English.

Description of intervention and outcome measures
After you have returned your signed consent, the link to your initial questionnaires will be emailed to you at the email address you have provided. Then, every week for 7 weeks, you will receive an email document with web links leading to educational information, relaxation exercises and other resources similar to information and exercises given to individuals who attend face-to-face self-management programs. In addition, you will fill out weekly questionnaires online to let the researcher know how useful the information was to you, and whether you think it helped with your pain, your mood and your overall general health. The questionnaires will be stored on a secure website, and your name or other identifying information will not be stored with the questionnaires.

Alternative Therapies
There are treatments for your condition that may be available in your community and may provide some or all of the components in this computer-based intervention, including but not limited to the Chronic Pain Self-Management Education and Exercise program at the Kingston YMCA, individual consultation with a physiotherapist and/or psychologist, and comprehensive pain management programs. You can participate in this study even if you are part of other chronic pain programs or treatments.
Risk/Side-Effects
Data collection may take approximately 30 minutes each weekly session, depending on speed of your Internet connection, and your ease in reading information from a computer screen. If you feel tired, you may rest and complete the questionnaires and the computer-based interventions a little at a time.

Completing the questionnaires may make you worry about things that may happen. Inform the Principal Investigator right away if you do not wish to continue with the questionnaire. You may also wish to inform your doctor if this occurs, and he/she can talk to you about your concerns.

Benefits
You may benefit directly from this study and your feedback will help us improve the delivery of future self-management intervention programs for individuals with chronic pain.

Exclusions
You will not be considered for this study if you:
- are not able to read, write and understand English,
- are not able to use a computer independently, or
- do not have access to the Internet and an email address

Confidentiality
All information obtained during the course of this study is strictly confidential. You will be identified only by a participant number. Data will be stored on secure computer websites, and in locked files. It will only be available to the investigators. You will not be identified in any publication or reports. All identifying information will be destroyed after data collection is completed.

The researcher will have safeguards in place to minimize the risk of breach of confidentiality while on the Internet, such as secure log in for questionnaires, assigning a unique identifier for use online rather than using your name, and keeping your email address hidden when emailing information to a group.

Voluntary nature of study
Your participation in this study is voluntary. You may withdraw from this study at any time and your withdrawal will not affect your future medical care with the chronic pain specialist or with Providence Care.

Liability
By signing this consent form, you do not waive your legal rights nor release the investigators from their legal and professional responsibilities.

Payment
There will be no monetary cost to you to participate in this study, nor will you receive any monetary stipend for participating in this study.
SUBJECT STATEMENT AND SIGNATURE SECTION

I have read and understand the consent form for this study. I have had the purposes, procedures and technical language of this study explained to me. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information. If at any time I have further question, problems or adverse events, I can contact:

Principal Investigator: Jennifer Perry, PhD Student
                    8jap@queensu.ca

Thesis Supervisor: Dr. Elizabeth
                    VanDenKerkhof (613)
                    549-6666 ext 3964
                    ev5@queensu.ca

Department Head: Dr. Jennifer Medves
School of Nursing (613) 533-2669
Queen’s University jennifer.medves@queensu.ca

If I have questions regarding my rights as a research subject I can contact Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081.

If I have questions or comments regarding this study, and would like to speak with someone at Providence Care, where I remain on the Wait List to see a chronic pain specialist, I can contact Ms. Maureen McGuire, Administrative Leader, Physical Medicine and Rehabilitation at (613) 548-7222 ext. 2289.

By signing this consent form, I am indicating that I agree to participate in this study.

______________________________  ______________________________
Signature of Patient            Date

______________________________  ______________________________
Signature of Witness            Date

STATEMENT OF INVESTIGATOR

I, or one of my colleagues, have carefully explained to the subject the nature of the above research study. I certify that, to the best of my knowledge, the subject understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

______________________________  ______________________________
Signature of Principal Investigator Date
Amendment #1 to Computer-based Self-management Intervention for Individuals Awaiting Consultation with a Chronic Pain Specialist: A Feasibility Study

Research Proposal

June 21, 2011

This amendment will serve to open study enrolment to those with chronic pain in the geographical area served by Kingston University Hospitals, and not restricted to those on a wait-list to see a chronic pain specialist. In addition, opportunity for participation will be publicized via advertisement including social media such as Facebook.

A new consent and letter of information, both dated June 21 2011, will be used for those who consent to enroll from the general public rather than through chronic pain specialist wait-list. Both the consent and letter of information remove reference to Providence Care, as that facility participated through use of the wait-list, and remove reference to the wait-list for specialty care.

For the purpose of data analysis, the wait-list group will be analyzed separately and compared to the participant sample with chronic pain from the general public.

Rationale for expanding the enrolment: A larger sample can be enrolled in a reasonable amount of time if the inclusion criteria is changed to reflect open enrolment rather than wait-list population. In addition, as this is a computer-based study with web links, recruiting via social media will ensure familiarity with computers, email addresses and web-based format.
LETTER OF INFORMATION

RESEARCH STUDY

TITLE OF PROJECT: Computer-based Self-management Intervention for Individuals with a Chronic Pain: A Feasibility Study

BACKGROUND
If you have chronic pain; have access to a computer, the internet, and an email address; are able to use the computer independently; and are able to read, write and understand English; you will be invited to participate in a research study led by Jennifer Perry and overseen by Dr. Elizabeth VanDenKerkhof. The purpose of the study is to evaluate the usefulness of a computer-based self-management program for individuals with chronic pain. This study is being conducted by Jennifer Perry to fulfill the requirements for a Doctorate in Nursing at the School of Nursing, Queen’s University, Kingston, Ontario.

DETAILS OF THE STUDY
If you choose to participate in this study, you will receive 7 weekly emails with links to resources such as educational information, relaxation techniques, and gentle exercise suggestions. You will also be asked to set goals for yourself and to monitor your progress toward these goals. As part of the study, you will be asked to fill out weekly questionnaires through a secure website, in order to evaluate the usefulness of the website information, and whether having access to the information in this format has made a difference in your health and wellbeing. Data collection will take no more than 30 minutes weekly.

OTHER INFORMATION
You should continue with all other treatments as recommended by your usual health care provider. You may benefit from accessing the chronic pain websites recommended in this study, however if you do not benefit directly, the information you provide will assist in planning future research into computer-based interventions for individuals with chronic pain.

All information obtained during the course of this study is strictly confidential and your anonymity will be protected at all times. Your participation in this study is voluntary; you may withdraw from this study at any time.
Consent, Cohort 2

QUEEN'S UNIVERSITY SCHOOL OF NURSING
PATIENT CONSENT FORM
RESEARCH STUDY

TITLE OF PROJECT: Computer-based Self-management Intervention for Individuals with Chronic Pain: A Feasibility Study

BACKGROUND INFORMATION:
You are being invited to participate in a research study led by Jennifer Perry and overseen by Dr. Elizabeth VanDenKerkhof, to evaluate the usefulness of a computer-based self-management intervention in the treatment of chronic pain. Ms. Perry or delegate will contact you by email to discuss this consent form with you, describe procedures in detail, and answer any questions you may have. This study is being conducted to fulfill the requirements for a Doctorate in Nursing at the School of Nursing, Queen’s University, Kingston, Ontario. This study has been reviewed for ethical compliance by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board, and by the Providence Care Research Review Committee.

DETAILS OF THE STUDY

Aim
The purpose of this study is to assess the feasibility of a computer-based self-management intervention for individuals with chronic pain. You will be considered for the study if you have access to a computer, the Internet, and an email address; are able to use the computer independently; and are able to read, write and understand English.

Description of intervention and outcome measures
After you have returned your signed consent, the link to your initial questionnaires will be emailed to you at the email address you have provided. Then, every week for 7 weeks, you will receive an email document with web links leading to educational information, relaxation exercises and other resources similar to information and exercises given to individuals who attend face-to-face self-management programs. In addition, you will fill out weekly questionnaires online to let the researcher know how useful the information was to you, and whether you think it helped with your pain, your mood and your overall general health. The questionnaires will be stored on a secure website, and your name or other identifying information will not be stored with the questionnaires.

Alternative Therapies
There are treatments for your condition that may be available in your community and may provide some or all of the components in this computer-based intervention, including but not limited to the Chronic Pain Self-Management Education and Exercise program at the Kingston YMCA, individual consultation with a physiotherapist and/or psychologist, and comprehensive pain management programs. You can participate in this study even if you are part of other chronic pain treatments or programs.
Risk/Side-Effects
Data collection may take approximately 30 minutes each weekly session, depending on speed of your Internet connection, and your ease in reading information from a computer screen. If you feel tired, you may rest and complete the questionnaires and the computer-based interventions a little at a time.

Completing the questionnaires may make you worry about things that may happen. Inform the Principal Investigator right away if you do not wish to continue with the questionnaire. You may also wish to inform your doctor if this occurs, and he/she can talk to you about your concerns.

Benefits
You may benefit directly from this study and your feedback will help us improve the delivery of future self-management intervention programs for individuals with chronic pain.

Exclusions
You will not be considered for this study if you:
a) are not able to read, write and understand English,
b) are not able to use a computer independently, or
c) do not have access to the Internet and an email address

Confidentiality
All information obtained during the course of this study is strictly confidential. You will be identified only by a participant number. Data will be stored on secure computer websites, and in locked files. It will only be available to the investigators. You will not be identified in any publication or reports. All identifying information will be destroyed after data collection is completed.

The researcher will have safeguards in place to minimize the risk of breach of confidentiality while on the Internet, such as secure log in for questionnaires, assigning a unique identifier for use online rather than using your name, and keeping your email address hidden when emailing information to a group.

Voluntary nature of study
Your participation in this study is voluntary. You may withdraw from this study at any time and your withdrawal will not affect your future medical care with the chronic pain specialist or with Providence Care.

Liability
By signing this consent form, you do not waive your legal rights nor release the investigators from their legal and professional responsibilities.

Payment
There will be no monetary cost to you to participate in this study, nor will you receive any monetary stipend for participating in this study.

**SUBJECT STATEMENT AND SIGNATURE SECTION**

I have read and understand the consent form for this study. I have had the purposes, procedures and technical language of this study explained to me. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will receive a copy of this consent form for my information. If at any time I have further question, problems or adverse events, I can contact:

Principal Investigator: Jennifer Perry, PhD Student  
8jap@queensu.ca

Thesis Supervisor: Dr. Elizabeth VanDenKerkhof  
(613) 549-6666 ext 3964  
ev5@queensu.ca

Department Head: Dr. Jennifer Medves  
School of Nursing (613) 533-2669  
Queen’s University  jennifer.medves@queensu.ca

If I have questions regarding my rights as a research subject I can contact Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081.

By signing this consent form, I am indicating that I agree to participate in this study.

___________________________________  _____________________  
Signature of Patient     Date

___________________________________  _____________________  
Signature of Witness     Date

**STATEMENT OF INVESTIGATOR**

I, or one of my colleagues, have carefully explained to the subject the nature of the above research study. I certify that, to the best of my knowledge, the subject understands clearly the nature of the study and demands, benefits, and risks involved to participants in this study.

___________________________________  _____________________  
Signature of Principal Investigator     Date
Appendix H
Feasibility Questionnaire

Feasibility Questionnaire—Individual questions delivered via computer survey

How often did you work on the module at the computer this week?
0 days, 1 day, 2 days, 3 days, 4 days, 5 days, 6 days, 7 days

How many hours in total did you work on the module at the computer?
0 hours, 1-2 hours, 3-4 hours, 5-7 hours, 7-10 hours, >10 hours

How many hours did you work on module “homework” away from the computer this week?
0 hours, 1-2 hours, 3-4 hours, 5-7 hours, 7-10 hours, >10 hours
Appendix I

Usability Questionnaire

Usability Questionnaire—Individual questions delivered via computer survey

Overall, how satisfied were you with this week’s module?

Very satisfied, somewhat satisfied, neutral, somewhat dissatisfied, very dissatisfied

Please rate the module according to the following:

- Layout/design – poor, below average, average, good, excellent
- Quality of content
- Ease of navigation
- Usefulness of information

Was the following style of information delivery useful to you?

- Text (reading) Y/N
- Audio files (listening) Y/N
- Video Y/N

Was the information clear / easy to understand? Y/N

Please rate the components of the module according to the following:

- Module introduction poor, below average, average, good, excellent
- Education section poor, below average, average, good, excellent
- Activity section poor, below average, average, good, excellent
- Goal-setting/homework poor, below average, average, good, excellent
- Relaxation section poor, below average, average, good, excellent

What information did you find most useful in this module?
What information did you find least useful in this module?

Additional suggestions:
Appendix J

Chronic Pain Referral Form

Patient Name: ___________________________ D.O.B.: ____________________ (YYYY/MM/DD)

OHIP #: ___________________________ Version _______ WSIB #: ____________________

Home Phone: ___________________________ Work phone: ___________________________

Referring Physician: ___________________________ Family Physician: ___________________________

Marital Status: □ Single    □ Married    □ Divorced/Separated    □ Widowed

Work Status: □ employed    □ full time    □ part time    □ unemployed    □ < 2 years    □ retired    □ > 2 years

Disability Insurance: □ None    □ ODSP    □ OWP    □ WSIB    □ Private disability

Litigation: □ none    □ in progress    □ completed

Pain History

Location: (all affected areas)

□ back    □ neck    □ head    □ abdomen    □ shoulder    □ leg    □ arm    □ face    □ pelvis
□ other ___________________________

Severity: □ mild    □ moderate    □ severe

(□ does not interfere with daily activities)    (□ interferes with most daily activities)

Duration: □ < 6 months    □ 6 – 24 months    □ 2 –5 years    □ > 5 years

Current Underlying Diagnosis/Cause (if any): _________________________________________

Associated Symptoms

Sleep disturbance: □ yes    □ no    Fatigue: □ yes    □ no
Depressed mood: □ yes    □ no    Anxious mood: □ yes    □ no

Relevant Past Medical/Surgical/Psychiatric History

Surgery related to current pain complaint: □ yes    □ no

Details: _________________________________________
Substance Abuse:  □ yes  □ no
Details: ____________________________________________________________

Psychiatric conditions:  □ yes  □ no
Details: ____________________________________________________________

Other relevant (list): ________________________________________________

**Current Medications**

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<thead>
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<th>Dose</th>
<th>Response</th>
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<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
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Other Medications: ________________________________________________

**Previous/discontinued Pain Medications**

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<tr>
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<td>4.</td>
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**Non pharmacologic treatment to date**

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</tr>
<tr>
<td>Occupational therapy:</td>
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</tr>
<tr>
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<td></td>
</tr>
<tr>
<td>Psychology:</td>
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<tr>
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</tr>
<tr>
<td>Complementary Medicine:</td>
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<tr>
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<tr>
<td>□ massage</td>
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**Previous Relevant Investigations (Please attach all reports)**

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<td></td>
</tr>
<tr>
<td>CT</td>
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<td></td>
</tr>
<tr>
<td>EMG/NCS</td>
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<td></td>
</tr>
<tr>
<td>Other</td>
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**Previous Relevant Specialist Appointments (Please attach all reports)**

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<tr>
<td>Neurosurgery</td>
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<td></td>
</tr>
<tr>
<td>Psychiatry</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>Physical Med. &amp; Rehab</td>
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<td></td>
</tr>
<tr>
<td>Rheumatology</td>
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<td></td>
</tr>
<tr>
<td>Other</td>
<td>□</td>
<td></td>
</tr>
</tbody>
</table>

Please provide contact information for person completing referral form, in the event that additional information is required. ____________________________________________________________

Fax completed form to Physiatry: (613) xxx-xxxx
Appendix K

Demographic Data Questionnaire

Individual questions delivered via computer survey (fillable with check boxes and text fields)

Initials / Unique ID #
Age (yrs)
Gender M F
Highest Completed level of education (check one)
   Elementary School
   High school
   College or University
   Graduate Studies (Masters/ Doctoral)
Employment (check one)
   Student
   Employed full time
   Employed part-time
   Unemployed less than 2 years
   Unemployed more than 2 years
   Disabled
   Retired
Marital Status (check one)
   Single
   Married/common-law
   Divorced/separated
   Widowed
Area of pain (check all that apply)
   Head
   Neck
   Shoulder
Chest
Abdomen
Pelvis
Hip
Leg
Knee
Foot
Other
Length of time you’ve had this pain (check one)
   Less than 6 months
   6 months to 2 years
   2 to 5 years
   More than 5 years
Severity (check one)
   Mild
   Moderate
   Severe
Associated Symptoms (y / n)
   Sleep disturbance
   Fatigue
   Depressed mood
   Anxious mood
Surgery related to current pain problem? Y/N
Smoker (check one)
   Never
   Past
   Current
Alcohol use (check one)
   None
   1-2 drinks weekly
   3-6 drinks weekly
7 or more drinks weekly
History of drinking, but stopped now

Substance Use: (never, used in the past, currently use)
  Marijuana
  Other “street drugs”

Past or present problems with: (y / n)
  Depression
  Anxiety
  Post-traumatic stress disorder
  Addiction

Current pain medications: (never, used in the past, currently use)
  Acetaminophen, or Tylenol
  Ibuprofen, Aleve, Advil
  Naproxen, Celebrex
  Tramadol, Zytrar, Ultram, Tramacet, Ralivia
  Codeine, Tylenol #3
  Morphine, Statex
  Demerol
  Oxycontin, Percocet, Oxycocet
  Fentanyl, Duragesic
  Hydromorphone, Dilaudid, Hydromorph contin
  Methadone
  Gabapentin, Neurontin, Pregabalin, Lyrica
  Amitriptyline, Elavil, Nortriptyline
  Effexor, Venlafaxine, Duloxetine, Cymbalta

Have tried: (y / n)
  Physiotherapy
  Occupational therapy
  Psychology
  Chiropractor
  Acupuncture
Massage

Have seen other doctors? (y / n)

Other pain specialist
Orthopedic doctor
Neurosurgeon or neurologist
Psychiatrist
Rehabilitation specialist
Rheumatologist
Appendix L

Medical Outcomes Study Short Form 12 (SF-12)

SF-12® Questionnaire

1. In general, would you say your health is:
   _______ Excellent (1)
   _______ Very Good (2)
   _______ Good (3)
   _______ Fair (4)
   _______ Poor (5)

   The following two questions are about activities you might do during a typical day. Does YOUR HEALTH NOW LIMIT YOU in these activities? If so, how much?

2. MODERATE ACTIVITIES, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf:
   _______ Yes, Limited A Lot (1)
   _______ Limited A Little (2)
   _______ Not Limited At All (3)

3. Climbing SEVERAL flights of stairs:
   _______ Yes, Limited A Lot (1)
   _______ Yes, Limited A Little (2)
   _______ No, Not Limited At All (3)

   During the PAST 4 WEEKS (alternate: PAST 1 WEEK) have you had any of the following problems with your work or other regular activities AS A RESULT OF YOUR PHYSICAL HEALTH?

4. ACCOMPLISHED LESS than you would like:
   _______ Yes (1)
   _______ No (2)

5. Were limited in the KIND of work or other activities:
   _______ Yes (1)
   _______ No (2)

   During the PAST 4 WEEKS (alternate: PAST 1 WEEK), were you limited in the kind of work you do or other regular activities AS A RESULT OF ANY EMOTIONAL PROBLEMS (such as feeling depressed or anxious)?

6. ACCOMPLISHED LESS than you would like:
   _______ Yes (1)
   _______ No (2)

7. Didn’t do work or other activities as CAREFULLY as usual:
   _______ Yes (1)
   _______ No (2)
8. During the PAST 4 WEEKS (alternate: PAST 1 WEEK), how much did PAIN interfere with your normal work (including both work outside the home and housework)?
   _____ Not At All (1)
   _____ A Little Bit (2)
   _____ Moderately (3)
   _____ Quite A Bit (4)
   _____ Extremely (5)

The next three questions are about how you feel and how things have been DURING THE PAST 4 WEEKS (alternate: PAST 1 WEEK). For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the PAST 4 WEEKS (alternate: PAST 1 WEEK) –

9. Have you felt calm and peaceful?
   _____ All of the Time (1)
   _____ Most of the Time (2)
   _____ A Good Bit of the Time (3)
   _____ Some of the Time (4)
   _____ A Little of the Time (5)
   _____ None of the Time (6)

10. Did you have a lot of energy?
    _____ All of the Time (1)
     _____ Most of the Time (2)
     _____ A Good Bit of the Time (3)
     _____ Some of the Time (4)
     _____ A Little of the Time (5)
     _____ None of the Time (6)

11. Have you felt downhearted and blue?
    _____ All of the Time (1)
     _____ Most of the Time (2)
     _____ A Good Bit of the Time (3)
     _____ Some of the Time (4)
     _____ A Little of the Time (5)
     _____ None of the Time (6)

12. During the PAST 4 WEEKS (alternate: PAST 1 WEEK), how much of the time has your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your social activities (like visiting with friends, relatives, etc.)?
    _____ All of the Time (1)
     _____ Most of the Time (2)
     _____ A Good Bit of the Time (3)
     _____ Some of the Time (4)
     _____ A Little of the Time (5)
     _____ None of the Time (6)
Appendix M

Brief Pain Inventory

Individual questions delivered via computer survey. Diagram not included.
7. What treatments or medications are you receiving for your pain?

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

<table>
<thead>
<tr>
<th></th>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
<th>50%</th>
<th>60%</th>
<th>70%</th>
<th>80%</th>
<th>90%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Relief</td>
<td>Complete Relief</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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9. Circle the one number that describes how, during the past 24 hours, pain has interfered with your:

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<thead>
<tr>
<th>A. General Activity</th>
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<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>Does not Interfere</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B. Mood</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>Does not Interfere</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>C. Walking Ability</th>
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</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>Does not Interfere</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>D. Normal Work (including both work outside the home and housework)</th>
</tr>
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<tr>
<td>0</td>
</tr>
<tr>
<td>Does not Interfere</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>E. Relations with other people</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>Does not Interfere</td>
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</table>

<table>
<thead>
<tr>
<th>F. Sleep</th>
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<td>0</td>
</tr>
<tr>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>G. Enjoyment of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>Does not Interfere</td>
</tr>
</tbody>
</table>
Appendix N

Patients’ Global Impression of Change

Individual questions delivered in sequence via computer survey.

Patients' Global Impression of Change (PGIC) scale.

Name: ___________________________ Date: ___________ DOB: ______

Chief Complaint: ____________________________

Since beginning treatment at this clinic, how would you describe the change (if any) in ACTIVITY LIMITATIONS, SYMPTOMS, EMOTIONS and OVERALL QUALITY OF LIFE, related to your painful condition? (tick ONE box).

No change (or condition has got worse) □ 1
Almost the same, hardly any change at all □ 2
A little better, but no noticeable change □ 3
Somewhat better, but the change has not made any real difference □ 4
Moderately better, and a slight but noticeable change □ 5
Better, and a definite improvement that has made a real and worthwhile difference □ 6
A great deal better, and a considerable improvement that has made all the difference □ 7

In a similar way, please circle the number below, that matches your degree of change since beginning care at this clinic:

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<th>Much Better</th>
<th>No Change</th>
<th>Much Worse</th>
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</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Patient’s signature: ___________________________ Date: ___________

Appendix O

Weekly Changes in Treatment Questionnaire

Individual questions delivered in sequence via computer survey.

Have you had any changes in your pain medication in the past week? Yes/No

Have you INCREASED your dosage of any of the following medications in the past week?

- Acetaminophen, Tylenol, Ibuprofen, Advil, Aleve, Naproxen, Celebrex,
- Tramadol, Zytram, Ultram, Tramacet, Ralivia, Codeine, Tylenol #3,
- Morphine, Statex, Demerol, Oxycontin, Percocet, Oxycocet,
- Fentanyl, Duragesic, Hydromorphone, Dilaudid, Hydromorph Contin,
- Methadone, Gabapentin, Neurontin, Pregabalin, Lyrica
- Amitriptyline, Elavil, Nortriptyline, Effexor, Venlafaxine, Duloxetine, Cymbalta

Have you DECREASED your dosage of any of the following medications in the past week?

- Acetaminophen, Tylenol, Ibuprofen, Advil, Aleve, Naproxen, Celebrex,
- Tramadol, Zytram, Ultram, Tramacet, Ralivia, Codeine, Tylenol #3,
- Morphine, Statex, Demerol, Oxycontin, Percocet, Oxycocet,
- Fentanyl, Duragesic, Hydromorphone, Dilaudid, Hydromorph Contin,
- Methadone, Gabapentin, Neurontin, Pregabalin, Lyrica
- Amitriptyline, Elavil, Nortriptyline, Effexor, Venlafaxine, Duloxetine, Cymbalta

Have you seen a pain specialist for the first time in the last week? Yes/No

Have you tried any of the following treatments for the first time in the last week?
- Physiotherapy, occupational therapy, psychology, chiropractor, acupuncture, massage, other.
Appendix P

Study Timeline

1. Wait List individuals identified and pre-assessed for eligibility
   - Contacted by telephone or email, eligibility verified, offered enrolment
   - Consented and enrolled via email

2. Online advertisement showed to identified demographic, with instructions to email
   - Email: link to Intake Package--Demographics questionnaire, SF-36, BPI, Pain Catastrophizing Scale
   - Email Introduction

Weeks 0-2

Week 3
- Email Module 1
- Email post-module questionnaire

Week 4
- Email Module 2
- Email post-module questionnaire

Week 5
- Email Module 3
- Email post-module questionnaire

Week 6
- Email Module 4
- Email post-module questionnaire

Week 7
- Email Module 5
- Email post-module questionnaire

Week 8
- Email Module 6
- Email post-module questionnaire

Week 20
- Email link Post-module questionnaire (final)
## Appendix Q
### Participant Flow

#### Cohort 1 (Wait List) Study Flow

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<tbody>
<tr>
<td>Pre-screened</td>
<td>411</td>
<td>278</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Total = 133</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Duplicate information = 8</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Seen by other pain clinics or have an appointment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>scheduled in near future, so were no longer “waiting” on list = 119</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Inmate = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Deceased = 1</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Less than 18 years of age = 4</td>
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<td>93</td>
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<td></td>
<td></td>
<td>Busy/Can’t get through = 8</td>
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<td></td>
<td>No valid contact information = 5</td>
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<td></td>
<td></td>
<td>Busy life = 3</td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Prisoner, therefore difficult logistics = 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Deceased = 2</td>
</tr>
<tr>
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<td></td>
<td></td>
<td>Can’t hear = 1</td>
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<td>Total = 73</td>
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<td></td>
<td></td>
<td></td>
<td>Did not receive information due to email error =2</td>
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<td></td>
<td></td>
<td>No response to information email = 51</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>No email received from those requesting researcher address = 15</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Not interested after receiving study information = 5</td>
</tr>
<tr>
<td>Consent</td>
<td>20</td>
<td>17 e-signed</td>
<td>Did not consent = 3</td>
</tr>
<tr>
<td>Demographic information</td>
<td>17</td>
<td>16</td>
<td>Did not complete = 1</td>
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## Participant Flow Cohort 1

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<th>Completed questionnaire</th>
<th>Did not complete questionnaire</th>
<th>Withdrew</th>
</tr>
</thead>
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<td>Introduction</td>
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<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Module 1</td>
<td>16</td>
<td>13</td>
<td>2</td>
<td>1—computer problems</td>
</tr>
<tr>
<td>Module 2</td>
<td>15</td>
<td>12</td>
<td>2</td>
<td>1—vacation</td>
</tr>
<tr>
<td>Module 3</td>
<td>14</td>
<td>7</td>
<td>6</td>
<td>1—unable to keep up</td>
</tr>
<tr>
<td>Module 4</td>
<td>13</td>
<td>7</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Module 5</td>
<td>13</td>
<td>6</td>
<td>6</td>
<td>1—heat, slow dial-up</td>
</tr>
<tr>
<td>Module 6</td>
<td>12</td>
<td>7</td>
<td>4</td>
<td>1—unable to keep up, busy schedule</td>
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<tr>
<td>Post-intervention</td>
<td>11</td>
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<td>3</td>
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</tbody>
</table>
## Cohort 2 (Recruited online) Study Flow

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<tbody>
<tr>
<td>Contacted researcher to request information</td>
<td>68</td>
<td>30</td>
<td>38 (no reason given)</td>
</tr>
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<td>Consent link emailed</td>
<td>30</td>
<td>26</td>
<td>4 (no reason given)</td>
</tr>
<tr>
<td>Demographic information</td>
<td>26</td>
<td>25</td>
<td>1 (did not respond)</td>
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</table>

## Participant Flow Cohort 2

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</tr>
</thead>
<tbody>
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<td>Introduction</td>
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<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Module 1</td>
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<td>16</td>
<td>8</td>
<td>1—too busy</td>
</tr>
<tr>
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<td>13</td>
<td>10</td>
<td>1—no reason given</td>
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<tr>
<td>Module 3</td>
<td>23</td>
<td>10</td>
<td>12</td>
<td>1—too busy</td>
</tr>
<tr>
<td>Module 4</td>
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<td>10</td>
<td>9</td>
<td>3—computer issue, too many questions, “not up to continuing”</td>
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<td>Module 5</td>
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<td>0</td>
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<td>11</td>
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<tr>
<td>Post-intervention</td>
<td>19</td>
<td>6</td>
<td>13</td>
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</tr>
</tbody>
</table>
Summary at 12-weeks post-intervention:

**Cohort 1** – 16 signed consent and completed demographic data

--8 completed post-study questionnaire
--5 withdrew
--3 lost to follow-up

**Cohort 2** – 25 signed consent and completed demographic data

--6 completed post-study questionnaire
--6 withdrew
--13 lost to follow-up
Appendix R

Internet Advertisement

Small advertisement leading to larger advertisement with instructions:

![Chronic Pain Study](sites.google.com)

Needed: Participants with chronic pain to evaluate a computer-based self-management program.
Queen's University

We are currently recruiting participants for a research study investigating the usefulness of a computer-based self-management program for individuals with chronic pain.

The study is 6 weeks long, with a follow-up questionnaire 3 months later, and requires no in-person visits. The program is designed to provide education about your pain, and to get you thinking about ways to improve your overall health.

This study is open to anyone with chronic pain in Canada.

While participating in the study, you may continue all medications and treatments as directed by your healthcare provider.

For more information, please contact Jennifer Perry atjperry.queensu@gmail.com

Jennifer Perry RN(BC), MScN, NP-PHC is a PhD student in the School of Nursing at Queen's University.
**Appendix S**

**Advertising Summary**

Facebook Advertising Daily “Clicks” and Cost

<table>
<thead>
<tr>
<th>Date</th>
<th>Impressions</th>
<th>Clicks</th>
<th>CTR</th>
<th>CPC</th>
<th>CPM</th>
<th>Spent</th>
<th>Reach</th>
<th>Frequency</th>
<th>Unique Clicks</th>
<th>Unique CTR</th>
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<td>12</td>
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<td>0.83</td>
<td>0.27</td>
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<td>22695</td>
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<td>9/17/2011</td>
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<td>0.00%</td>
<td>0</td>
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**Note:** Chart, calculations and terminology generated by Facebook.

**Legend**

**Impressions:** Number of times advertisement is displayed

**Clicks:** Number of times viewers selected advertisement to obtain more information

**CTR:** Click Through Rate—Ratio of number of clicks to total impressions
**CPC:** Cost Per Click—Calculation of cost each time viewer clicks on advertisement

**CPM:** Cost Per Thousand (Roman Numeral “M”)—Calculation of cost per 1000 impressions

**Spent:** Total cost per day, in Canadian Dollars

**Reach:** Unique number of viewers exposed to the advertisement

**Frequency:** The average number of times each viewer was exposed to the advertisement.

**Unique Clicks:** Number of times unique viewer selected advertisement

**Unique CTR:** Ratio of number of unique clicks to total impressions

### Geographical Area of Facebook Advertisement Viewers September to November 2011

![Geographical Area Chart]

### Age and Gender of Facebook Advertisement Viewers

(Click-through statistics only available for October 2011)

#### September 2011

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Appendix T
Free-Text Comments

Comments from Study Participants--unedited

Module 1

Module 2

Module 3

Module 4

Module 5

Module 6

12-week Post-intervention
Module 1

Overall, how satisfied were you with this week's module? - Comments

this module did not relieve my pain level that I experienced this week

interesting but way too much content, still have things to read over

Very intense. Very educational, and understood. Looking forward to the future changes

CBT was something I had already started to explore. It was much to my amazement that it was one of the first awarenesses brought to my attention. Very happy. The breathing exercises to release the stress out of my muscles was extremely helpful - Thank you!!!

Very interesting I really like the information on goal setting and will use this approach to set some goals for myself. I have since registered for an introductory workshop on meditation and will book a massage and exercise more when I am not in pain. I also started mind-body psychotherapy.

I really like the information they give you it it very helpful to know:

Like the mixture of reading, audio and visual. Makes it more interesting and easier to absorb. Especially liked the info around CBT and pacing.

I am enjoying this module although I have only just begun. The information is interesting but I find a lot to read in a short period of time since I can only work at it on good days when my body pain and fatigue are at a good level together. At times I feel overwhelmed by it all.

The questions are making me more aware of things in general. I am more frustrated with the situation of not being able to do the activities I like to do rather than being anxious

I have found the breathing relaxation helpful. I know about this but find it difficult to discipline myself to use it as often as I should

Did you have any problems with the links to external websites? - Additional comments

pretty basic pain management stuff, but not sure yet how much I can really apply it to my back injury or fibro

I could not access by my Ipad

I like reading and having transcript available. Thanks.

You were already aware of them.

Just the one you pointed out was not working.

For some reason i couldn't open new browser windows with the links; i had to go back and forth to the main module message. Also, i couldn't get the links to the American Pain Association videos to load properly.

POWER OUTAGE

Have to download a newer version of Adobe in order to get the videos and audio files. being done this week.
video had an echo track... double voice over

**Please rate the components of the module according to the following: - Comments**

Goal setting will be a challenge along with the relaxation

Very good research!!! Very impressed!

It's refreshing to know how to manage pain with the info. provided. I have learned some of the techniques before from other sources.

A lot of reading to cover each week and to put all of it in practice. I spent a lot of time on the relaxation suggestions this week. The activity suggestions worked for me. I cut down on my walking to three days a week, took 35 or so minutes to do my 4 plus km instead of my usual 20/25 minutes. I felt better for it.

I was already doing an exercise program prior to this study... it keeps my back moving.. sitting too long seems to freeze up the back but it feels better after moving again.

**What information did you find MOST useful in this module? - Open-Ended Response**

- that chronic pain is real
- relaxation, pacing activities
- Relaxation
- Education
- Mindfulness Breathing
- SMART goal setting and information on pain management
- Planning physical activity carefully and regularly.
- BREATHING
- ways to relax
- all about your rights, how to relax and how to live a full happy life even with pain
- relaxation
- setting goals
- Goal-setting
- Relaxation and letting your self breathe and try to ease up.
- the reference to ACT
- CBT
- videos since I learn through visualization better than reading

I found all the information interesting and useful

CBT
the activity suggestions

As above

**What information did you find LEAST useful in this module? - Open-Ended Response**

the exercises in cognitive behavioral therapy as this deals with emotional issues, and I feel that I have not got extreme emotional issues like depression and anxiety. I am a person experiencing chronic groin pain that is real

need more specific back pain injury exercise program, scared to do some of the exercises in video, causes pain
Goal-Setting

Relaxation videos, as I am unable to get to the floor// no ideas were given for adaption

Monitoring and pacing - I have a two year old and I'm a single mother - not always will this one be able to be applied - you wanted one, I picked on this one.

n/a

The part which makes it sound like i just need to "suck it up".

none

?? found everything useful:)

discussion about group work as it is not applicable

nothing really

Reading and taking in information

broken links

The articles re depression, I am more frustrated than depressed or anxious

video was poor reception on my computer.

Additional Comments or Suggestions: - Open-Ended Response

I answered these questions based on what I felt in the last 24 hours, if I had answered this questionnaire based on 3 to 4 days ago when I was experiencing a very high level of pain and was unable to work, I would have rated the pain scores much higher, the scores that are reported on this survey are being answered while on pain-killers which is currently helping to control my pain level

Being agorophobic and depressed especially over holidays makes exercise, socializing, concentration difficult, so I was not even motivated much to do this. will try harder in future.

I am enjoying this program. Thanks for taking the time, and giving me an opportunity. I learned so much this 1st week, I'm excited to see what coming up in the weeks to come :-D

I don't have anything to add, very good research and I look forward to the next module.

I'VE HAD R.A. FOR 50 YEARSSO FAR NOTHING I HAVEN'T HEARD BEFORE BUT A GOOD REMINDER! I'M IN A WHEELCHAIR SO A LOT OF WALKING DOESN'T APPLY.

When I am more active my pain level goes up, of course my pain medication is less effective, I may be a little Grumpy due to increased Pain levels but my general mood is more upbeat as I am active & engaged. Sorry, I’m a cynic. . . Tks. . .

No additional comments or suggestions at this time.

I am away next week.. but will try to do the next module at my son's house...
Module 2

**Did you have any problems with the links to external websites?**

- *Additional comments*

Didn't get time to check it out.

The first link as indicated and I did have a few problems with the guided imagery but it rectified itself.

- Introduction link
- only with one link at the beginning

My HD SSD went down last week, could not return due to Postal strike, So no use of my own Computer

n/a

still unable to use the video and audio even though I had downloaded the Adobe Flash several times.

**Please rate the components of the module according to the following:**

- *Comments*

Working with a physiotherapist, I will continue with the exercises he has me doing compared to the ones in the videos (the videos are too advanced for me at this point-in-time - I'm still stabilizing my core).

Again, there wasn't much new

I have found through receiving the 2nd module I now follow the relaxation and meditation exercises often and am using the deep breathing for moments of stress as I should have been doing all along. I am finding they help me tremendously. Thankyou for jogging me into using these methods.

- none of the rest applied

**What information did you find MOST useful in this module?**

- *Open-Ended Response*

the pacing of activity etc. anxiety and depression cycles.

**EDUCATION**

- videos

n/a

Info on guided imagery and depression and anxiety text info.

The differences in the feelings (Depression, Anxiety and Anger). I felt it was easier to cope with each emotion when I could tell which emotion I was actually dealing with.

Pacing in relation to exercise and goal setting

really like the breathing relaxation section

Quite a few things - relaxation, meditation, pacing. Receiving a module each week has set me into a routine which is helping me cope with pain and stress.

relaxation techniques
Education section
relaxation and exercise
Depression mod was most interesting
Guided Imagery
only received the week 2 questions...no additional material
discussing how to not over do activities as this can cause a setback
PACE MYSELF
The relaxation section
What information did you find LEAST useful in this module? - Open-Ended Response
video of exercises, would prefer something to print out to use..with pictures instead of a video.
EXERCISE
the amount of reading
n/a
n/a
n/a
The redundant going over information. Created more reading than necessary.
Relaxation is hard to do from information provided
dealing with depression
Exercise. I have tried over the years to exercise more but it only intensifies the pain and makes me feel weak and nauseous. I do stretch exercises and walk a little, garden a little but do not seem to be able to do more than that.

n/a
None
I find all the information useful.

n/a
content was vague and too generalized
BLUE AND RED IN BREATHING
I find them all useful
Additional Comments or Suggestions: - Open-Ended Response
I will continue to practice what I have learned.
Maybe make the second module a bit more varied than the first.
The excessive links are helpful but created too much to grasp in one week.

I wish I hadn't signed up for this study.

As I have been fighting CP for so long now, depression, mood & anger Swings are the keys to success, (for me) but regressively its become a losing battle, with no middle ground anymore, my days are either great or plan nasty, no matter how much preparation the day prior.
Module 3

Did you have any problems with the links to external websites? - Additional comments

Beginner Yoga

"Beginner Yoga Link" did not work for me. "Household Chores" & "Setting Goals" were the same link for me. I would prefer when the downloadable forms (in Adobe) show as landscape forms, that they print landscape - not letter format (would make for easier writing in them when using them). Adobe could be changing this...

The very first link (7 min. video) unable to view, i will attempt on another PC

Household chores; could not access

Please rate the components of the module according to the following: - Comments

I seem to have set myself a programme related to your texts. My pain level has not changed but I have spent more time outside doing some garden work in times that I have had some energy.

My Homeopath & Osteopath both agree that due to my chronic fatigue that my naps are necessary for my healing process and that I should not fight them. I am still sleeping 7 - 10 hours at night even with 3 - 4 hour naps during the day. They are telling me that I am in my "catch-up stage" and if I feel the need to nap, to do so. So, unfortunately, I'm going against this part of this week's lesson. I am aware of the consequences that can arise if this continues for too long, but my doctors are aware of my case and of what my body is going through. I'm not normally a napper and I'm sure this behaviour will not continue on an ongoing basis.

I LIKE THE BREATHING EXERCISE. AND STICK TO THAT.PERIOD.

What information did you find MOST useful in this module? - Open-Ended Response

Sleep info

The section on how to modify tasks when you suffer from backpain.

Related to sleep problems

Relaxation, meditation, anxiety, pacing, accepting my situation but making the best of it.

"Sleep Diary" and "Positive Affirmations". ( Might have been "Beginner Yoga" had it loaded/linked.)

JUST RELAX MORE

Goal setting & fatigue and sleep

Information on Relaxation

Education

movement content

finding all information useful
What information did you find LEAST useful in this module? - Open-Ended Response

Relaxation -- it is becoming repetitious

None

Exercise which I find causes more pain and fatigue, apart from walking some days

"Household Chores" and "Setting Goals" being the same link.

If one is not familiar with yoga, more instruction needs to be given. eg- Lesson 1: what's the tailor fashion? Lesson 2: Child's pose? Lesson 5: Vinyasa, series of postures not explained Lesson 6 : tadasana - not explained

WHEN IN A LOT OF PAIN I JUST GET INTO IT...

Relaxation Exercises

The introduction to the module.

exercise

Sleep content.

I control my emotions quite well so thats the least useful to me

Additional Comments or Suggestions: - Open-Ended Response

I am very grateful I was introduced to your programme and think of your suggestions all the time. CBT is becoming more and more fascinating to me. I look forward to learning more about it. As I do so, I learn more and more about myself. As a result, I'm living a happier life :-) 

HOPING FOR IMPROVEMENT THIS WEEK AS NEW MEDS KICK IN.

Thanks
Module 4

Did you have any problems with the links to external websites? - Additional comments

The yoga one does not seem to have appropriate links and the alternative thoughts does not work.

Link to Healthy Eating & Depression brought up publications to buy. Didn't see free brochure.

Some links did not work.

Module 3 and 4 I couldn't reach the presentation site.

I was unable to view the video - overview of module 4.

Link for Healthy Eating & Depression took me to Mental Health foundation Publications: a website with no obvious relevance/connection to the free brochure mentioned. Unable to bring up several of the links, when I go back I sometimes can get the information.

Please rate the components of the module according to the following: - Comments

Don't think that the relaxation section comes across that well online.

I Liked the Pain & Fatigue Diary

As Module 4 relates to communication skills, I find I have become more aware of my wish for a support group with which to work. Talking with friends and family is not an option I want to choose......it's enough to live with pain, without discussing ad nauseam with those dear to me.

I take one item each week and spend more time on it, the relaxation was this past weeks, and it makes such a difference !! I now find I can walk further, maybe not faster, I love my walks it is such a joy to be able to get out there and go.

What information did you find MOST useful in this module? - Open-Ended Response

...Meditation links.

Mindful meditation audio files and the continued CBT information :-)

Communication style
Mindfulness, Perspectives

relaxation and exercise tips

Communication Styles Pain & Fatigue Diary
Communications related information.

Mindfulness of thoughts-leaves in the stream

LEARNING TO CONCENTRATE
Unhelpful thinking habits

relaxation section

234
What information did you find LEAST useful in this module? - Open-Ended Response

...

Breaking down activities log, a bit too detailed for me.

Nutrition information - my system is so specific...I work along with a Naturopath to help figure this one out. Most of this information I already knew.

Relaxation

It was all Ok

none

keeping a diary - ugh!

Behaviour, communication styles

Additional Comments or Suggestions: - Open-Ended Response

Find appropriate yoga links with exercises and even stretches. I think this would be extremely helpful.

This was a tough week for me with the Ministry being a stress trigger. My fluctuation in BP might also have something to do with this added stressor along with my child's father suddenly, temporarily, re-entering our life. Tough week for me ;-) I'm glad I had these 3 1/2 weeks under my belt when all this hit me :-)

I have spent less time on Module 4 than I would have liked due to a severe reaction to flu shot

Thanks
Module 5

Did you have any problems with the links to external websites? - Additional comments

Didn't try them all e.g. pain medications

Links not yet complete but known & stated.

missing the direct link to site of presentation "module 5"

I was not able to access the module 5 overview -6 min. video or the patient doctor tool.

Please rate the components of the module according to the following: - Comments

I find if I overdo any activity (not very much) the fibromyalgia pain becomes worse. / I rest several times a day and often sleep for a short time.

Relaxation & Guided Imagery, just have to set the goals & JUST DO IT . . .

What information did you find MOST useful in this module? - Open-Ended Response

relaxation segment

Information on relaxation.

Chronic Pain Conditions - to be aware of what the differences are in the conditions. And again, the CBT information.

Patient doctor communication

Relaxation, Meditation, especially the audio.

talking with your doctor and effects of pain medication

Smart Goals, Positive Thoughts, Relaxation Response & Guided Imagery

Information related to medication

Info on chronic pain conditions particularly spinal stenosis

I played 9 holes of golf twice this week with a cart, had a lot of pain those nights and the next day, but used the relaxation tips and they were very helpful

What information did you find LEAST useful in this module? - Open-Ended Response

medications segment

I found the information on painkillers (video) a bit too long.

Synthetic Pain Medications Information - for personal reasons.

Info re pain meds but mostly because already familiar with this info

Activity and medication. I have tried numerous drugs all to no avail. Tylenol 3 gives me some relief.
Meds Info

none

Info on drugs as I have drug sensitivities and try to avoid taking anything other than tylenol.

Additional Comments or Suggestions: - Open-Ended Response

I am loving the CBT information!!! I'm finding it is helping me the most throughout this study. I like how its laid out and effectively 'planted into my head'. Thank you.

Thankyou. I now do the relaxation exercises each day and whenever I feel the need, although the concern over my daughter this week (as above) I couldn't control as I would have liked.

Good Module
Module 6

Did you have any problems with the links to external websites? - Additional comments

The Very 1st Link was dead

Overview of module6

CBT Summary (Self Help, Step 7) Practice..."Repeat these steps (1-6) over and over"......What steps are being referred to? There should have been a link at this point to direct reader to what specific 6 steps are meant. Many details and links in these modules can be difficult to comprehend/are confusing.

Please rate the components of the module according to the following: - Comments

I found it a bit repetitive from other modules, but I understand that it is a summary as well.

Doctors & treatments at the best they could & should be, but really are quite poor.

What information did you find MOST useful in this module? - Open-Ended Response

treatment decisions
Relaxation/relationship information
CBT and Communication.

Communication

I find the coping strategies, relaxation, cognitive thinking, etc. very helpful. Especially "thought stopping" followed by meditation and relaxation

all the pain information is very interesting and helps to understand what is going on with my body

Complementary treatments

on alternative medicine

Info on Complementary Treatments

I find the relaxation . and suggestions re activities the most helpful

What information did you find LEAST useful in this module? - Open-Ended Response

social support

n/a

Significant Relationships

Relaxation

Probably the activity section. Activity sets off pain and fatigue. I do a little tidying up in the garden and small household tasks.

Communicating with your health care team
The articles on depression, I do not get depressed I do get frustrated.

**Additional Comments or Suggestions: - Open-Ended Response**

I was quite sick this week (found out it had to do with hormones...). Sorry for my late response. I still need to do some studying on this week to effectively learn the entire content. I will continue to study despite reporting already. Thank you for permitting me to be a participant. I've learned so much and I look forward to continue practising what I've learned along the way!

I have found receiving the modules each week has disciplined me into following through with relaxation and meditation and thought stopping. I am much better at it than previously and use the above often.

I know this past week the pain level is higher but chasing after an active 17 month old and an almost 4 year old I THINK had something to do with it, but would not have changed it for the world.
**12-week Post-Intervention**

**What information did you find MOST useful overall in this program? - Open-Ended Response**

Breathing exercises, and physical exercises

The reminder that there are other kinds of methods to manage pain other than chemicals.

CBT and relaxation techniques.

Relaxation

I found it all very useful, especially understanding more about the pain I have

general knowledge, relaxation therapies

I found the various meditations most helpful and continue to use them.

relaxations, suggested exercises,

Planned, moderation of activities

- attitudinal thinking - exercises

**What information did you find LEAST useful overall in this program? - Open-Ended Response**

Hard to personalize due to being multi-disabled

Broken links

Medication Info.

meditation exercises hard to do online

n/a

none

The information on Medications - I have many drug sensitivities and benefit more from acupuncture and TENS treatments.

Nothing noteworthy that stands out, even the least helpful was a distraction from pain

**Additional comments. - Open-Ended Response**

Had knee replacement 8 weeks ago so pain decreased and physical activity increased as a result

I am very grateful to have had the opportunity to participate in this study.
I have kept all the material and - there is so much valuable information on the Pain Action website.
Thank you for inviting me to participate.

There is a degree of usefulness to all the informations, that was provided. I also found out that on holidays the pain was not as severe., I do believe it was from not doing vacuuming, changing beds pulling heavy wet laundry from the machine, and other such activities that is an every day occurrence in a household that cannot be avoided, with out help.

Thanks, very interesting
Appendix U

Second Literature Review

Synopsis of Second Review

Inclusion Criteria

**Types of participants.** Men and women aged 18 years and older who are diagnosed with or self-report chronic pain.

**Types of interventions.** Computer-based interventions studies which met inclusion criteria and scientific rigour included cognitive behavioural therapy interventions. Some interventions included in the study also had self-management training or education delivered via computer. Studies were excluded if the intervention included therapeutic interaction with medical staff, i.e. electronic mail (email), between participants and therapists with the purpose of asking questions or receiving individualized advice, moderated discussion boards, individual telephone calls to provide advice).

**Types of outcomes.** Primary outcomes included:

--Pain intensity

--Physical and emotional functioning

--Participant global impression of change

**Types of studies.** Both qualitative and quantitative studies were considered for inclusion. After assessing methodological quality and rigour, randomized controlled trials were included.

Search Strategy
A search for published and unpublished studies in the English language was undertaken. The search included EBM, CINAHL, Medline, PsycINFO, AMED, EMBASE and ProQuest Dissertations and Theses (International). Reference lists of identified articles were examined for additional studies. The search spanned published papers from 1966 to November 2012, and was limited to English language papers only.

**Methods of Review**

Each study was appraised using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Experimental Studies. Studies were included if they met a minimum of six of ten criteria for evaluating scientific rigour in research listed on this checklist.

**Results**

Seven randomized controlled trials met the inclusion criteria and were included in the review. Two studies were conducted with individuals who experienced chronic headache, two with chronic back pain, two with chronic pain in general and one with fibromyalgia. All studied interventions had a computer-based cognitive behavioural component. In addition, five of the studies had other components of interest in the treatment of chronic pain (self-management instruction and education), with one study having one of these extra components and four studies having both in addition to the CBT, all delivered via computer. Pooling of data was not appropriate due to variation in outcome measures; therefore the findings were summarized in narrative analysis and tables. Improvement in pain intensity was found in four of six studies that measured this, improvement in physical functioning was found in two of seven studies, improvement in
emotional functioning was found in three of six studies and participants reported improved overall status in the three studies of three that used the PGIC as an outcome.

**Conclusions from the Review**

The results of this review suggest that computer-based interventions in individuals with chronic pain can be effective even without a personalized therapeutic contact component. Further larger population studies are suggested, particularly in the area of minimum effective “dose” of this self-directed intervention format, and to explore the characteristics of those for whom the intervention is most likely to be effective.

**Relevance to Thesis Work**

The studies described in this review had similar components to the intervention designed for this study. While some of the research included in the review showed that CBT interventions delivered via the computer were effective for pain intensity, physical functioning and/or emotional functioning, this intervention had similar results. The most positive outcome for this study was in emotional functioning. There was no appreciable change in physical function for the group, although some individual participants did experience significant positive change. Pain intensity and pain interference data had some minimally positive results. Most participants perceived that overall at the least, they had improved “a little” as a result of using the intervention.

**Background**

A preliminary review of literature conducted at the time of development of the intervention tested for the purpose of this thesis (2010) and describing interventions for the population with chronic pain revealed that the small amount of research available had shown effectiveness of CBT, self-management training and education when delivered via
a computer or the Internet. At that time, however, there were only two randomized controlled studies conducted in the adult population using a computer-based non-pharmacological intervention that did not also include individualized clinician-client interaction; Devineni & Blanchard (2005) studied a stand-alone intervention in a population with chronic headache, and Berman, Iris, Bode & Drengenberg (2009) studied a stand-alone intervention in an elderly population with chronic pain. Chapter 2 of this thesis presents the literature review conducted in preparation for development of the study intervention given the absence of similar evidence-based interventions in 2010.

**Objectives**

This review was initiated in order to assess the availability, composition and effectiveness of interventions appropriate for delivery to individuals with chronic pain while waiting for specialist care. The purpose of this review was to provide the best available evidence on the effectiveness of stand-alone computer-based interventions that used cognitive behavioural principles for the management of chronic pain. A second goal was to assess documentation of the effectiveness of existing interventions to determine implications for practice and further research.

**Review Question/Objective**

What is the effect of a computer-based cognitive behavioural intervention on pain intensity, pain-related interference or physical functioning, mood (depression, anxiety) or emotional functioning, global impression of change, in adults with chronic pain?

**Criteria for Considering Studies for this Review**

**Types of Studies**
Qualitative and quantitative studies, both published and unpublished, were considered for this review. Randomized controlled trials were retrieved. Other research designs, such as non-randomized controlled trials, cohort and case control studies, observational studies and qualitative studies were considered.

Types of Participants

This review considered all studies reporting computer-based interventions that included participants aged 18 years and older with chronic pain of any type.

Types of Interventions

The interventions of interest for this review were those that incorporated CBT delivered solely via a computer-based format. Other components commonly delivered via computer included self-management and education. These were acceptable in conjunction with the CBT. Interventions that incorporated individualized therapeutic communication with health care personnel, or communication via moderated chat boards, were excluded from the review.

Types of Outcome Measures

Primary outcomes of interest for this review included the following:

--Pain intensity

--Physical and emotional functioning

--Participant global impression of change

Any validated tool that measured one or more of these was acceptable in documenting study outcomes.
Search Strategy

The literature search was conducted systematically in order to identify published and unpublished studies in the English language. A three-step search strategy was used as described below. Initial key words used were: computer, Internet, chronic pain, pain and chronic disease. MeSH terminology and key words were adapted based on what each different database required.

**Step One**

An initial literature search was conducted using MEDLINE, EMBASE and CINAHL. Upon examination of the articles returned, index terms and key words were confirmed. Keyword searches included (computer and pain), (Internet and pain), (computer and chronic pain), (computer and chronic disease and pain), (Internet and chronic pain), (Internet and chronic disease and pain).

**Step Two**

A second search using all identified key words and index terms was performed across all included databases. This second stage search, conducted in November 2012, included the following databases: MEDLINE (1966 to present), CINAHL (1983 to present), EMBASE, EBM, PsycINFO, and AMED.

The search for unpublished studies included conference proceedings, theses and dissertations, and abstracts. The systematic search of electronic databases identified a large number of potentially relevant articles through matching keywords and title words.

The references were imported into RefWorks 2.0 software through Queen’s University Library interface. All duplicate references were removed. The titles and
abstracts of the remaining articles were assessed against inclusion and exclusion criteria, and full text articles were obtained for those relevant references.

**Step Three**

The reference lists of all identified articles were searched for additional studies.

**Methods of the Review**

**Assessment of Methodological Quality**

Papers selected for retrieval were assessed for methodological validity using the JBI Critical Appraisal for Experimental Studies tool. Those studies documenting less than six out of the ten criteria of scientific rigor were excluded from the review.

**Data Collection**

Initial data extracted from papers included in the review were summarized into a spreadsheet. Data of interest at this stage included specific details about components of the intervention, number of sessions of the intervention, required time per session, overall length of intervention, role of healthcare staff in intervention, population, outcomes measured and tools used, and time points of data collection.

**Data Synthesis**

Although the studies included in the review sought to document similar outcomes, the measurement tools used varied widely. This precluded conducting a meta-analysis. For this reason, data have been summarized in tables, and using narrative analysis for the purpose of comparison.

**Review Results**

**Description of Studies**
The systematic search of electronic databases identified 641 articles as being potentially relevant through matching keywords and title words. The search was purposefully broad as the author did not want to miss any potentially relevant research by limiting the search to only the articles that included the term “cognitive behavioural therapy”. Upon further review of the abstracts, 418 were excluded as they were off topic, and upon entry into RefWorks software, 178 were identified as duplicates. This process left forty-five articles to be retrieved and read. Twenty-nine of these were excluded for not meeting inclusion criteria. Nine additional articles met less than six out of the ten criteria of scientific rigour on the JBI Critical Appraisal Checklist for Experimental Studies and therefore were excluded as they did not meet methodological criteria. Hand searching of article bibliographies produced titles of three additional studies to assess; however, upon further review, these were excluded as they were off topic. Seven articles met inclusion criteria, including the assessment of scientific rigor, and were included in this review (Figure 1).

The studies selected for inclusion document research conducted on a total of 1165 participants overall, with females comprising 77.5% of the sample (individual studies report female participant percentages from 64 to 95%). Participants were recruited via physician practices and/or the Internet. Only two studies did not recruit online; Berman et al. (2009) recruited from a community and Williams, Kuper, Segar, Mohan, Sheth and Clauw (2010) recruited from a referral list to a clinic, both setting being the United States (US). The other five studies (Devineni & Blanchard, 2005; Chiauzzi, Pujol, Wood, Bond, Black, Yiu & Zacharoff, 2010; Ruehlman, Karoly & Enders, 2012; Carpenter, Stoner, Mundt and Stoelb, 2012; Bromberg, Wood, Black, Surette, Zacharoff & Chiauzzi, 2012)
recruited participants through Internet advertisements, pain websites, and social networking sites. All researchers were based in the US.

**Methodological Quality**

Overall, the research selected for inclusion in this systematic review was of good to very good quality, with three studies (Berman et al., 2009; Devineni & Blanchard, 2005; Ruehlman et al., 2012) scoring six on the critical appraisal tool, two studies...
(Bromberg et al., 2012; Chiauzzi, 2010) scoring seven, and the remaining studies scoring eight (Carpenter et al, 2012) and nine (Williams et al., 2010).

**Results**

Of the 1165 participants who met inclusion criteria and were randomized within the seven studies, 922 went on to provide data at the respective endpoints of the studies. In all trials, the intervention studied included a cognitive behavioural component. Five interventions contained participant education, and four interventions added some self-management instruction to contain all three components of interest. Two of the four studies that used an intervention with all three components studied the same intervention (painACTION website), although the chronic pain populations using the intervention were different.

**Participants.** Participants were recruited primarily through two means—physician practices/clinics and the Internet. Two studies did not have an online recruitment component, one recruiting from the community (Berman et al., 2009) and one recruiting from a referral list to a clinic (Williams, Kuper, Segar, Mohan, Sheth & Clauw, 2010), both within the United States. The remaining five studies (Devineni & Blanchard, 2005; Chiauzzi, Pujol, Wood, Bond, Black, Yiu & Zacharoff, 2010; Ruehlman, Karoly & Enders, 2012; Carpenter, Stoner, Mundt and Stoelb, 2012; Bromberg, Wood, Black, Surette, Zacharoff & Chiauzzi, 2012) recruited participants through Internet advertisements, pain websites, and social networking sites. In these studies, the recruiting procedure originated in the United States, and via American websites, but given the reach of the Internet, it is unclear whether all participants were American; Devineni and Blanchard (2005) acknowledge that while the majority of
participants recruited to this study were American, there were also some international participants. Two studies (Chiauzzi et al., 2010 and Bromberg et al., 2012) recruited via both Internet sites and clinic lists.

Mean age when reported ranged from 42.5 to 65.8 (Devineni et al. did not report mean age of total group). Attrition rates for the studies (defined as the number of participants who did not complete final assessment data) ranged from 10.2-38.1%. There did not seem to be any correlation between length of intervention and attrition rate, as one of the 4-week interventions had the highest rate, followed closely by the 12-week intervention, and the 6 month intervention had the lowest rate (Table 1).

Table 1. Comparison of Interventions.

<table>
<thead>
<tr>
<th>Author</th>
<th>Total n randomized</th>
<th>% female</th>
<th>Mean age</th>
<th>Intervention Components</th>
<th>Duration of intervention</th>
<th>Attrition</th>
<th>Pain intensity</th>
<th>Physical /Emotional function</th>
<th>PGIC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berman et al. (2009)</td>
<td>78</td>
<td>88</td>
<td>65.8</td>
<td>CBT</td>
<td>6 weeks</td>
<td>12%</td>
<td>No change(^a)</td>
<td>No change / No change(^a)</td>
<td>ND</td>
</tr>
<tr>
<td>Bromberg et al. (2012)</td>
<td>185</td>
<td>89</td>
<td>42.6</td>
<td>CBT, E, SM</td>
<td>12 weeks</td>
<td>37.5%</td>
<td>ND</td>
<td>No change / Impr.</td>
<td>Impr.</td>
</tr>
<tr>
<td>Carpenter et al. (2012)</td>
<td>141</td>
<td>83</td>
<td>42.5</td>
<td>CBT, E</td>
<td>6 weeks</td>
<td>19.5%</td>
<td>No change</td>
<td>Impr / ND</td>
<td>ND</td>
</tr>
<tr>
<td>Chiauzzi et al. (2010)</td>
<td>199</td>
<td>67.7</td>
<td>46.1</td>
<td>CBT, E, SM</td>
<td>4 weeks</td>
<td>25.8%</td>
<td>Impr</td>
<td>No change / Impr.</td>
<td>Impr.</td>
</tr>
<tr>
<td>Devineni &amp; Blanchard (2005)</td>
<td>139</td>
<td>79</td>
<td>ND</td>
<td>CBT</td>
<td>4 weeks</td>
<td>38.1%</td>
<td>Impr</td>
<td>Unclear / Unclear(^c)</td>
<td>ND</td>
</tr>
<tr>
<td>Ruehlman et al. (2012)</td>
<td>305</td>
<td>64</td>
<td>44.9</td>
<td>CBT, E, SM</td>
<td>6 weeks</td>
<td>31.8%</td>
<td>Impr</td>
<td>Unclear / Impr.</td>
<td>ND</td>
</tr>
<tr>
<td>Williams et al. (2010)</td>
<td>118</td>
<td>95</td>
<td>50.5</td>
<td>CBT, E, SM</td>
<td>6 months</td>
<td>10.2%</td>
<td>Impr</td>
<td>Impr / No change</td>
<td>Impr.</td>
</tr>
</tbody>
</table>

CBT= Cognitive behavioural therapy, E=Education, SM= Self-management, ND= no data, Impr. = Improvement
\(^a\)=improvement in both treatment and control group
\(^b\)=incomplete data set
\(^c\)=decrease in pain-related disability; did not discriminate between physical and emotional
\(^d\)=decrease in pain-related interference in some functional tasks

**Interventions.** Interventions reported in the studies consisted of CBT, with some including one or both of two other main components: education and self-management. In
addition, some studies included other online components such as unmoderated forums and potential for independently pursued social networking.

**Cognitive Behavioural Therapy.** All studies included in this review reported techniques consistent with CBT as a main component of the computer-based intervention, although it was not always documented in that terminology. Content recognized as CBT included:

- “cognitive stress coping therapy” (Devineni & Blanchard, 2005, p. 281)
- “mind-body exercises… writing about positive experiences, writing about negative experiences, …positive thinking” (Berman et al., 2009, p. 70)
- “education, behavioral and cognitive skills designed to help with symptom management, and …to facilitate adaptive life style changes” (Williams et al., 2010, p. 696)
- “CBT to improve self-efficacy, manage thoughts and mood, set clinical goals, work on problem-solving life situations and prevent pain relapses” (Chiauzzi et al., 2010, p.1046)
- “emotional coping, …managing negative thinking.”(Bromberg et al., 2012, p. 246),
  *Note: this intervention was also used in the Chiauzzi et al. 2010 study.
- “awareness of thinking patterns, evaluating thoughts, disputing and replacing thoughts, and cognitive reframing and training in accepting and disregarding thoughts”, (Carpenter et al., 2012, p.15)
- “cognitive, behavioural, social and emotional regulation” (Ruehlman et al., 2012, p. 321)

**Education.** Five interventions included a formal educational component. Chiauzzi et al. (2010) included “wellness activities to enhance good sleep, nutrition, stress management and exercise practices” (p.1046) using the painACTION website. Education in the Ruehlman et al. (2012) study involved teaching major concepts related
to “thinking better, doing more, relating better and feeling better” (p. 321) using a multimedia format with interactive activities. Bromberg et al. (2012) described their intervention as one that delivered lessons on pain self-management skills, encouraged the use of tools to construct knowledge, and added user-generated content in the form of advice, and real-life examples in a variety of presentation styles (p. 246). This painACTION website intervention was tested by Chiauzzi in an earlier study. The intervention tested by Carpenter et al. (2012) was broken down into “chapters” which were presented online. Each chapter had didactic material and interactive exercises which related to the main topic for the section (p. 15). Similarly, each of the thirteen modules in the Williams et al. (2010) intervention had a supplemental educational section which was crafted specifically for the main topic of that section.

**Self-management.** Self-management principles were presented in four out of the seven interventions included in this review. Concepts such as recognizing pain triggers, learning biofeedback (Bromberg et al., 2012), using relaxation techniques (Bromberg et al., 2012, Ruehlman et al., 2012), implementing goal-directed behavior (Ruehlman et al., 2012; Williams et al., 2010), sharing in decision-making with health professionals (Chiauzzi et al., 2010), and monitoring progress through the use of self-evaluation (Williams et al., 2010) were woven through sections of the interventions.

**Dose of intervention.** It was challenging to implement “dosing” of the interventions, and indeed even to track dosage, as the interventions in the studies involved asynchronous “logging on”. There was no particular time that the participant was required to be online, and although there was a suggested minimum amount of intervention time in some of the studies, there was no way to enforce or monitor this. In
six of the seven interventions, the participants received an email prompt from the research staff if there had been no activity logged in the intervention (when there was tracking capability), or if the time-sensitive questionnaire had not been completed. Table 2 outlines the studied dosage of each intervention.

**Table 2. Dosage of Interventions.**

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>#sessions</th>
<th>Duration sessions</th>
<th>Frequency</th>
<th>Duration of intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berman et al.</td>
<td>2009</td>
<td>6</td>
<td>variable</td>
<td>once weekly</td>
<td>6 weeks</td>
</tr>
<tr>
<td>Bromberg et. al.</td>
<td>2012</td>
<td>not clear</td>
<td>not clear</td>
<td>not clear</td>
<td>12 weeks*</td>
</tr>
<tr>
<td>Carpenter, et al.</td>
<td>2012</td>
<td>not clear</td>
<td>variable</td>
<td>variable</td>
<td>6 weeks</td>
</tr>
<tr>
<td>Chiauzzi et al.</td>
<td>2010</td>
<td>8</td>
<td>at least 20 min</td>
<td>twice weekly</td>
<td>4 weeks*</td>
</tr>
<tr>
<td>Devineni</td>
<td>2005</td>
<td>not clear</td>
<td>variable</td>
<td>variable</td>
<td>4 weeks</td>
</tr>
<tr>
<td>Ruehlman, et al.</td>
<td>2012</td>
<td>not clear</td>
<td>variable</td>
<td>variable</td>
<td>6 weeks</td>
</tr>
<tr>
<td>Williams et al.</td>
<td>2010</td>
<td>not clear</td>
<td>variable</td>
<td>variable</td>
<td>6 months</td>
</tr>
</tbody>
</table>

*These studies used the same website, painACTION, as the intervention.

**Outcomes**

Similar outcomes were explored in many of these studies; however, the outcome measures used were varied, and the follow-up intervals were not comparable. As a result, meta-analysis is not possible, and therefore data are presented in narrative style.

Although only two of the studies (Chiauzzi et al., 2010; Bromberg et al., 2012) specifically note that they considered IMMPACT recommendations (pain intensity, physical and emotional functioning, participants’ impression of change) (Turk et al., 2006) when setting up outcome measurements, the other studies included similar primary and secondary outcomes.

**Berman et al., (2009).** In a population of older adults with chronic pain, Berman et al. (2009) studied the effect of an online mind-body intervention that was focused on CBT principles. Women comprised 88% of the treatment group and 87% of the comparison group. Three-quarters of the sample (total n=78) was under the age of 70,
with a mean age of 65.8 years. The median number of website visits for those in the treatment group of the 6 week intervention was 22.5 visits. Time spent in the intervention was not recorded; however, 78% of participants indicated that they planned to work on components of the intervention offline on their own and at study follow-up, 95% of participants stated they had used techniques from the intervention on their own offline.

**Pain intensity.** The BPI was used to measure pain intensity, documenting worst, least, and average pain. There were statistically significant improvements in all of these for both the treatment and comparison groups, with no significant difference between the groups in gains from baseline to follow-up. When considering the average mean of the four intensity items measured on the BPI, the change was -0.86 (p<0.01) in the treatment group and 0.99 (p<0.001) in the comparison group.

**Physical and emotional functioning.** Berman et al. (2009) used the Pain Interference subscale of the BPI to document the impact of pain on physical and emotional functioning, as well as the CES-D and STAI-Y6 to report on depression and anxiety in their chronic pain participants. There were statistically significant improvements in pain interference in both groups; however, there were no differences between groups at follow-up as compared to baseline (p. 74). Although there was also a slight improvement in depression and anxiety for the treatment group as compared to the control, these differences were not statistically significant.

**PGIC.** This outcome was not assessed in this study.

**Bromberg et al. (2012).** In a trial of a web-based CBT intervention with educational and self-management components, in a population with migraine headache,
185 participants were randomized to either treatment or control arms of the study (Bromberg et. al, 2012). The mean age of the sample was 42.6 years, with 89% of participants being female. In this study, time in intervention was tracked, and participants were classified as either using “low-dose” intervention (≤153 minutes in intervention) or “high-dose” (>153 minutes).

**Pain intensity.** Pain intensity was recorded in a Daily Headache Record during the run-in period of the intervention, but there was no subsequent measurement, and therefore, pain intensity was not documented as an outcome.

**Physical and emotional functioning.** Bromberg et al. (2012) used the Migraine Disability Assessment Questionnaire to assess migraine interference with activity, although it did not specify whether the limitation was emotional or physical. In this study, there was no significant effect of intervention over time when comparing treatment and control groups.

The Depression/Anxiety/Stress Scale questionnaire scores demonstrated a significantly greater decrease in depression from baseline to 3-month (t=3.66, p<0.01) and 6-month (t=2.50, p=0.04) time points for those in the treatment group as compared to control. In addition, there was a greater decrease in stress in the treatment group, but no significant change in anxiety between groups over time.

**PGIC.** Participants in the intervention group reported greater improvement post-intervention (t=3.78, p<0.01), at 3 months (t=5.23, p<0.01) and at 6 months (t=4.32, p<0.01).

**Carpenter et al. (2012).** Carpenter et al., (2012) tested an online CBT educational intervention in chronic low back pain participants. The 141 participants who
were randomized to treatment or wait list control had a mean age of 43 years, and 83% were female. Self-reported data revealed that 59% of participants in the treatment arm used the intervention at least 6 hours per week, and 28% at least 10 hours weekly for the 3 weeks of treatment.

**Pain intensity.** The researchers used a pain assessment questionnaire, requiring one week recall, to rate average, highest and lowest levels of pain on a scale of one to ten (one represented no pain, and ten represented worst pain imaginable). Average pain in the intervention group was 5.2 (SD 1.5) at both baseline and week 3 measurement time points, while the control group remained at 5.7 (SD 1.7) for both time points (p=0.51). Lowest pain was 3.1 (SD 1.8) at baseline and 3.3 (SD 1.9) at week 3, while the control group reported scores of 3.7 (SD 2.0) and 4.0 (SD 2.0) (p=0.55). Highest pain rating in the intervention group at baseline was 7.2 (SD 1.6) and 7.0 (SD 1.8) at week 3, while the control group rated their highest pain at 7.4 (SD 1.6) at baseline and 7.3 (SD 1.6) at week 3 (p=0.78). This data demonstrates that there was no statistically significant change in average pain, lowest pain or highest pain between the baseline and week 3 measurements in either the treatment group or the wait list control group.

**Physical and emotional functioning.** The Roland-Morris Disability questionnaire was used in research by Carpenter et al. (2012) to assess changes in pain-related physical disability. In the treatment group, the mean decreased from baseline 16.3 (SD 5.3) to 13.5 (SD 5.8) at week 3, which was the end of the intervention, and then to 11.9 (SD 5.9) at the 6 week time point. The control group experienced a reduction from 17.1 (SD 4.7) at baseline to 16.3 (SD 5.2) at week 3, and 12.9 (SD 6.9) at week 6. This effect was statistically significant (p=0.01), at medium effect size (d=-0.45) for the
between group effect at week 3. This study did not assess emotional functioning as such, but did include measures of self-efficacy (Pain Self-efficacy Scale), catastrophizing (Pain Catastrophizing Scale), strength of belief that one can regulate one’s own negative moods (Negative Mood Regulation Scale), and attitudes about pain (Survey of Pain Attitudes). While results from these outcome measures were reported using subscale scores, it is not possible to form a conclusion about emotional functioning; these tools measure attitudes and beliefs rather than emotional response or function.

**PGIC.** This outcome was not assessed in this study.

**Chiauzzi et al. (2010).** Chiauzzi et al. (2010) studied the use of the painACTION website in a population with chronic back pain. This website combines CBT with self-management and educational components. While there is opportunity to “personalize” the information a participant has access to, this site requires some self-direction in navigating through the large volume of information. Of the 199 randomized participants, 67% were female, and mean age was 46.

**Pain intensity.** The BPI was used to document pain intensity in this study. The researchers analyzed data through scoring of the questionnaires, and then reanalyzed data with consideration of the group recruited via online strategies, versus those recruited from the pain clinic. While there were no statistically significant differences between those exposed to the intervention and the control group, when the treatment group was subdivided those recruited online reported a significant mean decrease in “worst pain” from baseline to post-test, \( (t=2.71, p<0.05) \) whereas those recruited from the pain clinic reported no difference. Similarly, those recruited online and exposed to the intervention had a decrease in “average” pain from baseline to 3 months \( (t=2.52, p<0.05) \) while those
recruited from the pain clinic again reported no change. While there were no statistically significant changes via traditional scoring, there was a clinically significant difference in the treatment group as compared to the control group when IMMPACT criteria was applied to the measure of “current” pain. IMMPACT has set the definition of minimally clinically significant change at 10% (Dworkin, 2008); therefore the treatment group with a 12.3% decrease would be considered to have reached minimally improved status, whereas the control group with a 7% decrease in current pain intensity did not satisfy criteria for a clinically significant change.

**Physical and emotional functioning.** Chiauzzi et al. (2010) used the Oswestry Disability Questionnaire and the Pain Interference subscale of the BPI to assess changes in physical functioning. The Depression Anxiety Stress Scales (DASS) questionnaire was used to document emotional functioning. The researchers report that the intervention did not have any statistically significant effect on physical functioning over time for those in the treatment arm as compared to the control. There was no change over time in the DASS scales for the control group; however, the intervention group experienced changes in emotional functioning from baseline to post-intervention that was maintained at the 3- and 6-month follow-up. In this group, anxiety scores decreased from 9.66 (SD 0.85) at baseline to 7.22 (SD 0.92) at the 6-month follow-up, depression 13.20 (SD 1.14) to 10.55 (SD 1.24) and stress 15.07 (SD 0.94) to 11.89 (SD 1.07), which were statistically significant using pairwise post hoc tests (Bonferroni-adjusted p<0.05).

**PGIC.** Data from the Chiauzzi et al. (2010) research revealed that the intervention group reported a greater improvement in condition at post-test (t= 3.01,
p<0.01), at 3 months (t=2.71, p<0.01) and 6 months (t=2.83, p<0.05) as compared to the control group.

**Devineni and Blanchard (2005).** Devineni and Blanchard conducted a randomized controlled trial of an Internet-based self-directed behavioural intervention in a population with chronic headache. Participants were mostly female (76/88 in the treatment arm, and 50/79 in the Wait List arm), with a mean age of 44 (treatment) / 41 (Wait List).

**Pain intensity.** The researchers hypothesized that those in the treatment arm would show a decrease in headache activity and headache medication usage post-treatment. The Headache Index was used to document clinical improvement, although it was not specified how the score was calculated, and the Medication Index documented medication usage by scoring mean daily doses of all headache medications for each participant. In study completers, clinically significant improvement (>50% reduction in Headache Index scores without increase in medication) was documented in 38.5% of the treatment group, as compared to 6.4% of the Wait List group at the post-treatment measurement (p<0.001). In addition, those in the treatment group (n=49) demonstrated a significant reduction in medication index scores from baseline (score 1.15) to post-treatment (score 0.88) (p<0.05).

**Physical and emotional functioning.** Devineni and Blanchard (2005) used the Headache Disability Index to document functional status in their chronic headache population. Data analysis did not discriminate between physical and emotional functioning. There was a significant reduction in headache-related disability (d=0.54) in the treatment arm as compared to the Wait List control. While mean score for the Wait
List dropped from 54.2 (SD 20.5) pre-intervention to 49.6 (SD 23.1) post-intervention, the treatment arm score decreased from 52.9 (SD 18.8) to 38.0 (SD 19.5) (p<0.05).

**PGIC.** Participant’s overall perception of their own change in health status as a result of study participation was not assessed in this study.

**Ruehlman et al. (2012).** In a randomized controlled trial, Ruehlman et al. (2012) tested an online chronic pain CBT and educational self-management program in a population of 305 adults, 64% women, mean age 45 years.

**Pain intensity.** Pain severity was assessed using the Profile of Chronic Pain Extended Assessment (PCP-EA). The researchers analyzed data using a linear growth model. In the 162 treatment arm participants, pain severity was slightly higher at baseline (mean 24.47, SD 2.11) than in the 143 wait-list control participants (mean 23.93, SD 3.49), however, the pain level decreased more steeply in the treatment group over time moving toward the 14 week follow-up (mean 22.41, SD 4.31) than in the control group (mean 22.34, SD 4.61). The standard mean difference for the pain severity data was 0.20, consistent with Cohen’s d small effect size.

**Physical and emotional functioning.** Ruehlman et al. (2012) studied the effect of the online intervention on ten functional limitations in daily living, including routine physical activity. While there was a significant between group effect for items such as pain-related interference with social life, sleep, recreational activities, household chores and work, there was no significant change for routine physical activity. Changes in emotional functioning were measured using the DASS and the CES-D. Using a linear growth model for analysis, data from the treatment group showed statistically significant improvement in CES-D depression scores, and DASS depression, anxiety and stress
scores over time as compared to data from the control group. The CES-D score at baseline was 25.58 (SD 13.30) for the treatment group and 21.78 (SD 13.13) for the control group. Scores at the 14 week follow-up were 21.98 (SD 12.45) and 21.45 (14.36) respectively. When the growth model was applied, the baseline difference between treatment and control groups was 2.5 (p=0.08) with a growth difference between the two groups at -1.64 (p=0.03), indicating that the treatment group experienced a greater decrease in depression scores compared to the control group. The DASS scores showed similar results.

**PGIC.** This outcome was not assessed in this study.

**Williams et al. (2010).** Williams et al. (2010) conducted a randomized controlled trial of an Internet-based CBT, exercise, education and self-management program in 118 participants with fibromyalgia. Women comprised 95% of the sample, and mean age was 50.46 years.

**Pain intensity.** The BPI was used to assess pain intensity. From baseline to the 6 month timepoint, those receiving the intervention experienced a drop in score from (mean) 5.1 to 4.3 while those receiving standard care remained at (mean) 4.9 at both time points. The proportion of “pain responders” experiencing a 30% or larger decrease in mean pain score from baseline to 6 months was greater in the treatment group (29%) than in the standard care group (8%) (p<0.01).

**Physical and emotional functioning.** The SF-36 Physical Functioning scale was used in the Williams et al. (2010) study for assessment of physical functioning, and the CES-D and STPI were used in assessing depression and anxiety respectively. The treatment arm showed improvement in physical functioning from baseline to the six
month time point (M 38.9, SD 8.6 to M 41.1, SD 8.7) as compared to the group receiving standard care (m 38.9, SD 9.5 to m 38.9 SD 8.6) (p<0.03). There was no statistically significant difference between groups in the analysis of CES-D and STPI data.

**PGIC.** In the Williams et al. study (2010), PGIC data was recoded from the seven outcome variables into two categories, “improvement” or “no change or worsening”. Although data was not available for all participants, 57% of the 35 participants who completed the questionnaire in the intervention group reported some improvement, compared to 21% of the 33 participants in the standard care group who completed the questionnaire (p< 0.003, Fisher’s exact test). As only 58% of the total number of participants in the study completed the PGIC, this data must be interpreted cautiously.

**Discussion**

The aim of this review was to present the best available evidence related to the effectiveness of computer-based interventions for the population with chronic pain. While research has been done on Internet-based interventions in other disease processes, and on non-computer-based interventions in chronic pain, little research has addressed the use of computers to deliver interventions in participants with chronic pain until recently. Studies in this review incorporated computer-delivered cognitive behavioural interventions with some adding educational and/or self-management components. While other reviews have included research detailing interventions that included moderated forums, peer support, or clinical support, this review deliberately focused on interventions that required no ongoing “human” support or clinician involvement. In most of the studies included in this review, “dosage” of the intervention (frequency, number of sessions, duration of sessions) was unclear, consistent with self-directed and
self-paced use of the Internet. Three of the studies exposed the participant to the
intervention for six weeks, while two studies used a four week intervention, one study
used a twelve week intervention and one study used a six month intervention.

Five of the seven studies reported some improvement in pain intensity for the
group using the computer-based intervention, with one study reporting no change, and
one study not documenting pain intensity. Results for physical and emotional
functioning were less conclusive. Two studies reported some improvement in physical
functioning in the treatment group, three studies reported no physical function
improvement in the treatment group, one study reported an improvement in physical
functioning in both groups, and one study reported a decrease in pain-related interference
in some activities of daily living but no change in others. Three studies reported some
improvement in emotional functioning, two studies reported no change and one study did
not document change in emotional function (Table 2).

Patients’ Global Impression of Change in health status after study participation
was only documented in three studies. Although all of these studies reported
improvement in the treatment group, one study was not able to collect data from more
than 40% of participants, making their conclusion less strong. In all studies where PGIC
had improved, at least one of pain intensity, physical function or emotional function had
improved as well.

Limitations

As the studies included in this review structured their interventions differently,
using different combinations of components (CBT, education, self-management) it is not
possible to assess the effect of any one part of the intervention on the outcome measures,
and therefore no recommendations can be made, based on these studies, regarding which computer-based components are necessary to effect change in health status in the chronic pain population. In addition, as there is no measure of time in intervention reported for most of these studies, it is not possible to assess whether there is a correlation between longer time in intervention and likelihood or magnitude of improvement in condition. Timing of outcome measurement was also not consistent across all studies, and some of the follow-up times were relatively short.

Most studies had small sample sizes, recruiting participants mostly from the United States. Some recruited via clinic lists, community advertisements and other non-Internet means, some via Internet, and some via both methods. While one study (Chiauzzi et al., 2010) that recruited via Internet and clinic attempted to report results according to recruitment method, the sample size was small, thus results need to be interpreted cautiously. In addition, attrition rates were fairly high in these studies, although intention to treat analysis minimized the effect of attrition.

Conclusions

Implications for Practice

While this review provides preliminary evidence about the effectiveness of CBT, education and/or self-management training delivered in a structured online format, it is not robust enough to form a basis for the development of best practice guidelines. This is a rapidly expanding area, with much of the research being undertaken in the present; thus as the evidence evolves, nurses can continue to evaluate ongoing studies to assess the feasibility of incorporating structured Internet-based programs into their care of those with chronic pain.
Implications for Research

Based on assessment of the studies in this systematic review, the following priorities for further research have been identified:

1. There is a need for research into the effectiveness of computer-based interventions in the chronic pain population, using consistent outcome measures such as those suggested in the IMMPACT recommendations.

2. “Dosage” of intervention needs to be well-documented in the study protocol, and follow-up tracking of time in intervention should be reported.

3. Larger scale randomized controlled trials should be conducted to give more power to the studies, and effects of the intervention should be assessed in longer follow-up to document whether changes to health status are maintained.

4. Specific components of the intervention should be assessed independently to assess which components have the greatest impact in the chronic pain population when delivered via computer-based format.

5. As these interventions depend on some self-directed independent work by the participants, research should focus on which participant characteristics have an impact on likelihood of completion of the intervention and success of the intervention. This would also include larger scale studies comparing self-referred participants to those initially contacted by the researcher, and even measuring readiness to change prior to intervention.

6. The interventions should be tested in stand-alone format and with a component of support (telephone contact, email, moderated discussion, peer
support) to assess effectiveness, likelihood of completing the intervention and cost-effectiveness of adding personnel to facilitate.

The use of stand-alone computer-delivered chronic pain interventions is still in its relative infancy. Most quality research on evidence-based intervention components delivered to those with chronic pain via computer has been done in the last five years. This review looked at the effectiveness of computer-based CBT interventions, with some incorporating education and self-management principles, for individuals with chronic pain. The results showed that the participants experienced no change or some improvement in pain intensity, physical and emotional functioning and self-reported improvement in condition after study participation; however, most of these studies were conducted with small population sample size. In addition, comparison of data from different studies was hampered by differences in duration and components of the intervention, and differences in outcome measurement time points and tools. Overall, results suggest that exposure to CBT concepts via a computer-based intervention, either with or without educational components and introduction of self-management concepts, can have a positive effect, at least in the short term. Further structured research is necessary in this developing area.