SELF-MANAGEMENT OF CHRONIC PAIN:
INTERVENTIONS, STRATEGIES, BARRIERS AND FACILITATORS

by

Elizabeth Gayle Mann

A thesis submitted to the School of Nursing
in conformity with the requirements
for the degree of Doctor of Philosophy

Queen’s University
Kingston, Ontario, Canada
(September, 2013)

Copyright © Elizabeth Mann, 2013
“Some victims of chronic pain deteriorate. They become querulous and exploit their privileged position as invalids to practice domestic tyranny. But the wonder is that the failures are so few and the heroes so many; there is a challenge in physical pain which most can recognize and answer.”

R. Havard, MD, quoted in The Problem of Pain by C. S. Lewis
Abstract

Background & Purpose

Chronic pain is a prevalent chronic condition for which the best management options rarely provide complete relief. Individuals with chronic pain with neuropathic characteristics (NC) report more severe pain and experience less relief from interventions. Little is known about current self-management practices. The purpose of this dissertation was to inform self-management of chronic pain with and without NC at the individual, health system, and policy levels using the Innovative Care for Chronic Conditions Framework.

Methods

The study included a systematic search and review and cross-sectional survey. The review evaluated the evidence for chronic pain self-management interventions and explored the role of health care providers in supporting self-management. The survey was mailed to 8,000 randomly selected Canadians in November 2011, and non-respondents were followed-up in May 2012. Screening questions were included for both chronic pain and NC. The questionnaire captured pain descriptions, self-management strategies, and self-management barriers, and facilitators.

Results

Findings of the review suggested that self-management interventions are effective in improving pain and health outcomes. Health care professionals provided self-management advice and referred individuals to self-management interventions. The questionnaire was completed by 1,520 Canadians. Those with chronic pain (n=710) identified primary care physicians as the most helpful pain management professional. Overall, use of non-pharmaceutical medical self-management strategies was low. While use positive emotional self-management strategies was high, individuals with NC were more likely to use negative
emotional self-management strategies compared to those without NC. Multiple self-management barriers and facilitators were identified, however those with NC were more likely than those without NC to experience low self-efficacy, depression and severe pain which may impair the ability to self-management.

Conclusions

Health care professionals have the opportunity to improve chronic pain outcomes by providing self-management advice, referring to self-management interventions, and addressing self-management barriers and facilitators. Individuals with NC may require additional health services to address their greater self-management challenges, and further research is needed to identify non-pharmaceutical interventions effective in relieving chronic pain with NC. Public policy is needed to facilitate health systems in providing long-term self-management support for individuals with chronic pain.
Co-Authorship

1. Elizabeth VanDenKerkhof, RN, DrPH
   Professor, School of Nursing and Dept of Anesthesiology & Perioperative Medicine
   Career Investigator, OWHC/CIHR (2008-2013)
   Senior Scientist Practice and Research in Nursing (PRN) Group
   Queen's University, 78 Barrie Street, Kingston, Ontario K7L 3N6

   Dr. Elizabeth VanDenKerkhof, thesis supervisor, provided guidance on the overall thesis
   design, implementation, data analysis and interpretation, and co-authored each
   manuscript. She also provided funding for the survey through her Pfizer Canada
   Neuropathic Pain Award.

2. Sandra LeFort, RN, PhD
   Professor, School of Nursing
   Memorial University of Newfoundland
   300 Prince Philip Drive, St. John’s Newfoundland, A1B 3V6

   Dr. Sandra LeFort, doctoral committee member, provided guidance on the overall thesis
   design, co-authored each manuscript, and provided significant guidance on the review
   manuscript (chapter 3).

3. Margaret B Harrison, RN, PhD
   Professor, School of Nursing Community Health and Epidemiology
   Director Queen’s Joanna Briggs Collaboration
   Senior Scientist Practice and Research in Nursing (PRN) Group
   Queen’s University, 78 Barrie Street, Kingston, Ontario K7L 3N

   Dr. Margaret B. Harrison, doctoral committee member, provided guidance on the overall
   thesis design, co-authored the two quantitative manuscripts (chapters 4 and 5), and
   provided guidance and feedback on the review manuscript (chapter 3).
Acknowledgements

I feel incredibly blessed to have spent the past four years working with my excellent supervisor, Dr. Elizabeth VanDenKerkhof. After first encouraging me to pursue a PhD, she provided me with a balance of guidance and opportunity to work independently. Her expertise in chronic pain research, survey methodology, and statistical analysis was invaluable. Dr. Margaret B Harrison was instrumental as a supervisory committee member in helping me think through the conceptual organization of my study and providing feedback throughout the research process. Dr. Sandra LeFort added self-management practice and research expertise to my supervisory committee, and played a key mentorship role in the review manuscript.

I have spent the past four years learning under the guidance of excellent professors at Queen’s University School of Nursing, including Dr. Jennifer Medves, Dr. Joan Tranmer, and Dr. Dana Edge who were especially helpful and encouraging throughout the research process. The support staff at the School of Nursing also played significant roles in the day-to-day organization required throughout this degree, and provided regular encouragement. My classmates helped to create a positive learning environment and provided constructive feedback.

I would like to thank Dr. Sandra LeFort and the faculty and staff of Memorial University of Newfoundland’s School of Nursing for welcoming me to their St. John’s campus and allowing me to learn from them. I would like to acknowledge the Canadian Pain Society’s Trainee Research Interchange Program (TRIP) Award for funding the travel and living expenses of this learning experience.

Many individuals helped me with the process of preparing, mailing, receiving, and entering the data from the thousands of questionnaires. I would like to specially thank Don Dean and the staff at Queen’s Postal Services for their physical help, Daniel Rudmin for technical
support, my girlfriends for helping me apply stamps, and the various research assistants who
helped throughout the process.

The funding that made this study possible was provided by the Ontario Graduate
Scholarship in Science and Technology, Ontario Graduate Scholarship, and Queen’s University
Graduate Award. The survey study was funded through my supervisor by Pfizer Canada.

Finally, I would like to thank my husband, Stephen Mann, for supporting my decision to
pursue this degree and allowing our apartment to be shared with 40 boxes of surveys, 32 boxes
of envelopes, 2 boxes of cover letters, and 1 box of stamps.

“So whether you eat or drink, or whatever you do, do all to the glory of God.”

1 Corinthians 10:31
# Table of Contents

Abstract ........................................................................................................................................ iii

Co-Authorship ................................................................................................................................. v

Acknowledgements ......................................................................................................................... vi

Table of Contents ........................................................................................................................... viii

List of Figures .................................................................................................................................. xii

List of Tables .................................................................................................................................. xiii

Chapter 1 – Introduction .................................................................................................................. 1

  Background and Framework ........................................................................................................... 1

  Research Purpose and Objectives ................................................................................................. 4

Thesis Format ................................................................................................................................. 6

Contributions to Knowledge .......................................................................................................... 10

References .................................................................................................................................... 13

Figure 1.1 ....................................................................................................................................... 14

Chapter 2 – Literature Review of Chronic Pain ............................................................................ 15

  Introduction ................................................................................................................................. 15

  Burden of Chronic Pain ............................................................................................................... 15

  Neuropathic Pain as a Distinct Subgroup .................................................................................... 18

  Need for a Shift to Self-Management ........................................................................................... 22

Conclusions .................................................................................................................................... 23

References .................................................................................................................................... 25
Chapter 3 – Self-Management Interventions for Chronic Pain

<table>
<thead>
<tr>
<th>Practice Points</th>
<th>34</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>35</td>
</tr>
<tr>
<td>Introduction</td>
<td>36</td>
</tr>
<tr>
<td>Research Purpose and Objectives</td>
<td>37</td>
</tr>
<tr>
<td>Overview of Self-Management Interventions</td>
<td>37</td>
</tr>
<tr>
<td>Evidence for Self-Management Interventions</td>
<td>40</td>
</tr>
<tr>
<td>Health Care Providers’ Role in Self-Management</td>
<td>43</td>
</tr>
<tr>
<td>Conclusion &amp; Future Perspective</td>
<td>46</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>48</td>
</tr>
<tr>
<td>References</td>
<td>49</td>
</tr>
<tr>
<td>Tables</td>
<td>66</td>
</tr>
</tbody>
</table>

Chapter 4 – Self-Management of Chronic Pain with and without Neuropathic Characteristics

| Abstract and Keywords                                                           | 72 |
| Introduction                                                                    | 73 |
| Research purpose and objectives                                                 | 74 |
| Methods                                                                         | 74 |
| Results                                                                         | 79 |
| Discussion                                                                      | 82 |
| Conclusion                                                                      | 87 |
Chapter 5 - Barriers and Facilitators of Chronic Pain Self-Management for Individuals with and without Neuropathic Characteristics..............................................107

Abstract and Keywords.....................................................................................108

Introduction.........................................................................................................110

Research purpose and objectives ....................................................................110

Material and Methods .......................................................................................111

Results................................................................................................................115

Interpretation........................................................................................................118

Acknowledgements............................................................................................122

References..........................................................................................................123

Tables..................................................................................................................133

Chapter 6 – Discussion .....................................................................................141

Overview.............................................................................................................141

Key Findings and Implications ..........................................................................141

Summary.............................................................................................................149

Conclusion.........................................................................................................157

References.........................................................................................................159

Table....................................................................................................................163
Figure 6.1 ............................................................................................................. 166

Appendices............................................................................................................. 167

Appendix 1 – Innovative Care for Chronic Conditions Framework....................... 167
Appendix 2 – Innovative Care for Chronic Conditions Framework applied to this thesis ............................................................................................................................................... 168
Appendix 3 – Additional methods for chapter 3..................................................... 169
Appendix 4 – Ethics approval .............................................................................. 227
Appendix 5 – Initial cover letter ........................................................................... 228
Appendix 6 – Follow-up cover letter .................................................................... 229
Appendix 7 – Survey questionnaire ...................................................................... 230
Appendix 8 – Overview of pilot study .................................................................... 251
Appendix 9 – Additional methods for chapters 4 and 5 ....................................... 269
Appendix 10 – Additional methods for chapter 5.................................................. 278
List of Figures

Chapter 1 – Introduction

Figure 1.1 – Overview of dissertation and manuscript preparation timeline ......14

Chapter 6 – Discussion

Figure 6.1 – Chronic pain self-management strategies, context, and outcomes as identified in this study.................................................................166

Appendix 3 - Additional details of the methods used to review the literature on self-management for chronic pain, and retrieved and included articles

Figure A3.1 - Selection process of articles reviewed for descriptions and evaluations of self-management interventions........................................173

Appendix 8. Overview of pilot study

Figure A8.1 - Flow of participants through pilot study ........................................268

Appendix 9. Larger survey study methods

Figure A9.1 – Summary of participant recruitment and group assignment ........275
List of Tables

Chapter 3 – Self-Management Interventions for Chronic Pain

Table 3.1. Overview of common self-management interventions .................. 66

Table 3.2. Overview of self-management intervention organization and
Delivery ........................................................................................................ 68

Table 3.3. Barriers and facilitators of self-management ............................... 69

Table 3.4. Factors predicting or associated with positive outcomes of self-
management intervention ........................................................................ 70

Chapter 4 - Self-Management of Chronic Pain with and without Neuropathic
Characteristics

Table 4.1. Sociodemographic characteristics of study participants ............. 99

Table 4.2. Health status of study participants ............................................. 101

Table 4.3. Pain characteristics of study participants ................................. 102

Table 4.4. Medical self-management type and facilitating health professional .. 103

Table 4.5. Effect of neuropathic characteristics on health care visits .......... 104

Table 4.6. Emotional self-management strategies ...................................... 105

Table 4.7. Satisfaction with ability to control pain .................................... 106

Chapter 5 - Barriers and Facilitators of Chronic Pain Self-Management for
Individuals with and without Neuropathic Characteristics

Table 5.1. Sociodemographic characteristics ............................................. 133

Table 5.2. Self-selected self-management barriers and facilitators ............. 134
Table 5.3. Self-management support ................................................................. 135
Table 5.4. Self-efficacy .................................................................................. 136
Table 5.5. Depression .................................................................................... 137
Table 5.6. Relationship between self-efficacy, depression, and pain and emotional self-management ................................................................. 139
Table 5.7. Relationship between self-efficacy, depression, and pain and medical self-management ................................................................. 140

Chapter 6 – Discussion

Table 6.1. Recommendations for practice, education, research, and policy........ 163

Appendix 3 - Additional details of the methods used to review the literature on self-management for chronic pain, and retrieved and included articles

Table A3.1. Databases, search terms, and total and included articles ............. 174
Table A3.2. Data extraction table .................................................................. 175

Appendix 9 – Larger survey study methods

Table A9.1. Overview of variables, items, and instruments ......................... 276

Appendix 10 – Additional methods for chapter 5

Table A10.1. Summary of barriers and facilitators included in self-management models ......................................................................................... 282
Table A10.2. Summary of barriers and facilitators included in chronic pain self-management studies

Table A10.3. Overview of barriers, facilitators, and instruments included in study
Chapter 1 – Introduction

Background and framework

Chronic conditions as a health care priority.

Chronic conditions are considered the greatest burden for health care systems of developed countries (1). The prevalence of chronic conditions is rising internationally for a variety of reasons including increasing average population ages, life expectancies, and engagement in unhealthy lifestyle behaviours (1). By definition, chronic conditions require management over a period of years to decades, thus health care systems must be organized to provide effective and efficient chronic care. As health care systems were initially structured to address acute health issues, a reorganization of roles and resources is necessary to meet the challenges of chronic care (1).

Chronic care models.

Various models have been proposed to organize policy, research, education, and health care systems to provide care for chronic conditions. The Chronic Care Model is a commonly used model that depicts positive health outcomes resulting from the interaction of informed and activated patients with a prepared and proactive practice team (2, 3). A literature review was conducted to identify effective interventions for inclusion in the Chronic Care Model; these interventions include providing self-management support (e.g., skills training), creating decision-support tools for clinicians (e.g., practice guidelines), organizing collaborative teams for the provision of care (e.g., health care teams with clearly defined roles), and optimizing use of information systems (e.g., surveillance systems). Since its conception, various elements of the model have been implemented with resulting improvements in condition-specific outcomes, health-related quality of life, and/or health care use (2).
Although the original Chronic Care Model is still being used, it has been adapted to create the Expanded Chronic Care Model (3) and the Innovative Care for Chronic Conditions Framework (4). The Expanded Chronic Care Model was created to address the need for health promotion and provision of care for chronic conditions, and highlights the relationship between health care systems and communities. It focuses on the interaction between patients, practice teams, and communities, and includes the additional intervention targets of creating healthy public policy, supportive environments, and strengthening community action (3).

The World Health Organization developed the Innovative Care for Chronic Conditions Framework (ICCCF) to build on the original strengths of the Chronic Care Model while integrating the perspectives of developing countries and emphasizing the role of policy (appendix 1) (1, 4). The ICCCF posits that optimal outcomes for chronic conditions result from the interaction of individuals and families, practice teams, communities, and policy. These partners are grouped into the micro-level of individuals, families, community partners, and health care teams; the meso-level of communities and health care organizations; and the macro-level of the policy environment. Additional intervention targets, or ‘building blocks,’ were added on all levels to reflect the challenges and opportunities of developing countries. In the added policy or macro-level, building blocks include developing and allocating human resources, promoting consistent financing, and providing leadership and advocacy (1).

Based on the international applicability and inclusion of the policy level, the ICCCF was selected to guide the conceptualization and organization of this dissertation. The ICCCF is based on five guiding principles: evidence-based decision making, population focus, prevention focus, quality focus, and integration. According to these principles, management of chronic conditions needs to be based on evidence, including descriptions of the extent of the issue, effectiveness of
interventions, and health resources and skills required for optimal management (1). Health care systems need to focus on population needs, reducing the risk of health issues, and ensuring that health resources are used and allocated appropriately. Finally, individual, system, and policy levels need to be informed, engaged, and integrated to be working together to improve care of chronic conditions (1). In summary, the ICCCF presents a way of organizing resources on three levels to reduce the burden of chronic conditions by emphasizing the active role of the individual and organization of health care systems for maximal efficiency.

Chronic pain.

Chronic pain represents a prevalent chronic condition which is taxing health care systems. In Canada chronic pain costs are estimated to be almost $15,000 per affected individual per year (5). Despite a growing understanding of pain mechanisms and the development of pain management practice guidelines, the research evidence suggests that current interventions provide only small reductions in pain intensity and small improvements in functional abilities (6). Thus the current management options for chronic pain are costly yet minimally effective.

Multiple gaps exist when the ICCCF is applied to chronic pain. On the micro-level, little is known about the degree to which affected individuals are motivated, informed and prepared to engage in self-management of their pain and what role their healthcare providers play in motivating, informing and preparing them for this active role. Internationally, failure on the part of health care providers to support self-management and communicate clearly in patient interactions (e.g., too little time to assess and address education gaps) have been identified as the key concerns in the management of chronic conditions on the this level (1), however it is unknown whether these issues accurately reflect the challenges of individuals with chronic pain in Canada.
On the meso-level, health care professionals should be active in supporting self-management, however, little is known about the role that is played by health care professionals providing this support. Internationally, the key issues at the meso-level include the current focus on diagnosis and treatment of individual concerns rather than creating a long-term plan for an individual’s care, a lack of both provider expertise in supporting self-management and research evidence to inform this supporting role, and a failure to maximize community resources (1). For Canadians with chronic pain, it is currently unknown what challenges they face in their attempts to self-manage, thus health care professionals lack the necessary information to facilitate self-management actions.

At the macro-level, the general framework organizing care of chronic conditions may need to be reorganized to maximize efficiency of Canadian health care systems. Internationally noted concerns at this level include governments investing in interventions that lack evidence to support their effectiveness, and failing to provide financial incentives for health care providers engaging in cost-effective and innovative care (1). Within chronic pain, interventions currently used in Canada demonstrate minimal effectiveness, thus these interventions may need to be tailored and targeted at specific chronic pain groups to improve the resulting outcomes (6). With a shift in focus from diagnosis and treatment to long-term care, new remuneration systems may be necessary to support health care professionals in taking the required time to provide care targeting chronic disease management.

**Research purpose and objectives.**

Thus, outcomes for Canadians with chronic pain and the resulting impact on the Canadian economy may benefit from modifying the organization of care on the individual, system, and policy level as outlined by the ICCCF, however there is a paucity of evidence to
inform these modifications. The purpose of this dissertation was to inform management of chronic pain by addressing the following ICCCF building blocks: prepare, inform and motivate patients and families (micro-level); support self-management and prevention (meso-level); promote consistent financing (macro-level); and develop and allocate human resources (macro-level) (appendix 2).

The research objectives were as follows:


3. To describe the sociodemographic and pain characteristics of those with and without NC (chapter 4 – manuscript prepared for Pain)

4. To compare self-management strategies and satisfaction with the ability to control pain between participants with chronic pain with and without NC (chapter 4 – manuscript prepared for Pain)

5. To describe and compare barriers and facilitators of self-management in individuals with chronic pain with and without NC (chapter 5 – manuscript prepared for Annals of Family Medicine)

6. To explore the role of barriers and facilitators in the use of self-management strategies in individuals with NC (chapter 5 – manuscript prepared for Annals of Family Medicine)
Thesis Format

Overview.

This dissertation is organized in a manuscript style. The three manuscripts are presented in chapters 3, 4, and 5. Each manuscript’s abstract and section headings have been formatted according to the requirements of the journal to which it has been, or will be, submitted. Thus, the abstracts included below have been written for the purpose of outlining these manuscripts in this chapter and complement those included in chapters 3, 4, and 5. Additional methodological information for each manuscript is included in appendices. An overview of the dissertation timeline, manuscripts, and research objectives is presented in figure 1.1.

Chapter 1 – Introduction.

This chapter outlines the background, format, and content of this dissertation. First, background information on chronic disease management is reviewed and the research gap is highlighted. Second, the dissertation format is outlined, and the key content included in each chapter is summarized. Finally, an overview of dissertation’s contribution to knowledge is presented.

Chapter 2 - Literature review of chronic pain.

The literature review provides the background information which informed the design of this dissertation. First, the current evidence for the prevalence, burden, and management of chronic pain are outlined to describe the magnitude of the issue. Second, the research findings are outlined which suggest that individuals with chronic pain with NC are a distinct sub-group within chronic pain and need to be analyzed separately. The review concludes with applying the reviewed evidence to the ICCCF, highlighting the need for a shift in chronic pain management towards self-management.
Chapter 3 – Self-Management Interventions for Chronic Pain (abstract for manuscript 1).


Objectives. To (1) describe and evaluate the evidence for self-management interventions and (2) identify the health care provider’s role in supporting self-management of chronic pain.

Method. A systematic search and review of CINAHL, MEDLINE, EMBASE, AMED, and PsychINFO databases was conducted to identify studies published in the past five years which addressed either study objective. Interventions were screened for inclusion using Kate Lorig’s definition of self-management.

Results. Eighty-three studies were identified to address objective 1 and 24 studies for objective 2. The evidence suggests that self-management interventions are effective in improving pain, health-related quality of life, mental health, and health care use outcomes in chronic pain. The role of health care providers includes providing on-going self-management education and advice about management options, and screening individuals for their readiness and ability to engage in self-management.

Conclusion. Clinicians play an important and on-going role in supporting self-management, which may include referral to self-management interventions to optimize health outcomes for their patients.

Fit with ICCCF. The results reported in this manuscript inform the role of the clinician at the meso-level and resource allocation at the macro-level.

Chapter 4 – Self-management of chronic pain with and without neuropathic characteristics (abstract for manuscript 2).
**Objectives.** To (1) describe the sociodemographic and pain characteristics of those with and without neuropathic characteristics (NC), and (2) compare self-management strategies and satisfaction with the ability to control pain between the two pain groups.

**Methods.** This study used a cross-sectional survey design, which was imbedded in a larger national survey. Respondents were considered to have chronic pain if they reported pain for more than three months, and NC if they scored 12 or higher on the Self-Report Leeds Assessment of Neuropathic Symptoms and Signs Pain Scale.

**Results.** Of 710 survey respondents with chronic pain, 188 screened positive for NC. Participants with NC reported a lower socioeconomic status and pain that was constant, severe in intensity, and affected more body areas than those without NC. Participants identified that medications were the primary medical means by which they self-managed their pain, and family physicians were the health professional they found to be most helpful in pain management. They most frequently used emotional self-management strategies that are associated with positive health outcomes. Complete satisfaction with ability to control pain was rare. Individuals with NC emerged as a distinct sub-group; they were less likely to use non-pharmaceutical self-management strategies, and more likely to use emotional self-management strategies associated with poor health outcomes, and be completely dissatisfied with their ability to control pain.

**Conclusion.** Individuals with chronic pain are using a variety of self-management strategies. Those with NC have distinct pain and self-management experiences, including use of potentially harmful self-management strategies, when compared to those without NC. Health professionals may need to consider pain type when assessing self-management strategies and providing self-management support.
Fit with the ICCCF. The results reported in this manuscript inform current behaviours of individuals at the micro-level and identify assessment points to guide health care systems at the meso-level.

Target Journal. Pain

Chapter 5 – Barriers and facilitators of chronic pain self-management for individuals with and without neuropathic characteristics (abstract for manuscript 3).

Objectives. To (1) describe and compare barriers and facilitators of self-management in individuals with chronic pain with and without NC, and (2) explore the role of barriers and facilitators in the use of self-management strategies in individuals with NC.

Methods. Seven hundred and ten individuals reported chronic pain on a recent, cross-sectional survey of randomly selected Canadians and were included in this analysis. NC were identified using the Self-Report Leeds Assessment of Neuropathic Symptoms and Signs. Potential self-management barriers and facilitators were identified in a literature review and included self-efficacy, depression, family/friend support, relationship with health care provider, and pain intensity.

Results. Individuals with chronic pain most commonly identified self-efficacy, support from family/friends, and relationship with their healthcare provider as barriers or facilitators to self-management. Those with NC (n=188) were more likely to have severe pain intensity, co-morbid depression, and low self-efficacy, which increased their risk of using potentially negative self-management strategies. Individuals with NC that had high self-efficacy were more likely than those with low self-efficacy to use potentially positive self-management strategies.

Conclusions. There are multiple barriers and facilitators of chronic pain self-management. Individuals with NC encounter more barriers to self-management than those
without NC, and may thus require additional health resources (e.g., clinician time to screen for
depression). Health care professionals may want to consider assessing for, and addressing, these
factors to support self-management.

**Fit with the ICCCF.** The results reported in this manuscript describe the challenges
faced by individuals at the micro-level, inform role of health care professionals at the meso-level
and identify new responsibilities in need of financial incentive at the macro-level.

**Target Journal.** *Annals of Family Medicine*

**Chapter 6 – Discussion.**

The unique contribution of each manuscript to informing the three levels of the ICCCF
are outlined in the discussion chapter. The clinical, research, education, and policy implications
of these findings are outlined, including the organization of the findings into a model of chronic
pain self-management, and the evidence for whether individuals with chronic pain with NC act
as a distinct sub-group in self-management. Strengths and limitations of the dissertation are
reviewed, and final conclusions are made.

**Contributions to Knowledge**

As outlined by the ICCCF, the management of chronic conditions requires coordinated
activities on multiple levels that are informed by evidence. In the case of chronic pain, multiple
gaps exist in the evidence base to inform these activities. The findings presented in this thesis
provide insight into the self-management experience of Canadians with chronic pain and the role
of health care providers in supporting these behaviours, as well as identifying the distinct needs
of individuals with NC to guide allocation of resources and funding decisions.

There is currently little known about the strategies used by Canadians with chronic pain
to manage their symptoms and the effect of these symptoms on their lives. In the absence of this
information, there is little guidance for health care providers to follow the ICCCF recommendations of informing individuals with chronic pain about the self-management behaviours they should consider using and preparing them with the needed skills. This gap is addressed in chapter 4 (Self-Management of Chronic Pain with and without Neuropathic Characteristics) through a description of the nature of the pain being managed, the socioeconomic resources available with which to manage the pain, current self-management strategies, and current satisfaction with ability to control pain. Consistent with the principles of the ICCCF, this information is based on a population-level sample and explores whether individuals with NC require additional or different health resources to optimize their self-management compared to those with chronic pain without NC.

While health care providers may agree that self-management behaviours should be supported, there is a paucity of information about the challenges faced by individuals in their attempts to self-manage. The results reported in chapter 5 (Barriers and Facilitators of Chronic Pain Self-Management for Individuals with and without Neuropathic Characteristics) identify barriers that can be modified and facilitators that can be encouraged by health care providers. This information highlights the context in which chronic pain self-management occurs and can guide clinical assessment and referral for treatment or intervention. The comparison between pain groups highlights the unique needs of individuals with NC. The literature review in chapter 3 (Self-Management Interventions for Chronic Pain) also provides insight into the role of health care providers as identified by both individuals with chronic pain and health care professionals.

To ensure that funding and human resources are allocated to support effective interventions, the evidence for self-management interventions was examined and high needs groups identified. The findings presented in chapter 3 (Self-Management Interventions for
Chronic Pain) identify the outcomes that are consistently improved in participants of chronic pain self-management interventions, and the need for on-going support from health care providers. The findings presented in chapter 5 (Barriers and Facilitators of Chronic Pain Self-Management for Individuals with and without Neuropathic Characteristics) add to these results by identifying barriers and facilitators specific to Canadians that may require additional health care resources to address. As the evidence supports the effectiveness of self-management interventions, health care funding should support organization of, and referral to, these interventions. Similarly, financial reimbursement for health care provider time would reflect the importance of screening and addressing self-management barriers and facilitators.

Finally, the results of this dissertation are integrated into a chronic pain self-management model that identifies self-management strategies, barriers, and facilitators of Canadians with chronic pain with and without NC. This preliminary model organizes the results such that clinicians, researchers, and policy-makers can identify potential targets for interventions to improve the overall health outcomes of individuals with chronic pain. Further, the results of this enquiry have been explicitly linked to recommendations for practice, education, research, and policy and are presented in chapter 6.
References


Figure 1.1. Overview of dissertation and manuscript preparation timeline.

Ethics amendment to incorporate thesis approved (August 2011)

Pilot study (September-October 2011)

Survey questionnaire mailed (November 2011)

Data entry (November 2011-April 2012)

Follow-up survey questionnaire mailed (May 2012)

Data entry (May 2012-November 2012)

Data collection ended (September 2012)

Data analysis and manuscript preparation (December 2012-July 2013)

Canadian Pain Society Trainee Research Interchange Program award received (March 2011) and used to fund one month stay at Memorial University of Newfoundland (February 2012)

Chapter 3 Objectives:
(1) To describe and evaluate the evidence for self-management interventions
(2) To identify the health care provider’s role in supporting self-management of chronic pain

Chapter 4 Objectives:
(1) To describe the sociodemographic and pain characteristics of those with chronic pain with and without neuropathic characteristics
(2) To compare self-management strategies and satisfaction with ability to control pain between the two pain groups

Chapter 5 Objectives:
(1) To describe and compare barriers and facilitators of self-management in individuals with chronic pain with and without neuropathic characteristics
(2) To explore the role of barriers and facilitators in the use of self-management strategies in individuals with neuropathic characteristics
Chapter 2 - Literature Review

Introduction

This chapter provides the broad context for this dissertation by reviewing the prevalence, description, consequences, and management challenges of chronic pain, while chapter 3 is a review of self-management interventions. Notably, this chapter highlights the emerging evidence that individuals with chronic pain with neuropathic characteristics (NC) have distinct pain and management challenges; a distinction that has not been explored in the self-management literature. The majority of the studies reviewed in this chapter were surveys of the general population with a few studies using database/chart review or systematic review methods, thus the information presented in this chapter is largely based on descriptive, cross-sectional data provided by large (e.g., 200-2,000+) samples. This chapter concludes with outlining how the reviewed literature informs and fits with chronic pain self-management interventions.

Burden of Chronic Pain

Pain persisting for at least three months is reported by 7.4-58.0% of community-dwelling adults internationally (1-9). The most common locations for chronic pain are the low back and lower limbs (1-3, 5, 9-11), and multiple body sites of pain are often reported (1, 10-12). Individuals with chronic pain are more likely to be female (1, 5), older in age (1, 3, 4, 6), have other co-morbid chronic conditions (1, 8), live in rural areas (9) and have a lower socioeconomic status (13) including being unemployed, retired, or working part-time (1, 2) having low education (2, 6) and income (4, 13), and being divorced or separated (1, 6).

Negative health outcomes.

Living with chronic pain is associated with a variety of negative health outcomes including pain-related disability and interference (2, 3, 10), mental illness (14-16), and reduced
health-related quality of life (HRQoL) (9, 17-21). Up to 35% of individuals with chronic pain experience moderate to severe pain-related disability and interference in at least one area of their life (2). The most commonly identified areas of disability/interference include work activities (2, 3), family and home responsibilities (2), recreation activities (2), and ability to sleep and rest (2, 19, 22). Interference with work activities and/or hours has been reported by 49% of individuals with chronic pain (2), with 4-6% being unemployed due to pain (3). The risk for having moderate to severe pain-related disability/interference is higher for women (2), those with comorbid depression (2) and those experiencing pain of high intensity (2), in multiple body locations, especially the limbs (10).

The prevalence of mental illness is higher in chronic pain groups than the general population (14, 19, 23-25) and individuals with acute pain (19). Depression is the most commonly studied mental illness in chronic pain groups, however the evidence suggests that anxiety disorders, addiction, and post-traumatic stress disorders are also more prevalent in chronic pain groups than the general population (14, 16, 26). Between 13-46% of individuals with chronic pain have at least one mental illness (14-16, 23). The risk of comorbid depression and/or anxiety is higher in groups with pain of severe intensity (23, 24, 27), persisting night and day (24), present in more body areas (24), located in the head or chest (25), and resulting in increased interference (23). Although the correlation between pain and depression is bi-directional (24, 26), the evidence suggest that pain precedes the onset of depressive symptoms in over half of the cases of co-morbid chronic pain and depression (24).

Individuals with chronic pain rate their HRQoL lower than population norms (9, 17-21). The presence of pain may also have a distinct role in reducing HRQoL scores in chronic disease, as stroke survivors with resulting chronic pain have reported lower HRQoL than stroke survivors.
without chronic pain (28). The effect of pain on HRQoL is especially apparent in the dimension of role performance (17), including work, social, and daily activities (19). Lower scores of HRQoL have been correlated with various aspects of pain including higher intensity (9, 17), shorter duration (17), multiple pain diagnoses (29), neuropathic characteristics (21), and more impairment (30). In addition to aspects of pain, HRQoL scores vary by other health and sociodemographic variables such as culture (31), social support (9, 17), co-morbid depression (18, 20, 30), coping (30), perceived occupational success (9), and perceived adequacy of healthcare resources (9). The evidence is mixed as to whether men or women with chronic pain report poorer HRQoL (17, 32).

**Chronic pain management.**

Similar to other chronic diseases, untreated chronic pain results in progressive physical and mental decline (19). Management recommendations are aimed at both reducing pain and improving HRQoL. Current general recommendations for management include multimodal and inter-disciplinary therapy with intermittent follow-up appointments to address the complex and changing nature of chronic pain (33-35). While pharmacologic management is considered the main element of therapy (33-38), multimodal therapy may include the addition of physical therapy (33, 35, 36, 38), cognitive and behavioural therapies (e.g., acceptance and commitment therapy) (33-38), acupuncture (33, 35, 36, 38), injections (e.g., botulinum toxin) (33-35), nerve-targeted interventions (e.g., transcutaneous nerve stimulation) (33-36, 38), and more invasive procedures targeting spinal and intrathecal areas (e.g., intrathecal infusion of analgesics) (33-35). In trials of various management modalities, the best reported outcomes are a reduction in pain intensity of 30% in half of the treated participants (35).
Surveys and database searches have been used to identify which practitioners and modalities are being used by individuals with chronic pain. The majority of individuals with chronic pain identify their general practitioner as the health care professional they consult most frequently for pain management (39). In accordance with recommendations, individuals with chronic pain report using medications and complementary and alternative medicine (CAM) therapies to manage their pain, and multiple pain-related visits to health care providers. Use of analgesics is reported by 76.4-90% of individuals with chronic pain (4, 40), and is higher in women and those in higher intensity pain (4). In a one year period, 47-90% of individuals with chronic pain reported at least one pain-related visit to a health care professional (4, 41), 12.2-47% reported using complementary and alternative medicine (4, 40), and 21.4% reported at least one pain-related hospitalization (41). Total pain-related visits are higher for individuals with higher pain intensity (4), and total visits for both pain and other reasons are higher for individuals with high levels of pain disability (42).

**Cost of chronic pain.**

The costs associated with chronic pain arise from both direct medical costs to the health care system (e.g., frequent health care visits) and indirect costs to the economy (e.g., absenteeism) (43). These costs vary by diagnosis, degree of pain-related disability, and co-morbid conditions, but estimates of average annual costs range from $2,841 to $13,575 Canadian dollars per person with chronic pain (3, 44).

**Neuropathic Pain as a Distinct Subgroup**

In the last seven years of research, individuals with neuropathic pain have emerged as a distinct subgroup within chronic pain. Neuropathic pain is defined as “pain arising as a direct consequence of a primary lesion or disease affecting the somatosensory system” (45), and is
reported by 3.3-17.9% of international samples (7, 46) or 17.0-51.1% of those reporting chronic pain (7, 11, 47, 48). Neuropathic pain may be a chronic condition on its own (e.g., trigeminal neuralgia), or result from other chronic diseases (e.g., cancer, AIDS) (3, 49-51). It is generally classified as central or peripheral depending on the location of the damage. Common peripheral neuropathic pain conditions include painful diabetic neuropathy, trigeminal neuralgia, traumatic neuropathy (e.g., chronic post-surgical pain), spinal radiculopathy, and carpal tunnel syndrome (50-53). Central neuropathic pain conditions include pain resulting from multiple sclerosis (50, 51, 54) and stroke (50, 51).

Diagnosis of neuropathic pain is generally based on health history; the presence of somatosensory abnormalities including allodynia, hyperalgesia, and spontaneous burning or shooting pain; and increased autonomic activity (e.g., abnormal skin temperature in painful area) (50, 52, 53, 55). Due to the difficulty with diagnosis and the possibility for chronic pain to be the result of both neuropathic and non-neuropathic causes, individuals may be diagnosed with 'probable' or 'possible' neuropathic pain (45, 55).

Several screening instruments have been developed to identify NC for clinical assessment and research purposes. These instruments include the Neuropathic Pain Questionnaire, Douleur Neuropatique, Leeds Assessment of Neuropathic Symptoms and Signs Scale (S-LANSS), PainDETECT, and ID Pain. The items on these instruments screen for the symptoms of somatosensory and autonomic dysfunction typical of neuropathic pain (e.g., allodynia) (55). For example, the ability of the S-LANSS to correctly identify NC has been compared with diagnosis made by clinical exam, and had a sensitivity of 83-85% and specificity of 80-87% when a cut-off score of 12 was used (56, 57).
Use of these screening tools has allowed for comparison between participants with and without NC in chronic pain research. Those with NC report pain that is more intense (7, 11, 47, 48, 51), experienced in more body areas (11, 47), located in peripheral areas (11, 47) and more variable in intensity throughout a 24-hour period (47). Compared to those without NC, individuals with NC are more likely to be female (7, 11, 47, 48, 58), older (7, 11, 47, 58), have lower levels of education (7, 11), be manual workers or farmers (47), unable to work (11), live in rurally located (47) rented accommodations (11), and perceive themselves as economically disadvantaged (48). Mixed results exist as to whether marital status is correlated with NC (7, 11, 47).

**Negative health outcomes.**

In addition to pain descriptions, the effect of living with chronic pain with NC also distinguishes this type of chronic pain. Individuals with chronic pain with NC report more pain-related disability and interference in multiple areas of daily life including social activities (7, 59), family relationships (7, 59), mobility (7, 48), sleep (7, 59, 60), and work activities (7, 59, 60) compared to those without NC. Forty-three percent of individuals with NC have reported the need to adjust their employment status, miss work, or adapt to the resulting work interference due to pain (60).

Both physical and emotional domains of HRQoL are lower for individuals with chronic pain with NC compared those without NC (21). These differences are only partially explained by differences in pain intensity (21, 48, 51, 59, 60), and may be related to the higher risk of co-morbid depression (51, 58).
**Chronic pain management.**

When pain management of individuals with and without NC is compared, individuals with NC are more likely to be prescribed and use medication (7, 51, 58), with 93% of those with NC being prescribed at least one medication (60). Individuals with NC are more likely to report frequent and recent use of painkillers (11), use of multiple medications (7, 40, 51), and use of opioid, compound, and/or anti-depressant medications (40, 58) than those without NC. Despite higher use of medications, those with NC report less resulting pain relief than those without NC (7, 40, 51, 61), with 75% reporting moderate to severe pain despite using medications (51).

In addition to medications, individuals with NC are more likely to report recent and/or frequent seeking of treatment for their pain (11). Individuals with NC are more likely to visit an emergency room and hospital, undergo diagnostic testing, and undergo both minor (e.g., nerve block) and major invasive procedures (e.g., nerve grafting) than those without NC (58). In a survey across six European countries, 76% of individuals with NC reported visiting a family doctor in the past four weeks, 42% reported using physical therapies in the past week, and 49% reported evaluation by a pain specialist at some point since the start of their pain (60). To date, referral and use of cognitive and behavioural therapies in chronic pain management have not been studied, but there is preliminary evidence that individuals with and without NC may be equally likely to visit psychologists and CAM practitioners (51, 58, 61). Thus individuals with NC use more health care resources than those with chronic pain without NC; this may be partially due to the poorer general health of individuals with NC (51) and may vary by specific pain diagnosis (61).
Costs of chronic pain with neuropathic characteristics.

The direct and indirect costs associated with chronic pain with NC are higher than those for general chronic pain. Indirectly, as noted above, individuals with NC are less likely to be employed and employed individuals with NC have higher rates of absenteeism and ‘presenteeism’ (62) contributing to economic costs. Direct medical costs have been estimated to be twice that of costs for chronic pain without NC (58, 62), for an estimate $14,606 (in Canadian dollars) spent per person with a neuropathy in combined indirect and direct annual costs (44).

Need for a Shift to Self-Management

These findings indicate that individuals with chronic pain with and without NC are presented with the challenge of managing complex pharmacologic regimens, frequently including additional management modalities, at great costs to the health care system and economy, and yet are failing to experience significant pain relief. As individuals with chronic pain are living with unrelieved pain on a day-to-day basis, supporting their ability to manage both the pain and the resulting negative health consequences is imperative. The failure of pharmacologic agents to adequately reduce pain intensity, the complexity of pharmacologic regimens, and the associated costs are especially pronounced in individuals with NC, thus they may require additional and/or different support in the day-to-day self-management of their pain.

The need for self-management of chronic conditions such as pain has been highlighted as an international priority by the World Health Organization’s Innovative Care for Chronic Conditions Framework (ICCCF) (appendix 1) (63). If this model is applied to chronic pain, it would suggest that optimal health outcomes result when (1) individuals are informed, motivated and prepared to self-manage their pain; (2) health care professionals support self-management behaviours; and (3) the policy environment supports both individuals and health care
professionals in their self-management roles. Currently, it is unknown how Canadians are self-managing their chronic pain, how health care professionals can support their self-management efforts, and whether individuals with NC require different support from health care professionals to address their different pain experience. Thus, there is a paucity of research to inform decisions about how to optimize chronic pain self-management.

As a potential tool to support chronic pain self-management, interventions have been developed and trialed. These interventions may be one means of informing, motivating, and equipping Canadians with skills for chronic pain self-management; providing or referring to a self-management interventions may be a way by which health care professionals can support their patients’ taking an active role in their health. The following chapter reviews the evidence for chronic pain self-management interventions and the role of health care professionals in supporting self-management behaviours.

Conclusions

Chronic pain is a prevalent condition that is both difficult and costly to manage. Without the ability to relieve pain completely, affected individuals must manage their pain themselves. Preparing individuals for this role, supporting their on-going self-management needs, and creating a supportive policy environment are three important aspects of providing effective care for chronic pain. In Canada, the research needed to inform this care is currently lacking, including (1) a clear definition of self-management programs and the evidence to support their use, (2) recommendations for specific actions health care professional can take to support chronic pain self-management, (3) insight into current chronic pain self-management practices and challenges, and (4) an awareness of whether individuals with chronic pain with NC differ in their self-management practices and challenges relative to those with chronic pain without NC.
The following three chapters will address these research gaps, and recommendations are provided in chapter 6.
References


Chapter 3
Self-Management Interventions for Chronic Pain

Co-Authors:
LeFort, S. & VanDenKerkhof, EG

Published in:
Mann EG, LeFort S, VanDenKerkhof EG. Self-management interventions for chronic pain.
Practice Points

1. Self-management interventions teach the skills required for day-to-day management of chronic pain conditions and may be based on the Stanford model, acceptance and commitment therapy, or cognitive-behavioural therapy.

2. Self-management interventions target self-efficacy and include peer role-modeling, practicing skills, feedback and support, and/or addressing emotions.

3. Self-management interventions delivered in group sessions include the benefit(s) of the group dynamic while being cost-effective and online interventions can be used to reach immobile or rural groups.

4. Self-management interventions are effective in reducing pain, and improving mental health and health-related quality of life in chronic pain groups.

5. Self-management interventions combined with antidepressant pharmacotherapy are more effective in reducing depression than either modality alone.

6. Individuals must accept the chronic nature of their pain before they are ready to listen to self-management teaching.

7. Self-management teaching needs to be tailored to individual functional abilities, include regular support and encouragement, and be consistent between clinicians.

8. Individuals encounter both barriers and facilitators of self-management that need to be first assessed and then addressed by either health care providers or self-management interventions to help individuals succeed.

9. The Pain Stages of Change Questionnaire can be a useful tool to help identify who is ready to self-manage their pain.
Abstract

Individuals living with chronic pain face daily challenges of managing symptoms, modifying roles and responsibilities, and coping with the negative emotional consequences of pain. Self-management interventions teach a variety of strategies to meet these challenges and build participants' self-efficacy for their use. These interventions have been delivered in individual, group, and online formats for a variety of different pain conditions. The evidence supports the efficacy of self-management interventions in improving pain, mental health, and health-related quality of life outcomes. Acceptance of the chronic nature of their pain is a necessary step before individuals are ready to self-manage. Clinicians can play a critical role in supporting self-management through answering questions, providing advice, addressing barriers and facilitators and encouraging self-management efforts.
Introduction

Chronic pain presents a worldwide challenge due to its high prevalence and cost. Recent international prevalence studies suggest that 11-45% of community-dwelling individuals report chronic pain (1-7) often experienced at multiple body sites (8). Chronic pain is associated with psycho-social distress and physical disability (9), and multiple interventions are often needed to achieve significant pain relief (10). When compared to other devastating conditions such as cancer, chronic pain results in significantly worse health-related quality of life (11), and healthcare costs (12).

Chronic pain, like all chronic conditions, requires day-to-day management by the affected individual or ‘self-management.’ Kate Lorig and Holman Halstead, leaders in the field for the past three decades, have delineated the key tasks involved in the self-management of a chronic condition to enhance quality of life. These tasks include managing medical interventions such as using medication appropriately and building partnerships with their health care providers; using cognitive and behavioral strategies to manage symptoms; modifying family, social, and work roles and responsibilities to maintain some normalcy in life; and dealing with the emotional consequences of a chronic condition. Daily challenges will be different for each individual and may change over time, thus transferable skills like problem-solving, decision-making, resource identification, and communication skills for partnering with healthcare providers are invaluable (13).

Self-management also requires the ability to appraise one's situation and resources, and decide on a course of action (13). This ability is called self-efficacy in social cognitive theory and can be enhanced by: (1) practicing and mastering a task or skill, (2) observing peers modeling the skill, (3) receiving reinforcement feedback and support, and (4) working on
improving one's emotional state (14). Self-management interventions (SMIs) have been
developed to target and improve self-efficacy, and thus include at least one, and most often a
combination, of the above four efficacy-enhancing strategies.

The following paper reviews the evidence for self-management interventions in chronic
pain groups. An intervention was considered an SMI if it met Lorig’s definition of self-
management; specifically, an intervention was included if it (1) taught a pain management skill,
(2) targeted self-efficacy through one of the previously mentioned strategies, and (3) involved
participants in pain management goals (13). Studies were also limited to those (1) published in
2007 or more recent, (2) included participants who reported pain for a minimum of three months,
(3) and provided a detailed description of the intervention. All studies addressing the clinician's
role were also included. As the focus of SMIs is equipping individuals with self-efficacy and
not on teaching specific exercises, a discussion of exercise approaches is a separate topic for
review.

**Overview of Self-Management Interventions**

**Intervention Types**

A wide variety of SMI programs are described in recent studies. Although some authors
specify no basis for their intervention protocols, three models are frequently cited as being used
or adapted to develop interventions (table 3.1). First, the Stanford model of patient self-
management aims to provide individuals with a toolkit of knowledge and skills for managing
pain and the physical, social, and emotional consequences. It is typically delivered in a
community setting, and facilitated by a health care professional and community volunteer with a
chronic pain condition or, more recently, by two trained lay leaders (16). The second type of
SMI, acceptance and commitment therapy, aims to help individuals change behaviours that are
motivated by fear of pain to those motivated by a desire to engage in valued activities despite pain (15). This SMI is generally delivered in a clinical setting by a clinical psychologist or an inter-disciplinary team consisting of psychologists, nurses, and occupational and physical therapists. Third, cognitive-behavioural therapy principles have been used to develop or supplement a pre-existing SMI. Cognitive-behavioural therapy seeks to help individuals identify the relationships between their thoughts, emotions and behaviours and encourage positive self-management behaviours (17). It is delivered in a clinical setting by a trained individual (17), typically a clinical psychologist or cognitive-behavioural therapist. The details of each SMI may or may not be tailored to meet specific needs of different chronic pain groups. For example, both unmodified (18, 19) and modified (20-22) acceptance and commitment therapy interventions have been tested and found effective in pain groups reporting high levels of pain distress, disability, and/or interference.

Format

SMIs are delivered using various formats, settings, and facilitators to reach a target pain population (table 3.2). Group sessions are the most common format, and are frequently cited as a strategic decision whereby the group dynamic is used to encourage problem-solving (19, 23-33) and role-modeling (27,35). Hurley tested a SMI in individuals with chronic knee pain that included both education topics similar to the Stanford model and an exercise component. Using a randomized cluster design, 418 participants were assigned to SMIs delivered in individual or group sessions or usual care. When all groups were compared six months after completing the intervention, participants receiving the SMI sessions in either format reported significantly improved physical function, health-related quality of life, pain, anxiety, and self-efficacy (25). Group sessions were less expensive to deliver (36), and there may be added benefits from group
processes (e.g., social interaction), validation from other group members, and the structure and routine of group meetings (37).

**Setting**

Hospital and clinic locations are the most common settings for SMIs. Less formal setting options include community locations such as seniors centres (29, 38), which may improve accessibility. Rarely, SMIs have been delivered by a facilitator in an individual's home when limited mobility presents a significant challenge (39, 40). Telephone- and internet-based interventions have been developed and tested more recently, and they allow participants to select their own setting and timing (18, 38, 41-53) (table 3.2).

**Facilitator**

SMIs are delivered by multi-disciplinary health care providers, or by trained lay leaders in the case of standardized interventions. Most SMIs are delivered by at least two facilitators whose roles may differ depending on their area of expertise. In group and individual sessions, facilitator roles may include educating (e.g., differences between acute and chronic pain) (54), instructing in skills (e.g., correct low back posture) (55), leading brainstorming and problem-solving discussions to help individuals reach their goals (56), and role-playing scenarios (e.g., communicating with family/primary care physician) (57). In SMIs delivered online or via telephone, facilitator roles include designing online content (58), providing feedback on discussion or journal posts (46, 59), problem-solving with an individual (41), and reviewing previously taught skills (60) (table 3.2).

**Participants**

SMIs have been tested in individuals across the life span living with varying conditions and levels of pain and disability. SMIs are most often delivered to adults aged 18 years or older
who are able to attend sessions in community or clinical settings, however SMIs are also commonly designed for, and offered to, groups of adults aged 50 years and older. Chronic pain of all types, back pain, and arthritis are the most commonly studied conditions (table 3.2).

Because pain occurs in a social context, partners and/or parents are often invited to attend at least one session or participate in a specially-designed partner/parent intervention (27, 60-63).

Participants were recruited from pain clinics (28, 35, 45, 54, 64-66), rehabilitation facilities (21, 22, 61, 67), primary care (19, 25, 33, 36, 41, 48, 56, 69-75), and community centers (23, 29, 30, 37, 55, 76) representing various levels of health status and access to health care services.

**Evidence for Self-Management Interventions**

**Feasibility**

SMI feasibility studies have focused on acceptability and utility of new delivery modes, and measures of cost-effectiveness have been included in other SMI studies. Costs and health care use were included in one pragmatic randomized controlled trial (26) and one cohort study (35) with those participating in the intervention having lower pain management costs (e.g., fewer follow-up appointments). Recipients of SMIs report decreased use of analgesics (69, 70, 77), hospitalizations (78), visits to emergency rooms and other medical/health consultations (30, 77, 79, 80), and overall self-reported health care use (21, 22, 81) compared to pre-SMI use or a usual care group.

The acceptability of group and individual self-management sessions has been largely established in prior research. Current studies have focused on whether individuals perceive SMIs delivered in an online format to be useful, acceptable, and satisfactory. Moderate to high ratings of acceptability, usefulness, and satisfaction with online formats have been reported in teenagers aged 11 to 17 years (50, 58) to adults aged 55 years or older (38). There were only two
studies where the online delivery of a SMI was either not well accepted in a small group of adults, or felt to be too labour-intensive when a lot of time using a hand-held device was needed to complete online journals and questions (46, 53). Generally, researchers reported lower adherence to programs with significant required time (e.g., attendance of both affected individuals and partners (62) and minimal contact with peers and/or health care providers (18) (table 3.2).

**Pain, Health-Related Quality of Life, & Mental Health**

Pain is the most commonly measured outcome of SMIs, and is generally measured as pain intensity, pain disability, and/or pain interference. In reviewed studies that included one of these pain outcomes, statistically significant immediate (e.g., measured at the end of intervention) (20, 24, 35, 44, 49, 55, 60, 61, 63-65, 77, 82-91) and sustained improvements (e.g., typically measured three to 12 months after the intervention ends) were reported (20, 22, 24, 25, 30, 31, 41, 47, 50, 54, 58, 60, 63, 64, 66, 68, 70, 76, 77, 79, 82, 86, 88, 90-93). Effect sizes for reduced pain intensity and interference fall between $d=0.27$ and $d=0.50$ (50, 58, 63, 79), with pain intensity ratings decreasing by one to three points/millimeters on an 11-point visual analogue or numeric rating scale (41, 50, 68, 94). Improvements in pain were noted immediately following the intervention and in the following months and years. An improvement immediately following the intervention did not predict whether improvement would be reported in the following months and years (e.g., groups with no immediate pain improvement reported improved pain at later follow-up), which suggests multiple processes underlying these improvements.

Measures of mental health are the second most common outcome of SMI research, including catastrophizing, depression, and anxiety. Participants of SMIs consistently report less
catastrophizing (33, 43, 44, 49, 51, 53, 69, 70, 81, 86, 87, 65, 93-95) and anxiety (18-20, 25, 45, 51, 55, 61, 63, 66, 70, 87, 88, 96-98) than pre-intervention or usual care group levels immediately following the intervention. This improvement was generally sustained in the following months to years, however, unlike pain there were no delayed gains in either catastrophizing or anxiety. This supports the work of Curran and colleagues who identified post-treatment improvement as the best indicator of long-term improvements in mood, self-efficacy, and catastrophizing (97).

The evidence for SMIs decreasing depression is mixed with both significant (19, 22, 44, 45, 50, 54, 55, 61-63, 66, 69-71, 77-81, 85, 95, 96, 98, 100) and null results reported (18, 23, 25, 26, 33, 40, 51, 61, 64, 65, 69, 70, 88, 89, 93, 99, 101). Individuals with depression are potentially less likely to be ready to self-manage their pain, and have higher levels of pre-treatment pain intensity and disability (86, 100). Despite these challenges, having co-morbid depression does not mean that an individual will not experience positive outcomes from a SMI. Glombiewski screened participants for depression prior to their starting a SMI. Having pre-treatment depression did not predict post-treatment variation in pain intensity scores (85). In interventions combining self-management and antidepressant pharmacotherapy, participants receiving the combined therapies reported significantly better mental health outcomes that those receiving usual care, just self-management, or just pharmacotherapy (71, 87). These findings suggest that maximum improvements in depression may require both self-management and aggressive antidepressant therapies.

The evidence for the role of SMIs in improving health-related quality of life is also relatively consistent both immediately and in the months following the delivery of a SMI (18, 19, 27, 32, 34, 35, 43, 48, 49, 60, 67, 68, 77, 84, 91, 101). This improvement has been reported in
both mental and physical domains of health-related quality of life, but is more common in physical domains. All long-term improvements in health-related quality of life were preceded by a short-term gain, thus the processes by which health-related quality of life can be improved through SMIs occur during the delivery phase.

**Health Care Providers' Role in Self-Management**

**Self-Management Advice**

Health care providers (HCPs) can support self-management by providing self-management advice and encouragement for those who are ready. Individuals with chronic low back pain have reported that, as a necessary first step in learning to self-manage, they had to make an internal shift to realize that their active participation was necessary for relief of pain (e.g., physiotherapy only helped if they performed their homework between visits). This shift helped them see themselves, rather than a clinician, as the agent of relief, and to view relief as a long-term practice rather than an immediate cure (102).

Helping individuals make this shift in focus from cure to active self-management was a key approach used by HCPs of multidisciplinary pain clinics when biomedical interventions had failed to provide relief (103). Facilitating this shift involved educating patients/clients about the ‘chronic’ nature of their pain, emphasizing self-management as a therapy similar to traditional biomedical treatments, sharing pain management plans with patients/clients, and shifting the perception of HCPs from one of medical intervention to one of skills education (e.g., stretches, relaxation) (103).

Once focused on management, individuals report being ready to hear self-management messages (102). When interviewed, patients with chronic pain reported that self-management
messages were most helpful when they were consistent between HCPs (104), individualized for their level of function (102), and supported with on-going reassurance and encouragement (102).

A discrepancy may exist between how HCPs and those living with chronic pain perceive the role of HCPs. When HCPs were asked to describe their role in supporting self-management for patients with chronic low back pain, they included encouraging exercise, prescribing analgesics, providing sickness certificates, and referring to specialists (105). Conversely, individuals with chronic spinal cord pain identified family physicians as the person to whom they address their management questions, although most reported that he/she was not able to answer them. Question topics included both traditional medical and alternative pain management therapies, pain causes, future expectations, how other people with similar conditions manage, and how to access information on their condition (106).

**Identifying and Targeting Self-Management Barriers and Facilitators**

Using qualitative interviews, individuals have been asked to describe barriers and facilitators of chronic pain self-management (table 3.3). Some barriers could be targeted directly; for example, an individual who is doing fairly well self-managing but reports a lack of family support may be encouraged to attend a support group or referred to a SMI that encourages family participation. Other barriers may highlight the need for referral to a SMI (e.g., an individual who feels that his/her current self-management strategies are ineffective). Still other barriers may be permanent but addressed through a SMI or self-management advice tailored to specific needs (e.g., modified exercises for individuals with spinal cord injuries).

Other personal or situational factors may present opportunities for clinicians to build on the individual's resources (table 3.3). Some of these factors may be addressed easily by HCPs, such as reinforcing the evidence (107) and encouraging self-management activities (108). Other
facilitators of self-management may be optimized through a SMI, such as receiving support from peers (109) and learning a variety of new skills (108).

**Selecting Individuals for Successful Self-Management Intervention**

Following participation in a SMI, specific qualities have been identified which seem to predict, mediate, or be associated with improved outcomes (table 3.4). Similar to the findings of qualitative research on the perquisites of listening to self-management advice, acceptance of the chronic nature of pain and willingness to take an active role in management were identified. These qualities can be used to recognize which individuals are likely to benefit from a SMI prior to their referral to an intervention.

The Pain Stages of Change Questionnaire has also been used to assess readiness to self-manage (110). This tool is based on the transtheoretical model of change and stages theory and categorizes individuals into one of four stages: *precontemplation, contemplation* (combined with the preparation stage from the model), *action*, and *maintenance* (111). Individuals in the *precontemplation* stage look to HCPs to manage and relieve their pain (110) and may have high levels of psychological distress, low self-efficacy, and fear of movement (112). These individuals are unlikely to be ready to engage in active self-management (113). Those in the *contemplation* stage have just started to consider involvement in pain management but may not have the necessary skills (110). Individuals in this stage may benefit from a SMI where they can gain the knowledge, skills, and self-efficacy to get started. In the *action* stage, individuals are learning and using self-management skills, and may turn to HCPs or SMIs to reinforce and teach new skills (110, 113). Individuals in this stage tend to have low levels of psychological distress, low fear of movement, and high levels of self-efficacy (112). Finally, individuals in the *management* stage use self-management strategies that they find useful and express confidence
in their ability to manage future pain (110). There is evidence to support the benefit of SMIs, resources, and support from HCPs for individuals in the contemplation and action stages of self-management (67, 114), thus assessing stage of change may help identify who will benefit from a SMI.

**Conclusion & Future Perspective**

Chronic pain is difficult to manage. Even with multiple treatment modalities and maximally tolerated doses of the best pharmacologic agents, pain intensity is often reduced by only 26-38% (10, 115), thus individuals are increasingly relying on SMIs to manage their pain. This paper includes a review of research on current approaches to SMIs, as defined by Lorig (13) and published in the past five years, when a critical mass of research in this field began to emerge. The results suggest that SMIs can reduce both the physical and psychosocial burden on affected individuals while reducing healthcare use. Although research participants may be different from the average individual with chronic pain (e.g., motivated to learn new pain management skills), these results include participants from various sectors of care and they support the need for HCPs to explore whether SMIs are an appropriate addition to their current chronic pain care.

HCPs play an important role in realizing these positive effects. To actualize this role, HCPs may require additional training in how to collaborate with their patients/clients in setting health goals and decision-making and tailoring SMIs to individual barriers, facilitators, and needs. The role of personality factors and traits as barriers to self-management have been identified in the literature, however they were not addressed in the studies included in this review.
Some of the current self-management barriers may be eliminated through the use of online SMIs. Self-management websites provide a cost-effective means of reaching individuals in their own homes, thus eliminating issues of mobility, transportation, and rural access. Online material also allows individuals to tailor interventions by providing opportunities for them to select topics of interest, re-read sections, and continue to receive self-management support outside of a specific number of sessions.

The shift in focus from cure to on-going care has been repeatedly identified as a critical step in learning to self-manage. Further work is needed to understand how to help individuals accept the chronic nature of their pain. Evaluating readiness to self-manage may help with identifying who is appropriate for referral to a SMI, however, more work is needed in developing tools for this purpose.
Acknowledgements

The authors would like to thank the Canadian Pain Society for providing funding through the Trainee Research Interchange Program which supported collaboration on this paper.
References


**Provides a comprehensive overview of self-management.**


An example of how self-management interventions can been tailored to meet the needs of unique groups.


*Highlights a new approach to addressing self-management in paediatric groups and involving the family unit.


95. Zautra AJ, Davis MC, Reich JW, et al. Comparison of cognitive behavioral and mindfulness meditation interventions on adaptation to rheumatoid arthritis for patients with and without


*Provides an overview of self-management barriers and facilitators.


*Outlines the use of the Pain Stages of Change Questionnaire for assessing readiness to self-manage.


Table 3.1. Overview of common self-management interventions.

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Common Topics</th>
<th>Typical Mode &amp; Length</th>
</tr>
</thead>
</table>
◦ goal-setting and action plans  
◦ pain management tools (e.g., use of medications, multiple cognitive strategies)  
◦ problem-solving  
◦ physical activity and exercise  
◦ healthy eating  
◦ dealing with difficult emotions and depression  
◦ fatigue and sleep  
◦ working with your healthcare provider | Group sessions:  
◦ 6 weeks with 2 hours of group sessions per week  
(total hours: 12)  
Online:  
◦ 6 weeks with 1-2 hours online per week to cover all 25 sessions (total hours: 6-12)  
Workbook provided for group and online sessions. |
| Acceptance and Commitment Therapy (15)                                      | ◦ principles of the pain-avoidance-suffering cycle  
◦ identifying values/values activities, and gradually increasing exposure to values-directed behaviour (instead of pain-directed behaviour)  
◦ cognitive defusion (identifying and observing negative thoughts without acting on them, and distancing oneself from them)  
◦ mindfulness  
◦ accepting and being willing to engage with pain  
◦ committing to action and identifying obstacles to desired action  
◦ planning for future action and obstacles | Group sessions:  
◦ 3-4 weeks of 6.5 hours/day for five days of each week  
◦ 8 weeks of one 1.5 hour sessions each week  
Workbook with telephone support +/- one individual session:  
◦ 6 weeks of scheduled workbook exercises with one telephone call per week |
| Modified Cognitive-Behavioural Therapy* (17)                               | ◦ cognitive restructuring (e.g., identifying and evaluating catastrophic thinking and constructing realistic alternatives)  
◦ identifying and restructuring pain avoidance beliefs and behaviours  
◦ behavioural activation (e.g., pacing, activity scheduling)  
◦ understanding biopsychosocial influences of pain  
◦ goal-setting  
◦ lifestyle changes (e.g., exercise)  
◦ self-regulatory skills (e.g., progressive muscle relaxation, breathing exercises) | Group sessions:  
◦ 5-12 weeks with one 1.5-2 hour session each week  
Individual sessions:  
◦ 6-25 weeks with 2-25 sessions  
Online:  
◦ 4-8 weeks with 1 or more modules per week |
<table>
<thead>
<tr>
<th>Intervention</th>
<th>Common Topics</th>
<th>Typical Mode &amp; Length</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>▪ pain management skills (e.g., attention diversion, stress-coping skills)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>▪ relapse prevention strategies</td>
<td></td>
</tr>
</tbody>
</table>

*This description reflects cognitive-behavioural therapy as it has been modified in the current literature to include elements of self-management and self-efficacy.*
Table 3.2. Overview of self-management intervention organization and delivery.

<table>
<thead>
<tr>
<th>Organizational Aspect</th>
<th>Variations</th>
</tr>
</thead>
</table>
| **Formats**           | - group sessions  
|                       | - individual sessions  
|                       | - telephone calls and/or self-study toolkits  
|                       | - online website  
|                       | - combinations (e.g., initial individual session followed by telephone calls)  |
| **Non-Completion and Withdrawals** | - percentage in group or individual sessions range from 0-58% (average percent reported = 21%)  
|                       | - percentage in online sessions range from 0-26% (average percent reported = 16%)  
|                       | - percentage in self-study toolkits range from 30-54%, (average percent reported = 42%)  |
| **Settings**          | - hospital/clinic  
|                       | - community centre  
|                       | - home (individual, online, or telephone formats)  |
| **Facilitators**      | - clinical psychologists  
|                       | - physical and occupational therapists  
|                       | - nurses and nurse practitioners  
|                       | - physicians  
|                       | - students or others trained in cognitive-behavioural therapy  
|                       | - social workers  
|                       | - fitness instructors  
|                       | - trained community volunteers living with the targeted chronic pain condition  
|                       | - combinations of professionals or a professional teamed with a trained volunteer  |
| **Participants**      | - aged 8 to 89 years  
|                       | - pain present for a minimum of 3 months  
|                       | - unknown, moderate or high levels of daily pain-related disability, interference, and/or anxiety  
|                       | - mild to severe pain intensity  
|                       | - pain conditions: general chronic pain, back pain, osteo- and rheumatoid arthritis, hemophilia, non-cardiac chest and angina pain, tempromandibular joint dysfunction pain, fibromyalgia syndrome, chronic widespread pain, headaches, irritable bowel syndrome, and spinal cord injury pain |
Table 3.3. Barriers and facilitators of self-management*

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td>-Lack of support from family and friends</td>
<td>-Encouragement from health care providers</td>
</tr>
<tr>
<td>-Limited physical resources</td>
<td>-Treated depression</td>
</tr>
<tr>
<td>-Depression</td>
<td>-Supportive family and friends</td>
</tr>
<tr>
<td>-Ineffectiveness of pain management strategies</td>
<td>-Having a variety of self-management strategies to use</td>
</tr>
<tr>
<td>-Time limitations and competing life priorities</td>
<td>-Social support from individuals with the same condition</td>
</tr>
<tr>
<td>-Activity avoidance due to fear of pain exacerbation</td>
<td>-Flexibility in self-management program scheduling</td>
</tr>
<tr>
<td>-Lack of tailoring of strategies to personal needs</td>
<td>-Tailoring of self-management program to level of disability</td>
</tr>
<tr>
<td>-Inability to maintain use of strategies outside of an intervention study</td>
<td>-Hearing concrete evidence supporting the effectiveness of self-management strategies</td>
</tr>
<tr>
<td>-Physical limitations</td>
<td></td>
</tr>
<tr>
<td>-Difficult patient-physician interactions</td>
<td></td>
</tr>
</tbody>
</table>

*These barriers and facilitators were identified from three studies (107-109)
Table 3.4. Factors predicting or associated with positive outcomes of self-management intervention.

<table>
<thead>
<tr>
<th>Factors</th>
<th>Predictors/Correlates/Mediators/Moderators of Positive Outcomes</th>
</tr>
</thead>
</table>
| Demographic                      | - Non-Caucasian ethnicity (116)  
- Older age (117)                                                                                                                                                                                                                                             |
| Health Status                    | - Pain intensity (118, 119)  
- Fewer comorbid conditions (117)  
- Physical activity (120)                                                                                                                                                                                                                                |
| Mental Health                    | - High baseline levels of pain-related anxiety (116)  
- Catastrophizing (118)  
- Optimism (117)                                                                                                                                                                                                                                           |
| Pain and Management Beliefs      | - High self-efficacy (100, 113, 120-122)  
- Sense of internal control over pain (100)  
- High perceived importance of self-management behaviour (122, 123)  
- High acceptance of chronic pain and perceived ability to manage it (118, 124)  
- Pain beliefs (125)  
- Stage of change/readiness to change (contemplation, action, or maintenance stage as per the Pain Stages of Change Questionnaire) (111, 122, 123, 126) |
| Current Self-Management Skills   | - Use of self-management strategies prior to intervention (119)  
- High level of mastery in skills related to care of condition (117)                                                                                                                                                                                   |
| Health Care Provider's Actions   | - Giving information on the effectiveness of self-management strategies and illness, and clarifying doubts and questions during clinical encounters (119)  
- Receiving loss-based messaging of self-management behaviours (e.g., "if you don't perform self-management behaviour X you may experience the following negative consequences...") (113)  
- High satisfaction with information provided by primary care physician (100)                                                                                                                   |
Chapter 4

Self-Management of Chronic Pain with and without Neuropathic Characteristics

Target Journal: *PAIN*

Co-Authors:

VanDenKerkhof EG; LeFort, S; & Harrison, MB
Abstract

The aim of this study was to describe and compare adults with chronic pain with and without neuropathic characteristics (NC) on sociodemographic and pain characteristics, self-management strategies, and satisfaction with ability to control pain. This analysis was based on participants reporting chronic pain in a cross-sectional survey of the general Canadian population. Respondents were considered to have chronic pain if they reported pain for more than three months, and NC if they scored 12 or higher on the Self-Report Leeds Assessment of Neuropathic Symptoms and Signs Pain Scale. Seven hundred and ten respondents reported chronic pain; 188 screened positive for NC. Participants with NC were more likely to have lower sociodemographic statuses, and report daily pain (Relative risk [RR]=1.26, 95% Confidence interval [CI]=1.08-1.37) of severe intensity (RR=1.94, CI=1.65-2.29) affecting five or more body areas (RR=1.34, CI=1.19-1.51) compared to those without NC. They were half as likely to self-manage their pain with solely non-pharmaceutical techniques (RR=0.51, CI=0.29-0.90), and over twice as likely to self-manage the emotional consequences of chronic pain through substance use (RR=2.38, CI=1.46-3.87), denial (RR=2.34, CI=1.55-3.54), and behavioural disengagement (RR=2.03, CI=1.40-2.95). They were also more likely to be completely dissatisfied with their ability to control pain (RR=1.72, CI=1.32-2.24). After adjusting for general health and sociodemographic characteristics, those with and without NC were equally likely to make five or more annual visits to a doctor (Odds ratio=1.13, CI=0.71-1.80). Individuals with and without NC have distinct pain and self-management experiences, and may benefit from tailored self-management assessment and support.

Keywords: chronic pain, neuropathic pain, self-management, pain management, satisfaction
Introduction

Chronic pain is reported by 7.4%-58.0% of community-dwelling adults internationally (1-9) with up to half of these adults (17-51%) reporting pain characteristics which suggest neuropathic mechanisms (e.g., allodynia) (7, 10-12). Over the past eight years of research, individuals reporting chronic pain with neuropathic characteristics (NC) have emerged as a distinct subset of individuals within those with chronic pain. They report higher average pain intensity (10-12), more daily variation (10), and a higher number of affected body areas (10, 11) compared to those without NC. The presence of NC are also associated with lower levels of health-related quality of life (12-14) and greater pain disability and interference with sleep, family relationships, mobility, work, and social activities (7, 13-15).

Despite the development and use of various management options, the best management outcome reported in the literature is a 30% reduction in pain intensity in half of the study participants (16). As complete pain relief is rare, self-management interventions have been developed to equip individuals with the necessary skills to manage the effect of pain on their day-to-day lives. Three general categories of self-management have been identified: medical self-management of physical symptoms, emotional self-management of psychological stress, and role self-management of valued behaviours (17). Comparison between pain groups suggests that medical self-management is more complicated in individuals with NC, including more frequent and/or recent use (11) of multiple (7, 18, 19) prescription strength (18, 20) medications. Despite greater use of medications, those with NC report less resulting pain relief (7, 18, 19, 21).

Emotional and role self-management have not been explored in individuals with NC. There is preliminary evidence that those with NC may be more likely to experience co-morbid depression (20), suggesting a greater need for emotional self-management. The pain associated
with NC may also increase the need for emotional self-management as a higher risk of depression and anxiety has been identified in individuals with chronic pain of higher intensity (22-24) and affecting multiple body locations (22).

Understanding these day-to-day self-management strategies would be a substantive support in guiding clinicians in their assessment of individual self-management capacity and resources, provision of self-management education, and discussion of management options (e.g., referral to a self-management program). Thus, the purpose of this study was to compare medical and emotional self-management strategies in individuals with chronic pain with and without NC. The research objectives were to: (1) describe the sociodemographic and pain characteristics of those with and without NC, and (2) compare self-management strategies and satisfaction with the ability to control pain between the two pain groups.

Methods

This study was reviewed for ethical compliance by the Queen's University and Affiliated Teaching Hospitals Research Ethics Board (ANAE-174-10) (appendix 4).

Participants

This study was part of a larger national survey of 8,000 Canadians randomly selected from telephone book listings (25) (appendices 5-9). Six hundred and ninety-five participants responded to the main survey and reported chronic pain and were included in this study sample. An additional 15 individuals with chronic pain learned about the survey from a family member or friend and asked to participate. No differences in pain characteristics were found in a sensitivity analysis between the random and non-random samples, therefore the samples were combined for a total sample of 710 individuals with chronic pain.
Case Identification

Participants were screened for chronic pain with NC using the methodology reported by Torrance and colleagues (2007). First, participants were asked two questions: "are you currently troubled by pain or discomfort, either all the time or on and off?" and "have you had this pain or discomfort for more than 3 months?" (appendix 7, item 1). Those who responded affirmatively to both questions were considered to have chronic pain. Second, the presence of NC was determined using the Self-Report Leeds Assessment of Neuropathic Symptoms and Signs Pain Scale (S-LANSS) (26, 27). The S-LANSS consists of seven items, which screen for sensory abnormalities and autonomic involvement (e.g., allodynia) with scores ranging from zero to 24 (appendix 7, items 36-42). Based on recommendations for use of the S-LANSS, scores of 12 or higher indicated the presence of NC and scores less than 12 denoted chronic pain without NC (26, 27). Using a cut-off score of 12, the S-LANSS has a sensitivity of 83-85% and specificity of 80-87% compared to diagnosis made by clinical examination (26, 27).

Objective 1: Describe the sociodemographic and pain characteristics of those with and without NC

Sociodemographic and general health information.

Participants were asked to provide sociodemographic information including age, gender, marital status, education, employment, household annual income, and ethnic origin (appendix 7, items 8-17). To capture general health, participants were asked to indicate their smoking status and select all diagnoses made by a health professional from a modified list of the chronic health conditions taken from the 2010 Canadian Community Health Survey (CCHS) (28) (appendix 7, items 7 and 18). Health-related activity interference was also captured by a modified item from the 2010 CCHS, which asked participants how many days in the past year their health interfered
with physical or daily activities including socializing (appendix 7, item 21). Responses for categorical sociodemographic and general health items were collapsed to create a minimum of five per cell and approximately equal groups.

**Pain characteristics.**

Pain intensity was captured with a numeric rating scale (NRS) (appendix 7, item 35) (29-31). As NRS responses did not meet the requirements for normalcy, they were categorized into none or mild (0-3), moderate (4-6), and severe (7-10) as has been recommended for neuropathy (32). Participants were provided a body diagram and asked to identify in which of the 35 possible areas they experienced pain (appendix 7, item 5). Responses were categorized into 1-2, 3-4, and 5 or more locations for comparison with the literature (11). Pain timing was captured using one item that asked participants how often they were bothered by pain with four possible options (appendix 7, item 2) (2, 33). Responses of "once per week" and “once per month” were collapsed to maintain a minimum of five per cell. Participants were provided with a list of common causes of pain (and a space to specify other unlisted causes) and were asked to select all causes with which they had been diagnosed (appendix 7, item 4).

**Objective 2: Compare self-management strategies and satisfaction with ability to control pain between the two pain groups**

**Pain self-management.**

Medical self-management was captured from the open-ended question on the Level of Expressed Need scale (LEN) (34): "what treatments or medications are you receiving for your pain?" (appendix 7, item 59). Responses to this question were categorized as none, non-pharmaceutical strategies only, medication only, combination of medication and non-pharmaceutical strategies, or other (e.g., waiting for surgery). The primary type of health care
professional involved in pain management was identified with the question, "which health professional(s) do you feel is the most helpful in managing your pain?" Options included family doctor, specialist doctor (e.g., rheumatologist), physical or occupational therapist, nurse or nurse practitioner, health care team, and a space to specify a practitioner not included in the list (appendix 7, item 99). Because many participants selected multiple health care providers from the list, the most common combinations are also presented. Visits to health care providers were captured with four items adapted from the 2010 CCHS (28) which asked participants to provide the number of visits to a doctor, specialist, walk-in clinic, emergency room (ER), and/or ‘other’ health care professional they had made in the past 12 months (appendix 7, items 19 and 22). Annual visits were not normally distributed and thus were categorized using the 75th percentile for visits to a doctor into < 5 or ≥ 5 annual visits to allow for the proportion of the most frequent visitors to be compared between pain groups. Due to the infrequency of visiting a walk-in clinic or ER, responses were categorized into 0 or ≥ 1 annual visits. Sixty-nine percent (n=487) of participants did not provide a response for items asking about the number of annual visits made to walk-in clinics and ERs. There were no significant differences between pain groups in the proportion of missing responses for walk-in clinics ($\chi^2=0.42$, p=0.52) or ERs ($\chi^2=1.33$, p=0.25), thus to make a conservative estimate, missing responses to these two items were coded as no annual visits.

Emotional self-management was captured with the Brief COPE (appendix 7, items 60-87) (35). This 28-item tool captures information on how frequently participants use 14 different strategies (e.g., substance use, venting, active coping) to deal with stress in their lives. Participants rate the frequency of their use from "I haven't been doing this at all" to "I've been doing this a lot" with possible scores for each strategy ranging from two to eight. For the
purpose of this study, participants were asked to think of how they deal with the stress caused by living with chronic pain when considering the response options. Responses to the two items reflecting each strategy are added to generate a score (35). Only two of the 14 strategies of the Brief COPE were normally distributed in both pain groups, thus medians are presented to allow for comparison with the literature. Scores for each strategy were categorized to reflect use (5+/8) and no or infrequent use (2-4/8) to allow for comparison between the two pain groups.

Satisfaction with ability to control pain.

Participants’ satisfaction with their ability to control pain was captured with one item adapted from the 2010 CCHS (28) which asked “in the past 12 months, how happy have you been with your ability to control your pain by means of medication or other therapy?” Participants had four response options: “not applicable, since I have no significant pain,” “completely dissatisfied,” “somewhat or fairly satisfied,” and “completely satisfied” (appendix 7, item 23). The first response option was included for survey respondents without pain who were included in the larger study for comparison purposes. The 12-month time frame in this question allowed for intermittent exacerbations and improvements, and seasonal changes (e.g., rheumatic diseases) to be captured in responses.

Analysis

Continuous variables were graphed and kurtosis values used to assess distribution. Descriptive statistics were used to compare sociodemographic and pain characteristics, self-management strategies, and satisfaction between participants with and without NC. Age was compared between pain groups using independent t-tests; all other variables were compared between groups using χ² tests, odds ratios (ORs), relative risk (RR), and 95% confidence intervals (CI). Five multivariable binary logistic regression analyses were conducted to test for
the effect of NC visits to health care professionals, including five or more annual visits to a (i) doctor, (ii) specialist, (iii) other health professional, and one or more annual visits to a (iv) walk-in clinic and (v) ER. All general health variables (smoking status, health-related activity interference, and number of co-morbid conditions) and sociodemographic variables (age, sex, marital status, highest education, employment status, type of residence, household income, and ethnicity), with p values less than 0.10 in bivariate analysis were entered simultaneously into each regression equation. The categories representing the better health state (e.g., no co-morbid conditions) were used as the reference group. Variables with p values ≥ 0.05 were manually removed from each model by removing the least significant variable and rerunning the model, until only variables with a p value < 0.05 remained. Categorized S-LANSS scores (< 12 and ≥12) were forced into all models. Hosmer and Lemeshow tests were used to assess model fit. All tests were two-tailed. Data were analyzed using SPSS version 21.0.

Results

Objective 1: Describe the sociodemographic and pain characteristics of those with and without NC

Sociodemographic characteristics.

In comparison with the general Canadian population, the study sample was older (average of 40 years vs. sample average age of 58-59 years) (36) which may partly explain why a smaller proportion of the sample was single (39.5% of Canadians vs. 7.9-8.6% of sample) (37) and working full- or part-time (62% of Canadians vs. 43-48% of sample) (38), and a larger proportion of the sample reported a household income less than $50,000 (28% of Canadians vs. 34-50% of sample) (39) (table 4.1). The sample reported a higher than average level of education, with a higher proportion of participants having a university degree (22.2% of
Canadian population vs. 22-32% of sample) (40) and a smaller proportion having a high school diploma or less (39% of Canadian population vs. 28-31% of sample) (40) compared to the Canadian population.

Of the 710 participants with chronic pain, 188 screened positive for NC and 522 screened negative for NC. Participants with NC were more likely to report having less education, living in rented (versus owned) residences, reporting an annual household income less than $50,000, and identifying their ethnicity as something other than ‘white’ (table 4.1). Compared to participants without NC, those with NC were 4.6 times more likely to select "unable to work and receiving or seeking disability compensation" (RR=4.59, 95% CI=2.55-8.25).

Participants with NC reported poorer general health than those without NC, including being 1.7 times more likely to be a current smoker (RR=1.68, 95% CI=1.17-2.41), 2.0 times more likely to report a minimum of two weeks of health-related activity interference in the past year (RR=1.98, 95% CI=1.62-2.41), and 3.0 times more likely to report three or more chronic conditions (RR=3.03, 95% CI=2.10-4.37) (table 4.2). Participants with NC were more likely to be diagnosed with all the common co-morbid conditions except for mood disorders (RR=1.42, 95% CI=0.84-2.41).

**Pain characteristics of participants.**

Those with NC were more likely to report daily or constant pain (RR=1.26, 95% CI=1.08-1.37), of severe intensity (RR=1.94, 95% CI=1.65-2.29), which affected five or more body areas (RR=1.34, 95% CI=1.19-1.51) compared to participants without NC (table 4.3). Back problems (NC=35.1%, without NC=37.0%) and osteoarthritis (28.0%, 29.4%) were the most commonly diagnosed pain conditions in both pain groups.
Objective 2: Compare self-management strategies and satisfaction with ability to control pain between the two pain groups

Medical self-management.

Participants with NC were half as likely to list solely non-pharmaceutical techniques (e.g., chiropractic intervention, massage therapy, and exercise) for pain management (RR=0.51, 95% CI=0.29-0.90) (table 4.4). Less than 25% in both pain groups used a combination of both pharmaceutical and non-pharmaceutical pain relief strategies. Many participants in both pain groups indicated multiple health care providers were helpful in pain management. Family physicians were the most frequently identified type of the health care professional that helped participants with pain management (NC=24.3%, without NC=28.6%) (table 4.4). Compared to those without NC, participants with NC were more likely to identify an ‘other’ health professional or combination of health professionals as ‘most helpful’ in pain management (e.g., massage therapist) (RR=1.35, 95% CI=1.09-1.67). They were also significantly more likely to report at least five annual visits to a doctor and specialist and at least one annual visit to an ER, however after adjusting for co-morbid health conditions, smoking status, weeks of health-related activity interference, and sociodemographic characteristics, the differences between pain groups were no longer significant (table 4.5).

Emotional self-management.

Acceptance (NC=83.1%, without NC=81.2%), active coping (67.4%, 57.1%), planning (55.2%, 46.7%) and self-distraction (56.8%, 37.9%) were the most frequently cited self-management strategies (table 4.6). A small proportion of participants with both types of pain (NC=4.1%, without NC=8.0%) did not use any of the emotional self-management strategies captured on the Brief COPE (RR=0.50, 95% CI=0.23-1.11). For the remaining participants who
used at least one of the emotional self-management strategies, those with NC were more likely than those without NC to use all but acceptance and humour (table 4.6).

**Satisfaction with ability to control pain.**

Complete dissatisfaction with ability to control pain was reported by 21.0% of individuals with NC and 11.9% without NC (RR=1.72, 95% CI=1.32-2.24) (table 4.7). Complete satisfaction with ability to control pain was reported by only a small proportion of participants (with NC=8.5%, without NC=16.8%).

**Discussion**

This is the first population-based study to compare reports of pain, self-management strategies, and satisfaction with ability to control pain by individuals with chronic pain with and without NC. The results of this study provide a benchmark of chronic pain self-management in Canada, thus identifying new areas for clinician assessment and action, and new targets for intervention research. Participants with NC reported pain that was more intense, more frequent, and located in more body locations than those without NC. They were less likely to self-manage with non-pharmaceutical strategies, identified a broader variety of health professionals helping with pain management, and reported greater use of emotional self-management strategies compared to participants without NC. Overall, participants with NC were more likely to be completely dissatisfied with their ability to manage pain.

The lower socioeconomic status reported by individuals with NC is consistent with previous comparisons between individuals with and without NC (7, 11). In contrast to the literature, female (7, 10-12, 20) and older (7, 10, 11, 20) participants in this study were equally likely to report NC as were male and younger participants. The results of this study do not support preliminary evidence suggesting a higher risk of depression in individuals with NC (20),
however this difference may reflect the higher likelihood of depression being diagnosed in clinical versus general population participant pools (2, 41, 42). The greater risk for multiple co-morbid conditions may contribute to the lower mental and physical health-related quality of life scores that have been previously identified in individuals with NC (12, 13).

The pain characteristics reported by participants with and without NC are consistent with results from studies conducted in France (10), the United Kingdom (13), and Alberta, Canada (12). NC were present in almost one third of individuals diagnosed with osteoarthritis; while contrary to the original view of inflammatory pain mechanisms, the results of this study are consistent with emerging evidence that some individuals with osteoarthritis may also experience NC due to nerve injury or irritation (43). With different recommendations for the pharmaceutical management of chronic pain with and without NC, screening all individuals with chronic pain for NC may be an important first step in making management decisions.

Medication was the primary means by which pain was self-managed in both pain groups, with only a minority of participants reporting sole or concurrent use of non-pharmaceutical strategies. Clinical practice guidelines have been developed for the management of chronic pain and are based on systematic reviews of clinical trials, individual trials, and consensus among practitioners. These guidelines recommend combining pharmaceutical and non-pharmaceutical strategies (44) such as physical therapy (16, 45-47), cognitive and behavioural therapies (16, 45-49), and acupuncture (16, 45-47), however use of these guidelines in clinical settings may be minimal (50-52). Testing of non-pharmaceutical strategies has focused on pain groups categorized by diagnosis rather than the presence of NC, thus the absence of guidelines specifically for non-pharmaceutical management of chronic pain with NC may contribute to the low use of these self-management options.
Participants in both pain groups identified family physicians as the most helpful health care professional in supporting self-management, which is consistent with previous studies (53). The higher number of annual health care visits is also consistent with the literature where frequent and/or recent seeking of treatment (11), visiting a hospital or emergency room, and undergoing treatment procedures are more common in individuals with NC compared to those without NC (20). This study is the first to control for differences in general health beyond pain intensity (11) and co-morbid depression (20), and has identified that the greater health-related activity interference of individuals with NC may explain differences in health care visits.

The common use of acceptance, active coping, and planning suggests that Canadians with chronic pain may be self-managing the resulting negative emotions in a way that minimizes the health risk. Use of acceptance has been associated with less pain-related disability (54, 55), depression (54), and anxiety (54, 56) and a higher likelihood of experiencing positive health outcomes following intervention (54, 57, 58). Use of active coping (e.g., trying a new pain management strategy) and planning (e.g., planning morning and afternoon breaks to save energy for an evening activity) have not been previously explored in chronic pain, however in other chronic conditions active coping and planning are commonly used (59-61) and have both been associated with decreased depression (62) and active coping has been correlated with positive affect (63). The results are mixed for self-distraction. Use of self-distraction has been correlated with the positive health outcomes of physical and social functioning, (60) and quality of life (60). Conversely, use of this strategy has also been associated with the negative health outcomes of anxiety (61) and low energy (64) in chronic disease groups.

Individuals with NC were twice as likely to report substance use, denial, and behavioural disengagement as emotional self-management strategies. As prolonged use of substances can
result in neuropathic pain (e.g., alcoholic neuropathy), it is unknown whether the use of substances to cope with stress started before or after the onset of chronic pain in study participants. Despite the unknown temporality of this association, the tendency to use substances to deal with negative emotions remains an important point of assessment for health care professionals as it may indicate a higher risk of opioid misuse and dependency in chronic pain groups (65, 66). The use of denial in chronic diseases may be protective in early illness phases but later may interfere with use of recommended self-management behaviours (67). In phenomenological studies, participants with chronic pain have described denial as useful in maintaining public appearances and avoiding stigma, but also distressing as their public and personal selves become dissonant (68, 69). Behavioural disengagement has not been studied in chronic pain groups however its use has been associated with depression and negative affect (63, 70), disability (59), and suicidal attitudes (70) in other chronic diseases.

Although treatment satisfaction has been the focus of research, there is preliminary qualitative evidence that perceived inability to self-manage is both a greater predictor of poor function and a greater motivator to seek care than pain intensity (71). The results of qualitative focus groups and interviews with individuals with chronic pain suggest that dissatisfaction with pain management may result from a lack of self-management support including poor communication of available services and management options (72, 73), guidance on restricted activities (72), listening to their management preferences (73), and consideration of complementary and alternative modalities (73). Thus, the lack of satisfaction in ability to manage pain may be addressed through health care professionals providing clear and specific self-management recommendations and collaborating with their patients/clients in management decisions.
A strength of this study is the drawing of participants from a random sample of the general population, which likely resulted in a healthier sample than would be drawn from a clinic population. Given that most Canadians wait at least one year to be seen in a multi-disciplinary pain facility (74) or may not even be referred due to their long wait lists (70), and 15% do not have a regular medical doctor (75), this sample may be more reflective of pain characteristics and self-management of chronic pain at the population level than clinic-based reports. The large sample size allowed for controlling of potential confounders such as co-morbid conditions. Inclusion of self-management strategies and satisfaction with ability to control pain provided a general description of day-to-day chronic pain management and satisfaction with self-management ability beyond describing pain characteristics.

The sample may be biased towards healthier and educated or literate individuals who were able to read and complete the questionnaire. With severe pain being more common in individuals with NC, the proportion of individuals with NC in this study’s sample of individuals with chronic pain may be smaller than is truly present in the population. Conversely, individuals with less severe chronic pain with NC may have been more eager to participate, thus the true influence of non-response may be negligible or the true severity may be higher in the general population. As the potential participant pool was drawn from telephone book listings, these results do not represent individuals without landlines or unlisted numbers. This method of selecting potential participants could have resulted in the exclusion of those unable to afford a telephone (73), and a smaller proportion of young and employed individuals with a high level of education, as these characteristics are associated with use of mobile telephones (76). The survey was available in both English and French, however, those speaking a different language (e.g., recent immigrants) were not able to participate. Individuals unable to participate for the above
reasons may use different self-management strategies that were not captured in this study. The strategies that were captured in this study were not exhaustive and self-management strategies that target role function were not addressed. There may be other important self-management strategies used by individuals with chronic pain that could be best elicited through other instruments or methodologies. The results are based on self-report, thus use of non-pharmaceutical pain relief strategies (e.g., pool exercises) may be underreported if they were not perceived as treatments.

Conclusion

Individuals with NC report a different pain experience than those without NC. Their use of multiple self-management strategies indicates that they may be ready to engage in self-management discussions with their health care provider and/or more formal interventions, however self-management interventions and clinical guidelines specific to those with NC do not exist. Because individuals with NC seem to self-manage differently, they may benefit from self-management interventions and support that teach non-pharmaceutical pain management strategies and positive ways of coping with the emotional stress of living with chronic pain.

Although emotional self-management strategies are not currently included in guideline recommendations for the assessment of chronic pain, understanding these strategies may help clinicians with selecting interventions for pain that aim to modify or enhance currently used strategies. Research is needed (1) to identify methods for integrating the use of clinical guidelines for chronic pain management into practice, (2) to evaluate whether non-pharmacological strategies are effective for NC, and (3) to test whether implementation of guideline recommendations and encouraging use of non-pharmaceutical strategies in clinical
practice will address the worse pain intensity and satisfaction with ability to control pain identified in those with NC.
Acknowledgements

The survey was funded by Pfizer Canada’s Neuropathic Pain Award (PI: EG VanDenKerkhof). It was also supported by a Queen’s University Graduate Award, Ontario Graduate Scholarship, and the Ontario Graduate Scholarship in Science and Technology.
References


### Table 4.1. Sociodemographic characteristics of study participants with chronic pain with (n=188) and without (n=522) neuropathic characteristics (NC)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Without NC</th>
<th>With NC</th>
<th>t (p) or RR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex, n(%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>275 (53.1)</td>
<td>85 (45.5)</td>
<td>1.00</td>
</tr>
<tr>
<td>Female</td>
<td>243 (46.9)</td>
<td>102 (54.5)</td>
<td>1.16 (0.99-1.36)</td>
</tr>
<tr>
<td><strong>Age, mean(SD)</strong></td>
<td>59.1 (12.9)</td>
<td>58.0 (12.5)</td>
<td>t = 1.005 (0.315)</td>
</tr>
<tr>
<td><strong>Marital Status, n(%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or living together</td>
<td>385 (74.3)</td>
<td>128 (68.4)</td>
<td>1.00</td>
</tr>
<tr>
<td>Single</td>
<td>41 (7.9)</td>
<td>16 (8.6)</td>
<td>1.15 (0.67-1.99)</td>
</tr>
<tr>
<td>Separated, divorced, widowed</td>
<td>92 (17.8)</td>
<td>43 (23.0)</td>
<td>1.31 (0.95-1.79)</td>
</tr>
<tr>
<td><strong>Education, n(%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>University or graduate degree</td>
<td>150 (31.6)</td>
<td>37 (21.9)</td>
<td>1.00</td>
</tr>
<tr>
<td>Trade/professional school</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diploma, CEGEP, or some</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>university</td>
<td>182 (38.3)</td>
<td>74 (43.8)</td>
<td>1.22 (1.03-1.43)*</td>
</tr>
<tr>
<td>High school diploma, or less</td>
<td>132 (27.8)</td>
<td>53 (31.3)</td>
<td>1.26 (1.02-1.56)*</td>
</tr>
<tr>
<td>Other</td>
<td>11 (2.3)</td>
<td>5 (3.0)</td>
<td>1.74 (0.64-4.74)</td>
</tr>
<tr>
<td><strong>Employment, n(%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working full- or part-time</td>
<td>253 (48.4)</td>
<td>81 (43.1)</td>
<td>1.00</td>
</tr>
<tr>
<td>Retired</td>
<td>202 (38.7)</td>
<td>62 (33.0)</td>
<td>0.98 (0.79-1.21)</td>
</tr>
<tr>
<td>Unable to work, seeking or</td>
<td>15 (2.9)</td>
<td>28 (14.9)</td>
<td>4.59 (2.55-8.25)**</td>
</tr>
<tr>
<td>receiving disability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other++</td>
<td>52 (10.0)</td>
<td>17 (9.0)</td>
<td>1.02 (0.62-1.67)</td>
</tr>
<tr>
<td><strong>Residence, n(%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Owned or mortgaged</td>
<td>464 (90.3)</td>
<td>153 (83.2)</td>
<td>1.00</td>
</tr>
<tr>
<td>Rented</td>
<td>40 (7.8)</td>
<td>26 (14.1)</td>
<td>1.83 (1.15-2.91)*</td>
</tr>
<tr>
<td>Other</td>
<td>10 (1.9)</td>
<td>5 (2.7)</td>
<td>1.50 (0.52-4.32)</td>
</tr>
<tr>
<td><strong>Household Income, n(%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; $100,000</td>
<td>129 (27.3)</td>
<td>31 (17.3)</td>
<td>1.00</td>
</tr>
<tr>
<td>$50,000-$99,999</td>
<td>182 (38.6)</td>
<td>59 (33.0)</td>
<td>1.12 (0.94-1.34)</td>
</tr>
<tr>
<td>&lt; $50,000</td>
<td>161 (34.1)</td>
<td>89 (49.7)</td>
<td>1.34 (1.15-1.54)**</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>470 (90.0)</td>
<td>157 (83.5)</td>
<td>1.00</td>
</tr>
<tr>
<td>Other</td>
<td>52 (10.0)</td>
<td>31 (16.5)</td>
<td>1.66 (1.10-2.50)*</td>
</tr>
</tbody>
</table>

+ Frequencies will not add up to total sample size due to missing responses. Valid percentages presented.
++RR (95% CI) = relative risk (95% confidence interval), analyses run with 'without NC' as the reference group, ‘1.00’ denotes reference category

+++ Other category includes "unemployed and looking for work," "at home and not looking for paid employment," "student," and "other." Categories were collapsed due to small cell counts.

* p < 0.05, ** p < 0.01
Table 4.2. Health status of study participants with (n=188) and without (n=522) neuropathic characteristics (NC).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Without NC+</th>
<th>With NC+</th>
<th>RR (95% CI)++</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking Status, n(%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never smoked</td>
<td>246 (47.7)</td>
<td>64 (34.2)</td>
<td>1.00</td>
</tr>
<tr>
<td>Previous smoker</td>
<td>209 (40.5)</td>
<td>91 (48.7)</td>
<td>1.28 (1.09-1.51)**</td>
</tr>
<tr>
<td>Occasional or current smoker</td>
<td>61 (11.8)</td>
<td>32 (17.1)</td>
<td>1.68 (1.17-2.41)**</td>
</tr>
<tr>
<td>Number of Chronic Conditions, n(%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>250 (48.0)</td>
<td>55 (29.3)</td>
<td>1.00</td>
</tr>
<tr>
<td>1-2</td>
<td>230 (44.1)</td>
<td>92 (48.9)</td>
<td>1.31 (1.18-1.52)**</td>
</tr>
<tr>
<td>3+</td>
<td>41 (7.9)</td>
<td>41 (21.8)</td>
<td>3.03 (2.10-4.37)**</td>
</tr>
<tr>
<td>Most Commonly Reported Chronic Health Conditions (ref=no)+++, n(%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>119 (22.8)</td>
<td>60 (31.9)</td>
<td>1.40 (1.08-1.82)*</td>
</tr>
<tr>
<td>Diabetes</td>
<td>42 (8.0)</td>
<td>38 (20.2)</td>
<td>2.51 (1.67-3.76)**</td>
</tr>
<tr>
<td>Bowel disorder</td>
<td>32 (6.1)</td>
<td>23 (12.2)</td>
<td>1.99 (1.20-3.31)**</td>
</tr>
<tr>
<td>Mood disorder</td>
<td>37 (6.1)</td>
<td>19 (10.1)</td>
<td>1.42 (0.84-2.41)</td>
</tr>
<tr>
<td>Anxiety disorder</td>
<td>18 (3.5)</td>
<td>18 (9.6)</td>
<td>2.77 (1.47-5.21)**</td>
</tr>
<tr>
<td>Heart disease</td>
<td>20 (3.8)</td>
<td>17 (9.0)</td>
<td>2.36 (1.26-4.40)**</td>
</tr>
<tr>
<td>Other</td>
<td>54 (10.3)</td>
<td>38 (20.2)</td>
<td>1.95 (1.33-2.85)**</td>
</tr>
<tr>
<td>Weeks of Health Interference with Daily Activities, n(%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 week</td>
<td>289 (61.7)</td>
<td>57 (35.4)</td>
<td>1.00</td>
</tr>
<tr>
<td>1-2 weeks</td>
<td>49 (10.4)</td>
<td>15 (9.3)</td>
<td>1.43 (0.85-2.42)</td>
</tr>
<tr>
<td>&gt; 2 weeks</td>
<td>131 (27.9)</td>
<td>89 (55.3)</td>
<td>1.95 (1.61-2.37)**</td>
</tr>
</tbody>
</table>

+ Frequencies will not add up to total sample size due to missing responses. Valid percentages presented.
++RR (95% CI) = relative risk (95% confidence interval), analyses run with 'without NC' as the reference group, ‘1.00’ denotes reference category
+++Participants were asked to select all applicable options, so numbers and percent will not add to 100%.
Categories of ‘asthma,’ ‘gastrointestinal ulcers,’ ‘chronic respiratory condition,’ ‘chronic fatigue syndrome,’ ‘multiple chemical sensitivities,’ and ‘stroke’ are not displayed due to small frequencies. Tests of relative risk were run with ‘without NC’ as the reference group and those who did not select the health condition (not shown) as the reference category.
* p < 0.05, ** p < 0.01
Table 4.3. Pain characteristics of study participants with \((n=188)\) and without \((n=522)\) neuropathic characteristics (NC).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Without NC+</th>
<th>With NC+</th>
<th>RR (95% CI)**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain Timing, n(%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once per week or less</td>
<td>82 (16.0)</td>
<td>9 (4.9)</td>
<td>1.00</td>
</tr>
<tr>
<td>Many days per week</td>
<td>203 (39.6)</td>
<td>59 (32.2)</td>
<td>1.21 (1.08-1.37)**</td>
</tr>
<tr>
<td>All the time or daily</td>
<td>228 (44.4)</td>
<td>115 (62.9)</td>
<td>1.26 (1.16-1.37)**</td>
</tr>
<tr>
<td>Pain Intensity over Past Week, n(%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No or mild pain (VAS 0-3)</td>
<td>190 (37.0)</td>
<td>24 (12.8)</td>
<td>1.00</td>
</tr>
<tr>
<td>Moderate pain (VAS 4-6)</td>
<td>194 (37.8)</td>
<td>75 (40.1)</td>
<td>1.50 (1.29-1.74)**</td>
</tr>
<tr>
<td>Severe pain (VAS 7+)</td>
<td>129 (25.2)</td>
<td>88 (47.1)</td>
<td>1.94 (1.65-2.29)**</td>
</tr>
<tr>
<td>Number of Body Areas Affected by Pain (35 total possible areas), n(%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2</td>
<td>152 (29.2)</td>
<td>32 (17.1)</td>
<td>1.00</td>
</tr>
<tr>
<td>3-4</td>
<td>149 (28.7)</td>
<td>33 (17.6)</td>
<td>1.03 (0.79-1.34)</td>
</tr>
<tr>
<td>5+</td>
<td>219 (42.1)</td>
<td>122 (65.3)</td>
<td>1.34 (1.19-1.51)**</td>
</tr>
<tr>
<td>Diagnosed Painful Conditions, n(%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>49 (9.9)</td>
<td>12 (6.6)</td>
<td>1.00</td>
</tr>
<tr>
<td>Yes***</td>
<td>448 (90.1)</td>
<td>170 (93.4)</td>
<td>1.04 (0.99-1.09)</td>
</tr>
<tr>
<td>Back problems</td>
<td>184 (37.0)</td>
<td>64 (35.1)</td>
<td>0.95 (0.76-1.19)</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>146 (29.4)</td>
<td>51 (28.0)</td>
<td>0.95 (0.73-1.25)</td>
</tr>
<tr>
<td>Pain from past surgery</td>
<td>61 (12.3)</td>
<td>40 (22.0)</td>
<td>1.84 (1.28-2.62)**</td>
</tr>
<tr>
<td>Diabetes</td>
<td>42 (8.5)</td>
<td>38 (20.9)</td>
<td>2.47 (1.65-3.70)**</td>
</tr>
<tr>
<td>Arthritis (other/unknown)</td>
<td>63 (12.7)</td>
<td>30 (16.5)</td>
<td>1.30 (0.87-1.94)</td>
</tr>
<tr>
<td>Migraine</td>
<td>52 (10.5)</td>
<td>29 (15.9)</td>
<td>1.52 (1.00-2.32)</td>
</tr>
<tr>
<td>Accident with nerve damage</td>
<td>31 (6.2)</td>
<td>27 (14.8)</td>
<td>2.38 (1.46-3.87)**</td>
</tr>
<tr>
<td>Fibromyalgia syndrome</td>
<td>15 (3.0)</td>
<td>20 (11.0)</td>
<td>3.64 (1.91-6.96)**</td>
</tr>
<tr>
<td>Chronic widespread pain</td>
<td>15 (3.0)</td>
<td>19 (10.1)</td>
<td>3.46 (1.80-6.66)**</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>32 (6.4)</td>
<td>18 (10.4)</td>
<td>1.54 (0.88-2.67)</td>
</tr>
<tr>
<td>Cancer</td>
<td>13 (2.6)</td>
<td>12 (6.6)</td>
<td>2.52 (1.17-5.42)*</td>
</tr>
<tr>
<td>Shingles</td>
<td>17 (3.4)</td>
<td>10 (5.5)</td>
<td>1.61 (0.75-3.44)</td>
</tr>
<tr>
<td>Other*</td>
<td>142 (28.6)</td>
<td>64 (35.2)</td>
<td>1.23 (0.97-1.57)</td>
</tr>
</tbody>
</table>

+ Frequencies will not add up to total sample size due to missing responses. Valid percentages presented.
++ RR (95% CI) = relative risk (95% confidence interval), analyses run with "without NC" as the reference group, ‘1.00’ denotes reference category
+++ Participants were asked to select all applicable options, so numbers and percent will not add to 100%. Test of relative risk were run with "without NC" as the reference group and those who did not select the diagnosis (not shown) as the reference category.
^ Categories of amputation, leg ulcers, and vulvodynia were included in the "other" category due to small frequencies
* \(p < 0.05\), ** \(p < 0.01\)
Table 4.4. Medical self-management type and facilitating health professional reported by study participants with (n=188) and without (n=522) neuropathic characteristics (NC).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Without NC+</th>
<th>With NC+</th>
<th>RR (95% CI)++</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain Management Type, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication + non-pharmaceutical techniques</td>
<td>110 (22.3)</td>
<td>44 (24.7)</td>
<td>1.00</td>
</tr>
<tr>
<td>Medication</td>
<td>242 (49.1)</td>
<td>103 (57.9)</td>
<td>1.02 (0.90-1.16)</td>
</tr>
<tr>
<td>Non-pharmaceutical techniques</td>
<td>70 (14.2)</td>
<td>11 (6.2)</td>
<td>0.51 (0.29-0.90)*</td>
</tr>
<tr>
<td>Other</td>
<td>14 (2.8)</td>
<td>6 (3.4)</td>
<td>1.06 (0.43-2.61)</td>
</tr>
<tr>
<td>None</td>
<td>57 (11.6)</td>
<td>14 (7.9)</td>
<td>0.71 (0.43-1.17)</td>
</tr>
<tr>
<td>Most Helpful Pain Management Professional++, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family doctor</td>
<td>141 (28.6)</td>
<td>44 (24.3)</td>
<td>1.00</td>
</tr>
<tr>
<td>Specialist</td>
<td>48 (9.7)</td>
<td>17 (9.4)</td>
<td>1.10 (0.68-1.76)</td>
</tr>
<tr>
<td>Physical/Occupational Therapist</td>
<td>65 (13.2)</td>
<td>12 (6.6)</td>
<td>0.68 (0.40-1.17)</td>
</tr>
<tr>
<td>Chiropractor</td>
<td>37 (7.5)</td>
<td>6 (3.3)</td>
<td>0.62 (0.28-1.39)</td>
</tr>
<tr>
<td>Family doctor + physical/occupational therapist</td>
<td>32 (6.5)</td>
<td>13 (7.2)</td>
<td>1.23 (0.70-2.18)</td>
</tr>
<tr>
<td>Family doctor + specialist</td>
<td>33 (6.7)</td>
<td>17 (9.4)</td>
<td>1.47 (0.88-2.44)</td>
</tr>
<tr>
<td>Other</td>
<td>109 (22.1)</td>
<td>63 (34.8)</td>
<td>1.35 (1.09-1.67)**</td>
</tr>
<tr>
<td>None</td>
<td>28 (5.7)</td>
<td>9 (5.0)</td>
<td>1.02 (0.52-2.03)</td>
</tr>
</tbody>
</table>

+Frequencies will not add up to total sample size due to missing responses. Valid percentages presented.
++ RR (95% CI) = relative risk (95% confidence interval), analyses run with ‘without NC’ as the reference group, ‘1.00’ denotes reference category
+++Participants were asked to select the one most helpful practitioner, but many selected/provided more than one so the most common combinations are also presented. Other combinations and categories of ‘nurse or nurse practitioner’ and ‘health care team’ were added to the “other” category due to small frequencies
* p < 0.05, ** p < 0.01
Table 4.5. Bivariable and multivariable logistic regression analyses of the effect of neuropathic characteristics (NC) on the odds of visiting various types of health professionals at least 5 times and various health settings at least once in the past year.

<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>Without NC+ n(%) n=522</th>
<th>With NC+ n(%) n=188</th>
<th>Unadjusted OR (95% CI)+++</th>
<th>Adjusted OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Doctor</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 5 visits/year</td>
<td>385 (80.4)</td>
<td>112 (66.7)</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>5+ visits/year</td>
<td>94 (19.6)</td>
<td>56 (33.3)</td>
<td>2.05 (1.38-3.03)**</td>
<td>1.13 (0.71-1.80)a</td>
</tr>
<tr>
<td><strong>Specialist</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 5 visits/year</td>
<td>282 (86.8)</td>
<td>108 (78.3)</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>5+ visits/year</td>
<td>43 (13.2)</td>
<td>30 (21.7)</td>
<td>1.82 (1.09-3.05)*</td>
<td>1.30 (0.72-2.35)b</td>
</tr>
<tr>
<td><strong>Other Health Professional</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 5 visits/year</td>
<td>301 (60.4)</td>
<td>94 (55.0)</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>5+ visits/year</td>
<td>197 (39.6)</td>
<td>77 (45.0)</td>
<td>1.25 (0.89-1.78)</td>
<td>1.02 (0.66-1.55)c</td>
</tr>
<tr>
<td><strong>Emergency Room</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No visits</td>
<td>446 (84.3)</td>
<td>146 (77.7)</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>1+ visits</td>
<td>76 (14.6)</td>
<td>42 (22.3)</td>
<td>1.69 (1.11-2.57)*</td>
<td>0.97 (0.57-1.63)d</td>
</tr>
<tr>
<td><strong>Walk-In Clinic</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No visits</td>
<td>440 (84.3)</td>
<td>154 (81.9)</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>1+ visits</td>
<td>82 (15.7)</td>
<td>34 (18.1)</td>
<td>1.19 (0.76-1.84)</td>
<td>0.92 (0.55-1.54)e</td>
</tr>
</tbody>
</table>

+Frequencies will not add up to total sample size due to missing responses. Valid percentages presented.
++ OR (95% CI) = odds ratio (95% confidence interval), analyses run with ‘without NC’ as the reference group, ‘1.00’ denotes reference category

a Model initially included smoking status, number of co-morbid conditions, health-related activity interference, employment, residence, and income; analysis based on 434 without NC and 147 with NC due to missing responses. Number of co-morbid conditions and health-related activity interferences remained in the model.
b Model initially included number of co-morbid conditions, health-related activity interference, education, and employment; analysis based on 292 without NC and 118 with NC due to missing responses. Health-related activity interference remained in the model.
c Model initially included health-related activity interference, age, sex, employment, residence, and income; analysis based on 421 without NC and 149 with NC due to missing responses. Health-related activity interference, age, sex, residence, and income remained significant.
d Model initially included number of co-morbid conditions, health-related activity interference, residence, income, marital status, and education; analysis included 431 without NC and 145 with NC due to missing responses. Missing responses to visits to an emergency room were included as ‘no visits.’ Number of co-morbid conditions, health-related activity interference, marital status, and education remained in the model.
e Model initially included health-related activity interference, residence, and age; analysis included 467 without NC and 161 with NC due to missing responses. Missing responses to visits to a walk-in clinic were included as ‘no visits.’ Health-related activity interference and age remained in the model.

* p < 0.05, ** p < 0.01
Table 4.6. Relative risk analyses of the effect of neuropathic characteristics (NC) on use of various emotional self-management strategies included in the Brief COPE questionnaire.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Without NC+ (n=522)</th>
<th>With NC+ (n=188)</th>
<th>RR (95% CI)***</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>median** Use n(%)</td>
<td>median** Use n(%)</td>
<td></td>
</tr>
<tr>
<td>Acceptance</td>
<td>6.0 410 (81.2)</td>
<td>6.0 152 (83.1)</td>
<td>1.02 (0.95-1.11)</td>
</tr>
<tr>
<td>Active coping</td>
<td>5.0 289 (57.1)</td>
<td>5.0 124 (67.4)</td>
<td>1.18 (1.04-1.34)**</td>
</tr>
<tr>
<td>Self-distraction</td>
<td>4.0 191 (37.9)</td>
<td>5.0 104 (56.8)</td>
<td>1.50 (1.27-1.78)**</td>
</tr>
<tr>
<td>Planning^</td>
<td>4.0 234 (46.7)</td>
<td>5.0 100 (55.2)</td>
<td>1.18 (1.00-1.39)*</td>
</tr>
<tr>
<td>Positive re-framing</td>
<td>3.0 144 (28.5)</td>
<td>4.0 87 (48.1)</td>
<td>1.69 (1.37-2.07)**</td>
</tr>
<tr>
<td>Use of instrumental support</td>
<td>4.0 157 (31.3)</td>
<td>4.0 80 (43.5)</td>
<td>1.39 (1.13-1.71)**</td>
</tr>
<tr>
<td>Use of emotional support</td>
<td>3.0 114 (22.5)</td>
<td>4.0 65 (35.1)</td>
<td>1.56 (1.21-2.01)**</td>
</tr>
<tr>
<td>Venting</td>
<td>3.0 88 (17.3)</td>
<td>4.0 57 (31.3)</td>
<td>1.81 (1.37-2.41)**</td>
</tr>
<tr>
<td>Religion</td>
<td>2.0 81 (16.2)</td>
<td>3.0 53 (30.3)</td>
<td>1.78 (1.32-2.41)**</td>
</tr>
<tr>
<td>Self-blame</td>
<td>2.0 67 (13.4)</td>
<td>3.0 44 (24.0)</td>
<td>1.80 (1.28-2.53)**</td>
</tr>
<tr>
<td>Humour</td>
<td>2.0 87 (17.3)</td>
<td>3.0 42 (23.1)</td>
<td>1.33 (0.96-1.85)</td>
</tr>
<tr>
<td>Behavioural disengagement</td>
<td>2.0 54 (10.7)</td>
<td>3.0 40 (21.7)</td>
<td>2.03 (1.40-2.95)**</td>
</tr>
<tr>
<td>Denial</td>
<td>2.0 42 (8.3)</td>
<td>2.0 36 (19.6)</td>
<td>2.34 (1.55-3.54)**</td>
</tr>
<tr>
<td>Substance use</td>
<td>2.0 31 (6.1)</td>
<td>2.0 27 (14.5)</td>
<td>2.38 (1.46-3.87)**</td>
</tr>
</tbody>
</table>

+Frequencies will not add up to total sample size due to missing responses. Valid percentages presented.
++Possible scores range from 2 to 8 with higher scores indicating more frequent use of the strategy.
+++ RR (95% CI) = relative risk (95% confidence interval). Reference= no or infrequent use.
^ Removal of the non-random participants resulted in there being no difference between the use of planning between those with and without NC (RR=1.17, 95% CI=0.99-1.38).
* p < 0.05, ** p < 0.01
Table 4.7. Relative risk analysis of satisfaction with ability to control chronic pain for those with (n=188) and without (n=522) neuropathic characteristics (NC).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Without NC+ n(%)</th>
<th>With NC+ n(%)</th>
<th>RR (95% CI)++</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction with Ability to Manage Pain, n (%)+++</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completely satisfied</td>
<td>79 (16.8)</td>
<td>15 (8.5)</td>
<td>1.00</td>
</tr>
<tr>
<td>Somewhat or fairly satisfied</td>
<td>336 (71.3)</td>
<td>124 (70.5)</td>
<td>1.10 (1.02-1.19)*</td>
</tr>
<tr>
<td>Completely dissatisfied</td>
<td>56 (11.9)</td>
<td>37 (21.0)</td>
<td>1.72 (1.32-2.24)**</td>
</tr>
</tbody>
</table>

+Frequencies will not add up to total sample size due to missing responses. Valid percentages presented.
++ RR (95% CI) = relative risk (95% confidence interval), analyses run with ‘without NC’ as the reference group, ‘1.00’ denotes reference category.
+++ 36 individuals with NC and 8 without NC selected “N/A, no significant pain” and were removed from this analysis.
* p < 0.05, ** p < 0.01
Chapter 5

Barriers and Facilitators of Chronic Pain Self-Management for Individuals with and without Neuropathic Characteristics

Target Journal: *Annals of Family Medicine*

Co-Authors:

VanDenKerkhof EG; LeFort, S; Harrison, MB
Abstract

Purpose: Personal and health system factors may influence self-management. This study compared individuals with chronic pain with and without neuropathic characteristics (NC) on self-management barriers and facilitators and explored their role in self-management of chronic pain with NC.

Methods: Individuals reporting chronic pain on a recent, cross-sectional survey of randomly selected Canadians were included (n=710). NC were identified using the Self-Report Leeds Assessment of Neuropathic Symptoms and Signs. Potential self-management barriers and facilitators (identified in a literature search) included: self-efficacy (Pain Self-Efficacy Questionnaire), depression (Patient Health Questionnaire-9), family/friend support and relationship with health care provider (Chronic Illness Resources Survey), and pain intensity (numeric rating scale). Self-management was captured with the Brief COPE and four items asking about pain treatments and health care visits. Analyses included relative risk (RR) and 95% confidence intervals (CI).

Results: Participants with NC (n=188) were more likely to report low self-efficacy (RR=2.1,CI=1.62-2.72), depression (RR=2.30,CI=1.73-3.06), and severe pain (RR=1.94,CI=1.65-2.29). There were no differences between groups for family/friend support or relationship with health care provider(s). Severe pain and depression increased the risk of using negative emotional self-management strategies and medications, and ≥ 5 annual health care visits in individuals with NC. High self-efficacy increased use of positive self-management strategies, and decreased medication use and health care visits in those with NC.
Conclusions: Individuals with NC are more likely to experience low self-efficacy, depression, and severe pain which negatively influences self-management. Health care professionals may need to assess and address these factors to support self-management of chronic pain with NC.

Keywords: chronic pain, neuropathic pain, self-management, pain management, self-efficacy, depression
Introduction

An estimated 3.3-17.9% of community-dwelling adults are living with chronic pain with neuropathic characteristics (NC) (1-6). These individuals most commonly present to family doctors for care (7) and report more intense pain (1, 3-5, 8), lower health-related quality of life (4, 8-11), more pain interference and disability (4, 5, 9, 10), and more frequent health care visits (12, 13) than individuals with chronic pain without NC. The management of chronic pain with NC is complicated and involves greater use of invasive procedures (13) and multiple prescription-level medications (5, 8, 12, 13) than pain groups without NC. However, despite these interventions, those with NC report less resulting pain relief (5, 8, 12, 14).

Self-management interventions were developed to equip individuals with the skills needed to manage day-to-day life with chronic pain. Although effective in improving pain and health-related quality of life outcomes, a proportion of participants do not complete these programs and/or maintain the improvements (15). Although no self-management models have been developed specific to chronic pain, theoretical work in chronic disease self-management has identified that self-management behaviour is influenced by the individual’s personal and health system contexts (16-20). This role for personal and health system factors in chronic pain self-management behaviour has been supported by the results of both qualitative and quantitative studies (15). As such, differences in reported self-management behaviours between individuals with chronic pain with and without NC (7) may be explained by their experiencing different barriers and facilitators, however, these two pain groups have not been compared. Thus, the objectives of this study were to (1) describe and compare barriers and facilitators of self-management in individuals with chronic pain with and without NC, and (2) explore the role of barriers and facilitators in the use of self-management strategies in individuals with NC.
Material and Methods

This study was reviewed and approved by the Queen's University and Affiliated Teaching Hospitals Research Ethics Board and (ANAE-174-10) (appendix 4).

The data for this study are from a recent survey of a random sample of Canadians who were selected from telephone book listings and sent a questionnaire about chronic pain (21) (appendices 5-9). Of the 21% who responded (1505/7134 after adjusting for erroneous listings), 695 reported chronic pain. An additional 15 individuals who learned about the study and sought permission to participate were also included in the current study sample for a final sample size of 710 (7). Respondents reporting chronic pain were asked about their self-management activities, barriers, and facilitators.

The following screening questions were used to screen for chronic pain: "are you currently troubled by pain or discomfort, either all the time or on and off?" and "have you had this pain or discomfort for more than 3 months?" (appendix 7, item 1) (3, 22). Participants who screened positive for chronic pain were assessed for the presence of NC using the Self-Report Leeds Assessment of Neuropathic Symptoms and Signs Pain Scale (S-LANSS) (23, 24). This 7-item screen asks respondents about the presence of symptoms (e.g., changes in skin colour or temperature) and includes two self-assessment items testing for allodynia and altered pain threshold (appendix 7, items 36-42). Using a score of 12 or higher to indicate the presence of NC, the S-LANSS has a sensitivity of 83-85% and specificity of 80-87% compared to diagnosis by physical exam (23, 24).

Sociodemographic characteristics included in this analysis were sex, age, marital status, education, household income, and ethnicity (appendix 7, items 8-17), and have been previously reported (table 4.1, page 95).
Barriers and Facilitators

Potential barriers and facilitators included in the questionnaire were identified through reviewing qualitative and quantitative research on chronic pain self-management as well as chronic disease self-management models (appendix 10). The most commonly identified variables were (i) self-efficacy (17-20, 25, 26), (ii) depression (17, 25, 27, 28), (iii) social support (16, 18, 19, 27), (iv) relationship with healthcare provider(s) (16-19, 29-31), (v) pain intensity (16, 18, 25, 28), (vi) access to health resources (16, 18), (vii) health literacy (17, 18), and (viii) fear of exacerbating pain (17, 19, 27). To explore whether the identified barriers and facilitators reflected the current experience of Canadians, respondents were presented with a list of these factors and asked to select which item(s) made it easier or harder for them to manage their pain. An 'other' category was provided where respondents could specify an option not included in the list (appendix 7, item 88). After completing this item, respondents completed brief instruments capturing the five most commonly identified barriers and facilitators, which were then used as outcome measure for the inferential analysis (items i-v above).

(i) Self-efficacy was measured using the Pain Self-Efficacy Questionnaire (32, 33). This 10-item tool asks respondents to rate their confidence in response to statements such as "I can still accomplish most of my goals in life, despite the pain" on a seven-point Likert scale. Each scale is anchored with "not confident at all" and "completely confident" with possible scores of zero to six on each scale (appendix 7, items 89-98). As scores of 40 or higher have predicted sustained functional improvement following injury (34), total scores were categorized as high (≥40) or low (<40). To allow for comparison, scale scores were also categorized into high (≥4) or low (<4). Testing indicates excellent internal reliability (Cronbach's alpha = 0.92) and correlation with Self-Efficacy Scale scores (32, 34, 35).
(ii) Depression was measured using the Patient Health Questionnaire 9-item scale (PHQ-9) (36). Each item corresponds to a symptom of depression listed in the DSM-IV. Respondents are asked to indicate the frequency with which they have experienced each symptom over the past two weeks with four options ranging from “not at all” to “nearly every day” and possible scores ranging from zero to 27 (appendix 7, items 115-123). Scores of 10 or higher indicate moderate to severe depression with a specificity and sensitivity of 88% compared to diagnosis made by a mental health professional (37, 38). Thus, PHQ-9 scores were categorized as no or mild depression (<10) versus moderate to severe depression (≥10). Each scale score was categorized for comparison using the mid-point score to reflect whether each symptom was experienced “not at all or several days” or “most days or nearly every day” of the past two weeks.

(iii-iv) Support from family and friends and relationship with health care provider(s) were captured with the family and friend (appendix 7, items 108-109) and doctor and health care team scales (appendix 7, items 100, 102-104) of the Chronic Illness Resource Survey (CIRS), respectively (39, 40). Items were selected to reflect the elements of support identified in the pain literature, thus respondents were asked to rate the extent to which their family and friends encouraged them to do the tasks involved with managing their condition (16, 18) and listened to what the respondents had to say about their condition (16). Four items from the doctor and health care provider scale were included and asked whether their health professional(s) treated them as equal partners in making decisions, strategies and goals (18, 19, 27, 29), explained what they need to do to manage their condition (18, 19, 27), answered their questions and addressed their concerns (27, 29), and listened to what they had to say (29). Items on both scales have five response options ranging from 'not at all' to 'a great deal' with higher scores indicating a more
supportive relationship. Testing indicates acceptable reliability for the family and friends scale (Cronbach’s alpha = 0.75) and excellent reliability for the doctor and health care team scale (Cronbach’s alpha = 0.91). Construct and predictive validity have been established by comparing scores with both validated tools and self-monitoring data (39, 40). Responses to the CIRS items were categorized to reflect ‘not at all’ (≤2) and ‘a moderate amount to a great deal’ (>3) to allow for comparison between pain groups.

(v) Pain intensity over the past week was measured using an 11-point numeric rating scale as per recommendations for both general (41, 42) and neuropathic (43) chronic pain groups (appendix 7, item 35). Scores were categorized into none or mild (0-3), moderate (4-6), and severe (7-10) using the recommended categories for neuropathy (44).

Self-Management Strategies

Emotional self-management strategies were captured with the Brief COPE (45, 46), and medical strategies with one open-ended item from the Level of Expressed Need scale (LEN) (47) and five items asking about visits to health professionals. The Brief COPE consists of 28 items asking about the frequency with which respondents use 14 (2 items each) emotional self-management strategies to cope with stress (appendix 7, items 60-87). Each item has four response options ranging from “I haven’t been doing this all” to “I’ve been doing this a lot,” and each strategy is scored by adding the two relevant items. Participants were asked to consider the stress of living with chronic pain when responding to the questionnaire. The 14 self-management strategy scores were categorized into use (5+/8) and no or infrequent use (2-4/8) to compare the two pain groups.

The medical self-management item from the LEN was: “what treatments or medications are you receiving for your pain?” (appendix 7, item 59). Responses were categorized as
medication (with or without a non-pharmaceutical strategy) or other (e.g. non-pharmaceutical strategies or nothing). Participants were also asked to indicate the number of visits they had made to a doctor, specialist, and other health care professional in the past 12 months (appendix 7, item 19). Visits were categorized into < 5 and ≥ 5 using the 75th percentile for visits to a doctor.

**Statistical Analysis**

Descriptive statistics included mean and standard deviation, or median, frequency, and percent. Kurtosis values were used to assess distribution of continuous variables. Age was the only normally distributed variable, therefore an independent t-test was used to compare the two pain groups. The relationship between the two pain groups with respect to barriers and facilitators, as well as sociodemographic characteristics, was assessed using relative risk (RR) with 95% confidence intervals (CI). Similarly, the relationship between the use of self-management strategies with respect to barriers and facilitators was assessed using RR and 95% CI. All tests were two-tailed. Data were analyzed using SPSS version 21.0.

**Results**

Of the 710 participants with chronic pain, 188 participants screened positive for NC. Participants with NC were more likely to describe high school or less as their highest level of education (RR=1.26, 95%CI=1.02-1.56), an annual household income less than $50,000 (RR=1.34, 95%CI=1.15-1.54), and an ethnicity other than ‘white’ (RR=1.66, 95%CI=1.10-2.50) compared to participants without NC (table 5.1).

Self-confidence in ability to manage pain (NC=71.2%, without NC=69.9%), support from family/friends (57.6%, 41.1%), and access to health care services (55.4%, 44.9%) were the most commonly selected barriers and facilitators by respondents in both pain groups (table 5.2). Participants with NC were almost twice as likely to select fear of making pain worse (RR=1.95,
95\%CI=1.54-2.48) and depression or feeling down (RR=1.90, 95\%CI=1.38-2.60) as barriers/facilitators compared to those without NC.

There were no differences in reports of supportive relationships with family and/or friends and health care providers between respondents with and without NC (table 5.3). Participants reported the highest level of self-management support from health care providers in their listening to their concerns (with NC=84.5\%, without NC=83.1\%) and the least support in being treated as an equal partner in making decisions and setting management goals (59.2\%, 59.2\%). Family and friends were equally supportive in listening (73.4\%, 69.7\%), and encouraging management (77.2\%, 71.3\%).

High self-efficacy was reported by 60.7\% (n=108) of respondents with NC and 81.3\% (n=404) of those without NC (RR=0.75, 95\%CI=0.66-0.85) (table 5.4). Those with NC reported lower self-efficacy on all PSEQ scales, especially for coping without medications (RR=0.71, 95\%CI=0.59-0.85) and accomplishing goals (RR=0.76, 95\%CI=0.67-0.85).

Thirty-six percent of participants with NC and 15.5\% of those without NC screened positive for moderate to severe depression (RR=2.30, 95\%CI=1.73-3.06) (table 5.5). Individuals with NC were at a higher risk for reporting all depressive symptoms, including being over five times more likely to report thoughts of self-harm and/or being better off dead (RR=5.47, 95\%CI=2.1-14.36), and over three times more likely to feel bad about self (RR=3.59, 95\%CI=2.40-5.40) and have trouble concentrating (RR=3.56, 95\%CI=2.28-5.56).

Forty-seven percent of participants with NC rated their pain intensity as severe compared to 25.2\% of those without NC, representing an almost doubled risk for severe pain (RR=1.94, 95\%CI=1.65-2.29).
In individuals with NC, there were differences in emotional and medical self-management in relation to severe pain, depression, and high self-efficacy. Respondents with high self-efficacy (reference category [RC] = low self-efficacy) were 49% less likely to use behavioural disengagement (RR=0.49, 95%CI=0.78-0.85) and 1.4 times more likely to use positive reframing (RR=1.45, 95%CI=1.02-2.06) (table 5.6). High self-efficacy also reduced the risk of five or more annual visits to doctors (RR=0.50, 95%CI=0.33-0.77) and specialists (RR=0.39, 95%CI=0.20-0.78) (RC=0-4 annual visits), and there was a small reduction in use of medication (RR=0.87, 95%CI=0.76-0.99) (RC=non-pharmaceutical or none) (table 5.7).

Respondents with moderate to severe depression (RC=none/mild) were more than twice as likely to use self-blame (RR=5.44, 95%CI=2.95-10.01), behavioural disengagement (RR=3.25, 95%CI=1.83-5.79), substance use (RR=7.6, 95%CI=1.32-5.77), denial (RR=2.16, 95%CI=1.20-3.90), and venting (RR=2.03, 95%CI=1.32-3.12) (table 5.6). The only effect of depression on medical self-management was observed in visits to a doctor and specialist, with depressed individuals being 2.2 times more likely to report at least five annual visits to a doctor (RR=2.18, 95%CI=1.42-3.33) and 1.9 times more likely to report at least five annual visits to a specialist (RR=1.87, 95%CI=1.01-3.47) compared to those with no or mild depression (table 5.7).

Severe pain (RC=none to moderate pain) increased the risk of using behavioural disengagement (RR=1.54, 95% CI=1.40-4.80), instrumental support (RR=1.41, 95% CI=1.01-1.96), and self-blame (RR=1.78, 95% CI=1.04-3.05) (table 5.6). Those with severe pain were 20% more likely to include medication(s) in their medical self-management (RR=1.20, 95% CI=1.05-1.37) (table 5.6). No effect was observed on annual visits to a health professional.
Interpretation

This is the first study to explore barriers and facilitators of self-management in chronic pain groups with and without NC. The results support the findings of prior studies on self-management barriers and facilitators in community-dwelling Canadians living with chronic pain. Individuals with NC were at a higher risk, compared to those without NC, for three of the measured barriers and facilitators: depression, self-efficacy, and pain intensity. Depression and severe pain increased the use of negative emotional self-management strategies (e.g., self-blame), and depression increased the risk of five or more annual health visits in individuals with NC. High self-efficacy decreased use of negative strategies (e.g., behavioural disengagement) and frequent health visits. There were no differences between pain groups in reported support from health care providers, family, and friends, however 40% of respondents reported that their health care provider did not treat them as an equal partner in treatment decisions and management goals.

The lack of collaborative decision-making and goal-setting reported by participants is consistent with prior research (48-50) and suggests that current patient-clinician relationships may not be optimizing treatment outcomes and patient satisfaction (50). Reports of interventions to improve collaboration in chronic pain management are limited, including patient-centered communication (50, 51) and patient/client access to personal health information (52). Although they have not been studied in chronic pain groups, a wide variety of collaboration-based interventions (e.g., patient decision aids) have been reviewed and recommended for general adult groups based on their ability to improve safety, knowledge, overall health experience, use of health resources, and self-management (53).
The prevalence of depression in both pain groups was within the range reported in the literature (54-57), however some individuals may have been erroneously classified as depressed due to some symptoms of depression being commonly experienced by individuals with chronic pain (e.g., sleep difficulties), thus the true prevalence of co-morbid depression may be lower. The increased risk of co-morbid depression and severe pain in individuals with NC is consistent with the literature (1, 3, 4, 8, 13, 57), although there was no difference between the pain groups in self-reported diagnosis of a mood disorder, as has been reported elsewhere (7). Although prior work has identified a higher risk of self-harm in chronic versus acute pain groups (58), this study adds that the risk is further increased by the presence of NC in chronic pain. Self-efficacy has not been compared between pain groups, but it has been identified as a buffer for the effects of pain intensity and depression on disability (59). Thus the lower self-efficacy reported by individuals with NC may explain their greater disability (4, 5, 9, 10).

High self-efficacy supported the use of self-management strategies that may improve mental health and health care use in individuals with NC. In chronic disease research, positive reframing has been correlated with improved mental health (60), positive affect (61) and decreased anxiety (62), while behavioural disengagement has been associated with depression (63), suicidal attitude (63), and impaired social functioning (64). Increased self-efficacy has been associated with reduced health care use in general chronic pain groups (65-67); the results of the current study support this relationship in individuals with chronic pain with NC.

Comorbid depression increased the risk of individuals with NC self-managing with frequent visits to a doctor and specialist, and emotional strategies that are considered maladaptive (68). Although little work has been done in chronic pain groups, both combined and individual use of denial, behavioural disengagement, self-blame, and venting have been
previously associated with poor mental health outcomes in other chronic disease groups (61, 68-71). Substance use has been associated with poor social function (64) and substance dependency (72). The more frequent visits to a doctor and specialist made by depressed individuals with NC supports prior research findings where individuals with comorbid depression accessed more health care services than individuals with just chronic pain even after controlling for psychiatric care (73-75).

The presence of severe pain had a similar effect of increasing the use of potentially negative emotional self-management strategies. Individuals with severe pain were more likely to use behavioural disengagement and self-blame which, as noted above, are correlated with negative health outcomes (60, 61, 63, 64, 76). A relationship between pain intensity and use of instrumental support has not been found in prior chronic pain research (77), and use of instrumental support is generally unrelated to health outcomes in other chronic disease groups (60, 61). The results of the current study do not support prior work which identified increased use of health resources with increased pain intensity (78-81), which suggests that other related variables associated with higher pain intensity (e.g., depression and self-efficacy) may account for these differences.

The random selection of participants from the general population allowed for individuals without a family doctor (approximately 15% of the population (82)) to be included in the participant pool, and may have resulted in a healthier sample than would be drawn from a clinical participant pool. This method of selection, however, did not allow for the inclusion of unlisted and cellular telephone numbers. Although the survey was available in both official languages, individuals uncomfortable with reading English or French were unable to participate. The large sample size allowed for barriers and facilitators with a potentially low prevalence to be
included (e.g., poor access to health resources), however potential participants with severe pain, depression, and/or other conditions (e.g., Alzheimer’s disease) may have been unable to participate and thus may be under-represented. The description of barriers and facilitators extends the current understanding of chronic pain self-management by addressing the context in which it occurs.

Armed with this evidence on barriers and facilitators, clinicians can begin to address them. Regardless of pain type, engaging in collaborative decision-making and goal-setting may be one means of supporting self-management in chronic pain groups. Individuals with NC reported a distinct self-management experience, and may require additional screening for suicide and self-harm, depression, and low self-efficacy. While pain intensity and depression are common targets of intervention, increasing self-efficacy may be a safe and effective means of reducing health care visits and disability in individuals with NC. Self-management interventions targeting individuals with NC may need to consider addressing fear of making pain worse, access to health care resources, depression, and social support in addition to building self-efficacy. Further research is needed to determine whether use of specific self-management strategies and interventions to support collaborative decision-making are effective in improving health outcomes in chronic pain groups.
Acknowledgements

This work was funded by Pfizer Canada’s Neuropathic Pain Award (PI: EG VanDenKerkhof).

Additional funding support was provided by a Queen’s University Graduate Award, Ontario Graduate Scholarship, and the Ontario Graduate Scholarship in Science and Technology.
References


130


Table 5.1. Sociodemographic characteristics of study participants with chronic pain with (n=188) and without (n=522) neuropathic characteristics (NC)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Without NC</th>
<th>With NC</th>
<th>t (p) or RR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>275 (53.1)</td>
<td>85 (45.5)</td>
<td>1.00</td>
</tr>
<tr>
<td>Female</td>
<td>243 (46.9)</td>
<td>102 (54.5)</td>
<td>1.16 (0.99-1.36)</td>
</tr>
<tr>
<td>Age, mean (SD)</td>
<td>59.1 (12.9)</td>
<td>58.0 (12.5)</td>
<td>t = 1.005 (0.315)</td>
</tr>
<tr>
<td>Marital Status, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or living together</td>
<td>385 (74.3)</td>
<td>128 (68.4)</td>
<td>1.00</td>
</tr>
<tr>
<td>Single</td>
<td>41 (7.9)</td>
<td>16 (8.6)</td>
<td>1.15 (0.67-1.99)</td>
</tr>
<tr>
<td>Separated, divorced, widowed</td>
<td>92 (17.8)</td>
<td>43 (23.0)</td>
<td>1.31 (0.95-1.79)</td>
</tr>
<tr>
<td>Education, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>University or graduate degree</td>
<td>150 (31.6)</td>
<td>37 (21.9)</td>
<td>1.00</td>
</tr>
<tr>
<td>Trade/professional school Diploma, CEGEP*, or some university</td>
<td>182 (38.3)</td>
<td>74 (43.8)</td>
<td>1.22 (1.03-1.43)*</td>
</tr>
<tr>
<td>High school diploma, or less</td>
<td>132 (27.8)</td>
<td>53 (31.3)</td>
<td>1.26 (1.02-1.56)*</td>
</tr>
<tr>
<td>Other</td>
<td>11 (2.3)</td>
<td>5 (3.0)</td>
<td>1.74 (0.64-4.74)</td>
</tr>
<tr>
<td>Household Income, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; $100,000</td>
<td>129 (27.3)</td>
<td>31 (17.3)</td>
<td>1.00</td>
</tr>
<tr>
<td>$50,000-$99,999</td>
<td>182 (38.6)</td>
<td>59 (33.0)</td>
<td>1.12 (0.94-1.34)</td>
</tr>
<tr>
<td>&lt; $50,000</td>
<td>161 (34.1)</td>
<td>89 (49.7)</td>
<td>1.34 (1.15-1.54)**</td>
</tr>
<tr>
<td>Ethnicity, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>470 (90.0)</td>
<td>157 (83.5)</td>
<td>1.00</td>
</tr>
<tr>
<td>Other</td>
<td>52 (10.0)</td>
<td>31 (16.5)</td>
<td>1.66 (1.10-2.50)*</td>
</tr>
</tbody>
</table>

+ Frequencies will not sum to total sample size due to missing responses. Valid percentages presented.
++RR (95% CI) = relative risk (95% confidence interval), analyses run with ‘without NC’ as the reference group, ‘1.00’ denotes reference category
* CEGEP refers to a public post-secondary collegiate institution that is part of the Quebec education system and is required to attend a Quebec university.
Table 5.2. Self-selected* barriers and facilitators of self-management in individuals with (n=188) and without neuropathic characteristics (NC) (n=522).++

<table>
<thead>
<tr>
<th>Variable</th>
<th>NC n (%)</th>
<th>Without NC n (%)</th>
<th>RR (95% CI) +++</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-confidence in ability to manage pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selected</td>
<td>131 (71.2)</td>
<td>346 (69.9)</td>
<td>1.02 (0.92-1.14)</td>
</tr>
<tr>
<td>Not selected</td>
<td>53 (28.8)</td>
<td>149 (30.1)</td>
<td>1.00</td>
</tr>
<tr>
<td>Support from family and/or friends</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selected</td>
<td>106 (57.6)</td>
<td>203 (41.1)</td>
<td>1.40 (1.19-1.65)**</td>
</tr>
<tr>
<td>Not selected</td>
<td>78 (42.4)</td>
<td>291 (58.9)</td>
<td>1.00</td>
</tr>
<tr>
<td>Access to health care services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selected</td>
<td>102 (55.4)</td>
<td>222 (44.9)</td>
<td>1.21 (1.03-1.42)*</td>
</tr>
<tr>
<td>Not selected</td>
<td>86 (45.7)</td>
<td>272 (55.1)</td>
<td>1.00</td>
</tr>
<tr>
<td>Relationship with health care provider(s)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selected</td>
<td>92 (50.0)</td>
<td>228 (46.2)</td>
<td>1.08 (0.91-1.29)</td>
</tr>
<tr>
<td>Not selected</td>
<td>92 (50.0)</td>
<td>266 (53.8)</td>
<td>1.00</td>
</tr>
<tr>
<td>Fear of making pain worse</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selected</td>
<td>78 (42.4)</td>
<td>107 (21.7)</td>
<td>1.95 (1.54-2.48)**</td>
</tr>
<tr>
<td>Not selected</td>
<td>106 (57.6)</td>
<td>386 (78.3)</td>
<td>1.00</td>
</tr>
<tr>
<td>Pain intensity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selected</td>
<td>68 (37.0)</td>
<td>121 (24.5)</td>
<td>1.51 (1.18-1.92)**</td>
</tr>
<tr>
<td>Not selected</td>
<td>116 (63.0)</td>
<td>372 (75.5)</td>
<td>1.00</td>
</tr>
<tr>
<td>Ability to read and/or understand health information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selected</td>
<td>66 (35.9)</td>
<td>170 (34.5)</td>
<td>1.04 (0.83-1.31)</td>
</tr>
<tr>
<td>Not selected</td>
<td>118 (64.1)</td>
<td>323 (65.5)</td>
<td>1.00</td>
</tr>
<tr>
<td>Depression or feeling down</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selected</td>
<td>51 (27.7)</td>
<td>72 (14.6)</td>
<td>1.90 (1.38-2.60)**</td>
</tr>
<tr>
<td>Not selected</td>
<td>133 (72.3)</td>
<td>421 (85.4)</td>
<td>1.00</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Selected</td>
<td>23 (12.4)</td>
<td>57 (11.0)</td>
<td>1.08 (0.69-1.70)</td>
</tr>
<tr>
<td>Not selected</td>
<td>162 (87.6)</td>
<td>463 (89.0)</td>
<td>1.00</td>
</tr>
</tbody>
</table>

+ Participants were asked to select all that applied from a list.
++Frequencies will not sum to total sample size due to missing responses. Valid percentages presented.
+++RR (95% CI) = relative risk (95% confidence interval), '1.00' denotes reference category, those without NC were the reference group.
*significant at p<0.05, ** significant at p<0.01
Table 5.3. Self-management support received by individuals with (n=188) and without (n=522) neuropathic characteristics (NC).

<table>
<thead>
<tr>
<th>Variable Description</th>
<th>with NC median</th>
<th>n (%)</th>
<th>Without NC median</th>
<th>n(%)</th>
<th>RR (95% CI) ++</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Doctor and Health Care Team</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Listened to concerns</td>
<td>4.0</td>
<td>4.0</td>
<td></td>
<td>4.0</td>
<td></td>
</tr>
<tr>
<td>not at all</td>
<td>28 (15.5)</td>
<td>82 (16.9)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>moderate amount, a great deal</td>
<td>153 (84.5)</td>
<td>404 (83.1)</td>
<td>1.02 (0.94-1.10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Answered questions</td>
<td>4.0</td>
<td>4.0</td>
<td></td>
<td>4.0</td>
<td></td>
</tr>
<tr>
<td>not at all</td>
<td>29 (16.0)</td>
<td>83 (17.1)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>moderate amount, a great deal</td>
<td>152 (84.0)</td>
<td>403 (82.9)</td>
<td>1.01 (0.94-1.09)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explained specific illness self-management actions</td>
<td>3.0</td>
<td>3.0</td>
<td></td>
<td>3.0</td>
<td></td>
</tr>
<tr>
<td>not at all</td>
<td>50 (27.8)</td>
<td>153 (31.5)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>moderate amount, a great deal</td>
<td>130 (72.2)</td>
<td>333 (68.5)</td>
<td>1.05 (0.95-1.18)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treated me as an equal partner in decisions, management and goals</td>
<td>3.0</td>
<td>3.0</td>
<td></td>
<td>3.0</td>
<td></td>
</tr>
<tr>
<td>not at all</td>
<td>73 (40.8)</td>
<td>197 (40.8)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>moderate amount, a great deal</td>
<td>106 (59.2)</td>
<td>286 (59.2)</td>
<td>1.00 (0.87-1.15)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family and Friend</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Listened about illness</td>
<td>3.0</td>
<td>3.0</td>
<td></td>
<td>3.0</td>
<td></td>
</tr>
<tr>
<td>not at all</td>
<td>49 (26.6)</td>
<td>150 (30.3)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>moderate amount, a great deal</td>
<td>135 (73.4)</td>
<td>345 (69.7)</td>
<td>1.05 (0.95-1.17)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encouraged management</td>
<td>4.0</td>
<td>3.0</td>
<td></td>
<td>3.0</td>
<td></td>
</tr>
<tr>
<td>not at all</td>
<td>42 (22.8)</td>
<td>141 (28.7)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>moderate amount, a great deal</td>
<td>142 (77.2)</td>
<td>350 (71.3)</td>
<td>1.08 (0.98-1.19)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

++Frequencies will not sum to the total sample size due to missing responses. Valid percentages presented.

++RR (95% CI) = relative risk (95% confidence interval), those without NC were the reference group.

*significant at p<0.05, ** significant at p<0.01
Table 5.4. Self-efficacy in individuals with (n=188) and without neuropathic characteristics (NC) (n=522).+

<table>
<thead>
<tr>
<th>Pain Self-Efficacy Questionnaire</th>
<th>with NC median</th>
<th>n (%)$^+$</th>
<th>Without NC median</th>
<th>n(%)$^+$</th>
<th>RR (95% CI)$^{++}$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Score</strong></td>
<td>43.0</td>
<td>51.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low self-efficacy</td>
<td>70 (39.3)</td>
<td></td>
<td>93 (18.7)</td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>High self-efficacy</td>
<td>108 (60.7)</td>
<td></td>
<td>404 (81.3)</td>
<td></td>
<td>0.75 (0.66-0.85)$^{**}$</td>
</tr>
<tr>
<td><strong>Scale Scores</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cope without medications</td>
<td>3.0</td>
<td>4.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>105 (57.1)</td>
<td>202 (39.5)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>79 (42.9)</td>
<td>309 (60.5)</td>
<td>0.71 (0.59-0.85)$^{**}$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Become more active</td>
<td>4.0</td>
<td>5.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>77 (42.1)</td>
<td>135 (26.5)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>106 (57.9)</td>
<td>374 (73.5)</td>
<td>0.79 (0.69-0.90)$^{**}$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accomplish goals</td>
<td>4.0</td>
<td>5.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>68 (37.0)</td>
<td>86 (16.9)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>116 (63.0)</td>
<td>424 (83.1)</td>
<td>0.76 (0.67-0.85)$^{**}$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Live a normal lifestyle</td>
<td>4.0</td>
<td>5.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>61 (33.3)</td>
<td>78 (15.3)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>122 (66.7)</td>
<td>433 (84.7)</td>
<td>0.79 (0.71-0.88)$^{**}$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socialize often</td>
<td>5.0</td>
<td>6.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>60 (32.4)</td>
<td>72 (14.1)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>125 (67.6)</td>
<td>438 (85.9)</td>
<td>0.79 (0.71-0.87)$^{**}$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do the things I enjoy</td>
<td>4.0</td>
<td>5.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>59 (32.1)</td>
<td>77 (15.1)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>125 (67.9)</td>
<td>434 (84.9)</td>
<td>0.80 (0.72-0.89)$^{**}$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enjoy things</td>
<td>5.0</td>
<td>5.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>51 (27.9)</td>
<td>81 (15.7)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>132 (72.1)</td>
<td>424 (82.3)</td>
<td>0.86 (0.78-0.95)$^{**}$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work despite pain</td>
<td>5.0</td>
<td>6.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>50 (27.3)</td>
<td>54 (10.6)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>133 (72.7)</td>
<td>456 (89.4)</td>
<td>0.81 (0.74-0.89)$^{**}$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cope with pain</td>
<td>5.0</td>
<td>5.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>48 (25.9)</td>
<td>60 (11.7)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>137 (74.1)</td>
<td>451 (88.3)</td>
<td>0.84 (0.77-0.92)$^{**}$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Household chores</td>
<td>5.0</td>
<td>6.0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>37 (20.1)</td>
<td>49 (9.6)</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>147 (79.9)</td>
<td>460 (90.4)</td>
<td>0.88 (0.82-0.96)$^{**}$</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

+$^+$ Frequencies will not sum to the total sample size due to missing responses. Valid percentages presented.

++RR (95% CI) = relative risk (95% confidence interval), '1.00' denotes reference category. Those without NC were the reference group. *significant at p<0.05, ** significant at p<0.01
Table 5.5. Depressive symptoms over the past two weeks reported by individuals with (n=188) and without neuropathic characteristics (NC) (n=522).

<table>
<thead>
<tr>
<th>Patient Health Questionnaire-9</th>
<th>with NC median n (%)</th>
<th>Without NC median n (%)</th>
<th>RR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Score</strong></td>
<td>6.0</td>
<td>3.0</td>
<td></td>
</tr>
<tr>
<td>No or mild depression</td>
<td>114 (64.4)</td>
<td>415 (84.5)</td>
<td>1.00</td>
</tr>
<tr>
<td>Moderate to severe depression</td>
<td>63 (35.6)</td>
<td>76 (15.5)</td>
<td>2.30 (1.73-3.06)**</td>
</tr>
</tbody>
</table>

**Scale Scores**

- **Feeling tired or having little energy**
  - Not at all or several days: 101 (54.6) vs. 383 (76.1)
  - Most days or nearly every day: 84 (45.4) vs. 120 (23.9)
  - RR: 1.90 (1.52-2.38)**

- **Trouble sleeping or sleeping too much**
  - Not at all or several days: 109 (58.6) vs. 354 (70.1)
  - Most days or nearly every day: 77 (41.4) vs. 151 (29.9)
  - RR: 1.38 (1.11-1.72)**

- **Poor appetite or overeating**
  - Not at all or several days: 121 (65.8) vs. 426 (84.9)
  - Most days or nearly every day: 63 (34.2) vs. 76 (15.1)
  - RR: 2.26 (1.70-3.02)**

- **Feeling bad about self**
  - Not at all or several days: 139 (75.1) vs. 471 (93.1)
  - Most days or nearly every day: 46 (24.9) vs. 35 (6.9)
  - RR: 3.59 (2.40-5.40)**

- **Little pleasure or interest in doing things**
  - Not at all or several days: 137 (75.3) vs. 449 (88.7)
  - Most days or nearly every day: 45 (24.7) vs. 57 (11.3)
  - RR: 2.19 (1.54-3.21)**

- **Trouble concentrating**
  - Not at all or several days: 146 (78.9) vs. 477 (94.1)
  - Most days or nearly every day: 39 (21.1) vs. 30 (5.9)
  - RR: 3.56 (2.28-5.56)**

- **Feeling down/depressed/hopeless**
  - Not at all or several days: 153 (82.7) vs. 482 (95.6)
  - Most days or nearly every day: 32 (17.3) vs. 22 (4.4)
  - RR: 2.29 (1.25-4.21)**
<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Moving or speaking slowly/being restless</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Not at all or several days</td>
<td>155</td>
<td>484</td>
</tr>
<tr>
<td>Most days or nearly every day</td>
<td>23</td>
<td>31</td>
</tr>
<tr>
<td>Thoughts of being better off dead or hurting self</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Not at all or several days</td>
<td>173</td>
<td>500</td>
</tr>
<tr>
<td>Most days or nearly every day</td>
<td>12</td>
<td>6</td>
</tr>
</tbody>
</table>

Frequencies will not sum to the total sample size due to missing responses. Valid percentages presented.

**RR (95% CI)** = relative risk (95% confidence interval), '1.00' denotes reference category. Those without NC were the reference group

*significant at p<0.05, ** significant at p<0.01
Table 5.6. Relationship between high self-efficacy, moderate or severe depression, and severe pain intensity and the use of emotional self-management strategies in individuals with neuropathic characteristics (NC) (n=188)+.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Self-Efficacy</th>
<th>Depression+++</th>
<th>Severe Pain Intensity^</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>High</td>
<td>Low</td>
<td>RR (95% CI) ++</td>
</tr>
<tr>
<td>Self-distraction</td>
<td>56.5</td>
<td>56.7</td>
<td>1.00 (0.76-1.30)</td>
</tr>
<tr>
<td>Active coping</td>
<td>69.4</td>
<td>64.7</td>
<td>1.07 (0.87-1.33)</td>
</tr>
<tr>
<td>Denial</td>
<td>19.6</td>
<td>20.3</td>
<td>0.97 (0.53-1.77)</td>
</tr>
<tr>
<td>Substance use</td>
<td>13.0</td>
<td>17.5</td>
<td>0.75 (0.37-1.52)</td>
</tr>
<tr>
<td>Use of emotional support</td>
<td>31.5</td>
<td>39.1</td>
<td>0.80 (0.54-1.21)</td>
</tr>
<tr>
<td>Behavioural</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>disengagement</td>
<td>15.7</td>
<td>32.5</td>
<td>0.49 (0.78-0.85)**</td>
</tr>
<tr>
<td>Venting</td>
<td>25.5</td>
<td>39.1</td>
<td>0.65 (0.42-1.01)</td>
</tr>
<tr>
<td>Use of instrumental support</td>
<td>40.0</td>
<td>46.4</td>
<td>0.86 (0.61-1.21)</td>
</tr>
<tr>
<td>Positive reframing</td>
<td>54.7</td>
<td>37.7</td>
<td>1.45 (1.02-2.06)**</td>
</tr>
<tr>
<td>Self-blame</td>
<td>19.4</td>
<td>31.9</td>
<td>0.61 (0.36-1.02)</td>
</tr>
<tr>
<td>Planning</td>
<td>54.7</td>
<td>53.6</td>
<td>1.02 (0.77-1.35)</td>
</tr>
<tr>
<td>Humour</td>
<td>26.2</td>
<td>18.9</td>
<td>1.39 (0.77-2.49)</td>
</tr>
<tr>
<td>Acceptance</td>
<td>84.1</td>
<td>82.6</td>
<td>1.02 (0.89-1.17)</td>
</tr>
<tr>
<td>Religion</td>
<td>26.9</td>
<td>29.0</td>
<td>0.93 (0.57-1.50)</td>
</tr>
</tbody>
</table>

+ Frequencies will not sum to the total sample size due to missing responses. Valid percentages presented.
++ Relative risk tests were run using low self-efficacy, no or mild depression, and no to moderate pain intensity as the reference group RR, 95% CI = relative risk, 95% confidence interval
+++ 'Yes' indicates moderate to severe depression (PHQ-9 ≥10), 'no' indicates no or mild depression (PHQ-9 < 10)
^ 'Yes' indicates severe pain (VAS 7+), 'no' indicates no to moderate pain (VAS < 7) *significant at p<0.05, ** significant at p<0.01
Table 5.7. Relationship between high self-efficacy, moderate or severe depression, and severe pain intensity and the use of medical self-management strategies in individuals with neuropathic characteristics (NC) (n=188)†.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Self-Efficacy</th>
<th>Depression+++</th>
<th>Severe Pain Intensity^</th>
<th>Pain management type</th>
<th>Medication +/- non-Pharmaceutical^^</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>High %</td>
<td>Low %</td>
<td>RR (95% CI) ++</td>
<td>Yes %</td>
<td>No %</td>
</tr>
<tr>
<td>≥ 5 visits to doctor</td>
<td>24.7</td>
<td>49.2</td>
<td>0.50 (0.33-0.77)''</td>
<td>51.8</td>
<td>23.8</td>
</tr>
<tr>
<td>≥ 5 visits to specialist</td>
<td>13.2</td>
<td>33.3</td>
<td>0.39 (0.20-0.78)''</td>
<td>32.6</td>
<td>17.4</td>
</tr>
<tr>
<td>≥ 5 visits to 'other' health professional</td>
<td>40.2</td>
<td>53.2</td>
<td>0.76 (0.54-1.06)</td>
<td>53.6</td>
<td>40.2</td>
</tr>
</tbody>
</table>

† Frequencies will not sum to the total sample size due to missing responses. Valid percentages presented.
++ Relative risk tests were run using low self-efficacy, no or mild depression, and no to moderate pain intensity as the reference group RR, 95% CI = relative risk, 95% confidence interval
+++ 'Yes' indicates moderate to severe depression (PHQ-9 ≥10), 'no' indicates no or mild depression (PHQ-9 < 10)
^ 'Yes' indicates severe pain (VAS 7+), 'no' indicates no to moderate pain (VAS < 7) *significant at p<0.05, ** significant at p<0.01
^^ Reference category was other, none or non-pharmaceutical strategies
Chapter 6 – Discussion

Overview

This thesis provides evidence which can inform the management of chronic pain as outlined in the World Health Organization’s Innovative Care for Chronic Conditions Framework (ICCCF) (appendix 1). When the results from my thesis manuscripts are integrated, they (1) provide a synthesis of the international evidence for self-management interventions for chronic pain with and without NC, as well as the role of clinicians in supporting chronic pain self-management and, in the Canadian context, (2) provide a profile of self-managers of chronic pain, the chronic pain that they are managing, and the strategies they use to manage it, and (3) describe the context (e.g., barriers and facilitators) in which these strategies are used. This information contributes to the knowledge needed to organize care, particularly in Canada, on the micro-, meso-, and macro-levels of the ICCCF. The key findings and implications of this thesis are outlined in table 6.1, and presented below as they fit with the three levels of the ICCCF.

Key Findings and Implications

Micro-level: Prepared, informed and motivated individuals with chronic pain.

*The individuals with chronic pain.*

Several sociodemographic variables may affect the degree to which Canadians with chronic pain are prepared, informed, and motivated to engage in self-management. While only 35% of study participants identified health literacy as either a barrier or facilitator, their relatively older age and higher risk for low income suggest that Canadians with chronic pain may be at a relatively higher risk of low health literacy (2). Although there was no difference between the proportion of participants with and without NC who identified health literacy as a barrier or facilitator, the greater risk of low levels of education and inability to work suggest that
the risk for low health literacy may be especially high in individuals with NC (2). As the ability to read and complete a questionnaire was necessary to participate in this study, the proportion of Canadians with chronic pain and low levels of education may be greater, and thus health literacy may be a more common barrier, than is reported in this study.

Financial constraints may also be a barrier to self-management, especially in individuals with chronic pain with NC. Thirty-four percent of participants without NC and 50% of participants with NC reported an annual household income of less than $50,000, which suggests that these individuals may not have disposable income to pay for recommended non-pharmaceutical medical self-management strategies (e.g., physical therapy). With over half of the sample (57% with NC, 52% without NC) not working full- or part-time, these individuals may not have insurance to cover medical expenses through their workplaces. These financial constraints may partly explain the low reported use of non-pharmaceutical strategies. This low use was especially evident in individuals with NC who were also more likely to be in the lowest household income category.

**Characteristics of the pain being self-managed.**

Canadians with chronic pain with and without NC are managing considerable chronic pain, despite their high reported used of medications as a medical self-management strategy. Many participants with and without NC reported that their pain occurred daily or almost daily, was at least moderate in intensity, and present in multiple bodily locations. Those with NC were at a higher risk for pain that was constant or experienced daily, severe in intensity, and located in five or more body locations. Thus despite medical intervention, Canadians are having to use self-management strategies beyond taking medication, because current treatment options are not reducing or localizing their pain.
Approximately half of Canadians with chronic pain are also self-managing at least one other chronic condition. The number of chronic conditions reported in this study may be a conservative estimate of the true prevalence in Canadians with chronic pain. For example, 14% of respondents identified that they had been diagnosed with a mood disorder by a health professional, yet 26% of them screened positive for moderate to severe depression. This difference may be due to shared common complaints (e.g., sleep difficulties) between mood disorders and chronic pain conditions with resulting erroneous categorization by the Patient Health Questionnaire 9-item scale, but may indicate that mood disorders and/or other chronic conditions were present but undiagnosed in this sample. Those with NC appear to be at a higher risk of having multiple co-morbid health conditions and, despite being equally likely to be diagnosed with a mood disorder, may be at a higher risk of depression and self-harm.

**Self-management strategies used by Canadians with chronic pain.**

Canadians are using a variety of medical self-management strategies for their chronic pain, but may not be using non-pharmaceutical strategies as recommended in current practice guidelines. Only one quarter of Canadians with chronic pain (25% with NC, 22% without NC) reported using a combination of pharmaceutical and non-pharmaceutical pain relief strategies. This may be due to multiple reasons, including lack of financial resources as noted above, however this may also be due to several of the self-management barriers identified in this study including poor access to health care services and/or a lack of patient collaboration in making management decisions.

Primary care health professionals played a prominent role in helping Canadians self-manage their chronic pain. This role was identified in the literature review where family doctors were the providers to whom individuals addressed their pain management questions, and this
finding was supported in my study where family doctors were identified as the most helpful health professional in pain management. As health-related activity interference was one of the main correlates of frequent health care visits, providing family doctors and primary care health professionals with the skills needed to support self-management of chronic pain and other conditions may help individuals continue participating in their valued activities and reduce overall health care use.

The findings of this study suggest that Canadians with chronic pain use emotional self-management strategies that have been identified as having positive health outcomes, including acceptance (3-6), active coping (7, 8), and planning (7, 8). Canadians with chronic pain with and without NC are also drawing upon their social support resources to facilitate their self-management as evidenced by the frequent use of both instrumental and emotional support, and their reporting that family and friends frequently listened to them when they needed to talk about their condition. Emotional self-management strategies associated with poor health outcomes in chronic disease research were more frequently used by individuals with NC compared to those without NC, including substance use (9, 10), denial (11-13), behavioural disengagement (7, 14, 15), and self-blame (16, 17). Use of one or more of these strategies was higher in individuals with NC who had depression and severe pain, but was buffered by their having high self-efficacy. Thus, primary care health professionals seeking to support self-management and improve health outcomes may need to address the ways in which individuals with NC self-manage their negative emotions as well as assess for depression, pain intensity, and self-efficacy.


The findings of this thesis suggest that Canadians with chronic pain with and without NC are in an emotional state where they are ready to listen to chronic pain self-management advice,
but not all health care providers are providing this support. Acceptance was identified in the review as a critical first step to engaging in self-management activities (18) and the survey identified that Canadians frequently used acceptance as a strategy to cope with the negative emotions resulting from chronic pain. Despite this potential readiness to engage, 28% of participants with NC and 32% of participants without NC reported that their health care provider did not explain specific self-management strategies. Primary care health professionals may benefit from additional training in the provision of self-management support as well as access to self-management tools. For example, the development of patient education materials (e.g., pamphlet listing recommended self-management activities) could help them in this supportive role by guiding chronic pain self-management discussions and providing a list of recommended activities (e.g., gentle exercise most days of the week) that they could use and modify as needed.

The high levels of self-efficacy reported by Canadians with chronic pain with and without NC may not be recognized and followed-up by their health care providers. A shift in the affected individual’s perception of the health professional’s role from intervention and diagnosis to education and skill-building is another important step to engaging in self-management activities (18). With high levels of self-efficacy, many Canadians with chronic pain may have the motivation and skill needed to assess their management options and decide on an appropriate course of action. Despite the need for this shift in the health professional’s role and high reported levels of self-efficacy reported in this study, 41% of participants with and without NC were not included as an equal partner in making management decisions and setting management goals. As such, primary care health professionals require additional training and tools to engage in collaborative decision-making. As collaborative decision-making interventions have been
effective in supporting self-management of other chronic diseases (19), potential interventions exist for testing and use in chronic pain groups.

Canadians with chronic pain are self-managing within a context that includes both self-management barriers and facilitators, and these findings are confirmed in the literature. Validated screening tools and/or simple questions can be used to identify self-management barriers and facilitators such as self-efficacy (20, 21), depression (22, 23), and health literacy (24). Screening for self-management barriers and facilitators would allow health care providers to support self-management activities, maintain the positive outcomes experienced by those referred to a self-management intervention, and identify individuals who may be at risk for poor self-management.

Individuals with chronic pain with NC described a distinct and more challenging self-management experience. For health care professionals, these individuals require additional screening for the potentially negative self-management strategies of substance use, denial, and behavioural disengagement and would benefit from self-management interventions that include teaching healthy emotional self-management strategies. Participants with chronic pain with NC were more likely to identify fear of making pain worse, support from family/friends, access to health services, pain intensity, and depression as self-management barriers and facilitators. In order to fully support the use of positive self-management strategies, health care professionals need to also identify and treat depression, provide reassurance to reduce fear of exacerbating pain, refer to support groups to develop a social support network, and decrease pain intensity where possible for the individuals for whom they provide care.
Macro-level: Policy environment.

Promote consistent financing.

The evidence suggests that self-management interventions are an effective means of improving pain, mental health, health-related quality of life, and health care use outcomes (18). From the various types and styles of interventions reviewed, the most appropriate type for Canadians may be those that, in addition to targeting self-efficacy and teaching self-management skills, specifically address the most commonly identified barriers and facilitators such as social support, innovative means of accessing health care services (e.g., online resources), improving relations with health care providers, and fear of exacerbating pain.

Reimbursement changes at the level of health care providers may also be necessary to support innovative care of chronic pain. The introduction of new remuneration systems could support and motivate health professionals in taking the time to assess self-management strategies, barriers, and facilitators; refer to self-management interventions; and provide on-going self-management education and support in clinical visits. As NC were present in chronic pain conditions typically thought to be nociceptive (e.g., osteoarthritis), the inclusion of at least a preliminary screen for NC may need to become a standard practice for all assessments of individuals reporting chronic pain. With the inclusion of this additional step, the time required for the assessment of an individual with chronic pain may need to be lengthened.

Funding is needed to support researchers in trialing non-pharmaceutical interventions for individuals with NC, developing guidelines, translating this information into clinical practice, and evaluating the effectiveness of the guidelines after implementation into practice. Current evidence supporting the use of non-pharmaceutical interventions has been largely based on pain groups without NC or with mixed pain mechanisms. As such, the evidence base to support
interventions for individuals with NC is lacking and therefore outcomes for individuals with chronic pain with NC are not being optimized.

**Develop and allocate human resources.**

Changes to education curricula should focus on training health care professionals in the skills needed to support self-management. As a baseline, Canadian universities spend an average of 13–41 hours on pain in their curricula for the health disciplines, which is less than the average of 87 hours provided to veterinarian students (25). To develop the human resources needed to support chronic pain self-management, I have identified several areas that may require additional education time:

1. Diagnosis of chronic pain must include screening for NC, even in seemingly nociceptive pain conditions like osteoarthritis, such that their distinct health experience can be addressed;

2. The importance of prescribing, or encouraging use of, non-pharmaceutical pain relief strategies needs to be highlighted as recommended in practice guidelines; and

3. Skills needed for the long-term management of chronic conditions (e.g., collaborative decision-making) must be taught such that health professionals are capable of teaching self-management strategies and providing on-going self-management support to their future patients/clients.

Individuals with NC require additional health care resources to optimize their self-management outcomes due to their potentially having lower socioeconomic statuses, poorer general health, more intense and widespread pain, more self-management barriers and facilitators, and greater use of potentially negative self-management strategies. This pain group may require additional screening specifically for health literacy, financial access to medical and
non-pharmaceutical self-management strategies, health-related activity interference, low self-efficacy, depression, and risk for self-harm. As those with NC are at a higher risk of intense pain, they may require additional time exploring non-pharmaceutical pain relief strategies to complement their use of medications.

Nurses and nurse practitioners were rarely identified as helping with pain management, suggesting that they may be under-utilized or under-recognized in care for individuals with chronic pain. The common identification of family doctors as being helpful in pain management suggests that most self-management support occurs in primary care settings – a setting where nurses also practice. With the findings of the review suggesting that the clinician’s role include providing support, education, and advice (18), nurses may be well suited to formally take on educator roles and provide the needed on-going self-management support.

Summary

When the results of this dissertation are integrated, they provide a preliminary model of chronic pain self-management for individuals with chronic pain with and without NC (figure 6.1). This is the first known model of chronic pain self-management that has been developed with the experience of individuals with chronic pain with and without NC analyzed separately. Although individuals with NC were more likely to use self-management strategies associated with poor health outcomes and identified more self-management barriers than those with chronic pain without NC, there were still many similarities between individuals with chronic pain with and without NC in the most commonly used self-management strategies (e.g., acceptance, medications) and identified self-management barriers and facilitators (e.g., self-efficacy). Based on these findings, the preliminary model outlines the barriers and facilitators which create the
context in which self-management decisions are made, the strategies used to self-manage, and the potential outcomes of chronic pain self-management for both pain groups.

As depicted in the proposed model, both the barriers and facilitators, and the strategies themselves could influence health outcomes, thus both of these levels are potential intervention targets. Improving some health outcomes may create a positive feedback loop whereby self-management barriers and facilitators are targeted (e.g., reduced pain intensity as an outcome may represent the reduction of a self-management barrier, further modifying self-management strategies and health outcomes). As very little work has explored the effect of using various self-management strategies on health outcomes and the proposed model is based on results from a cross-sectional study, it presents a preliminary description of chronic pain self-management in Canada. Further testing is needed to determine whether specific self-management barriers, facilitators, and strategies affect health outcomes, and whether different factors affect the health outcomes of individuals with and without NC.

Based on the findings of this dissertation as depicted in the proposed model, current self-management interventions may need to be combined to address the experience of Canadians with chronic pain with and without NC. Specifically, combining education points and skills taught in the existing and widely used Stanford model (e.g., working with healthcare providers) (26) with those taught in acceptance and commitment therapy (e.g., principles of the pain-avoidance-suffering cycle) (27) and providing the intervention in a group format may address the barriers and facilitators identified in this study (e.g., relationship with health care provider, fear of exacerbating pain, social support). Evaluation of the effectiveness of self-management interventions designed to meet the needs of Canadians with chronic pain is more likely to be accurate if they consider the nature of the pain (e.g., without NC).
There are several key findings from the results of this thesis that could propel the inclusion of self-management as a key component to living with, and managing, chronic pain. First, the findings highlight the important role of health care professionals in chronic pain self-management and, with their new roles, their new education needs. As the Canadian health care system shifts its focus from acute to chronic health issues, health care professionals will also have to transition in their roles from treatment of acute issues to management of chronic conditions. In management roles, health professionals will require skills in collaborative decision-making, providing on-going self-management reinforcement, and assessing self-management resources to create a supportive context for self-management. At the level of specific strategies and outcomes, health care professionals would benefit from the capacity to screen for the use of potentially negative self-management strategies, encourage the use of positive self-management strategies, and assess eligibility for self-management interventions. To support this transition in roles, changes to both health curricula and funding policies are necessary to ensure the acquisition and reimbursement of these necessary new skills and resources.

Second, there are multiple research gaps in the chronic pain self-management literature. While there is a strong body of literature supporting the use of self-management interventions for chronic pain, there is a paucity of evidence for interventions addressing the barriers and facilitators identified in this study (e.g., relationship with health care provider). Despite evidence supporting the effectiveness of self-management interventions (18), the resulting positive health outcomes may not be sustained if the barriers and facilitators are not arranged to support the continued use of the learned self-management strategies and skills. For example, the chronic disease literature supports the use of multiple interventions to improve collaboration between
health care professionals and the individuals for whom they provide care (19), yet these have not been studied for chronic pain and it cannot be assumed that the same interventions will work across different chronic conditions. Thus assessment of interventions to improve collaborative decision-making and goal-setting in chronic pain is needed. Furthermore, particular interventions that have been shown to be beneficial in chronic disease groups may not be effective for chronic pain. While use of self-blame, denial, and behavioural disengagement are associated with negative health outcomes in the chronic disease literature, the resulting outcomes for chronic pain is unknown.

Finally, the results of this dissertation highlight the distinct self-management experiences of individuals with NC. Until now, this group has not been identified specifically in the literature exploring self-management interventions; individuals with NC may be at a higher risk for poor health outcomes due not only to having a different type of pain, but also due to their lower socioeconomic status, poorer general health, greater use of potentially negative self-management strategies, and greater experience of self-management barriers (e.g., low self-efficacy) compared to other pain groups. For clinicians, individuals with NC may require additional human resources to optimize their health outcomes, such as extra clinician time to screen for risk of self-harm, depression, self-efficacy, and use of self-management strategies that may lead to negative health consequences. It is currently unknown whether existing chronic pain self-management programs are effective for individuals with NC, or whether the program curricula need to be fine-tuned to address their distinct self-management experience. Thus, there is a need to trial self-management interventions in individuals with chronic pain with NC to determine whether currently available interventions are effective in improving health outcomes.
**Strengths.**

This is the first known study to use the ICCCF as a guiding framework for care of chronic pain. The framework provided guidance for recommendations at the level of individuals, health care professionals, and policy-makers for optimizing care for Canadians with chronic pain. The review manuscript used explicit criteria to define what would be considered a self-management intervention, thus broadening the criteria to include interventions from the acceptance and commitment therapy and cognitive-behavioural therapy traditions. The review also included qualitative data to outline the role of health professionals in chronic pain, which is the first known review of this topic.

The two quantitative manuscripts were based on a survey of a random sample of Canadians living in the ten provinces, thus the majority of participants accessing care within all of the provincial health care systems were represented. Men with chronic pain represented approximately half of the sample, which is uncommon in pain research and allowed for the experience of both genders to be represented equally. The results provided a broad profile of chronic pain self-management in Canada, including a profile of individuals who self-manage their chronic pain, a description of the pain and general health of these individuals, the self-management strategies themselves, and the context in which self-management occurred. Combined, these findings identify multiple points at which intervention may be possible to improve health outcomes. The screening and stratification of individuals with and without NC allowed for the first national comparison of self-management between the two types of chronic pain. The findings identified the potential need for additional health services (e.g., screening for self-harm risk) of those with NC, informing future development and updating of current self-management interventions. The use of self-reported information allowed the individuals who
self-manage their chronic pain to describe their management activities as they perceived them, which allowed for the collection of self-management activities that may not be gleaned through chart review (e.g., use of self-distraction), or may be considered deviant (e.g., use of alcohol) or irrelevant (e.g., venting) and not reported to health care professionals.

**Limitations.**

While the review included a wide breadth of interventions, by grouping the frequency (e.g., ‘dose’) of all chronic pain interventions and formats, I was unable to identify particular aspects of self-management interventions that were especially effective or ineffective. This grouping was necessary due to the variability in interventions and dosing frequencies reported in the literature, therefore no minimum intervention ‘dose’ or recommended format could be identified.

The selection of potential survey participants may have biased the sample to consist of older participants due to the use of landlines rather than cellular telephones, healthier participants due to their living in the community and being able to complete a questionnaire, and wealthier participants due to their having a telephone. As such, the self-management strategies, barriers, and facilitators of younger individuals, those living in health care facilities, and those with limiting chronic conditions may not be represented in the findings. Canadians living in the Yukon, Northwest Territories, and Nunavut were not included in the survey, thus the self-management experience of Canadians with aboriginal identities and those with limited physical access to health care services may be under-represented in the findings. This may have led to self-management strategies, barriers, and facilitators being missed and/or misrepresented in this study (e.g., access to health services may be a more common than what was reported). Due to the length of the survey and the potential participants living with at least one chronic health
condition, self-management strategies specific to role function were not captured. Role and other medical and emotional self-management strategies are likely used by Canadians in addition to those captured in the questionnaire, and complementary data collection methods (e.g., interviews, focus groups) may be needed to elicit these additional strategies. The tool used to screen for NC has a sensitivity of 83-85% and specificity of 80-87% compared with diagnoses made by clinical exam (28, 29), thus while the majority of participants would have been accurately classified, some participants may have been erroneously classified as having the wrong type of pain resulting in regression toward the mean, and thus the differences between the two pain groups may be greater than described in this thesis. As the medical self-management strategies were based on self-report data, the use of non-pharmaceutical strategies (e.g., diet modifications) may be under-reported if they were not perceived to be an ‘intervention’ by some respondents.

**My next steps.**

Based on the findings of this thesis, I plan on conducting four more analyses of the survey data. First, I plan on further analyzing the simplified model of chronic pain self-management by conducting a path analysis to identify which factors are associated with positive and negative health outcomes. In conjunction with the larger study team, I plan on exploring which aspects of self-management are associated with the additional health outcomes captured as part of the larger study. Identifying variables that appear to influence these health outcomes will help with identifying potential targets for intervention. Based on the findings of this thesis, the role of NC will be considered when analyzing this model. Once these potential intervention targets are identified, the literature can be reviewed for interventions targeting these variables and their efficacy can be tested in chronic pain groups with and without NC.
Secondly, I will conduct a gender analysis. As the majority of individuals reporting chronic pain are generally female, the experience of males with chronic pain has been under-represented in the pain and self-management literature. With men representing roughly half of the respondents reporting chronic pain, it will be possible to compare males and females on their pain diagnoses, descriptions, self-management strategies, and self-management barriers and facilitators. Identifying whether there are differences in how males and females self-manage their chronic pain can guide health care professionals in their assessments of individuals with chronic pain and in deciding whether current self-management intervention curricula address the self-management needs of males.

Third, I will use current practice guidelines for chronic pain with and without NC and compare the recommendations for pharmaceutical management with the medications reportedly used by Canadians with chronic pain. Although there are multiple reasons why individuals may not be using recommended medications, including physicians not prescribing them and intolerable side effects, this analysis will provide a profile of medication use by Canadians with chronic pain. As this analysis will be based on reports by the affected individuals, the findings will provide a distinct view of medication use that could be complimented by future chart reviews.

Finally, the main study captured data on health care use. I will focus on the participants who reported the most frequent health care visits (e.g., ≥ 12 annual visits), and conduct an exploratory analysis to profile this group and identify which factors are associated with frequent health care visits. This analysis will provide some preliminary data to guide health care professionals in assessing for, and addressing, the factors which drive high use of health care professionals’ time.
Areas for further research.

The results of this study have identified several areas in which health care professionals can support chronic pain self-management, however, little is known about the needs experienced by providers in this supportive role. While self-management interventions exist for individuals with chronic pain, current health care professionals may also require an ‘intervention’ to gain the necessary skills while educational curricula are being updated. A needs assessment of primary care health professionals may identify resources that could be developed to facilitate their roles in supporting self-management.

From a nursing perspective, the role of the nurse in chronic pain management remains unclear. Study participants rarely identified nurses as helping with pain management, possibly because they attributed any management that occurred in primary care as being provided by the family physician, regardless of who may have provided the care. The role of primary care nurses and nurse practitioners requires further exploration. Possible means of exploring this role could include focus groups of primary care nurses and nurse practitioners or a chart review of the interventions they use when providing care for individuals with chronic pain.

Conclusion

The results of this enquiry present a baseline of chronic pain self-management in Canada, and add to the evidence needed to inform health care decisions on the individual, provider, and policy levels. In this first national benchmark, many Canadians are living with intense and widespread chronic pain and receiving care in health systems which may not be organized to care for chronic conditions. Changes are necessary in the curricula used to educate health professionals, the roles of health professionals, and the related policy to optimize outcomes. Despite a large body of literature in other chronic diseases, research is needed in chronic pain
groups to identify positive and negative self-management strategies, interventions to address negative self-management strategies, and methods of reducing self-management barriers and reinforcing facilitators. Finally, the unique nature and needs of individuals with NC must be considered when addressing chronic pain at all levels.

The findings of this thesis may be especially timely with current changes underway in the Canadian health system. As every Canadian will soon have an electronic health record, integration of best practice guidelines, screening tools for NC, and reminders to screen for health literacy, self-management resources, and risk of self-harm will be possible. Similarly, the increasing use of online personal health records may allow for better communication about self-management activities, barriers, and facilitators between individuals and health care professionals. As wait times for various procedures and specialists continue to be a health issue in Canada, health care professionals in primary care may be especially motivated to learn the skills needed to support self-management in a variety of chronic conditions to provide optimal care for those waiting for specialized services and potentially reduce the number of individuals requiring specialized care. With a health care system faced with balancing funding and competing health priorities, it is essential that each and every Canadian be actively involved in managing their health.
References


Table 6.1. Recommendations for practice, education, research, and policy.

<table>
<thead>
<tr>
<th>Thesis Finding</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Individuals with chronic pain, especially those with NC, may have difficulty with self-managing due to financial constraints and low education levels.</td>
<td>(a) Screen for self-management resources including financial resources and health literacy, especially in those with NC.</td>
</tr>
<tr>
<td>(b) Individuals with chronic pain, especially those with NC, report high pain intensities that are managed primary with medications.</td>
<td>(b) Encourage use of non-pharmaceutical pain relief strategies recommended in practice guidelines (e.g., physical therapy), especially in individuals with NC.</td>
</tr>
<tr>
<td>(c) Almost 40% of those with chronic pain screened positive for moderate to severe depression, and individuals with NC had a higher risk.</td>
<td>(c) Routinely screen individuals with chronic pain for depression, especially those with NC.</td>
</tr>
<tr>
<td>(d) Individuals with NC were at a high risk for thoughts of suicide and self-harm.</td>
<td>(d) Screen individuals with chronic pain with NC for suicide and self-harm thoughts.</td>
</tr>
<tr>
<td>(e) Some individuals with chronic pain did not have specific self-management actions explained.</td>
<td>(e) Provide specific advice as to what individuals with chronic pain should be doing to self-manage their pain (e.g., exercises)</td>
</tr>
<tr>
<td>(f) Some individuals with chronic pain were not included as an equal partner in making management decisions and setting management goals.</td>
<td>(f) Include the individual with chronic pain as a partner in pain management goal-setting and decisions.</td>
</tr>
<tr>
<td>(g) Health-related activity interference consistently predicted annual health visits.</td>
<td>(g) Problem-solve with the affected individual as to what activities they value and how to manage their health such that they can continue to participate.</td>
</tr>
<tr>
<td>(h) Canadians with chronic pain largely had accepted the chronic nature of their pain.</td>
<td>(h) Partner with individuals with chronic pain to support their shifting into the role of active self-manager.</td>
</tr>
<tr>
<td>(i) Individuals with chronic pain frequently used their family members for emotional and instrumental support and felt that they both listened and encouraged self-management.</td>
<td>(i) Where possible, include family members in interactions where self-management activities are recommended.</td>
</tr>
<tr>
<td>Thesis Finding</td>
<td>Recommendation</td>
</tr>
<tr>
<td>------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>(j) Individuals with NC were at a higher risk of using substance use, denial,</td>
<td>(j) Screen individuals with NC for use of potentially negative emotional self-</td>
</tr>
<tr>
<td>behavioural disengagement, self-blame, and venting to cope with their negative</td>
<td>management strategies.</td>
</tr>
<tr>
<td>emotions.</td>
<td></td>
</tr>
<tr>
<td>(k) Few health professionals explained specific self-management strategies to</td>
<td>(k) Provide individuals with chronic pain with a list of specific self-management</td>
</tr>
<tr>
<td>individuals with chronic pain.</td>
<td>activities or refer them to a self-management program which teaches the</td>
</tr>
<tr>
<td></td>
<td>recommended activities.</td>
</tr>
<tr>
<td>(l) Canadians encounter multiple self-management barriers and facilitators.</td>
<td>(l) Screen and target potential self-management barriers with an intervention</td>
</tr>
<tr>
<td></td>
<td>(e.g., clear advice on exercise to address fear of making pain worse), and</td>
</tr>
<tr>
<td></td>
<td>build on potential self-management facilitators (e.g., include family/friends</td>
</tr>
<tr>
<td></td>
<td>when suggesting a self-management activity to build on their support).</td>
</tr>
<tr>
<td>(m) Individuals with NC were more likely to identify fear of making pain</td>
<td>(m) Screening and addressing self-management barriers and facilitators is</td>
</tr>
<tr>
<td>worse, depression, pain intensity, support from family and friends, and access</td>
<td>especially important in supporting self-management in individuals with NC.</td>
</tr>
<tr>
<td>to health care services.</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>(a) NC were present across multiple pain diagnoses, including those typically</td>
<td>(a) Include screening for NC as a standard part of pain assessment.</td>
</tr>
<tr>
<td>considered neuropathic (e.g., post-operative chronic pain) and nociceptive</td>
<td></td>
</tr>
<tr>
<td>(e.g., osteoarthritis)</td>
<td></td>
</tr>
<tr>
<td>(b) Individuals with chronic pain have accepted the chronic nature of their</td>
<td>(b) Integrate strategies for collaborative goal-setting and decision-making</td>
</tr>
<tr>
<td>pain and have high self-efficacy for managing their condition.</td>
<td>into current curriculum.</td>
</tr>
<tr>
<td>(c) Self-management interventions are effective in improving pain, mental</td>
<td>(c) Include self-management interventions as a management option for chronic</td>
</tr>
<tr>
<td>health, health-related quality of life, and health care use outcomes in</td>
<td>pain.</td>
</tr>
<tr>
<td>chronic pain groups.</td>
<td></td>
</tr>
<tr>
<td>Research</td>
<td></td>
</tr>
<tr>
<td>(a) Nurses and nurse practitioners were rarely identified as the “most</td>
<td>(a) Delineate the role of the nurses and nurse practitioners in chronic pain</td>
</tr>
<tr>
<td>helpful” professional in pain management.</td>
<td>management in primary care.</td>
</tr>
<tr>
<td>Thesis Finding</td>
<td>Recommendation</td>
</tr>
<tr>
<td>----------------</td>
<td>----------------</td>
</tr>
<tr>
<td>(b) Non-pharmaceutical self-management strategies were infrequently used in combination with medications as per practice guidelines.</td>
<td>(b) Describe use of chronic pain practice guidelines in primary care and ways of translating these guidelines into practice.</td>
</tr>
<tr>
<td>(c) Non-pharmaceutical self-management strategies were infrequently used by individuals with NC.</td>
<td>(c) Trial non-pharmaceutical interventions (e.g., cognitive behaviour therapy) in individuals with NC to determine their efficacy and guide clinical recommendations.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Policy</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Nurses and nurse practitioners were rarely identified as the “most helpful” professional in pain management.</td>
<td>(a) Use primary care nurses to provide chronic pain self-management support (e.g., education).</td>
</tr>
<tr>
<td>(b) Self-management interventions are effective in improving pain, mental health, health-related quality of life, and health care use outcomes in chronic pain groups.</td>
<td>(b) Allocate funding for chronic pain self-management programs.</td>
</tr>
<tr>
<td>(c) Health care providers should be providing self-management advice and on-going support, screening for use of positive and negative self-management strategies, assessing self-management barriers and facilitators.</td>
<td>(c) New remuneration systems should be created to encourage and reimburse health care providers in supporting chronic pain self-management.</td>
</tr>
<tr>
<td>(d) Nurses were infrequently identified as helping with pain management despite their being capable of performing the clinician roles identified in the review.</td>
<td>(d) Support the inclusion of chronic pain nurse educators within primary care teams and settings.</td>
</tr>
</tbody>
</table>
Figure 6.1. Chronic pain self-management strategies, barriers and facilitators, and outcomes as identified in this study.

* HCPs – health care providers

** Used by individuals with chronic pain with neuropathic characteristics
Appendices

Appendix 1. World Health Organization Innovative Care for Chronic Conditions Framework.
Appendix 2. The Building Blocks of the World Health Organization’s Innovative Care for Chronic Conditions Framework that were Addressed in this Dissertation.

- Patients and families:
  - informed about chronic pain and necessary self-management actions
  - motivated to self-manage
  - prepared with behavioural skills

Positive Policy Environment
- Promote consistent financing
- Develop and allocate human resources

Health Care Organization
- Support self-management and prevention

Better Outcomes for Chronic Conditions
Appendix 3. Additional details of the methods used to review the literature on self-management for chronic pain, and retrieved and included articles.

Appendix Overview & Purpose

This review, published in the journal *Pain Management*, is aimed at health care providers who are responsible for identifying potential candidates for self-management interventions, referral to these programs, and providing continued support after the intervention. As per the journal's instructions, the methods within the review manuscript are brief. Thus, the purposes of this appendix are to provide more detail on (1) the methods used to search the literature and screen studies for inclusion and (2) the studies included in the review.

Review Methods and Results

Search strategy.

A search of the literature was conducted in February 2012 to meet the following two objectives: (1) to describe and evaluate the evidence for self-management interventions, and (2) to identify the health care provider’s role in supporting self-management of chronic pain. The search included CINAHL, MEDLINE, EMBASE, AMED, and PsychINFO databases, and was limited to studies published in the English language that involved human participants. In keeping with the journal’s requirements, the review included studies published between 2007 and 2012. Specific search terms used in each database and the number of articles retrieved are outlined in table A3.1.

Inclusion criteria.

To address objective 1, studies evaluating self-management interventions were included in the review if they met the following criteria: (i) study participants reported pain persisting for a minimum of 3 months, (ii) details of the intervention content were described, (iii) the
intervention fit with Kate Lorig's definition of self-management (1). Interventions were considered to meet Lorig's definition of self-management if they (i) taught pain management skills (e.g., relaxation), (ii) targeted self-efficacy through practicing skills, observing peers modeling the skills, and receiving feedback and support on use of the skills, and (iii) involved participants in setting goals of pain management (1). For objective 2, studies addressing the health care provider’s role were included if they addressed involvement in supporting chronic pain self-management from either the providers’ or patients’/clients’ perspective.

To determine whether a study met the criteria for both/either objectives, titles and abstracts were read. For studies with abstracts relevant to objective 1, the study’s inclusion criteria were reviewed to identify whether the participants’ pain had persisted for at least three months and the intervention description was reviewed for elements of self-management. Articles with abstracts relevant to objective 2 were reviewed for information on the role of the provider in chronic pain self-management.

**Search results.**

Eighty-three articles (describing 68 interventions) met the inclusion criteria for objective 1 and 24 studies addressed the health care provider’s role as per objective 2 (table A3.1). Two of the 83 intervention studies included information on the health care provider’s role and were included in the review for objective 2. Common reasons for exclusion were failure to meet the definition of a self-management intervention or provide enough detail about the intervention to determine whether it met the criteria, and publication of study protocols not yet implemented (figure A3.1).
**Data extraction and review.**

A data extraction table was created for the studies relevant to objective 1. The table was used to record each study's design, participants, mode of delivery, intervention setting and topics, control/comparison group, timing of follow-up, outcome measures, and results (table A3.2). The review was organized into three sections: overview, evidence, and health care professional's role. The overview section outlined the various types, formats, participants, settings and facilitators involved in self-management interventions. The evidence section summarized the effect of self-management interventions on the most commonly measured outcomes and how long after the intervention's completion the effects were measured. The final section was organized into three areas in which health care professionals can act to support self-management as identified in the retrieved articles.
Reference

Figure A3.1. Selection process of articles reviewed for descriptions and evaluations of self-management interventions (objective 1).

- Total articles retrieved: n=1,128
  - Excluded after reading title: n=460
  - Excluded for objective 1 after reading abstract (including repeated articles): n=668
  - Articles reviewed for inclusion criteria: n=158
    - Pain < 3 months: n=3
      - Poor intervention description: n=7
        - Published protocol only: n=12
        - Intervention failed to meet criteria: n=53
  - Met study inclusion criteria: n=83
Table A3.1. Databases, search terms, and total and included articles for review (objectives 1 and 2).

<table>
<thead>
<tr>
<th>Database</th>
<th>Search Terms</th>
<th>Total</th>
<th>Included (objective 1)</th>
<th>Support (objective 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CINAHL</td>
<td>[self-care OR self-management (keyword) OR patient education OR behaviour modification OR psychoeducation] AND [pain], limited to 2007-current, English language</td>
<td>363</td>
<td>42</td>
<td>16</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>[self-care OR self-management (keyword) OR psychoeducation (keyword) OR behaviour therapy OR cognitive behavioural therapy (keyword)] AND [pain management], limited to 2007-current, English language</td>
<td>268</td>
<td>21 (repeats=30)</td>
<td>5 (repeats=8)</td>
</tr>
<tr>
<td>EMBASE</td>
<td>[self-care OR self-management (keyword) OR patient education OR psychoeducation OR behaviour therapy OR cognitive therapy] AND [chronic pain], limited to 2007-current, English language, and articles</td>
<td>292</td>
<td>18 (repeats=10)</td>
<td>1 (repeat=1)</td>
</tr>
<tr>
<td>AMED</td>
<td>[self-care OR self-management (keyword) OR patient education OR psychoeducation OR behaviour therapy] AND [pain], limited to 2007-current</td>
<td>25</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>PsycINFO</td>
<td>[self-management OR self care skills OR psychoeducation OR client education OR cognitive behaviour therapy] AND [chronic pain], limited to 2007-current, English language, Human</td>
<td>180</td>
<td>1 (repeats=23)</td>
<td>1 (repeat=6)</td>
</tr>
</tbody>
</table>
Table A3.2. Data extracted from articles included in the review of descriptions and evaluations of self-management interventions (objective 1).

<table>
<thead>
<tr>
<th>Author &amp; Date</th>
<th>Method [Design, Age &amp; Pain Dx, N (n)]</th>
<th>Mode/Delivery</th>
<th>Intervention</th>
<th>Control</th>
<th>F-U</th>
<th>Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allen, et al. 2010</td>
<td>RCT hip or knee OA 515 (461)</td>
<td>-T x 12 monthly calls, AV edu materials</td>
<td>-primary care in Veteran Affairs -OA and SM edu -exercise -healthy eating/wt -meds -joint injections, sx -communication with HCPs -joint care and protection -CAMs -stress and relaxation -sleep -pt directed goals</td>
<td>-12 months</td>
<td>-Arthritis Impact Measurement Scale (pain, physical function, affect) -pain VAS -Arthritis Self-Efficacy -HCU -costs</td>
<td>At 12 months: -no AEs -small reduction in pain (1 point on VAS) -small improvement in walking and bending, and self-efficacy -$107/pt</td>
<td></td>
</tr>
<tr>
<td>Allen, et al. 2008; Leveille, et al. 2009</td>
<td>RCT Lower extremity mobility difficulty, depression OR chronic MSK pain &gt; 3 months 241 (233)</td>
<td>Internet, portal-based coaching intervention Nurse coach</td>
<td>Hospital-and communit y-based primary care physicians USA</td>
<td>Email to general health information websites -after index visit and 3 months after index visit</td>
<td>-Centre for Disease Control and Prevention’s Healthy Days Measures -PEPPI (confidence for communicating with HCPs) -experience of index visit (22-item online form created for this study)</td>
<td>-received specific advice from dr. -less likely to have meds changed -more likely to be referred to a specialist -no difference at 3 months</td>
<td></td>
</tr>
<tr>
<td>Alp, et al. 2007</td>
<td>RCT Menopausal or idiopathic osteoporosis 50 sedentary women</td>
<td>-Choices For Better Bone Health -GS of 50 min, 1/wk x 5 weeks</td>
<td>-balneotherapy and rehab centre</td>
<td>-osteoarthritis as part of aging -calcium and vit D -taking meds -negative feelings and emotional well-being -managing pain -no change in activity -5 weeks (end of Tx), 6 months</td>
<td>-pain VAS -SF-36 -Sensitized Romberg Test (balance) -Timed Sit to Stand Test (functional assessment)</td>
<td>-no between group differences reported at 5 weeks</td>
<td>At 6 months:</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/Setting</td>
<td>Intervention</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
</tr>
<tr>
<td>---------------------</td>
<td>---------------------------------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>---------</td>
<td>-------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Berman, et al. 2009</td>
<td>RCT</td>
<td></td>
<td></td>
<td>- safety and lowering risk of falls, exercise - teaching how to develop a personal plan for better bone health</td>
<td>WL</td>
<td>6 weeks (end of Tx)</td>
<td>- feasibility of, and satisfaction for, online intervention for older adults - Brief Pain Inventory – Short Form - Pain Self-Efficacy Questionnaire - Centres for Disease Control and Prevention - Health-Related Quality of Life - Healthy Days Core and Symptom Modules - CES-D 10 (depression) - STAI 6 (anxiety) - Pain Awareness Questionnaire - Self-care</td>
</tr>
<tr>
<td>Brown, et al. 2009</td>
<td>Prospective, randomized trial</td>
<td>GS x 2hrs/week x 12 weeks</td>
<td>-</td>
<td>-edu and CBT (identify and replace negative thoughts, relaxation, breathing, imagery) - physical therapy (stretch and self-) 1. oral amitriptyline (10-20mg/day) 2. topical triamcino</td>
<td>WL</td>
<td>12 weeks (end of Tx)</td>
<td>- McGill Pain Questionnaire</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Topics</td>
<td>Control</td>
<td>F-U</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>--------------</td>
<td>---------------</td>
<td>----------------------</td>
<td>--------</td>
<td>---------</td>
<td>-----</td>
</tr>
<tr>
<td>Buhrman, et al. 2011</td>
<td>RCT Chronic back pain, screened and excluded if depressed 54</td>
<td>-web-based, emails from instructors, homework 12 weeks</td>
<td>Community</td>
<td>-relaxation and breathing -edu about pain -goal-setting -exercise plan, stretching, warming-up, ergonomics -activity plans, pacing -cognitive restructuring -stress and stress management -thought records, coping diaries -mindfulness -sleep disorders -communication and conflict resolution skills -problem-solving -maintenance</td>
<td>Control not specified</td>
<td>12 weeks (end of Tx)</td>
<td>-Coping Strategies Questionnaire (catastrophizing) -Multidimensional Pain Inventory -Pain and Impairment Relationship Scale -Hospital Anxiety and Depression Scale -Quality of Life Inventory</td>
</tr>
<tr>
<td>Carpenter, et al., 2012</td>
<td>Pilot RCT Chronic low back pain &gt; 6 months and &gt; 4/10 intensity,</td>
<td>Internet-based, 3-weeks, mix of didactic teaching, patient stories, reflective thinking, and interactive exercises</td>
<td>internet</td>
<td>-edu about acute vs. chronic pain and various interventions -skills training for cognitive reframing, negative thoughts, and accepting thoughts</td>
<td>WL</td>
<td>Week 3 (end of Tx) and 6</td>
<td>-Survey of Pain Attitudes (pain-related beliefs) -Fear Avoidance Beliefs Questionnaire -Negative Mood Regulation Scale</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Intervention</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>----------------------</td>
<td>--------------</td>
<td>---------</td>
<td>-----</td>
<td>----------</td>
</tr>
<tr>
<td>Chiauzzi, et al. 2010</td>
<td>Pretest-post-test randomized trial Chronic low spine pain &gt; 3 months 209 (155)</td>
<td>painACTION-Back pain internet with tailored feedback x 4 wks</td>
<td>Pain centre, professional and patient contacts</td>
<td>-stress management and skills training in breathing -physical activity, goal-setting, motivation -progressive muscle relaxation, guided imagery, mindfulness meditation -collaborative decision-making with HCPs -CBT to boost self-efficacy, manage thoughts/mood, set goals, problem-solving, preventing relapses -wellness activities related to sleep, nutrition, stress management, and exercise e-mailed a back pain guide</td>
<td>1.3, and 6 months FU</td>
<td>-Pain Catastrophizing Scale -Roland Morris Disability Questionnaire -Pain Self-Efficacy Scale</td>
<td>At 3 &amp; 6 months: -lower stress -increased use of coping strategies (self-statements, use of social support) *clinically significant reduction in anxiety, stress, and depression as per IMMPACT guidelines</td>
</tr>
<tr>
<td>Davies, et al., 2011</td>
<td>Prospective cohort study Persistent pain (excluded NeP conditions)</td>
<td>Self-Training Educative Pain Sessions (STEPS) Pre-clinical, adult-learning GS for 8 hours over 2 days</td>
<td>Hospital multidisciplinary pain clinics Western Australia</td>
<td>-whole person engagement, multimodal therapy, pain does not mean damage, stress response systems, pain can’t be seen on x-rays -pacing -pts sharing stories (reflections on)</td>
<td>none</td>
<td>3, 6, and 12 months after end of Tx</td>
<td>-number of pts requesting an individual session -wait times -cost per pt -HCU -pt satisfaction -Global Perceived Impression of Change</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Intervention</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>----------------</td>
<td>----------------------</td>
<td>--------------</td>
<td>---------</td>
<td>----</td>
<td>---------</td>
</tr>
<tr>
<td>Dubin, et al. 2010</td>
<td>Case history Adults with non-cancer pain 6 (6)</td>
<td>Education/ exercise self-management program 2 x 1.5hr GS/wk x 10-12 wks</td>
<td>Physican and self-referral Communit y-based</td>
<td>Clinical psychologists, OT, PT, pain medicine physician</td>
<td></td>
<td>-gentle exercise (pool therapy yoga, tai chi, walking) -edu/self-management based on CPSMP (understanding pain, becoming a self-manager, pacing, communication, nutrition, problem-solving, dealing with emotions, and goal-setting)</td>
<td>-use of pain management strategies -SF-36 -Brief Pain Inventory -Pain Self-Efficacy Scale -Pain Disability Questionnaire</td>
</tr>
<tr>
<td>Dunstan, et al. 2007</td>
<td>Repeated measures pilot study Work-related</td>
<td>CBT, Multi-disciplinary work-related activity program + workbook</td>
<td>Rural communit y setting Australia</td>
<td>-education (models of pain disability, acute vs. chronic pain, pain perception, link between behaviour and thoughts/feelings,</td>
<td>none</td>
<td>Post-Tx, and 6 months</td>
<td>-pain severity (NRS) -Depression, Anxiety Stress Scales -Modified Roland and Morris</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>----------------------------------------</td>
<td>--------------</td>
<td>---------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>compensable MSK injury with pain &gt; 12 wks, at risk for prolonged disability (Orebo MSK Pain Q), aged 18+ years</td>
<td>½ day GS/wk x 6 wks Clinical psychologist and PT delivered Tx while working alongside the referring GPs and occupational rehab providers</td>
<td>benefits of exercise, safe postures and body mechanics) -goal-setting (setting meaningful and achievable short- and long-term goals) -physical upgrading (daily walking program, exercises, and stretches that increase on a time or quota-schedule) -activity management (daily activity schedule, building functional tolerance, prioritizing and pacing activities) -stress management (applied relaxation, distraction, problem-solving, sleep management) -cognitive techniques (identifying unhelpful thoughts and beliefs, thought challenging, coping self-statements) -social skills training (anger management, assertiveness, communication, conflict resolution, building trust,</td>
<td>Questionnaire (disability) -Pain Self-Efficacy Questionnaire -Pain Catastrophizing Scale -Tampa Kinesophobia Scale -physical function (sitting walking, standing, and lifting tests) -work resumption (paid work participation)</td>
<td>catastropheing, fear-avoidance, -increased pain self-efficacy, and ability to sit, stand, walk, and lift</td>
<td>At 6 moths: -shift to more functional status at work (medical certification designation)</td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/Setting</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>----------------------</td>
<td>--------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
</tr>
<tr>
<td>Dysvik, et al. 2010</td>
<td>Pretest, post-test quasi-experimental study Chronic pain &gt; 6 months, aged 18 years + 117 (113)</td>
<td>8-week multidisciplinary pain management program, GSs Nurse, PT, patient volunteer, psychologist, physician</td>
<td>Outpatient(s) of a rehab facility</td>
<td>developing positive attitudes) -maintenance (skill maintenance plan, flare-up management, relapse prevention plan) -facilitating return to work (applying skills and strategies to work, identifying problem-solving obstacles to return to work)</td>
<td>WL</td>
<td>8 weeks (end of Tx)</td>
<td>-SF-36 -Brief Pain Inventory -Pain Stages of Change Questionnaire -pt satisfaction</td>
</tr>
<tr>
<td>Elander, et al. 2011</td>
<td>RCT Hemophilia joint pain, aged 18+years</td>
<td>25-minute DVD + booklet 5 individuals with hemophilia-UK Haemophilia society</td>
<td>booklet</td>
<td>-5 individuals with hemophilia talking about their experience coping</td>
<td>booklet</td>
<td>6 months</td>
<td>-Pain Stages of Change Questionnaire (readiness to self-manage pain)</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Intervention Topics</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------------------------</td>
<td>---------------</td>
<td>----------------------</td>
<td>---------------------</td>
<td>---------</td>
<td>-----</td>
<td>----------</td>
</tr>
<tr>
<td>Ersek, et al. 2008</td>
<td>Clustered RCT&lt;br&gt;Pain &gt; 3 months and &gt; 2/10 VRS, with interference</td>
<td>Pain Self-Management Group Intervention&lt;br&gt;GS x 90min/wk x 7 wks; booster T calls at 12, 16, Retirement communities&lt;br&gt;USA</td>
<td>-basic principles of pain (mechanisms, pain myths in older adults, goals of management, signs requiring medical attention, problem-solving framework)</td>
<td>Edu control group (given book, received T calls)</td>
<td>Post-Tx, 6 and 12 months post-Tx</td>
<td>-Roland-Morris Disability Questionnaire&lt;br&gt;-BPI (pain intensity and interference)&lt;br&gt;-Geriatric Depression Scale</td>
<td>-no difference between groups</td>
</tr>
<tr>
<td>Ersek, et al. 2008</td>
<td>Pain &gt; 3 months and &gt; 2/10 VRS, with interference</td>
<td>related joint pain, small parts with a PT and a physician&lt;br&gt;UK</td>
<td>-beliefs about costs and benefits of self-managing pain&lt;br&gt;-learning histories&lt;br&gt;-contingencies&lt;br&gt;-personal experience&lt;br&gt;-modeling&lt;br&gt;-verbal persuasion&lt;br&gt;-perceive barriers&lt;br&gt;-behaviour-health links and consequences&lt;br&gt;-intention formation and barrier identification&lt;br&gt;-prompts to goal-setting&lt;br&gt;-modeling behaviour and encouragement&lt;br&gt;-role of negative thoughts, anger, and passive coping in low mood, social isolation, and restricted activities&lt;br&gt;-costs and benefits of painkillers&lt;br&gt;-benefit of hope</td>
<td></td>
<td></td>
<td>-Haemophilia Pain Coping Questionnaire&lt;br&gt;-Chronic Pain Acceptance Questionnaire&lt;br&gt;-SF-36&lt;br&gt;-pain intensity VAS</td>
<td>+ / -</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
</tr>
<tr>
<td>--------------</td>
<td>------------------------------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>--------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
</tr>
<tr>
<td></td>
<td>in daily activities, aged 65+ years</td>
<td>22, and 30 wks after final GS</td>
<td>2 nurses + 1 clinical psychologist</td>
<td>-exercise and physical activity as pain management (types and tips, getting started, relaxation, breathing, practice) -engaging in meaningful activities and pacing (pain limits, developing individualized plans using problem-solving strategies, pacing) -challenging negative thoughts and dealing with flare-ups (pain appraisal and behaviour, identifying negative thoughts, challenging negative thoughts, strategies for flare-ups) -non-drug pain therapies (practice and precautions for use, dealing with setbacks) -medications and complimentary medicine (role of medications, side effects, making informed treatment decisions)</td>
<td>-</td>
<td>-Arthritis Self-Efficacy Scale</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td>256 (217)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-Coping Strategies Questionnaire Catastrophization subscale</td>
<td>/</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-Chronic Pain Coping Inventory</td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Intervention</td>
<td>Topics</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------------------------</td>
<td>---------------</td>
<td>--------------</td>
<td>-------------------------------------------------------------------------</td>
<td>---------</td>
<td>-----------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Gardner-Nix, et al. 2008</td>
<td>RCT Chronic pain Management, present site vs. distant site 278 (215) [99 present site, 57 distant site, 59 WL]</td>
<td>Mindfulness-Based Chronic Pain Management, present site vs. distant site GS x 2hrs/wk x 10 wks Course instructor</td>
<td>Urban and rural hospitals, newly referred Present site: hospital Distant site: videoconferencing Canada</td>
<td>-review and making individualized maintenance plans -experiential exercises in Mindfulness practice -teaching in meditation -observing emotions about pain -nutrition -exercise -sleep -medication -visualization techniques</td>
<td>WL</td>
<td>10 wks (post Tx)</td>
<td>-SF-36 -Pain Catastrophizing Scale -usual pain NRS</td>
</tr>
<tr>
<td>Glombiewski, et al. 2010</td>
<td>RCT Chronic back pain &gt; 6 months on most days of the wk 128 (116)</td>
<td>CBT vs. CBT + biofeedback 25 x 1hr IS/wk Cognitive behavioural therapist, trained doctoral students Outpatient clinic for psychological Txs at a university Germany</td>
<td>Outpatient anesthesiology centres, GP s, or self-referral vauds</td>
<td>-biopsychosocial aspects of pain -goal-setting -progressive muscle relaxation -activity scheduling -cognitive therapy for restructuring pain cognitions -restructuring of pain avoidance beliefs -breathing exercises -attention diversion -relapse prevention strategies -stress-coping skills</td>
<td>WL</td>
<td>Post-Tx and 6 months</td>
<td>-German Pain Questionnaire NRS (pain intensity) -self-reported analgesic use -Pain Disability Index -Health-Related Life Satisfaction Scale (HRQOL) -Beck Depression Index -global perception of Tx effects (5-point scale) -patient satisfaction (two 5-point scales)</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Topics</td>
<td>Control</td>
<td>F-U</td>
</tr>
<tr>
<td>--------------</td>
<td>-------------------------------------</td>
<td>--------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>--------</td>
<td>---------</td>
<td>-----</td>
</tr>
<tr>
<td>Goeppinger et al. 2009</td>
<td>RCT OA, RA or FMS with chronic joint symptoms; aged 18+ years; 1 of 3 ethnic/racial groups: Spanish-speaking, non-Hispanic English-speaking African Americans or other non-Hispanic English-speakers 921 (648 at 9 months)</td>
<td>Arthritis Self-Management Toolkit State health department arthritis units, advertisem ents in magazines, face-to-face talks, radio/tv interviews, encourage profession al referral Mailed and self-completed</td>
<td>-self-test tool to assess effect of arthritis on the pt’s life and to self-tailor the toolkit -information sheets (working with your dr/health care system, exercise, medications, healthy eating, fatigue and pain management, finding community resources, and dealing with emotions) -information sheets on key processes (action planning, problem-solving, deciding what to try, individualizing and exercise program) -the Arthritis Helpbook -audio relaxation CD and exercise CDs -audio CD of all printed material</td>
<td>WL</td>
<td>4 months after toolkit mailing, 9 months</td>
<td>-visual numeric scales (pain, fatigue) -Health Distress Scale -Activities Limitation Scale -Health Assessment Questionnaire (disability) -Patient Health Questionnaire (depression) -National Health Survey item (global health) -behaviours: stretching/strengthening exercise, aerobic exercise, communication with dr. -health care use (visits, hospital stays) -use and usefulness</td>
<td>At 4 months: -reduced health distress, activity limitation, depression, disability, pain, fatigue -improved range of motion, communication with dr., general health, and self-efficacy -more time spent in aerobic exercise, At 9 months: -reduced health distress, activity limitation, disability, depression, pain, fatigue, -improved general health, self-</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------</td>
<td>---------------------------------------</td>
<td>--------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gustavsson, et al.</td>
<td>RCT Persistent neck pain &gt; 3 months, aged 18-65 years 156 (116, 102 at 1-2 years)</td>
<td>Pain and Stress Self-Management (PASS) 7 x 1.5 hour weekly GSs, booster session at 20 weeks PTs</td>
<td>Primary care centres Sweden</td>
<td>PT 10 and 20 wks, 1 and 2 years</td>
<td>-Self-Efficacy Scale -Neck Disability Index -Coping Strategies Questionnaire (catastrophizing and Appraisal of Control) -Hospital Anxiety and Depression Scale -Fear-Avoidance Beliefs Questionnaire -HCU -analgesic use</td>
<td>efficacy, time in aerobic activity, range of motion, and communication with dr. -reduced visits to ER *clinical significance also tested</td>
<td></td>
</tr>
</tbody>
</table>

At 10 and 20 wks:  
- increased appraisal of ability to control pain  
- increased self-efficacy  
- decreased catastrophizing  
- decreased neck related disability  
- lower use of analgesics  
- higher satisfaction with care  

At 1 and 2 years:  
- improved ability to control pain and self-efficacy for activities in spite of pain  


<table>
<thead>
<tr>
<th>Author &amp; Date</th>
<th>Method [Design, Age &amp; Pain Dx, N (n)]</th>
<th>Mode/Delivery</th>
<th>Intervention</th>
<th>Control</th>
<th>F-U</th>
<th>Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hammond, et al. 2008</td>
<td>Parallel-group RCT RA or psoriatic arthritis (PsA), aged 18+ years 218 (138)</td>
<td>Modular, group CBT programme</td>
<td>Each session included: -self-monitoring -skills training with individualized feedback and advice -goal-setting -action planning Module 1: joint protection Topics: -edu on RA, PsA, health beliefs, personal impact of arthritis, understanding multiple factors affecting symptoms, attitudes, personal experience of what helps, self-management methods, and motivation for change -application of ergonomic changes to reduce pain, hand exercises, fatigue management (activity pacing, microbreaks, planning, posture), benefits of splints Module 2: exercise Topics:</td>
<td>Standard, information-focus programme</td>
<td>6 and 12 months from baseline</td>
<td>-pain VAS -modified Health Assessment Questionnaire (fatigue, functional ability, perceived health, morning stiffness, psychological distress) -RA Self-Efficacy Scale (psychological status) -Arthritis Self-Efficacy Scale -Arthritis Helplessness Index Helplessness and Internality Subscale (perceived control) -Arthritis Stages of Change Questionnaire (readiness to self-manage) -self-reported HCU</td>
<td>-decreased catastrophic thinking</td>
</tr>
</tbody>
</table>

At 6 months: -reduced pain, fatigue, psychological distress and helplessness -improved functional ability, self-efficacy for both controlling arthritis symptoms and self-management, perceived health -improved use of health behaviours At 12 months: -reduced pain and helplessness -improved self-efficacy and psychological status -improved use of health behaviours (joint protection and fatigue management), perceived control
<table>
<thead>
<tr>
<th>Author &amp; Date</th>
<th>Method</th>
<th>Intervention</th>
<th>F-U</th>
<th>Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hansen, et al. 2010; Lamb et al. 2010</td>
<td>RCT Low back pain &gt; 6 wks, aged 18+ years 701 – control 233 (598)</td>
<td><strong>Intervention</strong>  - exercise beliefs, barriers, and problem-solving  - flexibility and strengthening exercise, graded home walking program, warm-up, 6 Tai Chi moves  - stress management, coping with automatic negative thoughts  - use of hot and cold massage, TENS, distraction and relaxation practice  - Review: progress with goals, drug therapy, investigations, communication with HPs, team care, and pt-selected topics</td>
<td>15 min active management advice + book</td>
<td>3, 6, and 12 months after randomization</td>
<td>- Roland Disability Questionnaire  - modified von Korff Scale (pain and disability)  - SF-12 (physical and mental quality of life)  - Fear Avoidance Beliefs Questionnaire  - Pain Self-Efficacy Scale  - self-rated benefit and satisfaction with Tx</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Topics</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>--------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Heutink, et al. 2012</td>
<td>RCT Spinal cord injury-related NeP &gt; 6 months and &gt; 4/10 NRS, aged 18+ years 61 (61)</td>
<td>The CONESCI Trial – multi-disciplinary cognitive behavioural program + book 10 x 3hr GS over 10wks + review session 3wks after final GS</td>
<td>PTs, OTs, nurses, and psychologists</td>
<td>-setting goals (SMART system, group feedback and problem-solving) -unhelpful thoughts and feelings (catastrophizing, thoughts and behaviours, identifying unhelpful thoughts) -relaxation (practice in session breathing tense/relax, autogenic and imagery) -re-starting activities or hobbies (fear-avoidance cycle, setting goals of re-starting activities) -when pain worries us (hypervigilance, medication, distraction) -coping with flare-ups</td>
<td>-HCU</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Intervention</td>
<td>Control</td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>----------------------</td>
<td>--------------</td>
<td>---------</td>
</tr>
<tr>
<td>Hurley, et al. 2007a; Hurley, et al. 2007b</td>
<td>Cluster RCT Chronic knee pain &gt; 6 months, aged 50+ years 418 (338)</td>
<td>Psychiatrist and PT or psychiatrist and NP</td>
<td>Enabling Self-Management and Coping with Arthritic Knee Pain through Exercise (ESCAPE-knee pain) program IS or GS (8 pts), 12 sessions over 6 weeks PTs</td>
<td>assertiveness and communication about pain -edu by role model -relaxation exercises -evaluating goals -mood, stress, and pain -social aspects -application in daily life -summary</td>
<td>UC</td>
</tr>
<tr>
<td>Jessep, et al. 2009</td>
<td>Pilot RCT Knee pain &gt; 6 months, aged 50+ years 64 (48)</td>
<td>Enabling Self-Management and Coping with Arthritic Knee Pain through Exercise (ESCAPE-knee pain) program</td>
<td>Outpatient PT depart., community centre</td>
<td>pts sharing of coping strategies -problem-solving and planning skills -active participation on a progressive exercise regimen that is modified and adapted by the individual according to his/her needs</td>
<td>Outpatient PT</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>-------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
</tr>
<tr>
<td>Johnston, et al. 2010</td>
<td>RCT High level of distress, otherwise not described 24 (11)</td>
<td>Acceptance and Commitment Therapy 6 wks of scheduled book and workbook readings and exercises + T support x 1/wk</td>
<td>Waiting list at pain psychologist clinic Homework -based New Zealand</td>
<td>WL with weekly T calls</td>
<td>-Chronic Pain Acceptance Questionnaire -Quality of Life Inventory -Satisfaction with Life Scale -Chronic Pain Values Inventory (values illness) -McGill Pain Questionnaire – Short-Form -Chicago Multi-Scale Depression Inventory -Beck Anxiety Inventory</td>
</tr>
<tr>
<td>Keefe, et al. 2011</td>
<td>RCT Non-cardiac chest pain, Coping Skills training + sertraline or Coping Skills</td>
<td>-edu on gate theory of pain and role of thoughts, feelings, and behaviours</td>
<td>Sertraline or placebo 34 weeks (end of Tx)</td>
<td>-VAS for chest pain unpleasantness and intensity -State-Trait Anxiety Inventory</td>
<td>-initial and sustained decrease in pain intensity in all treatment groups (only) +</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Intervention</td>
<td>Recruitment/ Setting</td>
<td>Topics</td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>--------------</td>
<td>----------------------</td>
<td>--------</td>
</tr>
<tr>
<td>aged 18-85 years</td>
<td>training + placebo</td>
<td>relaxation, imagery, and distraction</td>
<td>-activity-rest cycling -pleasant activity scheduling -cognitive re-structuring -pt development of a plan to cope with flare-ups -review of successes and difficulties</td>
<td>Psychologists</td>
<td>-Pain Catastrophizing Scale -Beck Depression Inventory -Sickness Impact Profile (physical disability) -Daily Coping Inventory (2 items – taking action to reduce pain and seeking emotional support) -Coping Strategies Questionnaire (2 items – perceived control over pain)</td>
</tr>
<tr>
<td>115 (84)</td>
<td>5 IS over 10 weeks + IS 6 sessions over 6 months</td>
<td>2, 6, and 12 wks via T</td>
<td>2, 6, and 12 wks via T</td>
<td>Physicians in medical or radiation oncology</td>
<td>-pain severity (average and worst, NRS) -Medical Outcomes Study Pain Impairment Scale (5/6 Qs, sleep omitted) -SF-12 -Short Barriers Questionnaire (pain misconceptions) -Perceived Efficacy in Patient-Physician Interactions Scale -Chronic Pain Self-Efficacy Scale (2)</td>
</tr>
<tr>
<td>Kravitz, et al. 2011</td>
<td>Ca-HELP (tailored edu and coaching) + National Cancer Institute booklet on pain control</td>
<td>Physicians in medical or radiation oncology</td>
<td>-assess current knowledge, attitudes, and preferences -correct misconceptions -teach pain control and patient-physician communication -plan (identifying goals and brainstorming for suitable pt-physician communication strategies -rehearse using role-playing -portray learned skills</td>
<td>Private space in oncology unit/clinic USA</td>
<td>Enhance d UC – health educator reviewed material in National Cancer Institute booklet on pain control</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Topics</td>
<td>Control</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------------------------</td>
<td>-----------------------------</td>
<td>----------------------</td>
<td>--------</td>
<td>---------</td>
</tr>
<tr>
<td>Kristjánsson, et al., 2011</td>
<td>Pre-trial study (feasibility study) Chronic widespread pain or FMS 6 [women only, 4 from multidisciplinary pain trial]</td>
<td>4-wk Tx delivered via mobile phone, initial IS followed by 3 diary entries (responding to Qs) and feedback on diary entries Nurse therapist</td>
<td>General practitioners and rehab centres</td>
<td>-mindfulness and awareness of thoughts, feelings, and behaviour -identifying valued behaviour and related challenges and goals -identifying positive and challenging thoughts</td>
<td>none</td>
</tr>
</tbody>
</table>
| Kerns, et al., 2010; Kroenke, et al. 2009; Kroenke, et al. 2007a; Kroenke, et al. 2007b; Hush, 2009 | Double-blind RCT MSK pain (back, hip, or knee) > 3 months and depression 250 (205) | Stepped Care for Affective Disorders and MSK Pain (SCAMP) 3 Phases: (1) 3 months x depression Tx algorithm followed by (2) 3 months SM (6 sessions over 12 weeks), followed by (3) 6 months of continued therapy (2x phone call re SM and dose) Veteran affairs primary care clinics USA | -self-management and pain -factors influencing pain -planning and goal-setting -feedback and problem-solving -dealing with negative emotions and fears -physical activities (stretching, strengthening, and walking) -relaxation and deep breathing -pain management -changing outlook with positive thinking | UC | 12 months (end of phase 3) | -Hopkins Symptom Checklist (depression) -Brief Pain Inventory -global change in pain (7-point Likert scale) -Graded Chronic Pain Scale -Roland Disability Scale -SF36 (health perception and vitality scale) -Generalized Anxiety Disorder -7 -HCU | -reduced pain severity and interference, depression, disability, anxiety, perceived general health and vitality -decreased HCU +
<table>
<thead>
<tr>
<th>Author &amp; Date</th>
<th>Method [Design, Age &amp; Pain Dx, N (n)]</th>
<th>Intervention</th>
<th>F-U</th>
<th>Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laforest, et al. 2008a, 2008b</td>
<td>RCT</td>
<td>I’m Taking Charge of my Arthritis! House-bound adults with arthritis (not leaving the home alone &gt; 2x/month), aged 50+ years, moderate to severe pain 125 (113)</td>
<td>Nurse care manager</td>
<td>Recruiting Setting Topics Control</td>
<td>At end of Tx</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
</tr>
<tr>
<td>------------------------</td>
<td>---------------------------------------</td>
<td>--------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
</tr>
<tr>
<td>Lipsitz, et al. 2011</td>
<td>Open trial Non-cardiac chest pain rated 3/5 or higher for intensity, aged 8-18 years 9 (7)</td>
<td>4 IS x 50 minutes with pt, 1 IS x 50 minutes with parents over 5 wks Clinical psychologist</td>
<td>Large medical centre ER Outpatient clinic USA</td>
<td>-pain as real but not dangerous -multicausal model of pain and psychological effects on pain -breathing retraining -parents: decreasing positive reinforcement of illness behaviours, encouraging positive coping behaviours -automatic thoughts, rational responses, and catastrophizing -anticipating challenges and practicing coping</td>
<td>none</td>
</tr>
<tr>
<td>Litt, et al. 2010</td>
<td>RCT Bi- or unilateral pain at TMJ &gt; 3 months (NeP excluded) 101 (74)</td>
<td>CBT + UC 6 ISs over 6 wks Master’s level therapists Dental clinics of university hospital and advertisements In clinic (?) USA</td>
<td>-introduction and rationale for therapy -relaxation training and homework practice -self-efficacy enhancement -biofeedback-assisted relaxation -combating negative thoughts and catastrophizing -stress management</td>
<td>UC (splint therapy, soft diet, oral anti-inflammatories, weekly “progress checks”)/ attention control</td>
<td>6 wks (post-Tx), and 12, 24, 36, and 52 wks</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Topics</td>
<td>Control</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>------------------------------------------------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Internet Arthritis Self-Management Program (bulletin board discussion, medication diaries, exercise logs) and Arthritis Helpbook</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- 25 sessions over 6 weeks (1-2 hours per week)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Program delivered online</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- 2 peer moderators to monitor posts for safety and to provide encouragement</td>
<td></td>
</tr>
</tbody>
</table>
|                       |                                      |               |                     | - VNS (pain and fatigue)                                               | UC      | 1 year | - Self-management principles - goal-setting/action plans
- pain management - relaxation, cognitive pain management - problem-solving steps - fitness/exercise - feedback/problem-solving - difficult emotions - healthy eating - osteoporosis - fatigue and energy conservation - medication - depression - working with your HCP - evaluating treatment plans - sleep |         |
<p>|                       |                                      |               |                     | - Health Distress Scale                                               |         |     | - Self-Rated Global Health Scale             |         |
|                       |                                      |               |                     | - Activities Limitation Scale                                         |         |     | - Health Assessment Questionnaire            |         |
|                       |                                      |               |                     | - stretching, strengthening exercises, aerobic exercise, use of cognitive symptom management, and use of communication techniques |         |     | - HCU                                      |         |
|                       |                                      |               |                     | - Arthritis Self-Efficacy Scale                                       |         |     | - OA                                       | +       |
|                       |                                      |               |                     | - increased global health and self-efficacy                           |         |     | - RA: decreased pain and activity limitation | +       |
|                       |                                      |               |                     | - increased global health                                               |         |     | - FMS: no difference                        |         |
| Lorig, et al. 2008    | RCT                                  | Internet USA  | Internet USA        | - Rheumatology clinics OR patient-                                    | UC      | 1 year | - West Haven-Yale Multidimensional Pain Inventory (spousal support and) |         |
|                       | OA, RA or FMS 855 (651)              |               |                     | - etiology and treatment of OA - pain self-management strategies      |         |     |                                               |         |
|                       |                                      |               |                     | - UC                                                                   |         |     |                                               |         |
|                       |                                      |               |                     | - 1 and 6 months after Tx                                              |         |     |                                               |         |</p>
<table>
<thead>
<tr>
<th>Author &amp; Date</th>
<th>Method [Design, Age &amp; Pain Dx, N (n)]</th>
<th>Intervention</th>
<th>Mode/Delivery</th>
<th>Recruitment/ Setting</th>
<th>Topics</th>
<th>Control</th>
<th>F-U</th>
<th>Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Matsubara, et al. 2010</td>
<td>Quasi-Ex (non-randomized clinical trial) Chronic non-cancer pain 12 (12)</td>
<td>CBT</td>
<td>IS until individual decision-making was started, then individually-set activities each week x 6 months PT</td>
<td>Multi-disciplinary pain centre outpatient clinic Japan</td>
<td>withdrawal of positive attention for pain behaviours and increasing enforcement of well behaviours -aimed at helping pts to reach their individual daily life goals, increasing activity, and modify distorted thoughts -edu on pain, management, and risk of activity -individual decision-making -planning and pacing an activity program -goal setting</td>
<td>None (If a pt decrease their pain intensity by 2 points at a follow-up, they were put in the “effective” group)</td>
<td>1, 3, and 6 months after beginning Tx</td>
<td>-Verbal Rating Scale (pain intensity) -Hospital Anxiety and Depression Scale -Physical Activity Level (accelerometer) -pain dairy</td>
<td>At 6 months post Tx start: -decreased pain intensity -higher minutes of total activity, mild activity and moderate activity</td>
</tr>
<tr>
<td>McBeth, et al. 2012</td>
<td>2x2 factorial RCT (stratified by disability and general health)</td>
<td>Telephone-delivered CBT + exercise</td>
<td>Initial IS for assessment + 1 session/wk x 7, + 1 session at 3 and</td>
<td>General practices At home for CBT and at fitness facilities</td>
<td>-setting of pt-identified goals -problem-solving barriers to improvement -relapse prevention -pts selected from forms of CBT: UC</td>
<td>6 months (post-Tx) and 9 months (3 months post-Tx end)</td>
<td>-Clinical Global Impression of Change, 7-point scale -Chronic Pain Grade Questionnaire Fatigue Scale</td>
<td>At 6 months: CBT + exercise: -improved impression of change, physical HRQOL, fatigue -increased use of active coping and</td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>----------------------</td>
<td>--------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic widespread pain, aged 25+ years</td>
<td>6 months post-randomization + manual +/- exercise x2/wk (6 months) Therapists (accredited by the British Association for Behaviour and Cognitive Psychotherapies) and fitness instructors</td>
<td>for exercise</td>
<td>France, Canada, Ireland, and England</td>
<td>1. behavioural activation (increasing, decreasing, and pacing activities) 2. cognitive restructuring (identifying and evaluating unhelpful thinking patterns) 3. lifestyle changes (managing sleep, fatigue, and irritability)</td>
<td>-Vanderbilt Pain Management Inventory -General Health Questionnaire Sleep Scale -Tampa Scale for Kinesiophobia -SF-36 -cost data</td>
<td>decreased use of passive coping CBT: -improved impression of change and sleep Exercise: -improved impression of change At 9 months: CBT + exercise: -improved impression of change, physical HRQOL, decreased use of passive coping and kinesiophobia CBT: - improved impression of change Exercise: -improved impression of change, physical HRQOL</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Intervention</td>
<td>Topics</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
</tr>
<tr>
<td>---------------------</td>
<td>----------------------------------------</td>
<td>---------------</td>
<td>--------------</td>
<td>--------</td>
<td>---------</td>
<td>--------------</td>
<td>--------------------------------------------------------------------------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>McCracken, et al. 2007</td>
<td>Cohort study Highly-disabled pts with chronic pain 53 (29 at 3 months)</td>
<td>Contextual CBT 80hrs over 3 wks Facilitator not specified</td>
<td>In-hospital accommodation and nursing care provided UK</td>
<td>Mix of: -daily general exercises (modified for high disability) -edu -skills training for activity management -psychology sessions Tx principles: -exposure -acceptance -cognitive defusion -mindfulness -values-based methods *goal: to increase psychological flexibility in dealing with unwanted experiences and improve engagement in activities valued by the pt</td>
<td>Clinical comparison group of non-disabled pts with chronic pain receiving a pain-management course</td>
<td>Post-Tx, and 3 months</td>
<td>-pain intensity -Sickness Impact Profile (health-related disability) -Beck Depression Inventory -Pain Anxiety Symptoms Scale -Chronic Pain Acceptance Questionnaire</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>McCracken, et al. 2011</td>
<td>Cohort study Pain from any cause &gt; 3 months, and significant pain distress and 3-4 wks of interdisciplinary care, based on Acceptance and Commitment Therapy (target: psychological flexibility), GS x</td>
<td>Tertiary care pain rehab unit UK</td>
<td>-acceptance of pain and other psychological experiences -contact with the present moment -self-as-observer -cognitive defusion -values</td>
<td></td>
<td>3 months after end of Tx</td>
<td>-Chronic Pain Acceptance Questionnaire -Acceptance and Action Questionnaire II -Mindful Attention Awareness Scale</td>
<td>-completers had lower depression scores, and more physical and psychological disability</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>--------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>disability, 18+ years of age 168 (111)</td>
<td>6.5 hrs/day x 5 days/wk Interdisciplinary: clinical psychology, PT, OT, nursing, medicine</td>
<td>committed action -experimental learning</td>
<td>-Chronic Pain Values Inventory -British Colombia Major Depression Inventory -Pain Anxiety Symptom Scale -Sickness Impact Profile -dr visits -pain intensity NRS</td>
<td>-large effect size for pain acceptance, values-based action, depression, pain-related anxiety -medium effect size for psyc acceptance, mindfulness, and physical disability -small effect size for medical visits and pain intensity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>McGillion, et al. 2008</td>
<td>RCT Chronic stable angina &gt; 6 months 130 (117)</td>
<td>Chronic Angina Self-Management Program (psychoeducation program) GS x 2hrs/wk x 6 wks plus workbook Nurse</td>
<td>Community (recruited from teaching hospitals) ON, Canada</td>
<td>overview of self-management and chronic angina -making action plans -relaxation/cognitive symptom management -feedback and problem-solving -common emotional reactions to cardiac pain -staying active/fitness -better breathing -fatigue/sleep management -energy conservation -eating for a healthy heart</td>
<td>WL UC 3 months (from baseline) -SF-36 (general) -Seattle Angina Questionnaire (disease-specific) -Self-Efficacy Scale -Self-Control Schedule (resourcefulness)</td>
<td>At 3 months: -improved physical function and general health -improved angina frequency and stability -improved self-efficacy to manage pain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------------</td>
<td>--------------------------------------------------------------------------</td>
<td>---------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mead, et al. 2007</td>
<td>Quasi-experimental pilot study</td>
<td>Pain coping strategies</td>
<td>Monitoring symptoms and deciding when to get help &lt;br&gt;-communication &lt;br&gt;-common medications &lt;br&gt;-evaluating new or alternative treatments &lt;br&gt;-cardiac pain and depression &lt;br&gt;-monitoring symptoms and informing health care team &lt;br&gt;-communication with HCP about pain &lt;br&gt;-future self-management plans</td>
<td>none</td>
<td>Hospital Anxiety and Depression Scale &lt;br&gt;-Canadian Occupational Performance Measure (perceived ease of activities of daily living) &lt;br&gt;-physical assessment</td>
<td>+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chronic pain (not specified)</td>
<td>Referred by various specialities</td>
<td>CBT Chronic Disease</td>
<td>1st IS: &lt;br&gt;-posture &lt;br&gt;-goal-setting &lt;br&gt;-relaxation &lt;br&gt;-education of gate-control theory of pain and pain pathways &lt;br&gt;-activities of daily living &lt;br&gt;-medications and healthy eating advice &lt;br&gt;-exercise &lt;br&gt;-pacing &lt;br&gt;-forward flexion</td>
<td>6 wks from end of Tx</td>
<td>-reduced anxiety and depression &lt;br&gt;-improved 3-min walk, sit-to-stand and forward flexion &lt;br&gt;-improved perception of ease of performing activities of daily living</td>
<td>+</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>--------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic refractory angina 271</td>
<td>Management Program IS + 2nd 1 hr IS within 8 wks of initial IS for new pts refractory angina centre UK</td>
<td>-explore beliefs about angina, pain and lifestyle via 5-item scale and open-ended questions to identify misconceptions and maladaptive behaviours -provide education above findings -setting a pt-defined objective -stress management advice -relaxation training -graduated exercise plan made to assist in meeting pt’s objective 2nd IS: (new pts only) -revisit of core beliefs and misconceptions -assessment of progress towards pt’s objective</td>
<td>during 1 yr pre-Tx enrollment for comparison</td>
<td>enrollment</td>
<td>bed occupancy, and myocardial infarctions</td>
<td>hospitalizations, hospital bed occupancy, and myocardial infarctions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Morely, et al 2008</td>
<td>Cohort study Chronic pain &gt; 1 year with associated disability, interference or distress 800 (600)</td>
<td>4.5 days/ wk x 4wk of GS Inpatient program UK</td>
<td>-edu on pain, sleep, disuse, and drugs -exercise routines for fitness, flexibility, muscle minimum strength, and gradual increases -goal-setting across all activities with quota increases and activity-rest scheduling</td>
<td>1 month and 9 months after Tx</td>
<td>-pain intensity, distress, and interference (NRS) -Beck Depression Inventory -Hospital Anxiety and Depression Scale -Coping Skills Questionnaire Catastrophization Subscale</td>
<td>-improvement in all outcomes at both 1 and 9 months (small-med effect sizes): -reduced pain intensity, distress, and interference; depression, anxiety, and catastrophization</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------</td>
<td>----------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>-------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Morlion, et al. 2011</td>
<td>Pretest-Posttest</td>
<td>Multi-disciplinary pain education program (MPEP), based on CBT and psycho-education</td>
<td>Post-Tx</td>
<td>SF-36 (bodily pain and health perception) -Hospital Anxiety and Depression Scale (depression scale only) -Tampa Scale of Kinesiophobia -Habitual Action-Proneness Questionnaire -Pain Catastrophizing Scale</td>
<td>-decreased pain, catastrophization, and action-proneness -improved health perception</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chronic, non-cancer pain &gt; 3 months</td>
<td>4 GS x 2hrs each, over 2wks PT, pain nurse specialist, clinical psychologist</td>
<td></td>
<td>Hospital Anxiety and Depression Scale (depression scale only) -Tampa Scale of Kinesiophobia -Habitual Action-Proneness Questionnaire -Pain Catastrophizing Scale</td>
<td>+</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>63 (53)</td>
<td>Outpatient pain centre at university hospital Belgium</td>
<td></td>
<td>Pain Self-Efficacy Questionnaire -5 Minute Walk</td>
<td>+</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- psychology sessions to improve problem-solving, changing and maintaining maladaptive behaviour, cognitive techniques to identify unhelpful beliefs and change them
- drug reduction for all ineffective analgesics
- applied relaxation
- relapse prevention and planning for crises
- sleep hygiene

-edu on pain symptoms, sleep hygiene, and medication
- stress and psychosocial influences on pain
- adaptive coping strategies
- benefits of physical exercise
- training in relaxation techniques and non-verbal communication
- learning to link exercise to pain and physical well-being
- increasing control and self-efficacy
<table>
<thead>
<tr>
<th>Author &amp; Date</th>
<th>Method [Design, Age &amp; Pain Dx, N (n)]</th>
<th>Mode/Delivery</th>
<th>Intervention</th>
<th>Topics</th>
<th>Control</th>
<th>F-U</th>
<th>Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morone, et al. 2008</td>
<td>Pilot RCT Chronic low back pain of moderate intensity, &gt; 3 months, community-dwelling, aged 65+ years 37 (25)</td>
<td>Mindfulness meditation 8 x 1.5hr GS/wk</td>
<td>Authors (physicians in psychiatry and internal medicine) Adult pain clinic in university hospital Community USA</td>
<td>Techniques: - body scan - sitting practice - walking medication Attitudes: - patience - non-judging - ‘beginners’ mind - acceptance - letting go - non-striving and trust - group discussions of pt experiences - group problem-solving of pt obstacles - educ re medication, pain, stress and the mind/body connection</td>
<td>WL</td>
<td>Post-Tx, 3 months</td>
<td>-McGill Pain Questionnaire Short Form - Chronic Pain Acceptance Questionnaire - SF-36 - Roland and Morris Questionnaire (physical function) - Short Physical Performance Battery</td>
<td>Post-Tx and 3 months: - improved pain acceptance, activities engagement, and physical function</td>
</tr>
<tr>
<td>Murphy, et al. 2008</td>
<td>Pilot RCT Symptomatic hip or knee OA requiring aid for basic tasks, aged 62+ years 54 (51)</td>
<td>Activity Strategy Training (AST) + exercise 7 x 1.5hr GS and 1 x 1.5hr IS over 4 wks + 2 follow-up sessions over 6 months</td>
<td>Senior housing facilities and senior centres OTs</td>
<td>Exercise: - progressive resistant exercises AST: - education, group discussion, and practice of techniques - activity pacing - joint protection - body mechanics - transfer techniques - addressing individual barriers with group problem-solving - IS: personalized, in-home assessment and</td>
<td>Exercise + edu</td>
<td>Post-Tx (not including review sessions)</td>
<td>- Western Ontario and McMaster Universities Osteoarthritis Index (pain) - Community Healthy Activities Model Program for Seniors questionnaire (subjective time spent in physical activity) - Arthritis Self-Efficacy Scale - accelerometer (objective physical activity measures)</td>
<td>-higher objective peak physical activity</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Intervention</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
</tr>
<tr>
<td>--------------------</td>
<td>----------------------------------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>--------------</td>
<td>---------</td>
<td>-----</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>Naylor, et al. 2008</td>
<td>CBT: Cohort study</td>
<td>CBT: 11 x 90min GS over 11 wks</td>
<td>Referred to MindBody Medicine Clinic USA</td>
<td>problem-solving by OT</td>
<td>-gate-theory of pain and effect of thoughts and feelings on pain -identifying problematic thoughts and reframing thinking -problem-solving -communication -self-monitoring of daily events and pain fluctuations -self-regulatory skills (relaxation – progressive muscle relaxation, imagery, autogenic training) -attention diverting methods -activity pacing -enhancing social support (partners invited to this session)</td>
<td>-end of CBT Tx</td>
<td>-McGill Pain Questionnaire – SF -Enhanced SF-36 TOPS (total experience of pain) -Coping Strategies Questionnaire -medication intake (analysis adjusted to account for improvement in symptoms and HRQOL due to medication changes)</td>
<td>End of CBT Tx: -improved HRQOL, ability to control pain, use of positive coping strategies (diverting attention, reinterpreting pain, activity), total pain experience -decreased catastrophizing 8 months after CBT (control group, sustained effect of CBT Tx) -improved perceived ability to control and decrease pain and catastrophizing TIVR (8 months after CBT Tx): -improved HRQOL, perceived ability to control and decrease pain and catastrophizing</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Intervention</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>--------------</td>
<td>---------</td>
<td>-----</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>Niederma nn, et al. 2011</td>
<td>RCT RA, ACR functional class II-IV 54 (53)</td>
<td>Pictorial Representation of Illness and Self Measure (PRISM) + Joint Protection (JP) 4x 45 min IS over 3 wks Rheumatology OTs Switzerland</td>
<td>Rheumatology department of 4 hospitals</td>
<td>-perceived burden of illness on pt-identified goals and valued behaviours, identification of edu goals -goal-setting -self-monitoring of activities causing pain -energy conservation -balancing activity and rest -selecting JP activities to meet goal (partners invited to attend final session)</td>
<td>Conventional JP edu (traditional teaching methods, demos of activities and assistive devices) -4 weeks (end of Tx) and 3 months from baseline (2 months post-Tx)</td>
<td>Joint Protection Behaviour Assessment -Arthritis Self-Efficacy Scale -Joint Protection Self-Efficacy Scale -Hospital Anxiety and Depression Scale -grip strength -Disease Activity Score -PRISM/PRISM+ (impact of disease, resources)</td>
<td>At 3 months: -improved joint behaviour assessment -increased arthritis and joint protection self-efficacy -both groups experienced deceased pain -74% of joint protection behaviour explained by baseline behaviour and intervention</td>
<td>+</td>
</tr>
<tr>
<td>Oerlemans , et al. 2011</td>
<td>Feasibility trial, open-label RCT IBS &gt; 3 months</td>
<td>CBT e-intervention using PDAs 4 wks</td>
<td>GPs and patient association s</td>
<td>-cognitions, emotions, and activities (making arrangements to engage in valued behaviours, including</td>
<td>UC End of Tx and 3 months</td>
<td>-Cognitive Scale for Functional Bowel Disorders (dysfunction cognitions)</td>
<td>At end of Tx: -improved quality of life -decreased catastrophizing and pain</td>
<td>+</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/Setting</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
</tr>
<tr>
<td>---------------------</td>
<td>---------------------------------------</td>
<td>---------------------------------</td>
<td>-------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>-----</td>
<td>--------------------------------------------------------------------------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>76 (61)</td>
<td>Psychologist (feedback)</td>
<td>Netherland s</td>
<td></td>
<td>exercise, avoiding worry) -eating and drinking (self-monitoring for irritating foods) -relaxation (identify cause, treatment, and people to help with stress reduction) -secondary complaints (sleep hygiene) -abdominal complaints (identifying aggravating factors and finding ways to cope with the symptoms) -situational feedback based on diary</td>
<td></td>
<td>-Irritable Bowel Syndrome Quality of Life Questionnaire -Pain Catastrophizing Scale -abdominal pain (5-point Likert scale) -pain/symptom diary 3x/day</td>
<td>At 3 months: -decreased catastrophizing</td>
<td></td>
</tr>
<tr>
<td>Osborne, et al. 2007</td>
<td>Cohort study Arthritis Self-Management Program 452 (304)</td>
<td>Arthritis Self-management Program 2hrs/wk of GS x 6 wks</td>
<td>State and territory arthritis foundations, communit y centres Australia</td>
<td>ASMP curriculum none 6 months and 2 years after Tx</td>
<td></td>
<td>-pain and fatigue VAS -Health Distress scale from Medical Outcomes Survey -Modified Health Assessment Questionnaire (diability) -Self-efficacy items from Stanford Scale -health care use</td>
<td>At 6 months and 2 years: -reduced pain, fatigue, and health distress; activities of daily living role limitations -increased self-efficacy, general health, aerobic activity, and range of motion -increased analgesic use -reduced physical therapy visits</td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Topics</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
</tr>
<tr>
<td>--------------</td>
<td>---------------------------------------</td>
<td>---------------</td>
<td>----------------------</td>
<td>--------</td>
<td>---------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
</tr>
<tr>
<td>Oslund, et al. 2009</td>
<td>Cohort study Chronic pain and referred for care 108 (80, 48)</td>
<td>8 sessions of individual behavioural medicine, 19 sessions of PT, 15 sessions of aquatic PT, 19 sessions of OT, 19 sessions of group edu, 11 sessions of group relaxation</td>
<td>University medical centre, referred for intensive outpatient treatment USA</td>
<td>-individual behavioural medicine (self-regulatory skills – relaxation training, distraction, pacing, CBT principles - development of multiple tools to improve coping) -physical therapy (tailored goals established at the start) -aquatic physical therapy -occupational therapy (developing adaptive changes in daily living) -group education sessions (nutrition, stress and pain, etc., peer information sharing and motivation) -group relaxation (relaxation and self-regulation,</td>
<td>none</td>
<td>6 months and 1 year</td>
<td>-Multidimensional Pain Inventory -Daily Life Questionnaire -perceived helpfulness of the Tx</td>
<td>At 6 months and 1 year: -decreased pain severity, and related interference, distress, helplessness, and hours spent resting -increased perceived control</td>
</tr>
</tbody>
</table>

*Self-efficacy was predicted by amount of program attended, and linked to pain, fatigue, disability, health distress and ADL limitations.
<table>
<thead>
<tr>
<th>Author &amp; Date</th>
<th>Method [Design, Age &amp; Pain Dx, N (n)]</th>
<th>Intervention</th>
<th>Recruitment/ Setting</th>
<th>Topics</th>
<th>Control</th>
<th>F-U</th>
<th>Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palermo, et al. 2009; Long, et al. 2009</td>
<td>RCT</td>
<td>Web-MAP: web-based management of adolescent pain</td>
<td>Multi-disciplinarity of pain, neurology, or gastroenterology clinics USA</td>
<td>-two sections: one for parents, one for children -interactive (pt answered questions and personalized feedback was provided, problem-solving over barriers to using skills, etc.) -included videos of teens with chronic pain role-modeling skills -edu on chronic pain -recognizing stress and negative emotions -deep breathing and relaxation -distraction -cognitive skills -sleep hygiene and lifestyle -staying active (goal-setting and pacing) -relapse prevention (parent modules included operation conditioning and communication)</td>
<td>WL</td>
<td>Post-Tx and 3 months</td>
<td>-NRS (pain intensity) -Child Activity Limitations Interview -Revised Child Anxiety and Depression Scale (depression scale only) -Adult Responses to Children’s Symptoms Protect subscale -acceptability of Tx -daily online diary</td>
<td>Post-Tx: -reduced activity limitation (large effect size) and pain intensity (medium effect size) 3 months (within-subject analysis only): -reduced pain intensity, activity limitations, and depression -reduced parental protectiveness -moderate to high levels of acceptability of, and satisfaction with, Tx Feasibility: -Web-MAP Content and Usability Questionnaire</td>
</tr>
<tr>
<td>Perry, et al. 2011; Perry, et al. 2010</td>
<td>Parallel cohort study (quasi-Ex)</td>
<td>(Spinal-ADAPT) 10 GS (45 hours) over</td>
<td>Referred to a clinical service for pain</td>
<td>-edu on spinal cord-specific pain -short- and long-term goal setting</td>
<td>UC at multi-disciplinary pain centre</td>
<td>End of Tx, 1 and 9 months</td>
<td>-pain intensity (NRS) -Moorong Self-Efficacy Scale -Spinal Cord Lesion-related Coping</td>
<td>Pooled time: -reduced life interference</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Topics</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
</tr>
<tr>
<td>---------------------</td>
<td>---------------------------------------</td>
<td>---------------</td>
<td>----------------------</td>
<td>------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>--------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Riddle, et al. 2011</td>
<td>Quasi-Ex cohort study Scheduled for knee replacement with high levels of Pain coping skills training 8 sessions: 2 IS - 1 month prior to and 1 month following surgery, 6 Orthopaedic surgery settings within medical centres</td>
<td>Pain coping skills training 8 sessions: 2 IS - 1 month prior to and 1 month following surgery, 6 Orthopaedic surgery settings within medical centres</td>
<td>-gate control model of pain and the role of thoughts, feelings, and behaviours -relaxation training (muscle tension, imagery, distraction)</td>
<td>Historica l cohort receiving UC 2 months after surgery</td>
<td>-Western Ontario and McMaster Universities Arthritis Index (pain and disability) -Pain Catastrophizing Scale</td>
<td>-improved WOMAC pain and disability, and catastrophizing (stat and clinically significant)</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Clinical psychologists, rehabilitation physicians, pain management consultants, PT, OT, nurses</td>
<td>manageme nt Australia</td>
<td>-activity pacing for identified goals and challenging tasks -relaxation to improve coping and sleep and reduce muscle tension -desensitization -functional exercise (individualized for pt goals) -stretching -cognitive therapy (identification of pain thoughts, and changing negative thoughts) -communication -medications (reducing when possible, self-monitoring for the right dose) -flare-up management and relapse prevention (differentiating between flare-ups and new issues and making a plan to address triggers)</td>
<td></td>
<td></td>
<td></td>
<td>-improved mental health component of HRQOL</td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>--------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ruehlman, et al. 2012</td>
<td>RCT pain &gt; 6 months, aged 18+ years 330 (241, 225 at post-Tx and 7 wks post-Tx, respectively)</td>
<td>Online Chronic Pain Management Program Unsupervised access x 6wks National pain and headache associations</td>
<td>National Chronic Pain Management Program</td>
<td>USA</td>
<td>Post-Tx, and 7 wks post-Tx end</td>
<td>-list of pain diagnoses -pain intensity in various locations -Centre for Epi Studies Depression Scale -Depression, Anxiety, and Stress Scale -test of pain knowledge -Profile of Chronic Pain: Screen (pain severity, interference and emotional burden) -Profile of Chronic Pain Extended Assessment (coping and functional limitations)</td>
<td>Scores averaged between follow-up times: -deceased pain severity, interference, and emotional burden -decreased perceived disability, catastrophizing, and pain-induced fear -reduced anxiety, depression, and stress -increased pain knowledge -decreased pain interference with daily functioning</td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------------------------</td>
<td>---------------</td>
<td>----------------------</td>
<td>--------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>Sahin, et al. 2011</td>
<td>RCT Chronic low back pain &lt; 8/10 on VAS, aged 18+ years 150 (146)</td>
<td>Back school + exercise and physical treatment 4 GS over 2 wks (each sessions = 1 hr) Physiatrist</td>
<td>Physical Medicine and Rehabilitation Clinic of a university hospital Turkey</td>
<td>-role of thoughts in pain, evaluating self-defeating vs. helpful thinking 2. doing more -developing an exercise plan, sample exercises with pictures, 3. relating better 4. feeling better -relaxation exercises, progressive muscle relaxation, goal-directed behaviour -role of emotion in pain</td>
<td>Exercise and physical treatment</td>
<td>End of Tx and 3 months after Tx</td>
<td>-VAS (pain) -Owestry Low Back Pain Disability Questionnaire</td>
<td>At 3 months and post-Tx: -reduced pain and disability +</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/Setting</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>-------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>Street, et al. 2010</td>
<td>Low back pain &gt; 3 months, aged 18-65 years, 35 (35) (grounded theory: 18)</td>
<td>5 months</td>
<td>Switzerland</td>
<td>wanted from the website</td>
<td></td>
<td></td>
<td>(results not tested for significance due to being a pilot)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rheumatologists and PTs alternated responded to questions</td>
<td></td>
<td></td>
<td>Main Sections: 1. Library (edu on chronic low back pain and management, ask a question option) 2. Gym (videos and descriptions of exercises for low back pain) 3. Forum and chat room (sharing of experiences) 4. Expert Q &amp;A (resources provided based on frequently asked questions) 5. ‘Tell A Story’ (sharing of experiences)</td>
<td></td>
<td></td>
<td>Qualitative findings: -reported improvements in self-comprehension, argumentative abilities (assertiveness/self-advocacy), orientation, development of self-confidence, and maintenance of high-level attention -some increased confusion from too much information and discouragement for some who felt the Tx was “not for me”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>RCT Cancer, aged 18-80 years, pain &gt; 4/10 with</td>
<td>Tailored education-coaching</td>
<td>Two health systems, 1 private practice clinic office</td>
<td>-assess pt learning needs, goals, values and preferences for pain management -build skill-building exercises to improve self-efficacy, enhance</td>
<td>During visit</td>
<td>-total and pain-specific active participation (observation of asking questions, being assertive, and expressing concerns)</td>
<td>-increased pain-specific active participation -physicians provided more information to actively</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-40min IS immediately prior to visit with</td>
<td></td>
<td></td>
<td>Eudcationally-enhanced usual care, given book</td>
<td></td>
<td></td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>Topics</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------------</td>
<td>--------------</td>
<td>--------</td>
<td>---------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>Thorn, et al. 2011; Day, et al 2011</td>
<td>Randomized parallel group design + post-Tx interview with thematic analysis Non-malignant Pain &gt; 3 months, aged 19+ years 83 (61 post Tx, 54 6 months)</td>
<td>CBT GS x 90min x10 wks USA Low-income primary care clinics in rural settings</td>
<td>-explain therapy rationale, goals, format, and rules -introduce stress-appraisal –pain connection -identify negative automatic thoughts and evaluate their accuracy -challenge distorted thoughts and construct realistic alternatives -identify intermediate belief systems and core beliefs -relaxation exercise -positive coping self-statements</td>
<td>Edu – no skill-building -therapy rationale and goals, etc. -chronic pain treatment -gate control theory of pain -costs of chronic pain Post-Tx, and 6 months post-Tx</td>
<td>Brief Pain Inventory (pain intensity and interference) -Roland-Morris Disability Scale -Pain Catastrophizing Scale -Center for Epi Studies Depression Scale -Quality of Life Scale (life satisfaction) -feasibility (drop-out rates, etc.)</td>
<td>Feasibility: -24% did not attend any session and had lower levels of literacy and edu and higher pain catastrophizing -26.5% drop-out rate (drop-outs had lower levels of edu and income) -equal satisfaction between Tx groups Post-Tx &amp; 6 months:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Intervention</td>
<td>Topics</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>--------------</td>
<td>--------</td>
<td>---------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
</tr>
<tr>
<td>Thorn, et al. 2007</td>
<td>RCT Chronic migraine or tension-type headache &gt; 3 days/month, aged 19+ years 45 (31 post-Tx, 13, 19)</td>
<td>CBT – Cognitive restructuring followed by cognitive coping and the reverse order 10 x 1.5 hr GS over 10 wks Clinical psychologist</td>
<td>Headache clinic, psycholog y or GP clinics Clinic USA</td>
<td>Cognitive restructuring: define and identify negative thoughts and associated negative emotional, behavioural and physical changes examine automatic thoughts (develop alternative/adaptive thoughts, identify emotional, behavioural, and</td>
<td>WL</td>
<td>Post-Tx, 6 and 12 months</td>
<td>-headache diary NRS (pain severity and unpleasantness, medication use) -Pain Catastrophizing Scale -Beck Depression Inventory 2nd Ed. -Beck Anxiety Inventory -Pain Anxiety Symptom Scale</td>
<td>Post-Tx: -reduced catastrophization and anxiety -increased self-efficacy 12 months: -reduce catastrophization and pain anxiety -increased self-efficacy</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------</td>
<td>-------------------------------------</td>
<td>--------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>[34 Tx, 11 WL]</td>
<td>physical changes resulting from alternative thinking -define and identify negative immediate and core beliefs, introduce techniques to modify maladaptive beliefs -introduce ‘coping cards’ as a method of modifying negative thoughts -construct and use positive self-statements -integration and maintenance of new concepts and beliefs <strong>Cognitive Coping Sessions:</strong> -passive muscle relaxation techniques -principles of assertiveness and plan assertive communication -introduce behavioural pacing, uptime vs. downtime, benefits of pacing -stress connection and cognitive model of pain</td>
<td>-Headache Management Self-Efficacy Scale</td>
<td>+ / -</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/Setting</td>
<td>Intervention</td>
<td>Topics</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>--------------</td>
<td>--------</td>
<td>---------</td>
<td>-----</td>
<td>----------</td>
</tr>
<tr>
<td>Thorsell, et al. 2011</td>
<td>RCT (Tx vs Tx) Chronic pain 115 (53 at 6 months, 32 at 12 months)</td>
<td>Acceptance and commitment therapy (ACT) IS x1, 7 wks of manual-based self-study with Tx 6, IS x1 (ISs – 90 min, T – 30 min) 8 psychology interns</td>
<td>Specialty pain clinic Sweden</td>
<td>Applied Relaxation (AR): -moving from progressive to rapid relaxation Acceptance and Commitment Therapy: -changing ideas about pain and the pain-avoidance-suffering cycle -identifying values and values as a way of living -cognitive defusion, deliteralizing thoughts, thought observation without judgement -mindfulness -acceptance and willingness to engage with pain -committed action (deciding what to do, doing it, and identifying obstacles) -identifying future obstacles and planning for the future</td>
<td>Coping-oriented Tx – applied relaxatio n</td>
<td>Immediately post-Tx, 6 and 12 months post Tx</td>
<td>-Satisfaction with Life Scale -Hospital Anxiety and Depression Scale -Orebro MSK Pain Questionnaire (level of function and pain intensity) -Chronic Pain Acceptance Questionnaire</td>
<td>-improved satisfaction with life, acceptance of chronic pain, activity engagement, pain willingness, depression, anxiety, and pain intensity at all time points in ACT group -AR also had a reduction in depression and anxiety between preTx and 12 months</td>
</tr>
<tr>
<td>Vowles, et al. 2011; Vowles, et al. 2008</td>
<td>Cohort study Pain &gt; 3 months, high level of mindfulness</td>
<td>Adapted Acceptance and Commitment Therapy + mindfulness Pain Rehab Clinic (pt lived in dorms adjacent to mindfulness training) -values clarification -exposure-based techniques -cognitive defusion exercises</td>
<td>none</td>
<td>Post-Tx, 3 months post-Tx, 3 years post-Tx</td>
<td>-Chronic Pain Acceptance Questionnaire -Chronic Pain Values Inventory</td>
<td>At Post-Tx and 3 months: -improvement in all outcomes At 3 years: +</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td></td>
<td>Control</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>--------------</td>
<td>-----------------</td>
<td>---------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>disability and distress</td>
<td>GS for 6.5hrs/day x 5 days/wk x 3-4wks</td>
<td>clinic during Tx)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>187 (171, 113 at 3 months; 108 at 3 years)</td>
<td>Psychologists, PTs, OTs, nurses, and physicians</td>
<td>England</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-physical conditioning</td>
<td>-physical conditioning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-activity skills management</td>
<td>-activity skills management</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-health education</td>
<td>-health education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vowles, et al. 2009</td>
<td>2 Pilot studies Chronic pain (not otherwise specified)</td>
<td>1. Acceptance and Commitment Therapy (ACT)</td>
<td>Recruitmet not specified</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1: 19 (11) 2: 11 veterans</td>
<td>8 x 90-min GS over 8 wks</td>
<td>university-based outpatient pain clinic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. ACT vs. CBT</td>
<td>Clinical psychology fellow</td>
<td>USA</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>ACT x 4 x 90-min GS via Post-doctoral fellow</td>
<td>2.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>CBT x 5 x 90-min GS via clinical psychologist</td>
<td>1.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-building awareness of the difficulty in effectively controlling pain</td>
<td>-building awareness of the difficulty in effectively controlling pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-improving engagement in meaningful and effective activities despite pain and distress</td>
<td>-improving engagement in meaningful and effective activities despite pain and distress</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-decreasing pain- and stress-avoidant behaviours</td>
<td>-decreasing pain- and stress-avoidant behaviours</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-identification of, and engagement of actions consistent with personally relevant values and goals</td>
<td>-identification of, and engagement of actions consistent with personally relevant values and goals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-improving present-focused awareness and mindfulness of</td>
<td>-improving present-focused awareness and mindfulness of</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>None (baseline data or comparison used)</td>
<td>None (baseline data or comparison used)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Post-Tx</td>
<td>Post-Tx</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-British Colombia Major Depression Inventory</td>
<td>-British Colombia Major Depression Inventory</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-Pain Anxiety Symptoms Scale-20</td>
<td>-Pain Anxiety Symptoms Scale-20</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-Sickness Impact Profile</td>
<td>-Sickness Impact Profile</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-Physical Performance Measures</td>
<td>-Physical Performance Measures</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-medication and healthcare use</td>
<td>-medication and healthcare use</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-walking distance</td>
<td>-walking distance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-sit-to-stand</td>
<td>-sit-to-stand</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>+ / -</td>
<td>+ / -</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-improvement in all outcomes except for usual pain intensity</td>
<td>-improvement in all outcomes except for usual pain intensity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1.</td>
<td>1.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-improved acceptance, pain, depression, disability, and anxiety</td>
<td>-improved acceptance, pain, depression, disability, and anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2.</td>
<td>2.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-similar improvements across groups</td>
<td>-similar improvements across groups</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/Setting</td>
<td>Intervention</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>--------------</td>
<td>---------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
</tr>
<tr>
<td>Wetherall, et al. 2011</td>
<td>RCT Chronic non-malignant pain &gt; 6 months and intensity &amp; interference</td>
<td>Acceptance and Commitment Therapy vs. CBT</td>
<td>90 min GS x 8 (1/wk) doctoral students</td>
<td>thoughts, feelings, and physiologic sensations (psycho-education provided: meds, sleep, conflict resolution, etc. and skills also taught: breathing/relaxation, exercise, etc.) 2. ACT: same as above but no psycho-education CBT: training to control/reduce pain -pain monitoring, pacing, increasing pleasant activities, progressive muscle relaxation, thought challenging, communication with HCPs, appropriate use of medications, reducing pain behaviours, and problem-solving skills</td>
<td>ACT: -limits of control and focus on experience -values and related short- and long-term goal setting -cognitive defusion -mindfulness -committed action</td>
<td>None</td>
<td>Post-Tx and 6 months post-Tx end</td>
<td>-Brief Pain Inventory Short Form -interference subscale -SF-12 -West Haven-Yale Multidimensional Pain Inventory General Activity Subscale</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Intervention</td>
<td>Outcome</td>
<td>Control</td>
<td>F-U</td>
<td>Results</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------------------------</td>
<td>--------------</td>
<td>---------</td>
<td>---------</td>
<td>-----</td>
<td>---------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wicksell, et al. 2007</td>
<td>Pilot Study, cohort study Idiopathic pain, aged 13-20 years 16 (14)</td>
<td>Acceptance and Commitment Therapy 5-29 weekly IS with pt, and 0-10 weekly IS with parents Clinical psychologist</td>
<td>Referred to pain Tx service at university hospital Sweden</td>
<td>-pain education and reassurance (mechanisms of pain, idiopathic nature of pain) -value assessment (identifying personally valued activities) -shifting perspectives from alleviating pain to participating in valued activities (identifying pain management strategies not working for long-</td>
<td>none</td>
<td>Post-Tx, 3 and 6 months</td>
<td>-Functional Disability Inventory-Child Form -school attendance -medication use -pain intensity and interference (NRS) -Pain Coping Questionnaire – Catastrophizing subscale -Children’s Depression Inventory</td>
<td>Pre-Post CBT: -decreased pain interference, depression and pain-related anxiety -improved mental HRQOL Between groups at 6 months: -no difference -higher satisfaction with ACT vs CBT</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/ Setting</td>
<td>Intervention</td>
<td>Topics</td>
<td>Control</td>
<td>F-U</td>
<td>Outcomes</td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>----------------------</td>
<td>--------------</td>
<td>--------</td>
<td>---------</td>
<td>-----</td>
<td>----------</td>
</tr>
<tr>
<td>Wicksell, et al. 2008</td>
<td>RCT Chronic pain related to whiplash-associated disorder &gt; 3 months, aged 20+ years 22 (20)</td>
<td>Exposure and Acceptance CBT 10 x 60-min IS over 8wks Psychologist and physician specializing in pain</td>
<td>Patient traffic accident organization Sweden</td>
<td>term pain relief, identifying pain management strategies that took pt further from participating in valued activities) -exposure (encouragement to increase values-directed behaviour and increasing psychological flexibility in situations of increased pain and distress) -acceptance and diffusion (acknowledgement and acceptance of negative thoughts and events)</td>
<td>Pain edu (chronic vs. acute pain, dysfunction of chronic pain, limitations of treatments) -values assessment (assessment of individual values in important life domains, setting behaviourally-oriented goals) -shifting perspectives (evaluation of previous pain- and</td>
<td>WL + UC</td>
<td>4 months and 7 months (Tx group only) after the end of Tx</td>
<td>-Pain Disability Index -Satisfaction with Life Scale -Tama Scale of Kinesiophobia -Impact of Event Scale -Hospital Anxiety and Depression Scale -pain intensity and interference VASs Process Variables:</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>--------</td>
<td>--------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wong, et al. 2011</td>
<td>Randomized comparative clinical trial</td>
<td>Mindfulness-Based Stress Reduction (MBSR) (with book and CD) vs. Multidisciplinary Pain Intervention (MPI) (with book and CD)</td>
<td>Post-Tx, 3 months post-Tx, 6 months post-Tx</td>
<td>-VAS (pain and pain distress)</td>
<td>-decreased pain and improved physical HRQOL in both groups</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pain &gt; 3 months at &gt; 4/10 VAS, aged 18-65 years</td>
<td>Communit ically-based clinics, hospitals, and community service centres Clinical psychologist – MBS Nurse, PT, RD – MPI China</td>
<td></td>
<td>-better adherence to MPI than MBSR</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>99 (83)</td>
<td>MBSR: -theoretical material on mindfulness, relaxation, meditation, yoga, and the mind-body connection -experiential practice of meditation and yoga -group activities focused on removing barriers to effective practice, practical applications of mindfulness, and supportive intervention between pts</td>
<td></td>
<td>-Chinese versions of: -Profile of Mood States -Centre for Epi Studies Depression Scale -State-Trait Anxiety Inventory -SF-12 -sick days in past 12 months (recall)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Psychological Inflexibility in Pain Scale

- deceased impact of event, depression, and pain interference
<table>
<thead>
<tr>
<th>Author &amp; Date</th>
<th>Method [Design, Age &amp; Pain Dx, N (n)]</th>
<th>Intervention</th>
<th>Topics</th>
<th>Control</th>
<th>F-U</th>
<th>Outcomes</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wu, et al. 2011</td>
<td>Quasi-Ex Knee OA, aged 50+ years 259 (205 - 114 in Tx, and 91 in control)</td>
<td>Taipei Osteoarthritis Program (self-management programme) 1 x 80-min GS x 4 wks Commuity health centres Trained research assistant and PT China</td>
<td>-edu on anatomy, pathology, and common treatments -introduction to, and practice of, exercises -protection and pain reduction strategies -reducing disability -goal-setting and peer support -coping skills for OA -skills on understanding and acting on problems -skills to enhance self-efficacy -DVDs, booklet, and group support *goal: increase self-efficacy</td>
<td>UC</td>
<td>1 and 8 wks post-Tx</td>
<td>-Arthritis Self-Efficacy Scale -Survey of Pain Attitudes (pain beliefs) -health care use (days of pain, days of disability and unplanned medical consultations)</td>
<td>1 wk post-Tx: -improved pain beliefs and reduced days of pain 8 wks post-Tx: -improved arthritis pain self-efficacy, other arthritis symptoms self-efficacy, pain beliefs, and number of unplanned medical consultations</td>
</tr>
<tr>
<td>Yip, et al. 2007, 2008</td>
<td>RCT Knee OA, aged 50+ years 182 (120 at 16 wks, 1 year subset of 95 pts)</td>
<td>ASMP + exercise component 2hr GS/wk x 6 wks Hospital out-patient clinics China</td>
<td>-overview of self-management principles -use of action plans -coping and managing pain, stress, fatigue, daily limitations -provision of skills -medical aspects of pain and management -joint protection -physical activity and exercise</td>
<td>UC</td>
<td>1 and 16 wks post-Tx, 1 year</td>
<td>-VAS (pain and fatigue) - diary (frequency and duration of exercise) -modified Health Assessment Questionnaire (disability in ADLs) -hamstring and quadriceps strength</td>
<td>At 16 wks post-Tx: -reduced current pain and fatigue -increased weekly duration of exercise -improved knee flexion At 1 year: -improved arthritis pain and</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/Setting</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
</tr>
<tr>
<td>----------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-----</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>Zautra, et al. 2008</td>
<td>Cluster RCT RA 144 (131)</td>
<td>CBT for pain vs. mindfulness meditation and emotional regulation therapy Weekly 2-hr GS x 8 wks Psychologist and clinical psychology student</td>
<td>USA Advertisements, GPs offices, rheumatologist referral, and Arthritis Foundation</td>
<td>CBT for pain: - intro and review of pain concepts - relaxation training - autogenic training and other methods of relaxation - activity pacing and managing daily activities - cognitive coping - alternative pain management approaches - memory and concentration - managing intense pain episodes - problem-solving Educatio n (attention placebo control, 8 weekly GS) Post-Tx pt diary: - daily pain NRS - Positive and Negative Affect Schedule - depression (6-item questionnaire for study) - coping efficacy for pain Likert scales (satisfaction and confidence) - pain catastrophizing (2 Likert scales) - perceived pain control (Likert scale) - laboratory and physician’s assessment</td>
<td></td>
<td>- unplanned, arthritis-related medical consultations other symptom self-efficacy - decreased current pain, pain at night, pain during walking - improved self-reported health and reduced number of unplanned arthritis-related medical consultations</td>
<td>+</td>
</tr>
<tr>
<td>Author &amp; Date</td>
<td>Method [Design, Age &amp; Pain Dx, N (n)]</td>
<td>Mode/Delivery</td>
<td>Recruitment/Setting</td>
<td>Intervention</td>
<td>F-U</td>
<td>Outcomes</td>
<td>Results</td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------------</td>
<td>---------------</td>
<td>---------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>-----</td>
<td>----------</td>
<td>---------</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-relapse prevention, generalization, and maintenance</td>
<td></td>
<td></td>
<td>+</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mindfulness &amp; emotional regulation: -mindfulness and bidimensional model of emotion</td>
<td></td>
<td></td>
<td>/</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-mindfulness and awareness -emotional clarity and well-being -acceptance, negative thoughts, and re-framing</td>
<td></td>
<td></td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-positive emotions and pleasant activity scheduling -enhancing social relations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>-intimacy, stress, and mindfulness -maintenance and generalization</td>
<td></td>
<td></td>
<td>-</td>
</tr>
</tbody>
</table>

*history of depression played a role in Tx outcomes
Key:
Dx – diagnosis
Tx – treatment/intervention
FU – follow-up
Pt - participant
T - telephone
WL – wait list
Edu – education
AV – audio-visual
UC – usual care
SM – self-management
Wt – weight
Meds – medications
Sx – surgery
HCPs – health care providers
CAMs – complimentary and/or alternative medicines
HCU – health care use
GS – group sessions
IS – individual sessions
RCT – randomized controlled trial
OA – osteoarthritis
NeP – neuropathic pain
RN – registered nurse
PT – physical therapist
OT – occupational therapist
AE – adverse event
NeP – neuropathic pain
Appendix 4. Ethics approval for student additions to original survey study.

Amendment Acknowledgment/Approval Letter

August 05, 2011

Dr. Elizabeth VanDenKerkhof
Department of Anesthesiology and Perioperative Medicine
Queen’s University

File #: 6005559 ANAE-174-10 The Epidemiology of Neuropathic Pain in Canada

Dear Dr. VanDenKerkhof

I am writing to acknowledge receipt of the following:

- Additional questionnaires for the study

- A revised cover/information letter

I have reviewed these materials 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
Appendix 5. Initial survey cover letter (printed on Queen’s University letterhead)

Dear Sir/Madame:

We invite you to participate in our study “The Epidemiology of Neuropathic Pain in Canada”. The purpose of our study is to estimate the prevalence of neuropathic pain (pain due to nerve injury or nerve disease) in Canada, the health care needs of those experiencing this pain, and the ways in which these individuals manage their pain day to day. You do not need to be experiencing pain to participate in this study. This study has been reviewed by Queen’s University Research Ethics Board.

Please find enclosed a questionnaire booklet and a self-addressed envelope to return the booklet whether or not you choose to complete it. In order to get a random sample of participants in our study, we ask that the adult (aged 18 years or older) in your household who most recently celebrated their birthday, complete the questionnaire. Answering the questions should take approximately 30 minutes. Your answers will be kept confidential. To do this, we have assigned you a unique study identification number which you will see on the booklet. We have a protected file containing your identifying information (e.g., address) matched to your study number. This is kept separate from your completed booklet. No identifying information is included on the booklet or with your questionnaire data. This survey can also be completed online at: http://ca.studentvoice.com/queens/neuropathicpain (your login ID is on the booklet).

Completing the booklet is voluntary; however, your participation will provide us useful information about the number and experience of Canadians living with pain. If you do not wish to participate, it would be helpful if you would answer the question on the front page of the booklet and mail it back to us.

Please contact your primary health care provider if you wish to discuss any health concerns related to the contents of the questionnaire. By completing and returning the booklet we will assume you have consented to participate in this study.

If you have any questions please do not hesitate to contact Ella Mann (the PhD student conducting this study, oegs@queensu.ca), or me. If you have concerns about your rights as a research participant please contact Dr. Albert Clark, Research Ethics Board (613-533-6081, clarkaf@queensu.ca).

We hope you consider participating in this study and look forward to your response.

Sincerely,

Elizabeth VanDenKerkhof RN DrPH, Professor and Principle Investigator
613-549-6666, x3964 ev5@queensu.ca
Appendix 6. Follow-up cover letter sent to non-respondents (printed on Queen’s University letterhead)

Dear Sir/Madame:

A few weeks ago, we sent you an invitation to participate in the study “The Epidemiology of Neuropathic Pain in Canada”. The purpose of this study is to estimate the percentage of people in Canada with neuropathic (nerve) pain, a type of chronic pain. In order to figure this out, it is important that we hear you even if you do not have pain. We are also gathering some information about some of the factors that may be related to pain and how it is managed.

Your name and address were randomly selected from publically available telephone books. It is important that the adult (aged 18 years or older) in your residence who most recently celebrated a birthday complete the questionnaire. In some cases, people have asked for other copies of the questionnaire for family or friends who have pain. We are happy to send extra copies for others to participate.

The responses we have received are helping to understand the number of Canadians with and without pain. We trust the final results of this study will be helpful for making decisions about healthcare policy.

To the best of our knowledge, we have not received your survey. We are writing a second time because it is very important that your survey is returned in order to accurately estimate the percentage of Canadians with nerve pain. Some individuals have decided not to participate and have returned their survey simply noting on the front that they do or do not have pain. This has been very helpful and we encourage you to use the enclosed stamped envelope to return the survey with any information you are willing to provide.

All information will be kept confidential. To do this, we have assigned you a unique study identification number which you will see on the booklet. No other identifying information is included on the booklet or with your questionnaire data. This survey can also be completed online at: http://ca.studentvoice.com/queens/neuropathicpain (your login ID is on the booklet cover).

By returning this booklet, we will assume that you have consented to our collecting any information you provided. If after completing the booklet you have any concerns about your health, please contact your primary health care provider.

If you have any questions about this survey please do not hesitate to contact Ella Mann (the PhD student conducting this study, 0egs@queensu.ca), or me. If you have concerns about your rights as a research participant please contact Dr. Albert Clark, Research Ethics Board (613-533-6081, clarkaf@queensu.ca).

We hope you consider participating in this study and look forward to your response.

Elizabeth VanDenKerkhof RN DrPH, Professor and Principle Investigator
613-549-6666, x3964 ev5@queensu.ca
Appendix 7. Survey questionnaire.

Epidemiology and Self-Management of Neuropathic Pain in Canada

This survey can also be completed online at: http://ca.studentvoice.com/queens/neuropathicpain
(Your ID number is: ___ ___ ___ ___ ___ ___)

If you do not wish to participate in this study, would you please help us by indicating a reason below:

☐ I have severe pain and am thus unable to participate.

☐ I have a health condition that prevents me from participating.

☐ Other (please specify): ___________________________________________
We may wish to contact you again to learn more about your health. If you are willing to be contacted about future research opportunities, please tick the box.

1. Are you currently troubled by pain or discomfort, either all of the time or on and off?
   - ☐ Yes
   - ☐ No
   
   If yes, have you had this pain or discomfort for more than 3 months?  ☐ Yes  ☐ No
   
   If no, please answer questions 7 – 34.

2. How often are you bothered by this pain or discomfort?
   - ☐ All the time or daily
   - ☐ Many days of the week
   - ☐ Once per week
   - ☐ Once per month

3. Are you experiencing pain at the time of completing this questionnaire?
   - ☐ Yes
   - ☐ No
   
   (If no, please answer any pain-related questions thinking of a painful episode you have had in the past three weeks)

4. Have you been diagnosed with any of the following common causes of pain?
   - ☐ Pain from past surgery
   - ☐ Back problems (such as a slipped disc, back surgery, or sciatica)
   - ☐ Diabetes
   - ☐ An accident that damaged a nerve
   - ☐ Amputation of a limb
   - ☐ Fibromyalgia
   - ☐ Leg ulcers
   - ☐ Shingles
   - ☐ Cancer
   - ☐ Chronic widespread pain
   - ☐ Migraine
   - ☐ Osteoarthritis (OA)
   - ☐ Rheumatoid arthritis (RA)
   - ☐ Arthritis (other than OA or RA): please specify: ________________________________
   - ☐ Vulvodynia
   - ☐ Other, please specify: ________________________________
   - ☐ None of the above
5. I experience pain in the area(s) marked with the number(s) ________________________________

6. I experience my most troublesome pain in the area marked with the number(s)________________
   (please indicate just one area, this may be one or two numbers depending on whether you
   experience your most troublesome pain on one or both sides of your body)
7. Have you been told by a health professional that you have any of the following chronic health conditions? (Please select all that apply)

☐ Asthma
☐ Anxiety disorder (e.g., phobia, obsessive-compulsive disorder, or panic disorder)
☐ Bowel disorder (e.g., Crohn’s disease, ulcerative colitis, irritable bowel syndrome, or bowel incontinence)
☐ Chronic bronchitis, emphysema, or chronic obstructive pulmonary disease (COPD)
☐ Chronic fatigue syndrome
☐ Diabetes
☐ Heart disease (e.g., heart attack, congestive heart failure)
☐ Hypertension or high blood pressure
☐ Mood disorder (e.g., depression, bipolar disorder, mania, or dysthymia)
☐ Multiple chemical sensitivities
☐ Intestinal or stomach ulcers
☐ Stroke
☐ Urinary incontinence
☐ Other, please specify: ____________________________________________________

8. Are you?  ☐ Male  ☐ Female

9. What is your current age? _____________

10. Which best describes your marital status?

☐ Single  ☐ Separated
☐ Married  ☐ Divorced
☐ Living together  ☐ Widowed

11. What is your highest level of education?

☐ Grade 8 or less
☐ Some high school without diploma
☐ High school diploma
☐ CEGEP, uncompleted
☐ Completed CEGEP
☐ Trade or professional school certificate/diploma
☐ Some university
☐ University degree
☐ Post-graduate degree(s)
☐ Other, please specify: ____________________________________________________
12. Which of the following best describes your current employment status:

☐ Working full time (35 hrs or more per week)
☐ Working part time (less than 35 hrs per week)
☐ Unemployed and looking for work
☐ Unable to work due to disability and receiving disability compensation
☐ Unable to work due to disability and seeking disability compensation
☐ Retired
☐ At home and not looking for paid employment
☐ Student
☐ Other, please specify: ________________________________________________

13. Is your home:

☐ Owned or mortgaged by you or your family
☐ Rented from a private landlord
☐ Rented from the city/council
☐ Other, please specify: ________________________________________________

14. How many persons usually live at this address as of August 1st, 2011? ____________

(Include all persons who have their main residence at this address, even if they are temporarily away. Children in joint custody should be included in the home of that parent where they live most of the time. Children who spend equal time with each parent should be included in the home of that parent with whom they are staying August 1st, 2011 (same as date above). Students should be included in their parents’ address, even if they live elsewhere while attending school or working at a summer job. Spouses or common-law partners temporarily away should be listed in the main residence of their family. Persons in an institution for less than 6 months should be listed at their usual residence)

15. Is your main source of income from:

☐ Employment
☐ Employment insurance/Workplace compensation/Welfare
☐ Senior’s benefits
☐ Other, please specify: ________________________________________________

16. Is your annual household income:

☐ Less than $19,999
☐ $20,000 to $49,999
☐ $50,000 to $99,999
☐ $100,000 to $149,999
☐ $150,000 or more
17. Please indicate your ethnic origin:

☐ White
☐ South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
☐ Chinese
☐ Black
☐ Filipino
☐ Latin American
☐ Arab
☐ Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian, Laotian, etc.)
☐ West Asian (e.g., Iranian, Afghan, etc.)
☐ Korean
☐ Japanese
☐ Other, please specify: ______________________________________________________

18. Which of the following best describes your smoking habits? (For this question, a regular smoker is someone who has smoked at least 1 cigarette per day for at least 1 year).

☐ I have never smoked
☐ I am an ex-smoker
☐ I smoke occasionally
☐ I am a regular smoker now

19. In the past 12 months, how many times have you seen your doctor, a specialist, visited the emergency department or visited a walk-in clinic? (if you have not visited one/all of the listed services, please write “0”)

☐ Doctor _____
☐ Specialist _____
☐ Walk-in _____
☐ ER _____

20. In the past 12 months, how many days of work, school, or other regular activities did you miss due to health-related issues? _____

21. In the past 12 months, how many days did your health interfere with physical or daily activities including socializing? _____

22. In the past 12 months, how many times have you seen other health care professionals (e.g., chiropractors, physiotherapists)? _____

23. In the past 12 months, how happy have you been with your ability to control your pain by means of medication or other therapy?

☐ Not applicable, since I have no significant pain
☐ Completely dissatisfied
☐ Somewhat or fairly satisfied
☐ Completely satisfied
The following questions ask for your views about your health. Answer every question by selecting your answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

24. In general, would you say your health is:

   Excellent □
   Very Good □
   Good □
   Fair □
   Poor □

25. Compared to one year ago, how would you rate your health in general now?

   Much better now than one year ago □
   Somewhat better now than one year ago □
   About the same as one year ago □
   Somewhat worse now than one year ago □
   Much worse now than one year ago □

26. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

   a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports  □ Yes, limited a lot □ Yes, limited a little □ No, not limited at all
   b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf  □ Yes, limited a lot □ Yes, limited a little □ No, not limited at all
   c. Lifting or carrying groceries □ Yes, limited a lot □ Yes, limited a little □ No, not limited at all
   d. Climbing several flights of stairs □ Yes, limited a lot □ Yes, limited a little □ No, not limited at all
   e. Climbing one flight of stairs □ Yes, limited a lot □ Yes, limited a little □ No, not limited at all
   f. Bending, kneeling, or stooping □ Yes, limited a lot □ Yes, limited a little □ No, not limited at all
   g. Walking more than a kilometre □ Yes, limited a lot □ Yes, limited a little □ No, not limited at all
   h. Walking several hundred meters □ Yes, limited a lot □ Yes, limited a little □ No, not limited at all
   i. Walking one hundred meters □ Yes, limited a lot □ Yes, limited a little □ No, not limited at all
   j. Bathing or dressing yourself □ Yes, limited a lot □ Yes, limited a little □ No, not limited at all
27. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

- a. Cut down on the amount of time you spent on work or other activities
- b. Accomplished less than you would like
- c. Were limited in the kind of work or other activities
- d. Had difficulty performing the work or other activities (for example, it took extra effort)

28. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

- a. Cut down on the amount of time spent on work or other activities
- b. Accomplished less than you would like
- c. Did work or other activities less carefully than usual

29. During the past 4 weeks, to what extent has your physical or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

- Not at all
- Slightly
- Moderately
- Quite a bit
- Extremely

30. How much bodily pain have you had during the past 4 weeks?

- None
- Very Mild
- Mild
- Moderate
- Severe
- Very Severe
31. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

32. These questions are about how you feel and how things have been with you during the past 4 weeks. 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 . . .

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Did you feel full of life?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>b. Have you been very nervous?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>c. Have you felt so down in the dumps that nothing could cheer you up?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>d. Have you felt calm and peaceful?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>e. Did you have a lot of energy?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>f. Have you felt downhearted and depressed?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>g. Did you feel worn out?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>h. Have you been happy?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>i. Did you feel tired?</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

33. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All of the time Most of the time Some of the time A little of the time None of the time

□ □ □ □ □
34. How TRUE or FALSE is each of the following statements for you?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Definitely true</th>
<th>Mostly true</th>
<th>Don’t know</th>
<th>Mostly false</th>
<th>Definitely false</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I seem to get sick a little easier than other people</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. I am as healthy as anyone I know</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. I expect my health to get worse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. My health is excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

35. On the scale below, please indicate how bad your pain (that you have previously identified on the body diagram) has been in the last week where: ‘0’ means no pain and ‘10’ means pain as severe as it could be.

NONE 0 1 2 3 4 5 6 7 8 9 10 SEVERE PAIN

*Think about how your pain that you showed in the diagram has felt over the last week.* Put a tick against the descriptions that best match your pain. These descriptions may, or may not match your pain no matter how severe it feels. Only circle the responses that describe your pain.

36. In the area where you have pain, do you also have ‘pins and needles’, tingling, or prickling sensations?

- [ ] NO – I don’t get these sensations
- [ ] YES – I get these sensations often

37. Does the painful area change colour (perhaps looks mottled or more red) when the pain is particularly bad?

- [ ] NO – The pain does not affect the colour of my skin
- [ ] YES – I have noticed that the pain does make my skin look different from normal

38. Does your pain make the affected skin abnormally sensitive to touch? Getting unpleasant sensations or pain when lightly stroking the skin might describe this.

- [ ] NO – The pain does not make my skin in that area abnormally sensitive to touch
- [ ] YES – My skin in that area is particularly sensitive to touch
39. Does your pain come on suddenly and in bursts for no apparent reason when you are completely still? Words like ‘electric shocks’, jumping and bursting might describe this.

- NO – My pain doesn’t really feel like this
- YES – I get these sensations often

40. In the area where you have pain, does your skin feel unusually hot like a burning pain?

- NO – I don’t have burning pain
- YES – I get burning pain often

41. Gently rub the painful area with your index finger and then rub a non-painful area (for example, an area of skin further away or on the opposite side from the painful area). How does this rubbing feel in the painful area?

- The painful area feels no different from the non-painful area
- I feel discomfort, like pins and needles, tingling, or burning in the painful area that is different from the non-painful area

42. Gently press on the painful area with your finger tip then gently press in the same way onto a non-painful area (the same non-painful area that you chose in the last question). How does this feel in the painful area?

- The painful area does not feel different from the non-painful area
- I feel numbness or tenderness in the painful area that is different from the non-painful area

43. Does the pain have one or more of the following characteristics?

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burning</td>
<td></td>
</tr>
<tr>
<td>Painful cold</td>
<td></td>
</tr>
<tr>
<td>Electric shocks</td>
<td></td>
</tr>
</tbody>
</table>

44. Is the pain associated with one or more of the following symptoms in the same area?

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tingling</td>
<td></td>
</tr>
<tr>
<td>Pins and needles</td>
<td></td>
</tr>
<tr>
<td>Numbness</td>
<td></td>
</tr>
<tr>
<td>Itching</td>
<td></td>
</tr>
</tbody>
</table>

45. Please use the scale below to tell us how intense your pain is. Place an “X” through the number that best describes the intensity of your pain.

<table>
<thead>
<tr>
<th>No pain sensation</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th></th>
</tr>
</thead>
</table>

The most intense pain imaginable
46. Please use the scale below to tell us how sharp you pain feels. Words used to describe “sharp” feelings include “like a knife”, “like a spike”, “jabbing” or “like jolts.”

Not sharp

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>

The most sharp sensation imaginable (“like a knife”)

47. Please use the scale below to tell us how hot your pain feels. Words used to describe very hot pain include “burning” and “on fire.”

Not hot

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>

The hottest sensation imaginable (“on fire”)

48. Please use the scale below to tell us how dull your pain feels. Words used to describe very dull pain include “like a dull toothache,” “dull pain,” and “like a sore muscle.”

Not dull

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>

The dullest sensation imaginable

49. Please use the scale below to tell us how cold your pain feels. Words used to describe very cold pain include “like ice” and “freezing.”

Not cold

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>

The coldest pain sensation imaginable (“freezing”)

50. Please use the scale below to tell us how sensitive your skin is to light touch or clothing. Words used to describe sensitive skin include “like sunburned skin” and “raw skin.”

Not sensitive

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>

The most sensitive pain sensation imaginable (“raw skin”)

51. Please use the scale below to tell us how itchy your pain feels. Words used to describe itchy skin include “like poison oak” and “like a mosquito bite.”

Not itchy

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>

The itchiest pain sensation imaginable (“like poison ivy”)

52. Which of the following best describes the time quality of your pain? Please check only one answer.

( ) I feel a background pain all of the time and occasional flare-ups (break-through pain) some of the time.

Describe the background pain: ________________________________

241
Describe the flare-up (break-through) pain: ______________________________________

( ) I feel a single type of pain **all the time**. Describe this pain: ______________________

( ) I feel a single type of pain only **sometimes**. Other times I am pain free.

Describe this occasional pain: ______________________________________________________

53. Now that you have told us the different physical aspects of your pain, and the different types of sensations, we want you to tell us overall how **unpleasant** your pain is to you. Words used to describe very unpleasant pain include “miserable” and “intolerable.” Remember, pain can have a low intensity, but still feel extremely unpleasant, and some kinds of pain can have a high intensity but be very tolerable. With this scale, please tell us how unpleasant your pain feels.

Not unpleasant          0 1 2 3 4 5 6 7 8 9 10 The most unpleasant sensation imaginable (“intolerable”)

54. Lastly, we want you to give us an estimate of the severity of your deep versus surface pain. We want you to rate each location of pain separately. We realize that it can be difficult to make these estimates, and most likely it will be a “best guess,” but please give us your best estimate.

**HOW INTENSE IS YOUR DEEP PAIN?**

No deep pain          0 1 2 3 4 5 6 7 8 9 10 The most intense deep pain sensation imaginable

**HOW INTENSE IS YOUR SURFACE PAIN?**

No surface pain       0 1 2 3 4 5 6 7 8 9 10 The most intense surface pain sensation imaginable

55. Have you sought treatment for this pain or discomfort recently? □ □

56. Have you sought treatment for this pain or discomfort often? □ □

57. Have you taken painkillers for this pain or discomfort recently? □ □

58. Have you taken painkillers for this pain or discomfort often? □ □
59. What treatments or medications are you receiving for your pain?

_____________________________________________________________________________

_____________________________________________________________________________

_____________________________________________________________________________

These items deal with ways you've been coping with the stress in your life since you developed chronic pain. Different people deal with things in different ways, but we are interested in how you have tried to deal with it. Each item says something about a particular way of coping. Please indicate how much or how frequently you have been doing each item. Don't answer on the basis of whether it seems to be working or not—just whether or not you are doing it. Make your answers as true FOR YOU as you can.

60. I've been turning to work or other activities to take my mind off things.

- [ ] I haven’t been doing this at all
- [ ] I’ve been doing this a little bit
- [ ] I’ve been doing this a medium amount
- [ ] I’ve been doing this a lot

61. I've been concentrating my efforts on doing something about the situation I'm in.

- [ ] I haven’t been doing this at all
- [ ] I’ve been doing this a little bit
- [ ] I’ve been doing this a medium amount
- [ ] I’ve been doing this a lot

62. I've been saying to myself "this isn't real."

- [ ] I haven’t been doing this at all
- [ ] I’ve been doing this a little bit
- [ ] I’ve been doing this a medium amount
- [ ] I’ve been doing this a lot

63. I've been using alcohol or other drugs to make myself feel better.

- [ ] I haven’t been doing this at all
- [ ] I’ve been doing this a little bit
- [ ] I’ve been doing this a medium amount
- [ ] I’ve been doing this a lot

64. I've been getting emotional support from others.

- [ ] I haven’t been doing this at all
- [ ] I’ve been doing this a little bit
- [ ] I’ve been doing this a medium amount
- [ ] I’ve been doing this a lot

65. I've been giving up trying to deal with it.

- [ ] I haven’t been doing this at all
- [ ] I’ve been doing this a little bit
- [ ] I’ve been doing this a medium amount
- [ ] I’ve been doing this a lot
66. I've been taking action to try to make the situation better.
   - I haven’t been doing this at all
   - I’ve been doing this a little bit
   - I’ve been doing this a medium amount
   - I’ve been doing this a lot

67. I've been refusing to believe that it has happened.
   - I haven’t been doing this at all
   - I’ve been doing this a little bit
   - I’ve been doing this a medium amount
   - I’ve been doing this a lot

68. I've been saying things to let my unpleasant feelings escape.
   - I haven’t been doing this at all
   - I’ve been doing this a little bit
   - I’ve been doing this a medium amount
   - I’ve been doing this a lot

69. I've been getting help and advice from other people.
   - I haven’t been doing this at all
   - I’ve been doing this a little bit
   - I’ve been doing this a medium amount
   - I’ve been doing this a lot

70. I've been using alcohol or other drugs to help me get through it.
   - I haven’t been doing this at all
   - I’ve been doing this a little bit
   - I’ve been doing this a medium amount
   - I’ve been doing this a lot

71. I've been trying to see it in a different light, to make it seem more positive.
   - I haven’t been doing this at all
   - I’ve been doing this a little bit
   - I’ve been doing this a medium amount
   - I’ve been doing this a lot

72. I’ve been criticizing myself.
   - I haven’t been doing this at all
   - I’ve been doing this a little bit
   - I’ve been doing this a medium amount
   - I’ve been doing this a lot

73. I've been trying to come up with a strategy about what to do.
   - I haven’t been doing this at all
   - I’ve been doing this a little bit
   - I’ve been doing this a medium amount
   - I’ve been doing this a lot

74. I've been getting comfort and understanding from someone.
   - I haven’t been doing this at all
   - I’ve been doing this a little bit
   - I’ve been doing this a medium amount
   - I’ve been doing this a lot
75. I’ve been giving up the attempt to cope.

☐ I haven’t been doing this at all
☐ I’ve been doing this a little bit
☐ I’ve been doing this a medium amount
☐ I’ve been doing this a lot

76. I’ve been looking for something good in what is happening.

☐ I haven’t been doing this at all
☐ I’ve been doing this a little bit
☐ I’ve been doing this a medium amount
☐ I’ve been doing this a lot

77. I’ve been making jokes about it.

☐ I haven’t been doing this at all
☐ I’ve been doing this a little bit
☐ I’ve been doing this a medium amount
☐ I’ve been doing this a lot

78. I’ve been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

☐ I haven’t been doing this at all
☐ I’ve been doing this a little bit
☐ I’ve been doing this a medium amount
☐ I’ve been doing this a lot

79. I’ve been accepting the reality of the fact that it has happened.

☐ I haven’t been doing this at all
☐ I’ve been doing this a little bit
☐ I’ve been doing this a medium amount
☐ I’ve been doing this a lot

80. I’ve been expressing my negative feelings.

☐ I haven’t been doing this at all
☐ I’ve been doing this a little bit
☐ I’ve been doing this a medium amount
☐ I’ve been doing this a lot

81. I’ve been trying to find comfort in my religion or spiritual beliefs.

☐ I haven’t been doing this at all
☐ I’ve been doing this a little bit
☐ I’ve been doing this a medium amount
☐ I’ve been doing this a lot

82. I’ve been trying to get advice or help from other people about what to do.

☐ I haven’t been doing this at all
☐ I’ve been doing this a little bit
☐ I’ve been doing this a medium amount
☐ I’ve been doing this a lot

83. I’ve been learning to live with it.

☐ I haven’t been doing this at all
☐ I’ve been doing this a little bit
☐ I’ve been doing this a medium amount
☐ I’ve been doing this a lot

245
84. I've been thinking hard about what steps to take.

☐ I haven’t been doing this at all  ☐ I’ve been doing this a little bit  ☐ I’ve been doing this a medium amount  ☐ I’ve been doing this a lot

85. I’ve been blaming myself for things that happened.

☐ I haven’t been doing this at all  ☐ I’ve been doing this a little bit  ☐ I’ve been doing this a medium amount  ☐ I’ve been doing this a lot

86. I’ve been praying or meditating.

☐ I haven’t been doing this at all  ☐ I’ve been doing this a little bit  ☐ I’ve been doing this a medium amount  ☐ I’ve been doing this a lot

87. I’ve been making fun of the situation.

☐ I haven’t been doing this at all  ☐ I’ve been doing this a little bit  ☐ I’ve been doing this a medium amount  ☐ I’ve been doing this a lot

88. From the list below, please select any of the things you feel have made managing your chronic pain either easier or harder (select all that apply):

☐ Self-confidence in your ability to manage your pain
☐ Support from family and/or friends
☐ Relationship with your health care provider(s)
☐ Access to health care services
☐ Depression or feeling down
☐ Intensity of your pain
☐ Fear of making your pain worse
☐ Your ability to read and/or understand health information
☐ Other, please specify: ______________________________________________________

Please rate how confident you are that you can do the following things at present, despite the pain. To indicate your answer, circle one of the numbers on the scale under each item, where 0 = not at all confident and 6 = completely confident. Remember, this questionnaire is not asking whether or not you have been doing these things, but rather how confident you are that you can do them at present, despite the pain.

89. I can enjoy things, despite the pain.

\[
\begin{array}{cccccc}
0 & 1 & 2 & 3 & 4 & 5 & 6 \\
Not\ at\ all\ confident & & & & & & \text{Completely confident}
\end{array}
\]
90. I can do most of the household chores (e.g., tidying-up, washing dishes, etc.), despite the pain.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all confident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

91. I can socialize with my friends or family members as often as I used to do, despite the pain.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all confident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

92. I can cope with my pain in most situations.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all confident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

93. I can do some form of work, despite the pain. (“work” includes housework, paid and unpaid work).

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all confident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

94. I can still do many of the things I enjoy doing, such as hobbies or leisure activities, despite pain.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all confident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

95. I can cope with my pain without medications.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all confident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

96. I can still accomplish most of my goals in life, despite the pain.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all confident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
97. I can live a normal lifestyle, despite the pain.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all confident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Completely confident</td>
</tr>
</tbody>
</table>

98. I can gradually become more active, despite the pain.

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all confident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Completely confident</td>
</tr>
</tbody>
</table>

Managing a chronic illness can be time-consuming and challenging. It can involve taking medicine daily, exercising, following a specific diet, regular doctor visits, and coping with the impact of the illness upon you and those with whom you interact. The following questions ask about a variety of different resources that people may use to manage their illness. For each item, select the number that best indicates your experience over the past 3 months.

99. Which health care professional(s) do you feel is the most helpful in managing your pain?

☐ Family doctor
☐ Specialist doctor (e.g., rheumatologist)
☐ Physical or Occupational Therapist
☐ Nurse or Nurse Practitioner
☐ Health care team
☐ Other (please specify): ___________________________________________

Please answer questions 100-106 thinking of the health care professional/team you identified above. Over the past 3 months, to what extent...

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

100. Has your doctor or other health advisor (nurse, dietician) clearly explained what you need to do to manage your illness? (If you have not had any health visits in the past 3 months, think back to the last visit you had.)

☐ ☐ ☐ ☐ ☐ ☐

101. Has your doctor or other health advisor provided support between visits such as telephone calls, reminder letters, or newsletters?

☐ ☐ ☐ ☐ ☐ ☐
102. Has your doctor involved you as an equal partner in making decisions and illness management strategies and goals?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

103. Has your doctor or other health care advisor listened carefully to what you had to say about your illness?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

104. Has your doctor or other health advisor (nurse, dietician) answered your questions and addressed your concerns during office visits?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

105. Has your doctor or other health care provider thoroughly explained the results of tests you have had done (e.g., cholesterol, blood pressure, or other laboratory tests)?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

106. How important are health care team resources to you in managing your illness?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

107. Have family or friends exercised with you?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

108. Have family or friends listened carefully to what you have to say about your illness?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

109. Have family or friends encouraged you to do the things you need to do for your illness?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

110. Have family or friends selected or requested healthy food choices when you ate with them?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

111. Have you shared healthy low-fat recipes with family or friends?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

112. Have family or friends helped you remember to take your medicine?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
113. Have family or friends bought food or prepared food for you that was especially healthy or recommended?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A moderate amount</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

114. How important is family and friend support in managing your illness?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Over the last 2 weeks, how often have you been bothered by any of the following problems?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>115. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>116. Feeling down, depressed or hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>117. Trouble falling or staying asleep, or sleeping too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>118. Feeling tired or having little energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>119. Poor appetite or overeating</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>120. Feeling bad about yourself – or that you are a failure or have let yourself or your family down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>121. Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>122. Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>123. Thoughts that you would be better off dead or of hurting yourself in some way</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

THANK YOU FOR YOUR PARTICIPATION!
Appendix 8. Overview of Pilot Study

Appendix Overview & Purpose

A pilot study was conducted to guide decision-making for the larger study. Thus the purpose of the following appendix is to outline the pilot study (1) background information, (2) methods, (3) results, and (4) implications and recommendations for the larger study methodology.

Introduction

Internationally, population-based surveys of chronic pain have been conducted using a variety of survey methods. Surveys are most commonly mailed (1-6), however telephone (7-9) and computer-assisted telephone interviews (10-12) and mixed modes (13) have also been used. In these studies, response rates vary from 25-85% after one to three contacts (1-13), with 69-85% of participants responding after the first contact (2, 13).

More recently, chronic pain surveys have been conducted using the internet and online data collection methods. National surveys such as the National Health and Wellness Survey of European and other countries and the Danish Health Survey have become internet-based and include information about chronic pain (14, 15). Other researchers have opted to conduct internet-based pain surveys facilitated by research companies that provide a panel of potential participants who have consented to be contacted about research opportunities. These companies randomly selects participant and may provide them with necessary technical support. For example, Johannes and colleagues used a research company to recruit a sample that would represent the general study population in a variety of demographic characteristics (16). Participants without internet access and/or a computer were provided free internet and were able to complete the survey using their televisions. From the panel of potential participants, 75.5%
agreed to participate. The resulting prevalence of chronic pain was similar to that reported by surveys using other survey modes.

Compared to postal mail and face-to-face interviews the advantages of online survey methods include their relatively lower administration costs (e.g., postage, data transcription and input), reduce response time (e.g., mailing or travel time), and opportunity for interaction (e.g., Skype interviews, inclusion of videos) (17). Compared to traditional paper-and-pen survey methods, online surveys may require additional ethics consideration for data storage, respondent anonymity, and the process of consent (17). Potential disadvantages of electronic surveys include the possibility of reduced data validity if questionnaire diagrams or images are distorted or presented differently on different devices. A selection bias may also be introduced, as individuals without a computer, access to the internet, or adequate computer literacy may not be able to participate (17).

Response rates to online surveys may be lower than paper-and-pen and interview modes as the quantity of spam and junk electronic mail is increasing leaving individuals less likely to open electronic mail from unknown senders (17). In studies comparing survey modes, both paper and online surveys may be preferable to telephone surveys (18), and paper preferred to online surveys (19). Furthermore, adding a pen-and-paper follow-up survey to those who did not respond to an electronic survey may increase response rate (20).

Despite generally lower preference, online information and interventions are being used by individuals with chronic pain. An estimated 24-63% of individuals with chronic pain report using the internet to access health information (21, 22). Pilot studies and trials of a variety of internet-based chronic pain interventions and assessment tools consistently report that participant satisfaction is high and the interventions are effective in reducing pain (23-27).
Thus, it is unknown whether postal or electronic chronic pain surveys administered in the
general Canadian public will return a higher response rate. The purpose of this pilot study was to
describe the feasibility of using postal and electronically mailed surveys to collect pain and self-
management data in a random sample of the Canadian population. Measures of feasibility will
included survey methodology issues (response rate, missing responses, preferred survey mode,
preferred survey language, and study costs), scores on pain screening items to inform sample size
decisions, and responses to primary outcome (self-management) and developed survey items to
determine whether the current tools and items are clear and appropriate to capture self-
management data.

Methods

An amendment was submitted for ethical review which included the addition of a pilot
study (ANAE-174-10) (appendix 4).

Survey methods.

One hundred names were randomly selected from telephone book listings by SM
Research, reflecting an estimated 80% of the general Canadian population across the 10
provinces. SM Research identified French households using surnames, which they estimate to
be at least 70% accurate in classifying households of French ethnicity. Potential participants
were randomly assigned a three-digit identification number to ensure privacy. Each of the 100
potential participants were contacted by telephone, given a brief outline of the study, and asked
whether they would be willing to receive the survey. Each potential participant was telephoned
at three different times: daytime on a week day, evening on a week day, and mid-afternoon on a
Saturday. If no contact was made after three attempts, then the potential participant was
recorded as unable to contact. If potential participants spoke only French, they were sent a French hardcopy survey due to the researcher not being fluent in French.

If an individual consented to receive a survey package, they were given the choice of receiving a mailed hardcopy version of the survey in French or English, or a link to the online survey, also available in both languages, provided they supplied an e-mail address. Both hardcopy and online surveys included a cover letter that explained the study purpose, protection of participant data, contact information, and an explanation of implied consent for returned surveys (appendices 4-6). The principle investigator’s (EG VanDenKerkhof) signature was stamped in blue ink on each cover letter. Mailed survey packages also included a stamped and addressed return envelope. The online survey was a forced-response format such that respondents were required to provide a response to each survey question on a given page before they were able to move forward to the next survey page.

If a survey was not returned three weeks after mailing or five days after e-mailing, a reminder telephone call was made. Two telephone reminders were made, and then a second mailed survey or e-mail with the survey link was sent. If a survey was not returned after these three contacts, the participant was considered lost to follow-up. All data was identified by the study identification code only, and entered into a password-protected database. Data collection occurred between September and October 2011.

**Pain screening items.**

Participants with pain were identified by one item which asked “Are you currently troubled by pain or discomfort, either all the time or on and off?” (appendix 7, item 1) (6). Those with pain were then asked, “Have you had this pain or discomfort for more than 3 months?” to screen for chronic pain (appendix 7, item 1) (6). A cut-off score of 12 on the Self-Report Leeds
Assessment of Neuropathic Symptoms and Signs Pain Scale (S-LANSS) was used to determine where a participant’s pain included NC where a higher score indicates a higher likelihood of neuropathic pain mechanisms (appendix 7, items 36-42) (28, 29).

**Primary outcome.**

The primary outcome was emotional and medical self-management strategies and instruments capturing this information was completed by participants who screened positive for chronic pain. Emotional self-management was captured using the 28-item Brief Cope (30, 31), which assesses the use of 14 different self-management strategies (appendix 7, items 60-87). Respondents were asked to indicate how frequently they used the given strategy to deal with the stress of living with chronic pain. Response options included “I haven’t been doing this at all,” “I’ve been doing this a little bit,” I’ve been doing this a medium amount,” and “I’ve been doing this a lot.” The two items that represent one strategy are summed with higher scores indicating more frequent use. Scores of 3/8 or higher indicate that a strategy is used at least ‘a little bit.’ Medical self-management was captured through one open-ended item from the Level of Expressed Need Scale (32) which asked “what treatments or prescriptions are you receiving for your pain?” (appendix 7, item 59).

**Items developed for this study.**

Responses were examined to two items developed for this study and were completed by participants who screened positive for chronic pain. First, one item asked which type of health professional was most helpful in pain management from a list of five common professions (e.g., family doctor, health care team) and an ‘other’ category (appendix 7, item 99). A second item asked participants to select all the variables that made managing their pain either easier or harder from a list of self-management barriers and facilitators that had been identified through
reviewing the literature (appendix 7, item 88). Respondents were also provided an ‘other’ option in which they could specify an additional variable that influenced their ability to self-manage. Responses to these two items were examined to assess whether the provided response options were appropriate or whether additional response options needed to be added (e.g., a new type option could be added to the list of providers if multiple respondents identified the same type of health care professional in the ‘other’ category).

Analysis.

Frequency and percent were used to describe the proportion of potential participants who (1) were unable to be contacted due to an error in their contact information, (2) were able to be reached by telephone and invited to participate, (3) consented to receive a survey, (4) accuracy of French designation in identifying participants preferring a French survey, (5) preference for, and response rates of, online and hardcopy surveys (number of surveys mailed or e-mailed/number of surveys returned), (6) missed responses to one or more survey items, and (7) consent to be contacted about future research opportunities. Survey costs are presented in Canadian dollars. Frequency and percent were also used to describe proportion of participants screening positive for chronic pain and NC, and frequency was used to describe which options participants selected on the items that captured the primary outcome and were developed for this survey. Data was analyzed using SPSS 21.0.

Results

Survey methodology.

Twelve of the telephone book listings of potential participants contained an error, leaving 88 eligible individuals (figure A8.1). Fifty-two potential participants (52/88=59%) were contacted by telephone, and 32 of these individuals (32/52=62%) consented to receive a survey.
When asked which survey format they would prefer, seven participants (7/32=22%) requested a hardcopy survey, nine participants (9/32=28%) requested an online survey, and 16 were automatically sent a French survey (see below) (16/32=50%).

Twenty of the potential participants (20/100=20%) were identified as French by SM Research, and 16 of these had working telephone numbers (16/88=18%). Three of these French potential participants were not successfully contacted by telephone (3/16=19%). Of the 13 potential participants identified as French and reached by telephone, 10 individuals reported that they only spoke French (10/13=77%), two spoke a little English but preferred French (2/13=15%) and one individual spoke and preferred English (1/13=8%). An additional six potential participants spoke only French but had not been identified as such by their surnames (6/52=12%). All French-speaking potential participants resided in Quebec. The 16 potential participants that spoke only French were automatically mailed a French survey.

Three of the hardcopy surveys (3/23=13%) were returned marked as ‘return to sender.’ Two of the returned surveys were returned due to an error in the telephone book listing; one potential participant spoke only French so the address could not be corrected, and the other potential participant could not be reached by telephone to correct the address. One survey was returned as undeliverable; when this participant was contacted, he confirmed that the address was correct but reported issues with receiving postal mail due to his remotely located residence (e.g., only city, province, and postal code in address).

Three hardcopy surveys (3/23=13%) were returned with a refusal to participate, 12 hardcopy surveys (12/23=52%) were never returned, and five hardcopy surveys (5/23=22%) were returned completed. Two of the completed hardcopy surveys (2/5=40%) were returned by French-speaking participants (e.g., those who were automatically sent a French survey after
determining that they did not speak English). Three of the completed surveys (3/5=60%) were returned after the initial mailing, and two more (2/5=40%) were returned after a follow-up telephone call was made three weeks after the initial mailing. Two of the completed and returned hardcopy surveys (2/5=40%) were missing two responses on the Health Care Utilization & Medication Use Questionnaire and one (1/5=20%) was missing a response to the pain screening asking about pain duration. No one who completed the hardcopy survey consented to being contacted about future research.

All participants requesting the online survey visited the survey link and selected the English version. Two participants (2/9=22%) went to the online survey link and refused to participate, and seven participants (7/9=78%) completed the online surveys. Three of the completed online surveys (3/7=43%) were accessed after the participant received the initial e-mail, three more (3/7=43%) were accessed after a follow-up telephone call was made five days after the initial e-mail was sent, and one more online survey (1/7=14%) was accessed after a second e-mail with the survey link was sent. As the online survey would not allow a participant to proceed to the next survey page if there was a missing response, all online survey datasets were complete. Six participants (6/7=86%) who completed the online survey consented to hearing about future research opportunities.

Overall, 12 surveys were returned completed, representing 38% (12/32=38%) of individuals who consented to receive the survey, 23% (12/52=23%) of individuals who were contacted by telephone, and 14% (12/88=14%) of all eligible potential participants. Five (5/12=42%) of the completed surveys were hardcopy surveys and seven (7/12=58%) were online surveys. Six the completed surveys (6/12=50%) were returned after the initial mailing, an
additional five surveys (5/12=42%) were returned after one follow-up contact, and 1 survey (1/12=8%) was returned after a second follow-up contact.

Because the survey was made available online at no cost through Queen’s University, telephone costs, which were incurred by both the online and hardcopy survey groups, were the only expense for the online survey. In addition to telephone costs, the hardcopy surveys included costs for printing, mailing supplies, and postage. Printing costs were $0.68, mailing supplies (labels and envelopes) were $0.08, and postage was $4.12 ($2.06 for items weighing 100-200 grams, thus $2.06 for each of the 10”x13” survey package weighing 125 grams and 9”x12” return package weighing 102 grams) for a total cost of $4.88 per package.

**Pain screening items.**

Pain or discomfort was reported on two hardcopy surveys and two online surveys, representing 33% (4/12=33) of participants. This pain had persisted for at least three months for two individuals (2/4=50%), less than three months for one individual (1/4=25%), and for an unknown duration for one participant (response missing) (1/4=25%). Pain intensity ratings provided on a numeric rating scale ranged from three to seven out of 10. Scores on the S-LANSS ranged from three to eight out of 24, indicating that all four respondents did not have pain with neuropathic characteristics.

**Primary outcome.**

All scales had at least one participant score ≥3/8 indicating that all emotional self-management strategies were used at least ‘a little bit’ by one participant. All participants had a score ≥3/8 on at least one emotional self-management strategy. Responses to the item asking about treatments or medications for pain varied and included drug classes (e.g., “inflammatory
pills”), drug trade names (e.g., “Advil”), and non-pharmaceutical interventions (e.g., “acupuncture”).

**Items developed for this survey.**

Family doctors were identified as the most helpful health professional in pain management by three participants, specialists were identified by two participants, and an ‘other’ professional was identified by one participant (two participants selected more than one professional despite being asked to identify one from the list). Participants selected between one and three self-management barriers/facilitators from the nine provided. Support from family and/or friends, self-confidence in ability to manage pain, access to health care services, and relationship with healthcare provider(s) were each selected by at least one participant.

**Larger Study Implications and Recommended Changes**

**Larger study methods.**

The results of this pilot study suggest that contacting potential participants by telephone is difficult regardless of day and time of contact. While fewer participants preferred the hardcopy survey, use of this format avoided the need for telephone contact and avoided language difficulties. In addition to being preferred by more participants, online surveys had the advantages of being less costly to administer, more likely to be returned, and more likely to gain participants’ consent to be contacted about future research opportunities. The online surveys also had complete datasets due to the forced response, however, this may have led to falsified responses if there were questions that the participants did not want to answer. Despite these potential advantages, the online survey required telephone contact with potential participants in order to gather e-mail addresses, and making telephone contact proved to be challenging and resulted in almost half of potential participants being unable to be contacted about participating.
in this study. Based on these results, a hardcopy survey with an online option removes the challenge of making telephone contact and may appeal to potential participants while still allowing for the advantages of online data collection.

All participants residing in Quebec, and all but one participant identified as French by surname, requested a French survey or spoke only French. Consequently, French surveys may need to be sent to not only those identified as French by surname, but also all potential participants residing in Quebec. Including both English and French versions of the cover letter will allow for potential participants to contact the researchers to request a survey in the alternate language and access the online survey available in both languages.

Due to Canada Post’s weight categories, the costs of distributing this hardcopy survey could be reduced. Decreasing the weights of the survey package by 26 grams and the return package by 5 grams would put both survey packages in a lower weight category, reducing the postage costs by 51.6% for a total savings of $2.52 per potential participant.

Assuming that the pilot sample was representative, sampling 8,000 Canadians (as per the main study proposal) with the same methodology will result in 240 invalid addresses (3/100 * 8000) and 960 surveys completed and returned (12/100 * 8000). Approximately 320 (4/12 * 960) participants will screen positive for any pain and 160 (2/4 * 320) for chronic pain. Using estimates from prior research, in the absence of any participants with NC in the pilot sample, a group of 160 individuals with chronic pain should include between 27 (17/100 * 160) and 82 (51/100 * 160) individuals with NC based on prevalence reported in studies (6-8, 13).

**Pain screening items, primary outcome, and items developed for this survey.**

The screening questions identified a subset of individuals with chronic pain, although the sample did not include anyone with chronic pain with NC. The tools used to capture self-
management seemed appropriate as evidenced by participants reporting some use of all emotional self-management strategies and the inclusion of both pharmaceutical and non-pharmaceutical medical strategies. Due to variability in how medications are reported (e.g., drug classes versus specific drug names), responses may need to be organized into general categories (e.g., prescription medication, anti-inflammatory medication). In the two items developed for this survey, participants selected both the health care provider most helpful with pain management and self-management barriers and facilitators from the lists provided with rare use of the ‘other’ option, thus no additional response options need to be added. The barriers and facilitators that were not selected from the list may indicate that these variables do not reflect the current experience of Canadians with chronic pain or the sample may have been too small to include individuals experiencing these barriers and facilitators (e.g., those with neuropathic characteristics).

**Conclusion**

Researchers using survey methodologies need to consider accessibility to, advantages and challenges of, and preferences for the various modes of contacting potential participants. The increasing use of cellular phones, caller display, and the internet necessitate changes to survey methodologies. Online surveys may be increasing in popularity as well as becoming more feasible as national e-mail databases are developed for census purposes.

Based on the results of this pilot study, the following changes were made to the larger survey study: (1) only telephone book listings with addresses that were considered deliverable by Canada Post were included in the pool from which the 8,000 potential participants were drawn, (2) the need for telephone contact was removed by sending all potential participants a hardcopy survey, (3) the survey paper weight was reduced to lower postage costs, (4) a link to
the online survey was included on the hardcopy survey and in the cover letter, (5) all potential participants living in Quebec and those identified as French by surname were sent a French survey and cover letters were printed double-sided to allow for both French and English to be sent to each potential participant, and (6) one follow-up contact was made to increase the total response rate.
References


Figure A8.1. Flow of participants through pilot study

Potential participants n=100

Ineligible n=12
(Wrong number n=6
Number not in service
n=6)

No contact made n=36
(answering machine
or no answer)

Refused participation n=20

Telephone contact made n=52

Consented to receive survey n=16
French-speaking only and automatically sent survey n=16

Requested hardcopy n=7
Sent French hardcopy n=16

Requested online n=9

Refused n=3
Return to sender n=3
Lost to follow-up n=12

Returned n=5
Initial mailing n=3
Follow-up call n=2
Second mailing n=0

Returned n=7
Initial email n=3
Follow-up call n=3
Second email n=1

Refused n=2
Lost to follow-up n=0
Appendix 9. Overview of the Main Study Methods and Additions of the Current Study

Appendix Overview & Purpose

The current study was embedded in a larger Pfizer-funded survey on the epidemiology of pain with neuropathic characteristics in Canada (PI: EG VanDenKerkhof) (1). Additional instruments and items were added to the epidemiological survey to address the research objectives of this thesis followed by a pilot test of the survey booklet and process of data collection. An ethics amendment was submitted to revise the cover letter to include the additional study objectives and include the additional questionnaires, online option, and pilot study (ANAE-174-10) (appendix 4). Thus, there is a main study (epidemiology paper), pilot study, and two self-management studies that analyzed data included in the study survey. As details of the methods are already published in the main paper, the purpose of this appendix is to provide additional methodological information. Specifically, this appendix outlines (1) development of the study survey and additions made specific to the objectives of this dissertation and (2) methods published in the main study.

Survey Development and Additions

Added instruments.

The main study already included screening tools for chronic pain and neuropathic characteristics, various pain measurement tools, medical self-management, satisfaction, general health, and sociodemographic items. Additional medical and emotional self-management and barrier and facilitator questionnaires were added for this thesis (table A9.1). As there are no specific instruments or commonly used means of capturing self-management strategies, Kate Lorig’s definitions of medical and emotional self-management were used to select instruments which captured these constructs (2).
Translation.

English and French versions of the survey were included in this study. Instruments which had been translated into French for use in prior research included the Self-Report Leeds Assessment of Neuropathic Symptoms and Signs Pain Scale and Brief COPE. Translations for the survey booklet included the cover letter; chronic pain screening questions; pain, general health, and sociodemographic characteristics; Health Care Utilization & Medication Use Questionnaire; Level of Expressed Need scale; Pain Self-Efficacy Questionnaire; Chronic Illness Resources Survey; and two additional items asking respondents to identify the discipline of their most helpful health professional and to select from a list all factors that made pain management easier or harder for them. Instruments were translated by a Québécois French-speaking student at Queen's University. After translation, they were piloted by three French-speaking health professionals and three lay individuals.

Online option.

Surveys were made available online using StudentVoice! which is a web-based questionnaire tool supported by Queen’s University at the time of the study. Both pilot and main study participants were provided with a link to the study survey and their personal identification code. If participants opted to visit the study link, they were asked whether they would prefer to continue in French or English. After selecting their preferred language, they were asked to enter their study identification code and proceed through the survey questions. All items were forced-response with the exception of the potentially sensitive sociodemographic questions of household income and ethnic origin.
Pilot study.

A pilot study was conducted between September and October of 2011 (appendix 8). The main results of the pilot study were as follows: (1) all of the participants living in Quebec reported that they did not speak English, (2) the hardcopy survey was preferred to the online format by the majority of participants, (3) reducing the mailed survey weight by two grams would put the survey package into a lower postage bracket. Based on this, it was decided that a hardcopy version of the survey would be sent to all potential participants with the online link and login included for those that preferred an online format. The date on the cover letter was updated to November 2011 to reflect the new mailing date, a sentence requesting that the household member aged 18 years or older with the next birthday complete the survey, and a scanned signature was added (appendix 5). Due to variability in preferred language, cover letters were printed with French on one side and English on the reverse.

Main Study Methods

Design, sample, and recruitment.

A list of 8,000 potential participants was generated by SM Research using the same method as the pilot study but with the pilot study participants removed from the pool. Data collection occurred between November 2011 and September 2012. Potential participants were randomly assigned a four-digit study identification code with the first two characters of their postal code added at the end. These last two characters were used in the event that two online datasets had been entered with the same participant identification code. A package containing the cover letter, return envelope, and survey was mailed to each potential participant, with the link to the online survey listed on both the cover letter and survey. Participants were instructed to use the six-character study identification code listed on the front of the survey as their login.
French surveys were sent to potential participants identified as having French surnames by SM Research (estimated to be over 70% accurate) and all Quebec residents. Fifteen additional surveys were mailed upon request to family members or friends of the original potential participants for a total of 8,015 surveys (figure A9.1).

A follow-up survey was mailed to non-respondents in May 2012 after the number of returned surveys dropped to less than 25 per week. The cover letter was updated to reflect the new date, and included a sentence about retrieving addresses from telephone books as this was a common question received after the initial mail-out (appendix 6).

**Data: entry, quality, and handling of missing data.**

Survey data was entered into a spreadsheet by the researcher and three trained research assistants. Once the final survey was entered, a quality check was conducted using the methodology suggested by King and Lashley where, at a minimum, every tenth survey was checked for data entry. If a survey was entered correctly, then nine more surveys would be skipped and the tenth checked; this process would continue until an entry error was found. If an item in the survey was entered incorrectly, then every survey would be checked until ten consecutive error-free surveys were reviewed (3). Once the quality check was completed, online survey data was downloaded into a file and merged with the manually-entered data.

Eighty-two participants were missing at least one item on the S-LANSS and thus could not be assigned to a pain group. Survey studies using the S-LANSS were reviewed and the authors contacted about how they addressed missing items. It was decided to examine each of the missing responses to determine whether the missing response would change whether the total score was above or below 12 and thus change group assignment. Using this technique, 42 participants were included in study analyses as inclusion of either response to the missing item
did not change group assignment, and 40 participants’ missing responses were necessary to determine group assignment and were excluded (figure A9.1).

Seventy-five participants were missing a response to the first screening question (“are you currently troubled by pain or discomfort either, all the time or on and off”) but indicated pain on the body diagram and a rating of intensity on the numeric rating scale. These participants were considered to have pain despite the missing response. All other missing responses were left as blank cells.

Some participants indicated two or more pain intensities on the numeric rating scale. To ensure a conservative estimate of average pain intensity over the past week, the lowest pain intensity was recorded in the database.
References


Figure A9.1. Summary of participant recruitment and group assignment

- 8,015 Surveys Mailed
- 2,615 Surveys Returned
  - 866 Returned to Sender
  - 4,541 Surveys Missing
  - 1,095 Refused
- 1,520 Surveys Completed
  - 554 Reported No Pain
  - 163 Missing Response for Pain Duration
  - 53 Reported Acute Pain (pain < 3 months)
  - 40 Missing Responses (unable to classify)
- 966 Reported Pain
  - 188 Pain with Neuropathic Characteristics (S-LANSS* = 12+)
  - 522 Pain without Neuropathic Characteristics (S-LANSS* < 12)
- 750 Reported Chronic Pain (pain > 3 months)

*Self-Report Leeds Assessment of Neuropathic Symptoms and Signs

a raw response rate = 2,615/8,015 = 32.6%  adjusted for listing error = 2,615/7,149 = 36.6%
b raw completion rate = 1,520/8,015 = 19.0%  adjusted completion rate = 1,520/7,149 = 21.3%
c proportion of respondents with pain = 966/1,520 = 63.6%
d proportion of respondents with chronic pain = 750/966 = 77.6%
e proportion of respondents with chronic pain with neuropathic characteristics = 188/710 = 26.5%
f proportion of respondents with chronic pain without neuropathic characteristics = 522/710 = 73.5%
Table A9.1. Overview of variables, items, and instruments.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Included in Main Study</th>
<th>Added Questionnaires</th>
<th>Chapter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case identification</td>
<td>- pain and chronicity items</td>
<td>- one item to identify the type of health professional most helpful in pain management: &quot;which health professional(s) do you feel is the most helpful in managing your pain?&quot;</td>
<td>4 &amp; 5</td>
</tr>
<tr>
<td></td>
<td>- Self-Report Leeds Assessment of Neuropathic Symptoms and Signs Scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain description</td>
<td>- body diagram</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>- timing</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- pain intensity numeric rating scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- list of diagnoses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical self-management</td>
<td>- Level of Expressed Need scale</td>
<td>- one item to identify the type of health professional most helpful in pain management: &quot;which health professional(s) do you feel is the most helpful in managing your pain?&quot;</td>
<td>4 &amp; 5</td>
</tr>
<tr>
<td></td>
<td>- Health Care Utilization &amp; Medication Use Questionnaire (5 visit items)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional self-management</td>
<td>- Brief COPE</td>
<td></td>
<td>4 &amp; 5</td>
</tr>
<tr>
<td>Satisfaction with ability to control</td>
<td>- Health Care Utilization &amp; Medication Use Questionnaire (satisfaction item)</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>pain</td>
<td>Self-management barriers and facilitators</td>
<td>- Pain Self-Efficacy Questionnaire</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>- 11-Point Numeric Rating Scale for pain intensity</td>
<td>- Patient Health Questionnaire 9-Item Scale</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Chronic Illness Resources Survey – family and friend, and doctor and health care team scales</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- one item asking “from the list below, please select any of the things you feel have made managing your chronic pain either easier or harder (select all that apply)”</td>
<td></td>
</tr>
<tr>
<td>General health</td>
<td>- Health Care Utilization &amp; Medication Use Questionnaire (health interference item)</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td>Socio-demographic information</td>
<td>-sex, age, marital status, education, employment, residence, household income, and ethnicity</td>
<td>4 &amp; 5</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 10. Overview of Studies Reviewed to Identify Self-Management Barriers and Facilitators

Appendix Overview & Purpose

The following appendix outlines the methods used to identify barriers and facilitators of chronic pain self-management for inclusion in the study survey. Thus, the purpose of this appendix is to (1) describe the search strategy, and (2) outline the search results in detail.

Search Strategy

To identify factors that influence self-management behaviour, a broad review was conducted in CINAHL and MEDLINE in April 2011. Initially, a search was conducted for models of chronic pain self-management using the search terms “self-management (keyword),” “self-care,” “chronic pain,” and “models, theoretical,” however no models were identified. Thus the search strategy was revised to include “chronic disease” and exclude “chronic pain.” Results were limited to studies using human participants and available in English. The results of this review are presented in table A10.1.

To identify additional factors specific to individuals with chronic pain, all abstracts reviewed for chapter 3 were also reviewed for analysis or report of factors affecting self-management. Both qualitative and quantitative studies published in 2000 or more recently were included. The results of this search are presented in table A10.2.

The factors identified in both of these reviews were analyzed for commonly identified factors influencing self-management behaviour, and instruments measuring these factors were added to the study survey (table A10.3). A list of the most commonly identified factors was also added and participants were asked to indicate all factors that made it easier or hard to manage.
their pain to explore whether these variables reflect the self-management experience of Canadians with chronic pain (table A10.3).
References


### Tables

Table A10.1. Summary of risk and protective factors for self-management identified in self-management models for chronic disease.

<table>
<thead>
<tr>
<th>Source</th>
<th>Modifiable Barriers and/or Facilitators</th>
<th>Process Factors</th>
<th>Unmodifiable Barriers and/or Facilitators</th>
</tr>
</thead>
</table>
| Self and Family Self Management Framework (1) | -Depression  
-Self-efficacy  
-Integration  
-Family function  
-Supportive social networks  
-Supportive community  
-Access to health care system | N/A | -Severity of illness  
-Complexity of regimen  
-Trajectory  
-Genetics  
-Age  
-Gender  
-Diversity  
-Socioeconomic status |
| Individual and Family Self Management Theory (2) | -Access to care  
-Setting/provider transition  
-Transportation  
-Perspective  
-Literacy | -Self-efficacy  
-Outcome expectancy  
-Goal congruence  
-Goal-setting  
-Self-monitoring and reflective thinking  
-Decision-making  
-Planning and action  
-Self-evaluation  
-Emotional control  
-Social influence, support, and collaboration | -Complexity of condition  
-Complexity of treatment  
-Trajectory  
-Culture  
-Social capital  
-Developmental stage  
-Information processing  
-Capabilities |
| Problem-Solving Model of Chronic Disease Self-Management (3) | -problem-solving approach  
-transfer of past experience  
-problem-solving perspective  
-disease-specific knowledge | -disease problem-solving | N/A |
| Home-Based Chronic Care Improvement (4) | -Health literacy  
-Self-efficacy  
-Depression | N/A | N/A |
| Motivational Model of Pain Self-Management (5, 6) | -Perceived importance (beliefs regarding cost/benefit ratio, learning history, current contingencies) | -readiness to change | N/A |
- Self-efficacy
  (personal experience, modeling, verbal persuasion, perceived barriers)
Table A10.2. Summary of barriers and facilitators of self-management identified in reviews or studies of self-management in chronic diseases.

<table>
<thead>
<tr>
<th>Source</th>
<th>Study Overview</th>
<th>Barriers and Facilitators</th>
</tr>
</thead>
</table>
| Matthias, et al, 2010 (7) | **Design**: qualitative study comparing patient communication between nurse care managers and physicians  
**Pain group**: MSK pain  
**Participant pool**: participants registered in a primary care self-management and depression intervention  
\( n = 18 \) | -relationship and support from health care provider |
| Cooper, Smith, & Hancock, 2009 (8) | **Design**: qualitative study on supporting long-term self-management after physiotherapy  
**Pain group**: chronic low back pain  
**Participant pool**: receiving physiotherapy at a primary care centre  
\( n = 25 \) | -follow-up support from health care provider |
| Bair, et al, 2009 (9) | **Design**: qualitative study on barriers and facilitators of self-management  
**Pain group**: MSK pain and depression  
**Participant pool**: receiving care through Veteran Affairs, recruited after participation in a self-management trial  
\( n = 18 \) | **Barriers**:  
- lack of support from friends and family  
- limited resources  
- depression  
- ineffectiveness of pain-relief strategies  
- time constraints and other life priorities  
- fear of pain exacerbation  
- lack of tailoring of strategies to personal needs  
- inability to maintain strategies after study completion  
- physical limitations  
- difficult patient-physician interactions  
**Facilitators**:  
- encouragement from nurse care managers  
- improved depressive symptoms  
- supportive family and friends  
- provision of a menu of different self-management strategies to use |
| Krein, et al 2005 (10) | **Design**: cross-sectional study of correlates of difficulty with self-management  
**Pain group**: chronic pain with diabetes | -pain intensity  
- depression  
- general health |
| Participant pool: patients receiving care through Department of Veteran Affairs | Glenn & Burns, et al, 2003, 2005 (11, 12) | Design: longitudinal study following individuals through an intervention  
**Pain group:** MSK pain  
**Participant pool:** receiving care at a multidisciplinary pain clinic  
*n = 993* |
|---|---|---|
| **Design:** longitudinal study on predictors of readiness to self-manage pain  
**Pain group:** individuals with chronic pain  
**Participant pool:** attending a multidisciplinary pain clinic  
*n = 65* | Hadjistavropoulos & Shymkiw, 2007 (13) | -pain severity  
-depression  
-self-efficacy  
-pain-related anxiety  
-physician information  
-self-efficacy  
-perceived internal or other control |
| **Design:** longitudinal study following participants through an interventional course on pain and fatigue self-management  
**Pain group:** individuals with cancer, pain and fatigue  
**Participant pool:** receiving care at one of two cancer centres  
*n = 214* | Kurtz, et al, 2008 (14) | -age  
-co-morbidities  
-skill mastery  
-optimism |
| **Design:** cohort study following participants through a self-management intervention to study the predictive ability of the Pain Stages of Change Questionnaire  
**Pain group:** general chronic pain  
**Participant pool:** attending a private rehabilitation centre  
*n = 107* | Strong, et al, 2002 (15) | -self-efficacy  
-stage of change |
Table A10.3. Overview of selected barriers and facilitators, and the instruments used to capture them in the study survey

<table>
<thead>
<tr>
<th>Barrier/Facilitator</th>
<th>Instrument</th>
<th>Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-efficacy</td>
<td>Pain Self-Efficacy Questionnaire</td>
<td>- all 10 items were used</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- added to list of most commonly identified barriers and facilitators: “self-confidence in your ability to manage your pain”</td>
</tr>
<tr>
<td>Depression</td>
<td>Patient Health Questionnaire 9-Item Scale</td>
<td>- all 9 items were used</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- added to list of most commonly identified barriers and facilitators: “depression or feeling down”</td>
</tr>
<tr>
<td>Family/friend support</td>
<td>Chronic Illness Resources Survey</td>
<td>- 2 items were selected for use based on how family/friend support was described in the reviewed studies: (1) listening about condition and (2) encouraging respondent to do self-management tasks</td>
</tr>
<tr>
<td></td>
<td>– family and friend scale</td>
<td>- added to list of most commonly identified barriers and facilitators: “support from family and/or friends”</td>
</tr>
<tr>
<td>Relationship with health care provider(s)</td>
<td>Chronic Illness Resources Survey</td>
<td>- 4 items were selected for use based on the aspects of the relationship identified in the reviewed studies: (1) inclusion in making treatment decisions and setting treatment goals, (2) explaining specific self-management strategies, (3) answering questions, and (4) listening to what the respondent had to say about his/her condition</td>
</tr>
<tr>
<td></td>
<td>– doctor and health care team scale</td>
<td>- added to list of most commonly identified barriers and facilitators: “relationship with your health care provider(s)”</td>
</tr>
<tr>
<td>Pain intensity</td>
<td>11-Point Numeric Rating Scale</td>
<td>- 1 item asking about pain in the past week</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- added to list of most commonly identified barriers and facilitators: “intensity of your pain”</td>
</tr>
<tr>
<td>Access to health services</td>
<td>-</td>
<td>- added to list of most commonly identified barriers and facilitators: “access to health care services”</td>
</tr>
<tr>
<td>Health literacy</td>
<td>-</td>
<td>- added to list of most commonly identified barriers and facilitators: “your ability to read and/or understand health information”</td>
</tr>
<tr>
<td>Fear of exacerbating pain</td>
<td>-</td>
<td>- added to list of most commonly identified barriers and facilitators: “fear of making your pain worse”</td>
</tr>
</tbody>
</table>