PERCEPTIONS, EXPERIENCES AND MANAGEMENT OF KNEE SYMPTOMS IN ADULTS AGE 35-65 YEARS – A QUALITATIVE STUDY

by

Crystal Jeanne MacKay

A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Institute of Medical Science
University of Toronto

© Copyright by Crystal Jeanne MacKay 2016
Perceptions, Experiences and Management of Knee Symptoms in Adults age 35-65 Years – A Qualitative Study

Crystal Jeanne MacKay
Doctor of Philosophy
Institute of Medical Science
University of Toronto
2016

Abstract

Background: Osteoarthritis (OA) is a highly prevalent and costly chronic condition which can begin as early as the third or fourth decade of life. To date, interventions have focused on older adults. There is an urgent need to focus on younger adults with OA symptoms to improve management and potentially limit progression of OA. However, there is an inadequate understanding of the perceptions, experiences and management of younger adults to begin to develop interventions which address peoples’ needs earlier in life.

Objectives: To explore, in adults aged 35-65 years with knees symptoms: 1) the meaning of knee symptoms to people; 2) how people manage knee symptoms; and 3) the consequences of knee symptoms on peoples’ lives.

Methods: Six focus groups and 10 one-on-one interviews were conducted with 51 participants (median age 49; 61% female) who self-reported knee OA or reported knee symptoms (i.e. pain, aching or stiffness) on most days of the past month. Constructivist grounded theory guided sampling, data collection and analysis. Data
were analyzed using a constant comparative method, in which comparisons constituted each stage of analysis.

**Results:** Central to participants' understanding of their knee symptoms was a perception that symptoms were preventable, meaning there was the potential to prevent the onset of symptoms and to alter the course of symptoms. Their approach to management was not linear, but rather, a process that moved back and forth between searching for “solutions” and active management (ongoing use of strategies). During the process, participants consulted health care providers but often perceived that medical care offered limited options and guidance. Participants experienced a range of disruptions and changes in their lives due to knee symptoms. They described the consequences of symptoms on their physical activity, social life and emotions. Participants reported a new awareness of their knee, a lack of trust in their knee and that their sense of self was altered.

**Conclusions:** This study provides new insights into the perceptions and experiences of adults age 35-65 years with knee symptoms. Findings have implications for the development of health policies and interventions to support primary and secondary prevention of knee symptoms.
Acknowledgements

There are numerous people who have been instrumental to the completion of my doctoral thesis. First, I would like to thank my supervisor, Dr. Aileen Davis, for her continuous support, encouragement and mentorship throughout this journey. I am forever grateful to you for generously sharing your expertise and insights, for your time and patience reviewing my work and for the many opportunities you afforded me. I would also like to thank my program advisory committee members, Dr. Elizabeth Badley, Dr. Susan Jaglal and Dr. Joanna Sale for your ongoing guidance and support throughout my training and your invaluable comments during the preparation of this thesis. I feel very fortunate to have an advisory committee with such a wealth of experience and expertise.

I would like to express a special thank you to the 51 study participants who generously shared their personal experiences and time with me for this study.

I have been tremendously fortunate to work with a wonderful group of colleagues at Toronto Western Research Institute over the years. I’d like to express a particular thank you to Samantha Bremner for assisting me in conducting the focus groups.

This work would not have been possible without the support of my family. To my parents-in-law, John and Elaine Ito, thank you for taking such an interest in my research, for your ongoing encouragement and for all of your assistance (the last minute babysitting and meal preparation you provided over the years did not go unnoticed!). To my sister, Shelly, and brother, John, thank you for your ongoing support and friendship. To my mother, Joyce MacKay, thank you for believing in me, for always being there for me and for all the child care support you provided along the way. I thank you and my late father, Sinclair MacKay, for fostering a love of learning, instilling in us the value of hard work and for your unconditional love. To my sons, Garrett and Griffin (who undoubtedly made this journey longer than I expected), you are a continuous source of joy and inspiration and I am grateful for the laughter you bring to my days.
Finally, I would like to thank my husband, Shawn, for his endless love and support, for his patience, for encouraging me when I needed it and for always believing in me.

I gratefully acknowledge the financial support from an Ontario Graduate Scholarship and a Canadian Institutes of Health Research Fellowship.
Contributions

Crystal MacKay (author) solely prepared this thesis. All aspects of this body of work, including the planning, execution, analysis, and writing of all original research and publications was performed in whole or in part by the author. The following contributions by other individuals are formally acknowledged:

Dr. Aileen Davis (supervisor) provided overall mentorship and provided guidance and assistance in: planning and executing the study, the analysis and interpretation of the data, and the preparation of the manuscripts and thesis.

Dr. Elizabeth Badley (program advisory committee member) provided mentorship and provided guidance and assistance in: planning and executing the study, the analysis and interpretation of the data, and the preparation of the manuscripts and thesis.

Dr. Susan Jaglal (program advisory committee member) provided mentorship and provided guidance and assistance in: planning and executing the study, the analysis and interpretation of the data, and the preparation of the manuscripts and thesis.

Dr. Joanna Sale (program advisory committee member) provided mentorship and provided guidance and assistance in: planning and executing the study, the analysis and interpretation of the data, and the preparation of the manuscripts and thesis.

Samantha Bremner provided assistance conducting the focus groups.
## Table of Contents

Abstract......................................................................................................................... ii  
Acknowledgments........................................................................................................ iv  
Contributions................................................................................................................ vi  
Table of Contents......................................................................................................... vii  
List of Tables................................................................................................................ xiii  
List of Figures............................................................................................................... xiv  
List of Appendices........................................................................................................ xv  
List of Abbreviations..................................................................................................... xiv  

Chapter 1: Introduction.................................................................................................... 1  

Chapter 2: Background and Literature Review............................................................. 5  
  2.1 Chapter Overview...................................................................................................... 6  
  2.2 What is OA? ........................................................................................................... 6  
  2.3 Epidemiology and Burden of OA........................................................................... 7  
  2.4 Risk Factors for OA............................................................................................... 10  
      2.4.1 Non-Modifiable Risk Factors ....................................................................... 10  
      2.4.2. Modifiable Risk Factors ............................................................................. 10  
          2.4.2.1 Obesity ................................................................................................. 16  
          2.4.2.2 Occupation ......................................................................................... 16  
          2.4.2.3 Physical Activity/Exercise .................................................................. 17
Chapter 3: Overview of Methods ................................................................. 46

3.1 Chapter Overview ................................................................. 47
3.2 Research Design ................................................................. 47
3.3 Theoretical Perspective ........................................................... 47
3.4 Grounded Theory Method ......................................................... 47
3.5 Positionality ........................................................................... 48
3.6 Approach to Data Collection ...................................................... 49

Chapter 4: A Qualitative Study Exploring the Meaning of Knee Symptoms to Adults Aged 35-65 Years ......................................................... 51

4.1 Chapter Overview ................................................................. 52
4.2 Introduction ............................................................................ 52
4.3 Methods .................................................................................. 53
  4.3.1 Study Design ...................................................................... 53
  4.3.2 Sampling and Data Collection .............................................. 53
  4.3.3 Analysis ............................................................................. 56
4.4 Results .................................................................................... 57
  4.4.1 Core Category: Knee Symptoms are Preventable ............... 61
    4.4.1.1 Explanation of Symptoms ............................................ 62
    4.4.1.2 Experience with Symptoms ........................................ 65
4.5 Discussion .............................................................................. 66
4.6 Conclusion .............................................................................. 69
Chapter 5: “We’re All Looking for Solutions”: A Qualitative Study of the Management of Knee Symptoms ................................................................. 70
  5.1 Chapter Overview................................................................................. 71
  5.2 Introduction......................................................................................... 71
  5.3 Methods.............................................................................................. 72
    5.3.1 Study Design.................................................................................. 72
    5.3.2 Sampling and Data Collection....................................................... 73
    5.3.3 Analysis......................................................................................... 75
  5.4 Results................................................................................................ 75
    5.4.1 Core Category: Taking Action on Knee Symptoms................. 82
      5.4.1.1 Control of Symptoms............................................................... 83
      5.4.1.2 Seeking Solutions.................................................................. 84
      5.4.1.3 Active Management............................................................... 86
  5.5 Discussion......................................................................................... 87
  5.6 Conclusion....................................................................................... 90

Chapter 6: A Qualitative Study of the Consequences of Knee Symptoms: “It’s like you’re an athlete and you go to a couch potato.” ................................................................................................................. 92
  6.1 Chapter Overview................................................................................. 93
  6.2 Introduction....................................................................................... 93
  6.3 Methods............................................................................................ 95
    6.3.1 Study Design................................................................................ 95
    6.3.2 Sampling and Data Collection.................................................. 95
7.5.3 Prevention ................................................................. 137
7.5.4 Self-Management Interventions ................................. 138
7.5.5 Health Care Support for People with Knee Symptoms..... 139
7.5.6 Community-Based Interventions ................................. 140
7.5.7 Targeting Younger Adults with Knee Symptoms ........... 141
7.5.8 Monitoring and Evaluation ......................................... 142
7.5.9 Summary ................................................................. 142
7.6 Knowledge Translation .................................................. 142
7.7 Strengths and Limitations .............................................. 147
7.8 Future Directions ........................................................ 147
  7.8.1 The Perspectives of People Living with Knee Symptoms .... 147
  7.8.2 Clinical Research ...................................................... 148
  7.8.3 Epidemiological Studies ............................................ 149
  7.8.4 Implications for Theory Development ........................ 151
  7.8.5 Summary ............................................................... 151
7.9 Conclusion .................................................................... 152

References ........................................................................ 153
List of Tables

Table 2.1  Summary of Systematic Reviews and Meta-analysis
Examining Modifiable Risk Factors of OA .......................... 12
Table 2.2  Summary of Systematic Reviews and Meta-analysis of
Management Strategies for OA ........................................... 21
Table 4.1  Question Guides: Focus Groups and Interviews ........... 55
Table 4.2  Participant Demographics ........................................ 58
Table 4.3  Knee Symptoms and Function .................................... 59
Table 4.4  Illustrative Quotes by Category:
The Meaning of Knee Symptoms ....................................... 59
Table 5.1  Question Guide: Focus Groups ................................... 74
Table 5.2  Participant Demographics ........................................ 76
Table 5.3  Knee Symptoms and Function .................................... 77
Table 5.4  Illustrative Quotes by Category:
Taking Action on Knee Symptoms ..................................... 77
Table 6.1  Question Guides: Focus Groups and Interviews .......... 97
Table 6.2  Participant Demographics ........................................ 100
Table 6.3  Knee Symptoms and Function .................................... 101
Table 6.4  Illustrative Quotes by Category:
Consequences of Knee Symptoms ..................................... 101
Table 7.1  Knowledge Translation Key Messages ......................... 144
List of Figures

Figure 4.1  Core Category: Knee Symptoms are Preventable………………… 62
Figure 5.1  Core Category: Taking Action on Knee Symptoms……………… 83
Figure 6.1  Core Category: Disruption and Change……………………….. 104
List of Appendices

Appendix A. Telephone Script (Focus Groups)................................. 184
Appendix B. Telephone Script (Interviews)........................................ 186
Appendix C. Screening Questionnaire............................................... 188
Appendix D. Consent Form (Focus Groups)....................................... 193
Appendix E. Consent Form (Interviews)............................................. 197
Appendix F. Participant Questionnaire............................................... 200
Appendix G. Research Ethics Board Approvals................................. 206
# List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACL</td>
<td>Anterior cruciate ligament</td>
</tr>
<tr>
<td>BMI</td>
<td>Body mass index</td>
</tr>
<tr>
<td>BOA</td>
<td>Better Management of Patients with OA program</td>
</tr>
<tr>
<td>CDSMP</td>
<td>Chronic Disease Self-Management program</td>
</tr>
<tr>
<td>CSM</td>
<td>Common-Sense Model of Self-Regulation of Health and Illness</td>
</tr>
<tr>
<td>ES</td>
<td>Effect size</td>
</tr>
<tr>
<td>GLA:D</td>
<td>Good Life with Arthritis in Denmark</td>
</tr>
<tr>
<td>GRADE</td>
<td>Grading of Recommendations Assessment, Development and Evaluation</td>
</tr>
<tr>
<td>KOOS</td>
<td>Knee Injury and Osteoarthritis Outcome Score</td>
</tr>
<tr>
<td>MRI</td>
<td>Magnetic resonance imaging</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NSAID</td>
<td>Non-Steroidal Anti-Inflammatory drugs</td>
</tr>
<tr>
<td>OA</td>
<td>Osteoarthritis</td>
</tr>
<tr>
<td>OARSI</td>
<td>Osteoarthritis Research Society International</td>
</tr>
<tr>
<td>OR</td>
<td>Odds ratio</td>
</tr>
<tr>
<td>PAC</td>
<td>Program advisory committee</td>
</tr>
<tr>
<td>PACE</td>
<td>The People with Arthritis Can Exercise program</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomized control trial</td>
</tr>
<tr>
<td>SMD</td>
<td>Standardized mean difference</td>
</tr>
<tr>
<td>TENS</td>
<td>Transcutaneous electrical nerve stimulation</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
</tr>
<tr>
<td>--------------</td>
<td>-----------</td>
</tr>
<tr>
<td>TKR</td>
<td>Total knee replacement</td>
</tr>
<tr>
<td>TJR</td>
<td>Total joint replacement</td>
</tr>
<tr>
<td>US</td>
<td>United States</td>
</tr>
</tbody>
</table>
Chapter 1: Introduction
Osteoarthritis (OA) is a highly prevalent and costly chronic disease (Bitton, 2009; Lawrence et al., 2008; Sharif, 2014), which has a significant impact on individuals and society (Hunter et al., 2014). It is a leading cause of disability and health care use world-wide (Badley, 1995; McKenna et al., 2005; Murray et al., 2012; Vos et al., 2012; Woolf et al., 2003). Individuals with OA experience pain, functional limitations, fatigue and lower health-related quality of life (Badley, 1995; Corti et al., 2003; Grotle et al., 2008; Guccione et al., 1994; Hawker et al., 2008; Hawker et al., 2010; Salaffi et al., 2014). OA can also have negative effects on mood, social and recreational activities and work participation (Ackerman et al., 2015; Agaliotis et al., 2014; Badley, 1995; Gignac et al., 2006; Hawker et al., 2011; Wilkie et al., 2014). The knee is the most commonly affected joint, accounting for 83% of OA disability (Vos et al., 2012). The prevalence of knee pain and knee OA have increased substantially; data from the Framingham study in the United States (US) indicated that the age- and body mass index (BMI)- adjusted prevalence of knee pain and symptomatic knee OA approximately doubled in women and tripled in men over a 20 year period (from 1983 to 2005) (Nguyen et al., 2011). While aging is a significant risk factor for OA, the majority of those affected with OA (64%) are of working age (15–64 years) (Losina et al., 2013). Approximately nine percent of the population of the US is diagnosed with symptomatic knee OA by age 60 years (Losina et al., 2013). Risk factors for knee OA, knee injury and obesity (Blagojevic et al., 2010; Silverwood et al., 2015; Toivanen et al., 2010), are on the rise and are likely to increase rates of OA at younger ages (Cooper et al., 2000; Niu et al., 2009; Wilder et al., 2002). Concomitantly, total knee replacements (TKR), a procedure for end-stage knee OA, have risen dramatically in recent years (Canadian Institute for Health Information, 2009; Kurtz et al., 2005; Ravi et al., 2012). The largest increases were among people who were 45-64 years of age, for whom the rates of TKR more than tripled (Kurtz et al., 2005). As a result, the increasing rates of knee OA may have a significant economic impact on an already burdened health care system. While knee OA presents a mounting public health problem, there are opportunities to address knee OA at an earlier stage in younger adults through primary and secondary prevention (Ratzlaff et al., 2010).
There is no cure for OA; however, there is evidence that strategies such as exercise and weight loss, decrease the pain and disability of knee OA (Bennell et al., 2011b; Bliddal et al., 2011; Christensen et al., 2007; McKnight et al., 2010; Wang et al., 2012). Despite the substantial impact of OA in people as early as their third of fourth decade of life (Kopec et al., 2007), interventions for adults with OA symptoms earlier in life are scarce. There is an urgent need to improve management of knee OA symptoms in younger adults to reduce symptoms and concomitant disability. Early intervention may have potential to halt or delay progression of OA and its associated morbidity and delay need for more costly interventions such as surgery. Currently, there is insufficient knowledge about younger adults with OA symptoms to target their needs with appropriate interventions. The perspectives of people living with illnesses are acknowledged to be important for service development within the health care sector (Wensing et al., 2003). Little is known about younger adults’ perceptions and beliefs about OA, experiences living with symptoms and how people manage knee symptoms. This thesis aims to address these gaps. By improving our understanding of the perceptions, experiences and management of younger adults with knee OA symptoms, we will be better placed to provide relevant support and care based on current best practices and new empirical evidence as it becomes available. Since younger adults may be less likely to have a diagnosis of OA or perceive symptoms to be OA, this thesis will focus on adults with OA-like knee symptoms.

This thesis is a paper-based thesis comprised of seven chapters. In chapter two, I set the stage for the thesis by reviewing the literature on OA epidemiology, risk factors, recommendations for OA management, health care management of OA and literature related to the thesis topic (perceptions, management and experiences of OA). Chapter three provides an overview of the research methods for the study. Chapters four to six include three distinct papers reporting on the qualitative study conducted for this thesis. These chapters are presented in a logical order to understand the research findings. First, chapter four illuminates how people understand and explain their knee symptoms. Chapter five explains how people
respond to and manage their knee symptoms. Finally, chapter six describes the consequences of knee symptoms on peoples' lives. Chapters four to six are written in a format for publication as individual articles in peer-reviewed journals (Chapters five and six have been published in peer-reviewed journals and chapter four has been accepted by a peer-reviewed journal). As a result, there may be areas of overlap across the chapters. In chapter seven, I conclude the thesis with a discussion highlighting: the findings of the three papers in the context of the overall thesis objectives, the contributions of the research to the literature, the implications of this research for policy and practice, strengths and limitations of the research and future directions.
Chapter 2: Background and Literature Review
2.1 Chapter Overview

This chapter reviews the relevant background literature on OA (OA epidemiology, risk factors, effectiveness of management strategies and health care for OA) to provide context for the thesis research and outline the current state of knowledge. Where possible, data specific to knee OA are presented. Next, the small body of literature related to the thesis topic on peoples’ perceptions of OA, management practices and experiences living with OA are discussed, highlighting gaps in our current knowledge.

2.2 What is OA?

OA is a heterogeneous condition characterized by structural changes to the entire joint, including: loss of articular cartilage, development of osteophytes, synovial inflammation, subchondral bone changes, meniscal damage, muscle weakness, and ligamentous laxity (Bennell et al., 2012b). OA is typically accompanied by pain; common forms of pain include intermittent but generally intense pain, or persistent background pain or aching (Hawker et al., 2008). Other signs and symptoms of OA include crepitus, restricted movement, stiffness, and reduced function. Multiple joint sites are often involved in OA (Mannoni et al., 2003; Nelson et al., 2013). The clinical course of knee OA tends to be highly variable with some people experiencing little change in pain and function or structural progression and others experiencing rapid progression (Felson, 2009).

Various case definitions of OA exist including radiographic, symptomatic or self-reported OA (Pereira et al., 2011). Radiographic definition only considers the pathophysiological joint signs present on radiographic images. Symptomatic OA considers OA cases when both radiographic and joint symptoms (e.g. pain, stiffness, loss of function) exist. Studies have also used self-report of previous health professional diagnosis of OA. In a systematic review, the case definition of radiographic OA presented the highest prevalence estimates, while self-reported
and symptomatic OA definitions appeared to have similar prevalence estimates within each joint site (Pereira et al., 2011).

2.3 Epidemiology and Burden of OA

The incidence and prevalence of OA varies depending on the definition of OA used and the population characteristics. Canadian research using administrative data in British Columbia estimated the overall incidence of OA to be 11.7 per 1000 person years (the case definition for OA was the first visit to a health professional or first hospitalization with a three digit International Classification of Diseases, 9th Revision code of 715 (OA and allied disorders)) (Kopec et al., 2007). Data were not available for the knee joint specifically in the Canadian study, but data are available from older American population-based samples. In a US study, the age- and sex-standardized incidence rate for symptomatic knee OA was estimated to be 240 cases per 100,000 person-years (Oliveria et al., 1995). Murphy et al. estimated the lifetime risk of developing symptomatic knee OA to be approximately 40% in men and 47% in women, with higher risks among those who are obese (Murphy et al., 2008).

The overall prevalence of OA for all age groups combined in British Columbia was 10.8% (Kopec et al., 2007). This is consistent with other research (Lawrence et al., 2008). For instance, NHANES III, a nationally representative health examination survey conducted by the Centers for Disease Control in the US estimated that the prevalence of symptomatic radiographic knee OA in adults in the US was 12.1% (Lawrence et al., 2008). Data from the Framingham study found that the prevalence of radiographic and symptomatic knee OA in adults 45 years or older was 19% and 7%, respectively (Felson et al., 1987).

The incidence and prevalence of OA varies by age and sex (Arden et al., 2006; Kopec et al., 2007; Neogi et al., 2013; Oliveria et al., 1995). Kopec et al. found that the incidence of OA increased significantly between ages 20 and 50 years with the largest number of incident cases in the 50-54 year age group (Kopec et al., 2007).
The prevalence of OA increases with age; however, there is a substantial impact in younger adults. For instance, in the age group 45–49 years, about 10% of the population had OA. After age 50, the prevalence increased linearly with age (Kopec et al., 2007). The prevalence of all OA, and knee OA specifically, has been shown to be higher in women than men (Neogi & Zhang, 2013).

The prevalence of OA has been rising; an estimated 27 million adults in the US reported to have OA in 2005, an increase from 21 million in 1995 (Lawrence et al., 2008). The prevalence of OA is projected to continue to increase (Hunter et al., 2014; Turkiewicz et al., 2014). In one study, the proportion of the population aged ≥45 with doctor-diagnosed OA was projected to increase from 26.6% in 2012 to 29.5% by 2032 (from 13.8% to 15.7% for the knee specifically) (Turkiewicz et al., 2014). Others have suggested that the number of people affected by OA will increase by about 50% over the next 20 years (with the caveat that past projections have underestimated future burden) (Hunter et al., 2014).

OA results in a considerable individual burden which includes pain, activity limitations (e.g. difficulties walking, stair climbing, getting in and out of a chair), fatigue, poor sleep and a lower health-related quality of life (Badley, 1995; Corti & Rigon, 2003; Dillon et al., 2006; Grotle et al., 2008; Guccione et al., 1994; Hawker et al., 2008; Hawker et al., 2010; Salaffi et al., 2005). In a cohort of people with confirmed radiographic knee OA, or who were considered at high risk of developing knee OA, using stairs was most likely to be the first activity to cause pain (Hensor et al., 2015). Eighty percent of people with established knee OA had some movement limitation and a quarter could not perform activities of daily living (Guccione et al., 1994). In another study of people with OA, more than 80% of all patients reported limitations in their activities of daily living, either for basic tasks, leisure activities, or work (Fautrel et al., 2005). This is particularly problematic because people with arthritis often have other chronic diseases and these limitations can make it difficult for them to exercise to control their co-morbid conditions (e.g. diabetes, heart disease) (White et al., 2012). The impact of OA is not limited to physical symptoms,
and can be manifested as depression or anxiety (Ackerman et al., 2015; Axford et al., 2010; Hawker et al., 2011; Sale et al., 2008; Scopaz et al., 2009). The symptoms of OA also limit aspects of life such as travel, leisure and social activities (Gignac et al., 2006; Hall et al., 2008) and employment (Ackerman et al., 2015; Agaliotis et al., 2014; Bieleman et al., 2011; Bieleman, 2014; Wilkie et al., 2014). A recent systematic review found strong evidence that knee pain or knee OA was associated with work absenteeism (Agaliotis et al., 2014). One study indicated that adults with knee OA reported more than 13 days of work lost because of health issues (Centers for Disease Control and Prevention, 2014). Another study attributed 2% of all sick days in the population to knee OA (Hubertsson et al., 2013). Finally, studies suggest that mortality is increased in individuals with OA compared with the general population (Hochberg, 2008; Nuesch et al., 2011). In one study, people with symptomatic OA had a 50% increase in all-cause mortality compared to that expected based on their age and gender distribution (Nuesch et al., 2011). Similarly, a recent Canadian study also found a significant association between greater OA-related disability and all-cause mortality (Hawker et al., 2014).

In addition to the impact of OA on individuals, it is also costly to society (Hunter et al., 2014). OA has an extremely high economic burden largely attributable to the effects of disability, comorbid disease, and the costs of treatment (Bitton, 2009). The cost of OA is estimated to account for between 1% and 2.5% of the gross national product of several Western countries (March et al., 1997). From 2010 to 2031, while the prevalence of OA increases from 13.8% to 18.6%, the total direct cost of OA is projected to increase from $2.9 billion to $7.6 billion, an almost 2.6-fold increase (in 2010 Canadian dollars) (Sharif, 2014). Long term disability due to morbidity accounts for the majority of the economic burden of arthritis and 70% of the costs are incurred by the 35-64 year age group (Lagace et al., 2010). The majority of health care costs for OA are for hospitalizations (Le Pen et al., 2005; Leardini et al., 2004; Loza et al., 2009). The bulk of hospitalizations involve total joint replacements (TJR), and these procedures are on the rise (Canadian Institute for Health Information, 2009; Kurtz et al., 2007; Ravi et al., 2012). With the higher
numbers of TJR in younger adults (Canadian Institute for Health Information, 2009; Kurtz et al., 2007; Ravi et al., 2012), revision procedures are likely to continue to increase and costs for revision surgery are greater than that of the initial surgery (Burns et al., 2006; Hunter et al., 2014). In a systematic review of national registers and clinical studies, the revision rate for TKRs was found to be 6.5% after five years, and 12.9% after ten years (Labek et al., 2011). Kurtz et al. projected that by 2030, the demand for TKRs by patients less than 65 years is projected to be 55% to 62% of primary or revision surgeries (Kurtz et al., 2009).

2.4 Risk Factors for OA

OA has a multifactorial etiology, with different sets of risk factors causing the onset in any given individual (Neogi & Zhang, 2013). Risk factors include non-modifiable and modifiable factors which affect incident knee OA and/or disease progression (Blagojevic et al., 2010; Neogi & Zhang, 2013; Silverwood et al., 2015). This review will focus predominantly on modifiable risk factors as these can be targeted in interventions for primary and secondary prevention.

2.4.1 Non-Modifiable Risk Factors

Known non-modifiable risk factors for development of knee OA are increasing age (Badley et al., 1998; Hart et al., 1999; Kopec et al., 2007; Perrucio et al., 2006), genetics (Hunter et al., 2003; Loughlin, 2005; Zhai et al., 2005) and female gender (Davis et al., 1991; Oliveria et al., 1995; Srikanth et al., 2005).

2.4.2 Modifiable Risk Factors

Mechanical stress has been shown to be the most important risk factor for knee OA (Visser et al., 2014) and many of the modifiable risk factors of knee OA represent types of mechanical overload of a joint (Felson, 2013). Obesity, physical activity/exercise, occupations and malalignment relate to chronic loading of the joint
and these will be discussed first. Muscle weakness is another risk factor for knee OA. While the mechanisms are unclear, it is suggested that muscle weakness increases excessive mechanical stress on articular cartilage, inducing a degenerative process (Felson, 2013). Finally, knee injury will be discussed. Knee injury is proposed to cause acute structural damage at the time of injury and gradual onset of damage due to mechanical stress on an injured joint (Buckwalter et al., 2013).

Table 2.1 summarizes data from systematic reviews and meta-analyses related to modifiable OA risk factors.
<table>
<thead>
<tr>
<th>Article</th>
<th>Study Design</th>
<th>Number of Studies and Participants Included (Participant characteristics included as available)</th>
<th>Quality Assessment</th>
<th>Main Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Obesity/Overweight</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Biagojevic et al., 2010 | Systematic review and meta-analysis | Obese: 17 studies (346,788 participants)  
Overweight: 23 studies (639,526 participants)  
Overweight or obese: 26 studies (353,081 participants)  
Papers reported up to January 2008 | Overall mean quality score for all risk factors 8.08 out of possible 14 points (SD 2.18) | Obese: OR 2.63 (95% CI 2.28, 3.05)  
Overweight: CR 2.18 (95% CI 1.86, 2.55)  
Overweight or obese: OR 2.96 (95% CI 2.56, 3.43) | |
| Runhaar et al., 2011 | Systematic review on biomechanics in obese individuals compared to normal-weight | 12 studies included up to November 2010 | No quality assessment | At self-selected speed, obese individuals walked slower, with shorter and wider steps, had longer stance duration and had a greater toe-out angle compared with normal-weight individuals. |
| Silverwood et al., 2015 | Systematic review and meta-analysis | Obese: 22 studies (401,119 participants)  
Overweight: 22 studies (398,251 participants)  
Obese or overweight: 25 studies (415,623 participants)  
Papers reported up to December 2012 | No quality assessment | Pooled OR:  
Obese: OR 2.66 (95% CI 2.15-3.28)  
Overweight: CR 1.98 (95% CI 1.57, 2.20)  
Obese or overweight: OR 2.10 (1.82, 2.42) |
<table>
<thead>
<tr>
<th>Article</th>
<th>Study Design</th>
<th>Number of Studies and Participants Included (Participant characteristics included as available)</th>
<th>Quality Assessment</th>
<th>Main Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Occupational Risk</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biagojvice et al., 2010</td>
<td>Systematic review</td>
<td>22 studies included up to January 2010</td>
<td>Overall mean quality score for all risk factors 8.08 out of possible 14 points (SD 2.18)</td>
<td>Increased risk with excessive kneeling, squatting, climbing steps, standing &gt; 2 hours/day, farming, construction work, and physical education teaching.</td>
</tr>
<tr>
<td>McWilliams et al., 2011</td>
<td>Meta-analysis investigating occupational risk of knee OA</td>
<td>51 studies (526,343 participants) included Mean age: 60 years 39% female Papers included between 1950-July 2010</td>
<td>Quality assessment by sub-group analysis showing considerable heterogeneity across studies</td>
<td>OR: 1.61 (95% CI 1.45, 1.78)</td>
</tr>
<tr>
<td>Silverwood et al., 2015</td>
<td>Systematic review</td>
<td>8 studies included up to December 2012</td>
<td>No quality assessment</td>
<td>Significant risks related to physically demanding work: kneeling, lifting, farming, construction work</td>
</tr>
<tr>
<td><strong>Physical Activity/Exercise</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Biagojvice et al., 2010       | Systematic review        | 27 studies included up to January 2010                                                       | Overall mean quality score for all risk factors 8.08 out of possible 14 points (SD 2.18) | - Mixed evidence on the effects of running  
- Increased risk with more regular or intense exercise  
- Higher risk in sportsmen/women                                                                  |
<p>| Silverwood et al., 2015       | Systematic review        | 16 studies included up to December 2012                                                        | No quality assessment                                                               | - Significant relationship with high levels or intense physical activity                                                                  |</p>
<table>
<thead>
<tr>
<th>Article</th>
<th>Study Design</th>
<th>Number of Studies and Participants Included (Participant characteristics included as available)</th>
<th>Quality Assessment</th>
<th>Main Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Malalignment</strong></td>
<td><strong>Tanamas et al., 2009</strong> Systematic review of the relationship between knee malalignment and progression and/or development of knee OA</td>
<td>14 studies included up to July 2008&lt;br&gt;Mean age range: 45.0-69.9 years&lt;br&gt;% female range: 30.0-81.0%</td>
<td>Mean quality score based on criteria of Lieverse et al.: 78.6% (range 45%-92%)</td>
<td>-Limited evidence for an association between knee malalignment and incident knee OA&lt;br&gt;-Strong evidence knee malalignment is a risk factor for progression of knee OA</td>
</tr>
<tr>
<td><strong>Muscle Weakness</strong></td>
<td><strong>Oiestad et al., 2015</strong> Systematic review and meta-analysis of association between knee extension muscle weakness and risk of OA</td>
<td>5 studies (5707 participants)&lt;br&gt;Mean age range: 46.9-70.8 years&lt;br&gt;% female: 38%&lt;br&gt;Studies included up to September 2013</td>
<td>Quality assessment using guidelines from Centre for Reviews and Dissemination: mean of 7.4 of 11 items acceptable</td>
<td>OR: 1.65 (95% CI: 1.23, 2.21)</td>
</tr>
<tr>
<td><strong>Knee Injury</strong></td>
<td><strong>Blagojevic et al., 2010</strong> Systematic review and meta-analysis</td>
<td>16 studies (16746 participants) included up to January 2008</td>
<td>Overall mean quality score for all risk factors 8.08 out of possible 14 points (SD 2.18)</td>
<td>Pooled OR: 3.86 (95% CI 2.62, 5.70)</td>
</tr>
<tr>
<td>Article</td>
<td>Study Design</td>
<td>Number of Studies and Participants Included (Participant characteristics included as available)</td>
<td>Quality Assessment</td>
<td>Main Results</td>
</tr>
<tr>
<td>----------------------</td>
<td>-------------------------------</td>
<td>-----------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>Muthuri et al., 2010</td>
<td>Meta-analysis</td>
<td>24 studies (20,997 participants) included up to October 2010 Age range: 24-96 years % female: 59%</td>
<td>Quality assessment by sub-group analysis found heterogeneity due to definition of knee injury</td>
<td>Pooled OR: 4.20 (95% CI: 3.11, 5.66)</td>
</tr>
<tr>
<td>Richmond et al., 2013</td>
<td>Systematic review and meta-analysis</td>
<td>16 studies (5 included in meta-analysis)</td>
<td>Median modified Downs and Black quality score was 16 out of possible 24 (IQR, 11.8-19.5)</td>
<td>Combined OR: 3.8 (95% CI 2.0, 7.2)</td>
</tr>
<tr>
<td>Silverwood et al., 2015</td>
<td>Systematic review and meta-analysis</td>
<td>13 studies (27,326 participants) included up to December 2012</td>
<td>No quality assessment</td>
<td>Pooled OR: 2.83 (95% CI 1.91, 4.19)</td>
</tr>
</tbody>
</table>
2.4.2.1 Obesity

There is considerable evidence that obesity is a risk factor for the development and progression of OA (Blagojevic et al., 2010; Silverwood et al., 2015). In a recent meta-analysis of risk factors for knee OA in adults over 50 years, the pooled odds ratio (OR) for obesity was 2.66 (95% confidence interval (CI) 2.15, 3.28) (Silverwood et al., 2015). In an earlier meta-analysis, researchers found that obese and overweight individuals had a 2.96-times higher risk of incident knee OA compared to normal weight individuals (Blagojevic et al., 2010). Jiang reported that a five unit increase in body mass was associated with a 35% increased risk of knee OA (Jiang et al., 2012). A recent study found that weight gain is strongly associated with increased progression of cartilage degeneration in middle-aged adults with risk factors for OA (Bucknor et al., 2015). Interestingly, those with risk factors for knee OA at baseline who gained weight over time progressed to incident knee OA more often than adults who did not gain weight (the weight gain group was three times more likely to show signs of progression on magnetic resonance imaging (MRI) studies). Increased joint load has often been proposed as the mechanism for resultant knee OA. However, more recently researchers have suggested that extra load on weight-bearing joints cannot be linked to the development of OA alone (Runhaar et al., 2011). In a systematic review, Runhaar et al. found that obese individuals alter biomechanics in everyday movements which could relate to the initiation of OA by changing the load-bearing regions of the articular cartilage (Runhaar et al., 2011).

2.4.2.2 Occupation

In systematic reviews, the authors found some evidence for an increased risk of OA with occupations with excessive kneeling, squatting, climbing steps, standing greater than two hours/day and lifting (Blagojevic et al., 2010; Silverwood et al., 2015). In a meta-analysis of occupational risks, the overall OR was 1.61, with considerable heterogeneity across studies (McWilliams et al., 2011). Specific occupations such
as farming, construction work and physical education teaching were shown to be risk factors (Blagojevic et al., 2010; Silverwood et al., 2015).

2.4.2.3 Physical Activity/Exercise

Studies have examined the risk of physical activity and exercise and the development of OA using various definitions. Most studies have purported to examine physical activity focusing on leisure-time physical activities such as running, walking for exercise or sports (Blagojevic et al., 2010; Neogi & Zhang, 2013; Silverwood et al., 2015). There is some conflicting evidence of the effect of physical activity on knee OA (Blagojevic et al., 2010; Silverwood et al., 2015). In systematic reviews, higher quality studies showed an increased risk of knee OA in those who exercised more intensely or participated in habitual and repetitive motion (e.g. regular running) (Blagojevic et al., 2010; Silverwood et al., 2015). For instance, one study found an increased risk in people who ran 20 miles or more per week (Cheng et al., 2000). Higher risk of OA has been reported in high-intensity athletes such as soccer players and weight lifters; however, this increased risk may be associated with knee injury in soccer players and increased BMI in weight lifters, rather than load bearing itself (Neogi & Zhang, 2013).

2.4.2.4 Alignment

A shift from neutral alignment can shift the load distribution across the knee and may contribute to abnormal mechanical forces (Johnson et al., 2014). There is limited evidence for a relationship between incident knee OA and malalignment of the knee joint. However, in a systematic review, the researchers reported that there is strong evidence that knee alignment is an independent risk factor for the progression of OA (Tanamas et al., 2009). Cerejo et al. found that medial compartment progression was four times more likely in individuals with varus alignment and lateral compartment progression was five times more likely in individuals with valgus alignment (Cerejo et al., 2002).
2.4.2.5 Muscle Strength

The quadriceps decelerates the lower limb during gait, absorbs lower limb loading and provides dynamic joint stability (Johnson & Hunter, 2014). In prior research, there was conflicting evidence for the role of quadriceps strength in risk for OA development. However, a recent meta-analysis showed an increased risk of developing symptomatic knee OA in participants with knee extensor muscle weakness (OR 1.65, 95% CI 1.23, 2.21) (Oiestad et al., 2015).

2.4.2.6 Knee Injury

Anterior cruciate ligament (ACL) tears, traumatic meniscal tears and direct articular cartilage damage from injury are linked to the development of OA (Lohmander et al., 2007). Research has shown that 10 to 20 years after an ACL or meniscus tear approximately 50% of people develop knee OA with associated pain and functional impairment (Lohmander et al., 2004). In a recent meta-analysis studying risk factors for knee OA, the pooled OR for previous knee injury was 2.83 (95% CI 1.91, 4.19) (Silverwood et al., 2015). In a previous meta-analysis, knee injury was a major risk factor for development of knee OA regardless of study design and definition of knee injury with an overall pooled OR of 4.2 (95% CI 3.11, 5.66) (Muthuri et al., 2011). Richmond reported a combined OR for knee injury of 3.8 (95%, CI 2.0, 7.2) (Richmond et al., 2013). This is particularly relevant to younger adults as ACL tears are most common in people under age 30 (Friel et al., 2013) and meniscal lesions are diagnosed at a mean age of 35 (Lohmander et al., 2007).

2.4.3 Summary

Studies have identified potentially modifiable risk factors for the development and progression of knee OA. There is considerable evidence that being overweight or obese or having a knee injury are risk factors for incident knee OA. Obesity is also a risk factor for OA progression (Blagojevic et al., 2010; Silverwood et al., 2015).
There is some evidence for occupational risks of developing knee OA (Blagojevic et al., 2010; Silverwood et al., 2015). Evidence is conflicting on the risk of physical activity and incident OA; authors conclude that higher quality studies indicate that more regular and intense physical activity is a risk factor (Blagojevic et al., 2010; Silverwood et al., 2015). There is evidence that alignment is a risk factor for knee OA progression but not incident knee OA (Tanamas et al., 2009). Finally, there is some evidence that reduced quadriceps muscle strength increases the risk of developing knee OA (Oiestad et al., 2015). A thorough understanding of modifiable knee OA risk factors is necessary to support development of appropriate public health prevention interventions (e.g. to reduce knee injuries) and effective management strategies to prevent OA progression (e.g. weight loss) (Johnson & Hunter, 2014).

2.5 The Effectiveness of OA Management Strategies

There are management strategies which have been shown to be effective in relieving pain and improving function in individuals with knee OA (Hochberg et al., 2012). Pharmacologic management is a mainstay of OA treatment; however, most drugs have small to modest effect sizes (ES) and have risks of adverse effects. Non-pharmacologic treatments are recommended as a first-line approach to management of OA (Hinman et al., 2015). As such, the primary focus of this review will be on the evidence of effectiveness of non-pharmacologic interventions which have been considered in clinical guidelines for knee OA, including self-management interventions, exercise, weight loss, biomechanical interventions and modalities. The majority of these studies examined the effectiveness of interventions in older adults.

A brief overview of recommendations for pharmacologic treatments for OA from recent clinical guidelines will be presented first. Then, a review of the evidence on the effectiveness of non-pharmacologic interventions will be discussed, prioritizing evidence from systematic reviews, meta-analysis, and guidelines. The target
populations for the studies varied with some studies including people with all OA, while others restricted the intervention to people with knee OA. Where possible, evidence on the management of knee OA is presented. Table 2.2 presents an overview of findings from systematic reviews and meta-analysis of non-pharmacologic interventions.
<table>
<thead>
<tr>
<th>Article</th>
<th>Study Design</th>
<th>Number of Studies and Participants</th>
<th>Intervention</th>
<th>Control</th>
<th>Quality Assessment</th>
<th>Main Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-Management Interventions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Brady et al., 2013 | Meta-analysis of the Chronic Disease Self-Management program (CDSMP) | 23 studies (8688 participants) included up until September 2009 | Stanford CDSMP regardless of delivery mode | Unspecified | No quality assessment | Effect sizes:  
Health distress: -0.23 (95% CI -0.32, -0.13)  
Self-efficacy: 0.20 (95% CI 0.08, 0.33)  
Cognitive symptom management: 0.37 (95% CI 0.26, 0.48) |
| Carnes et al., 2012 | Systematic review of self-management programs for musculoskeletal conditions | 46 papers (8539 participants) up until April 2009  
Mean age: 55 years  
% female: 72% | Self-management programs: structured, taught or self-taught course to improve health status by teaching skills | Usual care or wait-list control | 11 studies considered higher quality than the rest; higher quality studies had smaller effect sizes than the rest | -Health professional input showed more benefits  
-Longer course did not have better outcomes  
-Courses with psychological component had more benefit |
| Chodosh et al., 2005 | Meta-analysis of CDSMP for older adults | 53 studies included (14 for OA) until September 2004 | Systematic intervention (to help self-monitoring or decision making) | Usual care or control intervention | -Jadad scale  
-No evidence of publication bias in OA | Pooled effect size for OA:  
Pain: -0.06 (-0.1, -0.02)  
Function: -0.06 (-0.10, -0.02) |
| Du et al., 2011 | Systematic review and meta-analysis of self-management programs for musculoskeletal pain | 19 studies in total; 16 studies on arthritis (7305 participants) up until March 2010 | Self-management program focusing on: self-efficacy, self-monitoring, goal-setting, decision-making, problem-solving, | Usual care or wait-list control | Cochrane handbook: 5 studies rated as A level and 14 as B level | Pain SMD at 4 months: -0.23 (95% CI -0.36, -0.10)  
Pain SMD at 12 months: -0.14 (95% CI -0.23, -0.04)  
Disability SMD at 12 months: -0.17 (95% CI -0.27, -0.07) |
<table>
<thead>
<tr>
<th>Article</th>
<th>Study Design</th>
<th>Number of Studies and Participants</th>
<th>Intervention</th>
<th>Control</th>
<th>Quality Assessment</th>
<th>Main Results</th>
</tr>
</thead>
</table>
| Kroon et al., 2014 | Cochrane review of self-management education for OA | 29 studies (6753 participants) included until January 2013  
Mean age: 64.8 years  
% female: 68% | Structured self-management education for OA, arthritis or chronic disease. Components: fostering skills in management of OA, problem solving, goal-setting, decision making and self-monitoring | -Information only  
-No treatment  
-Usual care  
-Wait-list control  
-Alternative intervention | GRADE approach: Studies comparing self-management intervention to usual care or attention control were graded as low to moderate | Compared to usual care: SMD for pain: -0.19 (-0.28 to -0.10)  
SMD for function: -0.18 (-0.27 to -0.09)  
Compared to attention control: SMD for pain: -0.26 (-0.44 to -0.09)  
SMD for function: -0.19 (-0.5 to 0.11) |
| Nolte et al., 2013 | Systematic review of chronic disease self-management | 18 studies up until January 2007 | Disease specific or generic self-management interventions comparable with Stanford curriculum | Usual care | No quality assessment | -Small effect sizes on most outcomes except knowledge  
-ES for knowledge: 0.78  
-ES for pain: 0.10 |
| Panagioti et al., 2014 | Systematic review and meta-analysis of self-management interventions for chronic conditions | 184 papers up until June 2012  
Mean age: 58 years  
% female: 51% | Self-management interventions to develop patients' abilities to manage through education, training and support to develop patient skills, knowledge and psychological and social resources | Usual care or more intensive usual care (e.g. hospital use) | Dichotomous measure based on allocation concealment (according to Cochrane risk of bias tool): Studies at higher risk of bias had greater benefits in health outcomes and great reductions in hospitalizations | -Small effects on hospital use and costs  
-For arthritis, ES for combined hospital use: -0.06 (-0.22, 0.10) |
<table>
<thead>
<tr>
<th>Article</th>
<th>Study Design</th>
<th>Number of Studies and Participants</th>
<th>Intervention</th>
<th>Control</th>
<th>Quality Assessment</th>
<th>Main Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Warsi et al., 2004</td>
<td>Systematic Review of chronic disease management programs</td>
<td>71 RCTs of self-management education (24 on arthritis, 5056 participants) up until January 1999</td>
<td>Self-management education</td>
<td>Concurrent control group</td>
<td>No specific quality assessment identified</td>
<td>Effect size: Pain -0.12 (95% CI 0.00, 0.24) Disability – 0.07 (95% CI 0.00, 0.15)</td>
</tr>
<tr>
<td>Warsi et al., 2003</td>
<td>Systematic review and meta-analysis of arthritis self-management programs</td>
<td>17 studies (4114 participants) until October 1998 Mean age: 61 years % female: 69%</td>
<td>Self-management education</td>
<td>Concurrent control group</td>
<td>No specific quality assessment identified</td>
<td>Effect size: Pain 0.12 (95% CI 0.00, 0.24) Disability 0.07 (95% CI 0.00, 0.15)</td>
</tr>
<tr>
<td>Exercise</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fransen et al., 2015</td>
<td>Cochrane Review of exercise for knee OA</td>
<td>54 studies (5362 participants) included up until May 2013</td>
<td>Land-based therapeutic exercise (non-perioperative) aimed at relieving OA symptoms</td>
<td>Non-exercise or non-treatment control (wait-list control)</td>
<td>GRADE: quality rated high for pain and moderate for physical function</td>
<td>Effect Size Pain: SMD -0.49 (95% CI: -0.39,-0.59) Physical function: SMD -0.52 (95% CI 0.39, -0.64)</td>
</tr>
<tr>
<td>Juhl et al., 2014</td>
<td>Systematic Review and Meta-Regression</td>
<td>48 studies (4028 participants) included up until May 2012 Mean age: 64.3 years % female: 75%</td>
<td>At least one therapeutic exercise group</td>
<td>Non-exercise intervention control</td>
<td>Risk of bias: Sequence generation, concealment of allocation and incomplete outcome data in 30 (62.5%), 31 (64.6%) and 13 (27.1%) studies respectively</td>
<td>Similar effects for aerobic, resistance and performance exercise (SMD 0.67, 0.62, 0.48 P =0.733) Single type of exercise more effective than multiple types (SMD 0.61 versus 0.16 p&lt;0.001) More pain reduction when supervised exercise performed at least 3x/week</td>
</tr>
<tr>
<td>Article</td>
<td>Study Design</td>
<td>Number of Studies and Participants</td>
<td>Intervention</td>
<td>Control</td>
<td>Quality Assessment</td>
<td>Main Results</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------------------------------------</td>
<td>-------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Uthman et al., 2013</td>
<td>Systematic review incorporating trial sequential analysis and network meta-analysis</td>
<td>60 RCTs (8218 participants) included up until March 2012</td>
<td>Any therapeutic exercise (land or water based) regardless of content, duration, frequency or intensity</td>
<td>Other forms of exercise or non-exercise control</td>
<td>Cochrane collaboration's tool for assessing risk: generation of allocation sequence 60%, allocation concealment 42%, masked outcome assessors to allocation 52%, missing data 18%</td>
<td>For pain relief, strengthening, flexibility plus strengthening, flexibility plus strengthening plus aerobic, aquatic strengthening, aquatic strengthening plus flexibility, exercises were more effective than control. Strengthening, flexibility plus aerobic was more effective than control for improving physical function (SMD -0.63 95% CI -1.16, -0.10)</td>
</tr>
<tr>
<td>Yan et al., 2013</td>
<td>Meta-analysis</td>
<td>7 RCTs (348 participants) included up until September 2012</td>
<td>Tai Chi, Tai Ji Chuan, Tai Chi Qigong</td>
<td>Jadad scale: mean Jadad score 3.6 (range 3-4)</td>
<td></td>
<td>Pooled SMD:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Pain -0.45 (95% CI -0.70-- -0.20) P = 0.0005</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Stiffness -0.31 (95% CI -0.60-- -0.02) P = 0.04</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Physical function -0.61 (95% CI -0.85-- -0.37) P&lt;0.0001</td>
</tr>
<tr>
<td>Zacharias et al., 2014</td>
<td>Systematic review with meta-analysis</td>
<td>40 RCTs included up until February 2013</td>
<td>Exercise based rehabilitation programs (using voluntary contractions with a minimum duration of 6 weeks)</td>
<td>Usual care or alternative program with or without exercise</td>
<td>PEDro scale</td>
<td>High quality evidence for improved knee extension strength (SMD = 0.47, 95% CI 0.29, 0.66)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>High quality evidence for improved flexion strength (SMD=0.74, 95% CI 0.56, 0.92) with low-intensity resistance program</td>
</tr>
<tr>
<td>Article</td>
<td>Study Design</td>
<td>Number of Studies and Participants</td>
<td>Intervention</td>
<td>Control</td>
<td>Quality Assessment</td>
<td>Main Results</td>
</tr>
<tr>
<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></td>
<td></td>
<td>Moderate quality evidence for high-intensity resistance programs (SMD = 0.76, 95% CI 0.47, 1.06)</td>
</tr>
<tr>
<td>Weight Loss</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Christenson et al., 2007</td>
<td>Systematic Review and Meta-analysis</td>
<td>4 RCTs (454 participants) included up until April 2006</td>
<td>Any intervention where weight was reported explicitly (weight change was only difference compared to control group)</td>
<td>Not stated</td>
<td>Instrument to Measure the Likelihood of Bias</td>
<td>Pooled ES:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Pain 0.20 (95% CI 0 to 0.39)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Physical disability 0.23 (0.04 to 0.42)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Meta-regression analysis showed that disability could be significantly improved when weight was reduced over 5.1%</td>
</tr>
<tr>
<td>Biomechanical Interventions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moyer et al., 2015b</td>
<td>Meta-analysis</td>
<td>6 studies (445 participants) included up until January 2014</td>
<td>Valgus knee bracing for medial compartment knee OA (custom fit or off the shelf)</td>
<td>No orthosis (i.e. standard care) or another type of orthosis (e.g. neutrally aligned brace or sleeve)</td>
<td>Overall quality assessed using GRADE</td>
<td>Overall: Improvement in pain SMD: 0.33 (95% CI 0.13, 0.52), P = 0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Improvement in function SMD: 0.22 (95% CI 0.02, 0.41), P =0.03</td>
</tr>
<tr>
<td>Moyer et al., 2015a</td>
<td>Meta-analysis</td>
<td>17 studies (589 participants) included until May 2014</td>
<td>Valgus knee brace</td>
<td>With/without comparison to a neutral brace or lateral wedge orthotic</td>
<td>Overall quality using GRADE</td>
<td>Reduced external knee adduction moment during walking (SMD 0.61 (95% CI 0.39, 0.83), P &lt;0.001)</td>
</tr>
<tr>
<td>Article</td>
<td>Study Design</td>
<td>Number of Studies and Participants</td>
<td>Intervention</td>
<td>Control</td>
<td>Quality Assessment</td>
<td>Main Results</td>
</tr>
<tr>
<td>-------------------------</td>
<td>---------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Raja et al., 2011</td>
<td>Systematic review</td>
<td>25 studies (1196 participants) included from 1996 to June 2010</td>
<td>Interventions with knee brace or foot orthoses</td>
<td>Other interventions (e.g. off the shelf bracing)</td>
<td>Jadad score: 6 RCTs were high quality RCTs. Four received a score of 4/5 and two received a score of 3. Mean score: 4.16/5</td>
<td>Knee braces and foot orthoses decreased pain, stiffness and drug dosage. Knee braces improved proprioception, balance, Kellgren/Lawrence grading, and physical function scores</td>
</tr>
<tr>
<td>Zeng et al., 2014</td>
<td>Systematic review and network meta-analysis of ultrasound</td>
<td>12 RCTs (8 RCTs included in network meta-analysis (525 participants) included up until February 2014</td>
<td>Pulsed or continuous ultrasound</td>
<td>Blank or sham treatment</td>
<td>Modified Oxford score (out of 7)</td>
<td>Pulsed ultrasound: Pain SMD -0.59, 95% CI: -0.89, -0.26</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3 studies low quality (score = 3), 4 medium quality (scored 4 or 5), 5 high quality (6 or 7)</td>
<td>Function SMD -0.57 (95% CI -1.12, -0.01)</td>
</tr>
<tr>
<td>Zeng et al., 2015</td>
<td>Systematic review and network meta-analysis</td>
<td>27 RCTs included (20 studies included in network meta-analysis (995 participants) up until February 2014</td>
<td>Interferential current, neuromuscular electrical stimulation, noninvasive neuroactive stimulation, pulsed electrical stimulation or TENS</td>
<td>Blank or sham treatment</td>
<td>Modified Oxford score (out of 7)</td>
<td>Interferential Current: Pain intensity SMD -0.92, (95% CI -1.72, -0.05)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8 low quality studies (&lt;3), 10 medium quality (scored 4 or 5) and 9 high quality (6 or 7)</td>
<td>High Frequency TENS: Pain intensity SMD -0.78 (95% CI -1.34, -0.22)</td>
</tr>
</tbody>
</table>
2.5.1 Pharmacologic Treatments

Pharmacologic management is a mainstay of OA treatment. Analgesics are the first line pharmacological treatment of OA (Hochberg et al., 2012). OA guidelines recommend acetaminophen, nonselective Non-Steroidal Anti-Inflammatory drugs (NSAIDs), topical NSAIDs, selective COX-2 inhibitors and intra-articular corticosteroid injections (Hochberg et al., 2012; McAlindon et al., 2014). Osteoarthritis Research Society International (OARSI) guidelines recommend Duloxetine (a selective serotonin norepinephrine reuptake inhibitor which has been demonstrated to have a centrally acting analgesic effect) and Capsaicin (topical cream used to treat peripheral neuropathic pain) for people with knee OA without comorbidities (McAlindon et al., 2014). Tramadol, a type of opioid, was recommended by the American College of Rheumatology (Hochberg et al., 2012) but listed as uncertain in OARSI guidelines (McAlindon et al., 2014).

2.5.2 Non-Pharmacologic Treatments

2.5.2.1 Self-Management Interventions

Active self-management and interventions supporting people in the acquisition of skills and techniques to learn to live with their condition have been identified as key components of chronic disease management (Nolte & Osborne, 2013). The Institute of Medicine defines self-management as the tasks a person must undertake to live with one or more conditions (Adams et al., 2004). In other words, self-management is what people with chronic diseases do on a daily basis to feel better and pursue the life they desire (Brady et al., 2014). There has been a proliferation of interventions to support self-management of chronic diseases. While the terminology to describe specific self-management interventions varies, most fall under the category of self-management support, which is described as actions taken by health care professionals and others to support a person’s self-management. This includes self-management education which is interactive education designed to enhance self-management by building skills such as goal setting, decision making,
problem solving, and self-monitoring (Brady et al., 2014). Self-management support is primarily delivered in two ways: one-on-one by health care providers and group programs which may target chronic diseases in general or arthritis specifically (often all arthritis and not OA specific).

Most OA guidelines have moderate to strong recommendations for self-management programs (Nelson et al., 2014). However, systematic reviews and meta-analyses of chronic disease self-management and arthritis self-management programs found that effects on patient outcomes were generally small (i.e. typically with effect sizes around 0.2 or less for pain and disability) (Chodosh et al., 2005; Du et al., 2011; Kroon et al., 2014; Nolte & Osborne, 2013; Panagioti et al., 2014; Warsi et al., 2003; Warsi et al., 2004). In a systematic review and meta-analysis of self-management programs for all arthritis, researchers found that compared with the control group, the self-management group reported a small, significant effect on pain at 12 months (Standardized Mean Difference (SMD) -0.14, 95% CI -0.23 to -0.04) and disability (SMD= -0.17 95% CI -0.27 to -0.07) (Du et al., 2011). A meta-analysis of chronic disease self-management programs found small to moderate improvements in psychological health and selected health behaviors that remained after 12 months (e.g. ES: health distress -0.23 (95% CI −0.32, −0.13), self-efficacy 0.20 (95% CI 0.08, 0.33), cognitive symptom management 0.37 (95% CI 0.26, 0.48)) (Brady et al., 2013). Panagioti et al. found that self-management support interventions reduced health care utilization without compromising health outcomes, though, again, effects were small (Panagioti et al., 2014). In a 2014 Cochrane Review of self-management programs for OA specifically (mean age 64.8 years; 68% female; 70% White or Caucasian), there was low to moderate quality evidence indicating that self-management education programs resulted in no or small benefits in people with OA. Compared with attention control, the authors concluded that these programs probably do not improve self-management skills, pain, OA symptoms, function or quality of life, and have unknown effects on positive and active engagement in life. Compared with usual care, they may slightly improve self-management skills, pain, function and symptoms, although the authors concluded that these benefits are of
unlikely clinical importance (i.e. SMD for pain: -0.19 (-0.28 to -0.10) and function: -0.18 (-0.27 to -0.09)). The drop-out rate in programs was 13% (Kroon et al., 2014).

The contents and characteristics of interventions promoting self-management vary considerably (Carnes et al., 2012). In a systematic review examining the different self-management course characteristics and components for chronic musculoskeletal pain, the researchers found that: group-delivered courses with health professional input showed more benefit in pain, physical function and self-efficacy; longer courses did not necessarily achieve better outcome (more benefit of courses less than eight weeks than greater than eight weeks); and a psychological component showed slightly more consistent benefits over each follow-up period (Carnes et al., 2012). In a meta-analysis examining arthritis self-management education alone or with exercise to improve Arthritis Self-Efficacy Scale scores, the effect sizes were found to be small to moderate regardless of whether the intervention included exercise (Brand et al., 2013).

Characteristics of OA participants within studies typically had a mean age over 60 years, were predominantly female (often >70%) and often reported to be White/Caucasian (Kroon et al., 2014). Indicators of disease were not always reported in studies. However, most participants who attended self-management programs had a diagnosis for some time (Li et al., 2012) and some studies reported that participants had arthritis in multiple joints and had other comorbidities (Kroon et al., 2014).

### 2.5.2.2 Exercise

Exercise is physical activity that is planned, structured, repetitive, and performed with an intended health benefit (Caspersen et al., 1985). Exercise consists of cardiovascular conditioning, strength and resistance training, and flexibility. Recent systematic reviews have concluded that there is sufficient evidence supporting the benefits of exercise in reducing pain and improving function in OA (Fransen et al.,
Recent guidelines also strongly recommend exercise as a primary treatment for knee OA, including land-based, water-based, and/or resistance exercises (Hochberg et al., 2012; McAlindon et al., 2014). Guidelines and reviews are based primarily on studies of older adults, often with mean ages over age 60 years, with moderate knee OA. In a recently published Cochrane review, the authors concluded that there was high-quality evidence that land-based therapeutic exercise (traditional muscle strengthening, functional training, aerobic fitness programs) provides benefit in reducing pain for at least two to six months after cessation of treatment (SMD -0.49, 95% CI -0.39, -0.59), and moderate-quality evidence showing improvement in physical function among people with knee OA (SMD -0.52, 95% CI 0.39, -0.64) (mean age of study participants all over 60 years with majority over 65 years) (Fransen et al., 2015). The magnitude of the treatment effect would be considered comparable with estimates reported for NSAIDs (Fransen et al., 2015). Meta-analyses investigating T’ai chi specifically also found favorable benefits of T’ai chi for improving pain and physical function, though authors caution that the randomized control trials (RCTs) were small and the study designs heterogeneous (the pooled SMD was −0.45 (95% CI −0.70, −0.20, P = 0.0005) for pain and −0.61 (95% CI −0.85, −0.37, P<0.00001)) for physical function (Yan et al., 2013). In individuals studies, neuromuscular training programs designed to address sensorimotor function and functional stability have been shown to be effective in improving function and reducing symptoms in people with knee injury (a group at risk for OA) and people with degenerative knee disease (Ageberg et al., 2015). While most reviews focused on the effect of exercise on pain and disability, one systematic review and meta-analysis examined the efficacy of rehabilitation programs in improving lower limb strength in OA. Using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach, the researchers found there was high quality of evidence for improved knee extension and flexion strength with low-intensity resistance programs when compared to a control in the short term, defined as six to 13 weeks (knee extension strength SMD = 0.47 (95% CI 0.29, 0.66) and flexion strength SMD = 0.74, (95% CI 0.56, 0.92)); there was moderate quality of evidence for large effect sizes for high-
intensity resistance programs when compared to a control (SMD 0.76, 95% CI 0.47, 1.06) (Zacharias et al., 2014).

Few exercise studies have focused on outcomes in younger adults. A RCT of 61 people age 36-65 years (mean age 56 years), who participated in a high intensity exercise program twice weekly for six weeks, showed no improvement in pain or function but improvements in quality of life. The lack of improvement in pain and function may have been related to the severity of disease (moderate to severe) or the high intensity of the intervention (Thorstensson et al., 2005). A RCT of 273 adults (age 35-64 years) with knee OA compared participants of a nine month strength training program, a self-management program (12 weekly classroom sessions), and a combined program. All groups had a significant and large increase from pre- to post-treatment in all physical functioning measures; there were no differences between groups at two years (McKnight et al., 2010). More research is needed focusing on the effects of exercise on adults aged 35-65 years, particularly those with early symptoms.

Less is known about the optimal types and dose of exercise to achieve optimal benefits. In a recent meta-analysis of RCTs of exercise in adults with knee OA, mean age 64.3 years, similar effects for reducing pain were found for aerobic, resistance, and performance exercise (SMD 0.67, 0.62, and 0.48, respectively; P = 0.733) (the intervention was classified as lower extremity performance exercise if the patients were practicing a specific activity with the lower extremity) (Juhl et al., 2014). The effect of aerobic exercise on pain relief increased with more supervised sessions. More pain reduction occurred with quadriceps-specific exercise than with lower limb exercise and when supervised exercise was performed at least three times a week (Juhl et al., 2014). Similarly, a network meta-analysis to compare the effectiveness of different exercise interventions in OA showed that there was no significant difference in effect estimates between different types of exercise interventions. However, the data supported better results for exercise interventions
combining strengthening with flexibility and aerobic exercise (either land or water based) (Uthman et al., 2013).

Emerging research has studied the impact of exercise on knee cartilage. In a RCT of 45 individuals (mean age 46 years) who underwent partial medial meniscal resection three to five years previously (group at risk for OA), a supervised moderate exercise program improved knee cartilage glycosaminoglycan content compared to controls (Roos et al., 2005). These findings confirmed observations made in animal studies that exercise may protect against cartilage degeneration (Brismar et al., 2003; Galois et al., 2003; Otterness et al., 1998). However, a more recent RCT of 80 women (mean age 59 years) who participated in a supervised progressive exercise program for 12 months did not find any changes in the estimated biochemical composition of cartilage. The authors proposed that this may be due to the age of subjects or pathophysiological condition of knee cartilage (Multanen et al., 2014). More long term studies are needed to understand the implications of exercise on OA progression.

Findings of etiologic and treatment studies of physical activity suggest certain types of activity are risk factors for OA (Buckwalter et al., 1997; Kujala et al., 1994; Silverwood et al., 2015) while exercise and physical activity can also improve symptoms of OA (Fransen et al., 2009; Fransen et al., 2015; van Baar et al., 2001). While more research is needed to understand the role of physical activity in OA, recent evidence suggests moderate levels of physical activity may be optimal for slowing the progression of cartilage degeneration in asymptomatic middle-aged subjects (activity determined by a physical activity measure called Physical Activity Scale for the Elderly: moderate score defined as 153-207) (Lin et al., 2013).

In sum, there is consistent evidence that exercise reduces the pain and disability of knee OA (Fransen et al., 2015; Uthman et al., 2013). Similar effects on pain were found for aerobic, resistance and performance exercise (Juhl et al., 2014). The effect of aerobic exercise on pain relief increased with more supervised sessions (Juhl et
More research is needed to determine the effect of exercise on OA progression.

### 2.5.2.3 Weight Management

Several guidelines have recommended weight loss for knee OA (Fernandes et al., 2013; Hochberg et al., 2012; McAlindon et al., 2014). A meta-analysis of RCTs in adults (mean age 60 years) showed that disability could be significantly improved when weight was reduced over 5.1% (Christensen et al., 2007). Other studies and guidelines have suggested the ultimate goal should be an initial decrease in body weight of at least 10%, in order to reduce pain (Bliddal et al., 2014). In the meta-analysis, the effects on pain, function and weight loss from attending weight loss programs were small but significant (ES: pain 0.20 (95% CI 0.00, 0.39); physical function 0.23 (95% CI 0.04, 0.42); mean weight loss was 6.1 kg (95% CI 4.7, 7.6) (Christensen et al., 2007). In a RCT comparing weight loss interventions in 454 overweight and obese adults with knee OA (mean age 66 years) after 18 months, participants in the diet and exercise and diet groups had more weight loss and greater reduction in IL-6 levels (a cytokine implicated in OA pathogenesis) than those in the exercise group. Participants in the diet group also had greater reductions in knee compressive force than those in the exercise group (Messier et al., 2013). More research is needed to determine the effect of weight loss on OA progression.

### 2.5.2.4 Biomechanical Interventions: Knee Braces and Foot Orthoses

Knee braces are designed to provide an opposing valgus force and attenuation of load on the medial compartment of the knee. Most studies of knee braces were conducted in adults over the age of 50 years. Knee braces (including unloader braces with varus or valgus force) were recommended by some guidelines (Fernandes et al., 2013; Hochberg et al., 2012; McAlindon et al., 2014) but received
an inconclusive rating from others (American Academy of Orthopaedic Surgeons, 2013). OARSI guidelines recommended knee braces as directed, rating the quality of the evidence as “fair” (McAlindon et al., 2014). Results of a systematic review suggested that knee braces are effective in decreasing pain, stiffness, NSAID dosage, and severity and in improving balance, proprioception, condylar separation, and physical function in adults with varus or valgus knee OA (Raja & Dewan, 2011). However, the authors caution that due to the heterogeneity of studies and outcome measures and poor quality of some studies, conclusive evidence cannot be stated. A more recently published meta-analysis of valgus bracing for knee OA found that compared to a control group that did not use an orthosis, the effect size was moderate for pain (SMD 0.56 (95% CI 0.03, 1.09), P = 0.04) and function (SMD 0.48 (95% CI 0.02, 0.9), P = 0.04). However, compared to a control group that used a control orthosis, only a small, statistically significant effect for pain remained (SMD 0.33 (95% CI 0.08, 0.58), P = 0.01) (Moyer et al., 2015b). In another meta-analysis, researchers found that valgus knee bracing reduced the knee adduction moment during walking (SMD 0.61 (95% CI 0.39, 0.83), P <0.001) (Moyer et al., 2015a).

Foot orthoses are meant to alter the mechanical alignment of the lower leg by enhancing valgus correction of the calcaneous (Raja & Dewan, 2011). Recommendations for medial and lateral heel wedges were inconsistent across guidelines (Nelson et al., 2014). Results of a systematic review suggested that foot orthoses (e.g. lateral wedge insoles) were effective in decreasing pain, stiffness, NSAID dosage, and severity and in improving balance, proprioception, condylar separation, and physical function in adults with varus or valgus knee OA. Again, there was heterogeneity across studies and outcome measures and the quality of some studies was described as poor (Raja & Dewan, 2011).

### 2.5.2.5 Modalities

Modalities are used by health care providers to help people with knee OA manage symptoms. A recent systematic review and network meta-analysis examining the
efficacy of different electrical stimulation therapies for knee OA found that interferential current was the only therapy that significantly changed pain scores and pain intensity at last follow-up (mean ages of study samples mainly over 60 years). The authors caution that evidence is limited due to small number of trials and their heterogeneity. Recommendations for high frequency transcutaneous electrical nerve stimulation (TENS) were uncertain and low intensity TENS, pulsed electrical stimulation and noninvasive interactive neurostimulation were deemed not appropriate for pain relief (Zeng et al., 2015). Others also have reported that the efficacy for TENS is inconclusive; one recent study showed no significant difference for pain compared to a sham group (Atamaz et al., 2012). Recommendations for therapeutic ultrasound in OA clinical guidelines vary with some guidelines not recommending use of ultrasound. Zeng conducted a recent systematic review and network meta-analysis on ultrasound for knee OA (mean age in study samples 54 years or greater), finding that pulsed ultrasound was more effective than the control group in improving pain and function, while continuous ultrasound significantly improved pain (Zeng et al., 2014). Again, there was heterogeneity in ultrasound sessions, dosage and follow-up time across studies (Zeng et al., 2014).

2.5.2.6 Summary

Findings from systematic reviews and meta-analysis show that there is consistent evidence that exercise and weight management decrease pain and improve function in people with knee OA (Christensen et al., 2007; Fransen et al., 2002; Fransen et al., 2015; Uthman et al., 2013; Yan et al., 2013; Zacharias et al., 2014). Self-management interventions are routinely recommended though effects on pain and function are generally small (Brady et al., 2013; Brand et al., 2013; Carnes et al., 2012; Chodosh et al., 2005; Kroon et al., 2014; Panagioti et al., 2014; Warsi et al., 2003; Warsi et al., 2004). Biomechanical interventions have been shown to have some positive outcomes, though the quality of the studies has been rated as poor and there is heterogeneity across studies (Moyer et al., 2015a; Moyer et al., 2015b; Raja & Dewan, 2011). Evidence for the effectiveness of modalities in improving pain
is limited, with some authors providing evidence for the benefits of interferential current and ultrasound (Zeng et al., 2014; Zeng et al., 2015). This section describes the best available evidence for management of knee OA to date. Overall, findings have been driven by results of RCTs in older adults with OA. While these findings are promising, there is a need for more evidence on effectiveness of management strategies in younger adults with knee OA symptoms. As scientific progress is made in understanding the mechanisms responsible for OA progression and the effectiveness of management strategies in younger adults with earlier symptoms, health professionals can draw on this evidence to support clients with knee OA symptoms.

2.6 Health Care Management of OA

People with signs and symptoms of OA may seek help from health care providers to get a diagnosis and advice on how to manage their symptoms. The majority of care for OA is provided in primary care. In Canada, data on visits to physicians are available from administrative databases. Data from Ontario showed that 79.4% of people who visited any type of physician for OA saw a primary care physician at least once (Mackay et al., 2010). Studies suggest that visits to primary care for OA are likely to increase: one Swedish study estimated the future impact of OA on health care in 2032, suggesting there would be at least an additional 26,000 individuals per 1 million population aged ≥45 years consulting their doctor for OA (Turkiewicz et al., 2015).

Primary care physicians in Canada provide a broad scope of services for patients with a range of acute and chronic conditions (often with multiple and complex conditions) (Jaakkimainen et al., 2006). Musculoskeletal conditions, though very prevalent, represent only a part of a physicians’ caseload. In this context, studies have reported some deficiencies in primary care management of OA. Studies of physician management have documented inappropriate referrals (Roland et al., 1991; Speed et al., 2005), lack of physician confidence in musculoskeletal skills
(Glazier et al., 1996a; Lillicrap et al., 2003; Matheny et al., 2000) and suboptimal quality of care (Ganz et al., 2006; Li et al., 2011; McHugh et al., 2007; McHugh et al., 2012). Research has shown that recommendations for non-pharmacologic interventions, such as exercise and weight loss, in primary care were particularly low (Li et al., 2011). Health care provider knowledge, attitudes and beliefs may contribute to these deficits in primary care management of knee OA (Bennell et al., 2014). Research has shown that many health care providers lack awareness of OA (Alami et al., 2011; United States Bone and Joint Initiative, 2012) assuming it is an inevitable, progressive disease that accompanies aging (United States Bone and Joint Initiative, 2012) and trivialize it in clinical practice (Alami et al., 2011). Perhaps not surprisingly, studies of people with OA have shown that use of non-pharmacologic interventions recommended in clinical guidelines, such as exercise, are generally low (Haskins et al., 2014; Hinman et al., 2015; Li et al., 2004). Even patients who have received health care support and guidance on OA management can have difficulty adhering to treatment recommendations, such as maintenance of an exercise program (Campbell et al., 2001). In order to enhance care for people with OA within the health sector, it is critical to first understand the perspectives of the people living with symptoms.

2.7 The Perspectives of People Living with OA

The importance of understanding lay perspectives on health and illness is well established in sociology (Donovan, 1991). There is a body of research depicting the ways in which people make sense of and explain their illness, how they cope and manage a chronic condition, and the consequences of illness in peoples’ everyday lives (Newbould et al., 2006; Pierret, 2003). Much of this research has been conducted using qualitative methods. It is argued that giving voice to the “sufferers’ perspective” and understanding the illness experience can lead to important clinical reforms (Conrad et al., 2010). Authors of studies of lay perspectives suggest that clinicians’ failure to recognize how people understand disease causation and risk is one of the key obstacles to the success of public health programs (Marshall et al.,
Incongruence between patients’ explanations of their condition and health care providers results in less effective communication and poorer health care results (Kleinman A, 1988). Furthermore, others argue that an understanding of the effects of disease on peoples’ everyday lives is necessary to deliver accessible and acceptable care (Murray et al., 2009). I review the literature on the perspectives of adults with OA focusing on: peoples’ perceptions of OA, management of OA and the experiences and consequences of OA. These studies tend to focus on older adults with OA. Few studies have been conducted which shed light on the perceptions and experiences of younger adults with mild-moderate symptoms.

### 2.7.1 Perceptions of OA

Qualitative research in older adults has examined lay beliefs about OA joint pain finding that people primarily perceived symptoms to be the result of aging (Dickson et al., 2003; Gignac et al., 2006; Ong et al., 2011; Sanders et al., 2002; Turner et al., 2007). Older participants often normalized and minimized symptoms, believing it to be a natural, inevitable phenomenon that was likely to progress (Cedraschi et al., 2013; Gignac et al., 2006; Ong et al., 2011; Sanders et al., 2002; Turner et al., 2007). Other perceived causes of OA described in studies were “wear and tear”, occupations, weight and heredity or an interplay of various factors (Kee, 1998; Turner et al., 2007). One study provided a particularly comprehensive analysis of the meaning of OA to older participants (mean age 76 years). The researchers found that older participants portrayed symptoms as a normal part of their biography in old age. As a result, they often did not seek treatment (Sanders et al., 2002). However, the authors also noted that four participants who were younger than the majority of the sample did not perceive symptoms to be normal, inevitable or attributable to aging and hence, were more likely to seek formal treatment (Sanders et al., 2002). Similarly, in another study, two participants (in their fifties) among a sample of older adults with OA, expressed disbelief at their symptoms and attributed the symptoms to injuries rather than aging (Turner et al., 2007). The number of younger participants in these studies is small and it is difficult to draw any
conclusions. However, the findings do point to the need to investigate the perceptions of OA symptoms in younger adults.

Other studies of older adults have provided insight into how specific groups understand OA. Nui et al. studied the perceptions of OA in a developing nation and found that participants (mean age 62 years) related the cause to God’s will or contact with water, suggesting there may be cultural differences in how people understand symptoms (Niu et al., 2011). Turner et al. studied OA in ex-soccer players (mean age 64.5 years) and found they had a strong motivation to understand the cause of their symptoms and related it to aspects of their playing career, such as injury, trauma, playing in pain or surgery (Turner et al., 2002). The men adopted a stoical attitude and considered OA as something that had to be endured and accepted as “a price worth paying” (Turner et al., 2002). This research provides unique insight into the perceptions of men with OA. However, these findings were drawn from a sample of older, male ex-soccer players and may not reflect the views of younger men or women with knee symptoms who are not professional athletes.

While these studies of primarily older adults provide some insight into the ways in which people understand symptoms, people often make sense of their illness in terms of past experiences (Bury, 1982). Younger adults may have different experiences and explain symptoms in different ways. To date, there is little research specifically focused on how younger adults with OA symptoms understand their OA. I will discuss two studies of younger adults with knee OA which touched on this topic. First, Maly and Cott conducted a qualitative study in 26 adults age 40-65 years to understand the process of recognizing the emergence of chronic knee symptoms (Maly et al., 2009). In this research, the authors mentioned that younger adults were uncertain of the meaning and significance of their symptoms for years before becoming aware of a chronic problem. However, it was not the intent of the research to explore how people understood and explained symptoms in depth. Second, Kao and Tsai conducted a qualitative study with adults (mean age 49.5
years) with diagnosed knee OA in Taiwan, and found that people were unfamiliar with OA and often linked it to occupations, previous disease and aging (Kao et al., 2012). They also did not believe it was possible to control OA progression. While findings from this study provide promising insights into how people perceive OA, the sample primarily included labourers and may have limited applicability in the Canadian context (e.g. due to cultural differences).

In sum, a small body of literature has explored how older adults perceive OA, suggesting that symptoms are viewed as a normal part of aging (Dickson & Kim, 2003; Gignac et al., 2006; Ong et al., 2011; Sanders et al., 2002; Turner et al., 2007). There is a gap in our understanding of how younger adults with OA perceive their symptoms. Few studies have focused on people under age 60 and existing studies including younger adults report divergent findings related to participants perceptions of cause (one suggesting OA was a normal part of aging (Kao et al., 2014) and two other studies with a few younger participants attributing OA to other causes such as injuries (Sanders et al., 2002; Turner et al., 2007)). Understanding how younger people perceive symptoms is important as it has been linked to peoples’ responses to symptoms. For instance, Hampson et al. reported that patients who believed they were responsible for causing their OA were more likely to believe that they could alleviate symptoms through their own actions (Hampson et al., 1994).

2.7.2 How People Manage OA Symptoms

Qualitative studies have focused on older adults with OA, illuminating the actions people take to manage their OA within the context of their lives. Studies have suggested people have used strategies such as exercise, alternative therapies, medications and heat/cold to manage OA (Alami et al., 2011; Maly et al., 2007; Ong et al., 2011). Research has highlighted that people over 65 managed by making incremental adjustments and adaptations to maintain ‘normal’ daily life and fulfil social roles by experimenting and learning from experience (Morden et al., 2011;
Ong et al., 2011). The authors suggest participants do not tend to ask for help from clinicians, as OA is normalized as part of aging (Morden et al., 2011; Ong et al., 2011). However, given the sample only included those who were deemed to be self-managers and who had not had recent contact with their physician, it is unclear if, how and why others might seek health care for OA management. Another study of adults age 62-87 years with physician-diagnosed OA found that participants sought information from peers rather than physicians to make decisions about management (Maly & Krupa, 2007). In contrast, Kee’s study of adults age 62 to 92 found that participants did seek their doctor’s advice but were pragmatic about management, judging interventions by their own perceived effectiveness (Kee, 1998). From the limited literature on older adults to date, it is difficult to draw conclusions on how people manage OA and why they respond to symptoms in particular ways (e.g. seeking health care support or not).

Little is known about how younger adults manage knee symptoms. Maly’s study of 40-65 year olds with knee OA mentioned that participants used a variety of strategies including thermal modalities, over-the-counter remedies, neoprene sleeves, orthoses, diet and exercise. Even participants without a diagnosis of OA modified or gave up activity during the process of recognizing knee problems (Maly & Cott, 2009). Kao’s study in Taiwan provides further insight on the types of strategies used. Participants described modifying their posture to carry out activities, altering exercise to avoid knee pain, changing eating habits to control weight, and making adaptations at work to manage symptoms (Kao & Tsai, 2012; Kao & Tsai, 2014). While promising, it is unclear if these strategies reflect management in Western countries. Moreover, participants were recruited from orthopedic clinics (Kao & Tsai, 2012; Kao & Tsai, 2014); exposure to this type of health service may have influenced how they approached management.

In sum, studies of older and younger adults suggest people are making some efforts to manage OA (Kao & Tsai, 2012; Kao & Tsai, 2014; Maly & Krupa, 2007; Maly & Cott, 2009; Morden et al., 2011; Ong et al., 2011). However, there is a paucity of
data exploring management of OA in adults under age 60. Since the primary focus of studies including younger adults was not on management, the findings present what may be an overly simplistic depiction of the management of knee OA focusing on the types of strategies used. It remains unclear what processes younger adults with OA engage in as they respond to and manage symptoms.

2.7.3 Experiences and Consequences of OA

There has been some interest in peoples’ experiences with OA and the consequences of symptoms on their lives. Research from qualitative studies of older adults (mean ages typically over age 60 years) emphasized participants’ experiences living with pain and reduced mobility and the broader impact of OA symptoms on life including household activities, leisure and social activities, finances, work and family (Keysor et al., 1998; Maly & Krupa, 2007; Turner et al., 2002). Studies also described sedentary lifestyles and social isolation as a result of OA symptoms (Maly & Krupa, 2007). However, qualitative studies often have been narrow in scope (e.g. specific to experiences of pain or fatigue (Power et al., 2008), had very small sample sizes (Maly & Krupa, 2007) and included mainly older, retired adults with more advanced disease (Sanders et al., 2002). Busija et al. undertook to develop a conceptual model of the burden of OA that was broader in scope by conducting concept mapping workshops with patients and a range of health care providers (Busija et al., 2013). Patients were a mean age of 63.9 years (range 51-80 years) and recruited from rheumatology clinics. As such, it is possible they represented people with more advanced OA. The study generated eight aspects of the burden of OA: physical distress, fatigue, physical limitations, psychosocial distress, physical deconditioning, financial hardship, sleep disturbances and lost productivity (Busija et al., 2013). While this study provides useful insights into the areas that are affected by OA, it focused on generating concepts based on participant statements during the mapping process. As a result, it lacks the rich description within each concept that could help us understand the complex reality of living with OA.
Only a few studies of younger adults with OA explored peoples’ experiences and the consequences of symptoms on their lives. One qualitative study explored experiences in 25-45 year olds with knee OA secondary to injury suggesting life with OA involved pain, fear, isolation, and loss of function and identity (Keysor et al., 1998). The study was limited by a small sample size (n=4) and it is unclear if data saturation, the accepted criteria for stopping data collection (Tong et al., 2007), was achieved. Kao and Tsai studied middle-aged adults (mean age 49.5 years) with knee OA in Taiwan and touched on the consequences of symptoms, describing pain in physical tasks such as going up and down the stairs and difficulty squatting. Since participants were mainly manual labourers, findings emphasized the consequences on work and income (i.e. reductions in work and family income) (Kao & Tsai, 2012). Gignac et al. compared the experiences of middle and older aged adults with healthy controls in a qualitative study, highlighting the impact of OA on social roles (work, leisure activities), interpersonal relationships and mood (Gignac et al., 2006). However, the OA participants still represented a relatively older sample (mean age 59.8 years +/- 12 years) with established OA (fulfilling American College of Rheumatology criteria for OA) (Gignac et al., 2006).

With the exception of some work in older adults (e.g. Sanders et al., 2002), studies generally failed to provide detailed accounts of the consequences of OA. The limitations in the studies including younger adults (e.g. limited to those with injuries, mainly laborers) make it difficult to draw many firm conclusions from this literature. What we can glean from the literature is that OA has a broad range of consequences on peoples’ lives and that the general types of consequences appear to be similar in younger and older adults. Lacking is research which provides a comprehensive in-depth look at what it is like to live with mild or moderate OA symptoms earlier in life.
2.7.4 Summary

Despite the significant individual and societal burden of OA (Hunter et al., 2014), research exploring the perspectives of people with OA is sparse in general and particularly limited in younger adults. However, studies using qualitative methods have provided some useful insights into the perceptions and experiences of OA in older adults (Busija et al., 2013; Dickson & Kim, 2003; Maly & Krupa, 2007; Morden et al., 2011; Ong et al., 2011; Sanders et al., 2002; Turner et al., 2002; Turner et al., 2007). The lack of studies in younger adults and limitations within current studies leave a gap in our understanding of how younger adults perceive OA symptoms, the consequences on their lives and how they manage symptoms.

2.8 Study Rationale

The burden of OA is likely to increase with the aging of the population and increasing rates of obesity and knee injury (Hunter et al., 2014; Turkiewicz et al., 2015). While OA has often been viewed as an inevitable disease of older adults (Alami et al., 2011; United States Bone and Joint Initiative, 2012), the evidence suggests OA is a serious chronic condition affecting people relatively early in life (Losina et al., 2013). Yet, the primary focus of knee OA has been on older adults. In order to alleviate the mounting burden of OA, there is a need to shift our focus to younger adults and to reducing the pain and disability of knee symptoms at an earlier stage. Yet, we know very little about younger adults with knee symptoms. The review of the literature has highlighted that research has primarily focused on the perceptions, experiences and management practices of older adults with OA. Studies of older adults may not reflect the perceptions and experiences of younger adults with knee symptoms. Empirical evidence from studies of different chronic illnesses have shown that the experience of chronic illness varies by age and that peoples’ position in the life course may inform their disease perceptions (Atkin et al., 2000; Pierret, 2003; Sanders et al., 2002). Currently, there are gaps in our understanding of how younger people who have knee symptoms understand and
explain symptoms, the processes younger people engage in as they respond to and manage knee symptoms and what the consequences of symptoms are on their everyday lives. This thesis will address these gaps. By providing insight into this understudied population, we will be able to begin to support the development of interventions which facilitate primary and secondary prevention of OA symptoms at younger ages.

2.9 Goal and Objectives

The overall goal is to contribute an in-depth understanding of the perceptions and experiences of adults aged 35-65 years with knee symptoms to support the development of recommendations and interventions to reduce knee symptoms or prevent the progression of knee symptoms and associated disability in younger adults.

The specific objectives are as follows. To explore, in adults aged 35-65 years with knees symptoms:

1. the meaning of knee symptoms to people;
2. how people manage knee symptoms; and
3. the consequences of knee symptoms on peoples’ lives.
Chapter 3: Overview of Methods
3.1 Chapter Overview

This chapter provides an overview of the research methods. The specific details of the methods used to conduct the study can be found in the individual papers in Chapters four to six.

3.2 Research Design

A qualitative research design was selected to address the research objectives. Qualitative research uses an inductive approach to make sense of complex processes and offers the researcher the ability to attempt to understand the meaning or nature of experience of persons with problems such as chronic disease (Corbin et al., 2008) making it an appropriate approach for my objectives.

3.3 Theoretical Perspective

This research was situated within an interpretive research paradigm which aims to seek understanding of a phenomenon based on personal experiences, interpretations and perceptions (Denzin et al., 2000). It is posited that theory has many functions in qualitative research and can enter the research at different stages (Sandelowski, 1993). In addition to having an interpretive lens, there are also examples in which concepts inductively developed from the analysis of the data were then compared to concepts from the literature. For example, in Chapter six, I compare a category developed in the research process (a new way of thinking about the knee) to Gadow’s conceptualization of embodiment.

3.4 Grounded Theory Method

The principals and methods of grounded theory guided this study. Grounded theory is a tradition of inquiry consistent with the interpretive paradigm. Grounded theory
comprises a systematic, inductive and comparative approach for conducting inquiry in order to construct theory (Charmaz, 2006). It aims to describe, explain and predict complex processes and represent the perspectives of the person (Corbin & Strauss, 2008). This makes it an ideal approach to inductively explore the perceptions and experiences of people with knee symptoms from their perspective.

Grounded theory has been a commonly used qualitative method since its development in the 1960s. Permutations of grounded theory have evolved over time. Several authors have argued that there are some key features common to grounded theory; these include constant comparative analysis, iterative data collection and analysis, theoretical sampling, and memoing (Bryant et al., 2007). In my work, I was guided primarily by the key principles of constructivist grounded theory, developed by Charmaz, in which researchers are viewed as co-creators of data through interaction in the research process (Charmaz, 2009).

3.5 Positionality

Throughout the research process, I tried to recognize my role as a co-producer of participants’ accounts. I recognized that my presence, demeanor, demographic characteristics (Caucasian, university-educated, female in her thirties) and the questions and probes I used in the focus groups and interviews influenced what participants chose to speak about, what they avoided and how they presented themselves. I was aware that my clinical experience as a physical therapist and years of work in arthritis research sensitized me to recognize certain aspects of participants’ accounts. This awareness helped me to challenge some of my own assumptions throughout the research process. To promote reflexivity, I wrote memos about developing categories and concepts and kept a personal journal in which I captured my reflections, thoughts and feelings related to focus groups/interviews, interpretations of the data and developing concepts. I reflected on my underlying assumptions and analytic lenses through which I was seeing the data, particularly my clinical view. My thesis program advisory committee (PAC)
also helped to promote reflexivity by reviewing transcripts, asking questions, and
discussing alternate interpretations of the data at regular meetings. For example, in
early focus groups, there were instances when “clinical” language such as
“management” crept into my questions. By highlighting this, I became more aware
of the language I took for granted and made conscious efforts to avoid such “clinical”
language as much as possible, instead asking general questions such as “what do
you do about your knee symptoms?".

3.6 Approach to Data Collection

Both focus groups and one-on-one interviews were used for data collection. Multiple
sources of data have been advocated within a single qualitative study to enhance
the conceptualization of the phenomenon (Corbin & Strauss, 2008). Focus groups
and interviews have been combined to enhance data completeness by revealing
different parts of a phenomenon and contributing to a more comprehensive
understanding (expanding on the breadth or depth of findings) (Lambert et al.,
2008). There are a number of examples of the combined use of interviews and
focus groups in grounded theory studies (Dick et al., 2006; Lambert et al., 2009;
Molzahn et al., 2005; O'Brien et al., 2008). In previous research, focus groups have
been found to be useful at examining the range of participants’ experiences, while
individual interviews contributed to the detailing of the experiences (Lambert &
Loiselle, 2008). Combining data sources also enhanced the understanding of the
structure or context of the phenomenon (i.e. the circumstances in which problems,
issues, or events are situated) (Lambert & Loiselle, 2008). In my study, focus
groups were used to understand the breadth of participants’ experiences.

Management of knee symptoms was central to the discussion within the focus
groups (findings reported in Chapter five). Next, interviews were used to provide a
more in depth understanding of the meaning of knee symptoms to participants
(Chapter four) and the consequences of knee symptoms on peoples’ lives (Chapter
six). Focus groups also helped to refine interview questions. The interviews built on
the analysis of the focus group data, in that categories which were emerging from
analysis of focus groups were further developed and refined through analysis of interviews.

Specific details of data collection are provided within each paper in chapters four to six. The telephone scripts, screening questionnaire, participant questionnaire (including demographics and the Knee Injury and Osteoarthritis Outcome Score (KOOS)), consent forms and Research Ethics Board approvals are provided in the Appendices.
Chapter 4: A Qualitative Study Exploring the Meaning of Knee Symptoms to Adults Aged 35-65 Years
4.1 Chapter Overview

This chapter explores the meaning of knee symptoms to adults age 35-65 years. Data collected from the focus groups and one-on-one interviews with adults with knee symptoms were analyzed to develop a core category which explained the participants' central understanding of their knee symptoms. This chapter has been modified from an article which has been accepted for publication in the journal Arthritis Care and Research:

MacKay C, Sale J, Badley EM, Jaglal SB, Davis AM. A Qualitative Study Exploring the Meaning of Knee Symptoms to Adults Aged 35-65 Years. Accepted for Publication by Arthritis Care and Research July 2015 (MacKay et al., 2015).

4.2 Introduction

Osteoarthritis is recognized as one of the greatest public health challenges facing many societies. While the highest prevalence of OA is in older adults, the incidence of OA in adults age 20-50 years is substantial (Kopec et al., 2007). A recent study from the US reported that the median age at diagnosis of knee OA is 55 years, earlier than prior research (Losina et al., 2013). A variety of etiologic risk factors contribute to OA including obesity, genetics, aging and joint injury (Blagojevic et al., 2010; Lawrence et al., 2008; Silverwood et al., 2015; Toivanen et al., 2010; Valdes et al., 2009). Knee injury and obesity, both of which are on the increase (Cooper et al., 2000; Niu et al., 2009; Wilder et al., 2002), are likely to lead to even higher rates of OA in younger adults (Lobstein et al., 2004). In order to mitigate the increasing burden of OA, there is a pressing need to develop interventions which support management using evidence-based strategies (e.g. exercise, weight loss (Hochberg et al., 2012)) beginning in the third or fourth decade of life when symptoms may begin. A greater focus on preventing the onset of OA and altering the course of OA is also needed.
Illness meanings reflect peoples’ personal experiences and explanations of their conditions (Kleinman, 1988). Researchers have suggested that a failure of clinicians to understand how people understand their condition is one of the key obstacles to the success of public health programs (Lawlor et al., 2003; Marshall et al., 2012). Prior research related to illness meanings in OA has focused on what individuals over age 60 believed were the causes of OA, often citing “wear and tear” and aging (Pouli et al., 2013; Richardson et al., 2013; Sanders et al., 2002; Turner et al., 2007). It is less well understood how younger adults understand their knee symptoms. One study of Taiwanese adults (mean age 50), mainly labourers, found that participants attributed their knee OA to excessive joint loading, injury or other disease, diet, and genetics (Kao & Tsai, 2012). Given the paucity of research in this population, I aimed to explore the meaning of knee symptoms to people aged 35-65 years, focusing on how people understood or perceived their knee symptoms. A better understanding of how adults understand their knee symptoms is a critical first step in the development of interventions on OA prevention and management.

4.3 Methods

4.3.1 Study Design

This study used qualitative methods drawing on the principles and methods of constructivist grounded theory (Charmaz, 2006). In constructivist grounded theory, researchers aim to understand participants’ beliefs and actions from their perspectives and locate participants’ meanings within larger social structures and discourses (Charmaz, 2006).

4.3.2 Sampling and Data Collection

Individuals from the Greater Toronto Area were recruited using advertisements in a community paper, an acute hospital and community centres. Individuals were included if they were aged 35-65 years and self-reported a diagnosis of knee OA or
reported that they had knee symptoms (i.e. pain, aching or stiffness) on most days of the past month, recognizing that younger adults may not have a diagnosis or perceive their symptoms to be OA. The knee symptoms screening question was based on a widely used survey question on joint pain (Centres for Disease Prevention and Control, 2013). Participants were excluded if they: had a knee injury in the past year (to exclude acute injuries); had knee pain referred from the low back; had other types of arthritis (e.g. inflammatory arthritis); were waiting for, recommended or had undergone TJR; or had other chronic physical health conditions (e.g. Parkinson’s Disease, stroke) that affected their mobility. Knee pain referred from the hip was not an exclusion criteria; in a study of hip joint pain referral patterns only 2% of patients had knee pain (Lesher et al., 2008). Since some of the participants had OA-like symptoms (25/51 (49%)) but did not have diagnosed OA, I use the term knee symptoms. If findings pertained only to participants who self-reported diagnosed OA or who reported OA-like symptoms, this is specified in the results.

Purposive sampling was used, initially seeking variation across age and males and females. As data collection and analysis progressed, I continued to seek variation in age to explicate emerging categories. Data collection was stopped at the point of saturation, when no new information relevant to our research question (e.g. categories) was generated (Coyne, 1997).

This study employed focus groups and individual interviews. Focus groups were used to explore the range of participants’ experiences; individual interviews contributed to the detailing of the experiences (Lambert & Loiselle, 2008). Interviews built on the analysis of focus group data. First, six semi-structured focus groups (n=41) were conducted in hospital boardrooms. Participants were grouped in focus groups by age (35-49 years and 50-65 years) to create homogeneous age groups (Lambert & Loiselle, 2008). I moderated the focus groups and a second researcher kept a speaker log and took notes summarizing verbal and non-verbal communication. A focus group guide was used to facilitate discussions (Table 4.1).
Following the focus groups, 10 semi-structured one-on-one interviews were conducted with new participants. The interview guide was refined based on the analysis from the focus groups (Table 4.1). Interviews occurred in a private room at the hospital or the participant’s workplace. I conducted all interviews. The focus groups lasted 1.5-2 hours and interviews lasted approximately one hour.

Table 4.1 Question Guides: Focus Groups and Interviews

<table>
<thead>
<tr>
<th>Focus Group Guide</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tell me about what is happening with your knee(s).</td>
</tr>
<tr>
<td>2. We are interested in your experiences with your knee in your daily life. Can</td>
</tr>
<tr>
<td>you tell me how your knee fits into your daily life?</td>
</tr>
<tr>
<td>3. When you think of yourself 10 or 20 years down the road, what do you think</td>
</tr>
<tr>
<td>might happen with your knee?</td>
</tr>
<tr>
<td>4. What do you do for your knee?</td>
</tr>
<tr>
<td>5. After having your experience, what advice would you give someone else</td>
</tr>
<tr>
<td>who has just started to have knee issues?</td>
</tr>
<tr>
<td>6. Do you have anything else you wish to say about living with your knee</td>
</tr>
<tr>
<td>symptoms?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Interview Guide</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tell me about the problems you have been having with your knee(s).</td>
</tr>
<tr>
<td>2. How did your knee problems develop?</td>
</tr>
<tr>
<td>3. Has your knee changed things for you in your life? How?</td>
</tr>
<tr>
<td>4. What is your knee like on a day to day basis?</td>
</tr>
<tr>
<td>5. Tell me about a day when you don’t require much from your knee.</td>
</tr>
<tr>
<td>Tell me about a day when you require a lot from your knee.</td>
</tr>
</tbody>
</table>

6. Tell me about how you feel about your knee?
7. Thinking about your knee, what do you think about the future?
8. Do you have anything else you wish to say related to your knee? Is there
   anything else you’d like to raise that we didn’t talk about today?
All focus groups and interviews were audio-recorded, transcribed verbatim and entered into Nvivo9, a qualitative software program. Field notes were written to summarize data and reflect on any questions I had about the data. Following the focus group/interview, participants completed the KOOS. These data were used to describe participants’ knee symptoms and function to enable readers to place the findings of this study in the wider context of other studies of knee OA. This study was approved by the Research Ethics Board at University Health Network and the University of Toronto. Informed written consent was received from all participants.

4.3.3 Analysis

Data analysis was conducted concurrently with data collection to allow for developing themes to be pursued in subsequent focus groups/interviews. A constant comparative method of analysis was used (Charmaz, 2006). Analysis included open coding, axial coding, and developing a core category which explained the central theme of the data (Corbin & Strauss, 2008). I open coded the data and created a coding scheme which was reviewed by my PAC members. My supervisor read all the transcripts and other PAC members read the majority of the transcripts. We met regularly to discuss the data and ongoing analysis, including alternate interpretations of the data. Analysis included multiple readings of the transcripts to understand the meanings central to peoples’ understanding of knee symptoms. Memos were written to make comparisons across data from each participant and focus group, explicate categories and identify gaps in the analysis. Data were analyzed for patterns in younger and older age groups. If age was interpreted to influence the study findings (i.e. finding were more prominent in younger or older adults in the sample), this is indicated in the results.

I integrated principles for enhancing quality in qualitative research (Reynolds et al., 2011; Tracy, 2010) including using: a systematic approach to designing, conducting and analyzing the study; an audit trail (to document decisions throughout the study); a field diary to enhance reflexivity; and use of quotations. Methods recommended to
ensure quality in grounded theory were also incorporated (concurrent data collection and analysis, constant comparative analysis and memoing) (Charmaz, 2006; Elliott et al., 2005).

4.4 Results

Fifty-one individuals with moderately symptomatic OA based on their KOOS scores (de Groot et al., 2008) participated (Table 4.2 describes the participant demographics; Table 4.3 describes their knee symptoms and function (i.e. KOOS scores)). An overview of the core category is presented, followed by a more detailed description of the two categories which are subsumed under the core category. Illustrative quotes are presented in Table 4.4. All names are pseudonyms.
Table 4.2 Participant Demographics (n=51)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>49</td>
</tr>
<tr>
<td>Minimum</td>
<td>37</td>
</tr>
<tr>
<td>Maximum</td>
<td>65</td>
</tr>
<tr>
<td>Interquartile range</td>
<td>(44, 58)</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td>31 (60.8)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>5 (9.8)</td>
</tr>
<tr>
<td>Trades Certificate/Diploma or College Graduate</td>
<td>16 (31.4)</td>
</tr>
<tr>
<td>University Graduate</td>
<td>30 (58.8)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Married/Living as Married</td>
<td>21 (41.2)</td>
</tr>
<tr>
<td>Divorced/Widowed/Never Married</td>
<td>30 (58.8)</td>
</tr>
<tr>
<td><strong>Work</strong></td>
<td></td>
</tr>
<tr>
<td>Currently Working</td>
<td>40 (78.4)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>7 (13.7)</td>
</tr>
<tr>
<td>Retired</td>
<td>3 (5.9)</td>
</tr>
<tr>
<td>Student</td>
<td>1 (2.0)</td>
</tr>
</tbody>
</table>
Table 4.3 Knee Symptoms and Function

<table>
<thead>
<tr>
<th>KOOS Subscales</th>
<th>Scores (mean, SD)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms</td>
<td>67.02 (14.08)</td>
</tr>
<tr>
<td>Pain</td>
<td>63.69 (18.01)</td>
</tr>
<tr>
<td>Function in Daily Living</td>
<td>68.78 (18.26)</td>
</tr>
<tr>
<td>Function in Sport and Recreation</td>
<td>52.05 (27.86)</td>
</tr>
<tr>
<td>Knee Related Quality of Life</td>
<td>43.0 (19.22)</td>
</tr>
</tbody>
</table>

*KOOS scores range from 0-100 for each subscale with 100 indicating no symptoms and 0 extreme symptoms

Table 4.4 Illustrative Quotes by Category: The Meaning of Knee Symptoms

Explanation of Symptoms

Cause of Symptoms

“I’ve thought about it, but from what I understand it’s wear and tear. I mean I’ve worked a lot. I’ve been on my feet a lot. I’ve had my sports things that I used to do, like windsurfing and tennis and all these things, so maybe that’s caused some of it, and I’ve had sedentary periods.” (Audrey, age 63, interview)

“I was trying to get the casing off the light so I twisted and when I twisted, I lost my footing on the stepladder. I landed on my feet but when I landed my leg was twisted so it was just enough to kind of mess everything up.” (Emma, age 42, interview)

“But I played a lot of rugby. And I had a bad injury.” (Nigel, age 61, focus group 3)

“My problem also is with my left knee as well. I had a ski injury when I was in my 20s and now I’m in my late 40s. I never really had it formally diagnosed.” (Idelle, age 46, focus group 6)
“Mine goes back, it’s probably 15 to 20 years. It’s one of the things where I’ve pretty much always known, where I’ve always experienced the pain. I was heavier. I’ve lost like 100 pounds, and the main reason I did lose the 100 pounds was because it was very painful on the knee.” (Isabel, age 48, focus group 4)

**Prevention of Symptoms**

“If I could rewind, I would try and be as equally active as I ever was, but in different sports. I wouldn’t play collision sports because as well as knee pain, I mean there’s head trauma... But swimming or sports that don’t require unnatural strain and stresses on joints. If I could rewind for my sons, I would discourage them to play contact or collision sports as well because both did and who’s to say what will happen when they’re my age.” (Davis, age 61, focus group 5)

**Course of Symptoms**

“It’s a degenerative disease, so it’s going to be worse.” (Katia, age 43, focus group 4)

“I’m assuming it’s just going to be a life long condition, but I feel good now at least about how I can manage it.” (Rebecca, age 37, interview)

“I just think the future will be like this, unless I do something stupid like try to run or play hockey too much or do something that really injures it permanently.” (James, age 42, interview)

“Well I’m hoping they keep as they are, they don’t get any worse. So with good management and careful activity and consciousness of not breaking them or pushing the strain I can keep them as they are.” (Oscar, age 59, interview)

**Experience With Symptoms**

*Symptoms Made Participants Feel Old but were not Perceived as an Inevitable Part of Aging*

“It makes you feel like you’re older than you are and also that you can’t do as many things as you used to. So you go from one spectrum to the other.” (Emma, age 42, interview)
“I guess it’s more relating to people differently, more with older people, I guess. It doesn’t usually happen to kids, to teenagers, but then I didn’t think I was that old either. I guess it was sort of a little bit of a wakeup call that I’m middle-aged now.” (James, age 42, interview)

“Well yeah, I mean our generation is never going to get old.” (Rachel, age 55, focus group 1)

“Then my family doctor says you have to recognize the fact that you’re getting older. So you’re going to get pains. Then I started to say well, wait a minute.” (Nigel, age 61, focus group 3)

### 4.4.1 Core Category: Knee Symptoms are Preventable

Central to participants’ understanding of knee symptoms was a perception that symptoms were preventable, meaning there was the potential to prevent the onset of symptoms and to alter the course of symptoms. Participants conceptualized their symptoms as a health problem which had a physical cause that might have been prevented and should be amenable to control. This understanding was reflected in how participants explained symptoms and described their experiences with symptoms (Figure 4.1). When explaining symptoms, participants reflected on their understanding of the cause, prevention and course of symptoms. These conceptualizations were interconnected as their perceptions of cause influenced their views on how the onset of symptoms may have been prevented and their beliefs about the future course of symptoms. Participants often attributed symptoms to modifiable actions (e.g. jogging), incidents (e.g. injuries) or characteristics (e.g. being overweight). As a result, they often believed they might have been able to prevent the onset of symptoms had they changed their behavior earlier in life. Most participants believed symptoms could progress but that the course of symptoms
could be controlled to some extent through their actions. Moreover, participants reflected on their experience with symptoms, indicating that symptoms made them feel older than their current age. However, they did not perceive their symptoms as normal or acceptable for this stage of life.

Figure 4.1 Core Category: Knee Symptoms are Preventable

4.4.1.1 Explanation of Knee Symptoms

*Cause of Symptoms*

Participants explained knee symptoms by recounting their personal biographies and relating their symptoms to prior actions, incidents, personal characteristics or family history. While their explanations of the cause varied among participants, common across accounts was at least partial attribution of symptoms to actions or incidents that were modifiable.

Some participants, particularly adults with a diagnosis of OA, understood their symptoms as overuse of the joint. Participants described the activities they thought may have contributed to their knee problems including leisure activities (e.g. martial arts) and occupations that required extensive walking, kneeling or lifting. Participants used language such as “abuse”, “overuse” and “wear and tear” to describe the
cause. Some participants talked about how they “pushed” their bodies too far. They perceived the knee only had a certain capacity to withstand activity. For example, one participant, who attributed his knee pain to years of jogging and squash, stated: “What has happened is in some ways when you abuse or overuse it, there is a wear…in my case, I overused it more than a normal function which the body was supposed to do.” (Chata, age 65, interview)

Some participants, particularly younger participants, accounted for their knee symptoms by referring to a knee injury, some of which occurred as recreational athletes. Marta explained an injury she attributed to her knee symptoms: “I’m a master in tae kwon do. And I was in the [championship] in ’95 and I had to flex my knee and my knee popped. That was the first time that my knee gave out.” (Marta, age 44, focus group 2) Others recounted knee injuries from falls. Adam (age 54, interview) explained: “The right side was [injured] coming off of a stepladder.”

Being overweight was considered a cause or contributing factor to knee symptoms by putting excess load through the knee. One participant shared his understanding of the effect of weight on his knees: “I carry about 10 pounds, which I’ve been told that it’s multiplied by 15 on your knee.” (Peter, age 57, focus group 1) Another participant explained that carrying her backpack increased her knee pain. She then stated: “Obviously, what I’m carrying on my body must contribute to my knee pain.” (Yvetta, age 57, interview)

Some participants indicated family members had OA and suggested that heredity may have put them at risk for their knee symptoms. Samantha (age 44, focus group) explained: “It’s hereditary because my grandmother has it, my mom has it, my sister has it.” Interestingly, participants did not attribute their symptoms solely to age. Like heredity, when age was mentioned by a few participants as contributing to their symptoms, it was typically in conjunction with other causes.
**Prevention of Symptoms**

In linking their symptoms primarily to actions or incidents, some participants believed they could have prevented the onset of symptoms had they changed their behavior earlier in life. Some participants indicated that if they had not engaged in high impact activities, reduced the extent they performed activities, or avoided injuries, they might have prevented their knee symptoms. This was particularly common for older adults. For example, one participant told us: “What should I have done different? I think I would have stopped jogging. I would have gone more on a bike... It was nice at that time, but there is a payback.” (Chata, age 65, interview)

**Course of Symptoms**

Most participants believed that symptoms had the potential to “get worse” over time. In particular, participants with diagnosed OA believed that OA was a progressive “degenerative disease”. However, common to most participants’ accounts was a belief that they could halt or slow the progress of symptoms to some extent through behaviors, such as exercise and diet. One man reflected: “I think you can control the pace of it [degeneration] and I think you can control your lifestyle, your eating habits, and I think you can stretch it out.” (Brent, age 45, focus group 4)

Some participants with a history of knee injury believed that their symptoms would not progress as long as they did not “injure” their knee again. Others believed they could have limited progression of symptoms had a prior knee injury been dealt with at the time of injury (e.g. with appropriate health care interventions). For instance, one participant who injured her knee as a teen figure skating, recalled that neither she nor her family thought much of the injury at the time, and had not sought treatment. However, she believed the repercussions of the injury were long-term: “If you circle it all back, it goes right back to that knee injury and the inability really to get it solved permanently.” (Sadie, age 47, interview)
4.4.1.2 Experience with Symptoms

*Symptoms Made Participants Feel Old but were not Perceived as an Inevitable Part of Aging*

Participants expressed that the changes they experienced in their physical abilities due to their knee symptoms made them feel “old”. Participants suggested that their physical symptoms drew their attention to their age and made them think about what that age meant. It was particularly common for adults in their 50s and 60s to reflect on aging. One participant commented: “*I don’t like being reminded that I’m getting older.*” (Davis, age 61, focus group 5) Some younger participants also reported that their knee symptoms made them feel older. A 42 year old male spoke about how young he felt when he was running. After he gave up running due to his knee symptoms, he stated: “… *it’s like I’ve aged 20 years.*” (James, age 42, interview)

Another way participants indicated that their symptoms made them feel older was through shifts in their social relationships. Some participants conveyed that they related more to older individuals with health problems. For example, one participant indicated: “*I’ve had a couple of really good friends that have been there for me. And I mean they’re older people so they have their own health issues so they understand a bit better.*” (Emma, age 42, interview)

While symptoms may have made some participants feel older, they did not perceive their symptoms as normal or acceptable. Some participants in their thirties and forties had difficulty accepting a diagnosis of OA, when they perceived OA was a condition common to “older” adults. Other participants believed their bodies should still be capable of healing. For instance, one participant commented: “*As a youth, when you got injured, your body would repair itself. I still can’t figure out why my body is not repairing itself.*” (James, age 42, interview)
Older participants did not normalize symptoms as an inevitable part of aging. They compared themselves to peers who did not have symptoms and associated physical limitations as well as their expectations of their bodies which suggested to them this was not normal. Older participants often suggested that the social messages they received indicated that they would have long active lives in which they would not “grow old”. For example, one 63 year old woman reflected: “The other thing is all the ads. In my mind when I was this age, up until I was 90, I envisioned myself continuing to play tennis, continuing to ski, all these things that I like to do. My friends from California send me pictures and they’re hiking in the mountains with their partners and they’re the same age that I am.” (Audrey, age 63, interview)

While participants believed symptoms were not normal or inevitable, they often recounted experiences with health care professionals, in which their symptoms were viewed as something that could not be significantly changed. Some older adults felt symptoms were dismissed by their health care provider as an inevitable part of getting older. One participant recounted: “I went to a rheumatologist. He said you probably have osteoarthritis. That’s an old age thing. You just have to live with it.” (Sarah, age 57, focus group 3) This resulted in incongruence between their understanding of symptoms and their interpretation of the health care providers’ understanding of symptoms.

4.5 Discussion

Central to participants’ understanding of their knee symptoms was the perception that there was potential to prevent the onset and limit progression of symptoms. Symptoms were not perceived as normal or inevitable. These findings are in contrast to prior research in adults primarily over age 60, which suggested people constructed OA as a normal part of aging (Richardon J et al., 2013; Sanders et al., 2002; Turner et al., 2007). These findings have implications for how OA is managed. Initiatives targeting primary and secondary prevention of OA are still in their infancy. However, there are calls to shift the focus of OA management to
persons at high risk of developing OA, and to those with early disease where structural changes may be preventable or reversible (Hunter, 2011; United States Bone and Joint Initiative, 2012). While participants in this study did not use these terms, their understanding of symptoms as potentially preventable suggests that they may be open to primary and secondary prevention strategies.

Studies have shown that injuries and joint trauma are risk factors for OA (Roos, 2005; Von et al., 2004). Some participants in our study linked their symptoms to prior injury or “overuse” and suggested that their symptoms may have been prevented. However, they conveyed that they did not think much about injuries or actions at the time they occurred. There may be a need for public health messages that could provide information about the risk factors for OA and ways to maintain physical activity and healthy joints throughout life. Some inroads have been made in providing public health messaging on OA prevention and management in the US (Arthritis Foundation, 2013). However, more widespread interventions in schools and sports and recreation centres could create awareness of the musculoskeletal system, healthy joints and ways to prevent and treat injury at an early age.

Our findings suggest that there was a disconnect between some participants who believed their symptoms were preventable and their health care providers, who sometimes indicated OA symptoms were part of getting older. Others have found that some health care providers have a fatalistic view of OA (Alami et al., 2011), assuming it is an inevitable, progressive disease (United States Bone and Joint Initiative, 2012) and trivialize it in clinical practice (Alami et al., 2011). Any incongruence between patients’ explanations of their condition and health care providers could result in less effective communication and poorer health care results (Kleinman, 1988). Shifting how health care providers view OA is critical to ensuring that people feel supported in their health care interactions and receive up-to-date information. Primary health care providers have opportunities to provide personalized advice on OA risk factors and education on secondary prevention of pain and disability through exercise and weight management.
Prior research in older adults demonstrated that people believed “wear and tear”, occupation, diet and genetics contributed to their OA (Kao & Tsai, 2012; Turner et al., 2007). In contrast to our findings, most research in older adults has shown that people often perceived OA as a normal and natural part of aging (Grime et al., 2010; Pouli et al., 2013; Richardson et al., 2013; Turner et al., 2007). Research in older samples also found that people viewed OA as incurable and likely to progress (Pouli et al., 2013; Turner et al., 2007). While our participants believed symptoms may progress they also indicated they believed they could potentially delay this process. It is possible that the younger age of our participants may account for these differences. However, the contexts within which health and illness are defined and experienced are constantly shifting (Lawton, 2003) and it is also possible that a more general shift in how we construct health and illness is occurring.

While participants did not focus on aging as a cause of symptoms, they conveyed that their experience with symptoms made them feel older. It was not chronological age itself but their experience with their bodies that made them consider age. Laz argues that age gains meaning in social interaction and in the context of larger social forces; individuals draw on resources, such as media, community beliefs and relationships, to enact their age (Laz, 2003). In our study, participants compared themselves to others as they made sense of their symptoms. They also seemed to draw on broader social understandings of health such as healthy aging (Franklin et al., 2009) and healthism. Healthism assumes that ‘the problem of [and solutions to] health and disease are at the level of the individual’ (Crawford, 1980). Governments and individuals regularly speak of pursuing healthy lifestyles and being responsible for one’s own health (Cheek, 2008). Given these potential influences, it may not be surprising that participants constructed symptoms as preventable rather than as an inevitable part of aging.

The core category, knee symptoms are preventable, was common across participants. However, there was variation within categories suggesting some findings were more prominent in older or younger participants (e.g. it was particularly
common for older adults to reflect on aging). These findings highlight the need for health care providers to listen to patients to understand how they view their symptoms and provide support to people with knee symptoms regardless of age.

This qualitative study developed concepts which helped us better understand participants’ meanings of their knee symptoms. Most of this sample lived in an urban area, were working and had postsecondary education. Further research is needed to understand how different socioeconomic groups understand knee symptoms.

The study has limitations. To be included, participants self-reported a diagnosis of knee OA or reported that they had knee symptoms (i.e. pain, aching or stiffness) on most days of the past month. I was unable to verify that participants’ symptoms were due to OA. However, the question was based on a widely used survey question on joint pain (Centres for Disease Prevention and Control, 2013) and careful exclusion criteria to recruit participants more likely to have OA symptoms. Findings show that participants’ mean KOOS scores are similar to people with OA in other research (de Groot et al., 2008).

4.6 Conclusion

People age 35-65 years interpreted knee symptoms as potentially preventable, suggesting there may be opportunities to promote primary and secondary prevention strategies. As OA awareness and intervention improves, there is potential to reduce the impact on individuals and society. Further research is needed to design optimal interventions to address primary and secondary prevention in people at risk for or with early OA symptoms.
Chapter 5: “We’re All Looking for Solutions”: A Qualitative Study of the Management of Knee Symptoms
5.1 Chapter Overview

Chapter 5 explores how adults age 35-65 years respond to and manage knee symptoms. Data from the six focus groups conducted with adults with knee symptoms were analyzed for this chapter. Data collection and analysis were iterative. After completing six focus groups, it was concluded that further data gathering and analysis added little to the conceptualization of how participants managed knee symptoms. This chapter has been modified from the following peer-reviewed publication:


5.2 Introduction

While OA has mostly been viewed as a disease of older people, there is increasing evidence of the significant impact of OA symptoms earlier in life (Losina et al., 2013). The estimated incidence of OA increases exponentially in adults age 20-50 years, with the largest number of incident cases in the 50-54 year age group (Kopec et al., 2007). Approximately 9.3% of the population of the US is diagnosed with symptomatic knee OA, the most commonly affected joint, by age 60 years, with a higher prevalence in women than men (Losina et al., 2013). There is evidence that OA is progressing to severe disease in younger people as demonstrated by a 311% increase in the number of TKRs (from 772 to 3172 procedures) in 45-54 year olds in Canada between 1996/97 and 2006/07 (Canadian Institute for Health Information, 2009). Moreover, the majority of economic costs of OA accounted for by long-term disability are incurred by those ages 35-64 years (Lagace et al., 2010). Despite the considerable impact of OA symptoms in people as early as the third or fourth decade of life (Kopec et al., 2007), there is a paucity of research on OA management early in life. Rather, research has focused on OA management in older adults (Albert et
Scientific progress is being made in understanding the development of the disease, mechanisms responsible for progression, and potential advances in management (Pelletier et al., 2006). There is evidence that interventions such as exercise and weight loss, decrease the pain and disability of OA (Bennell & Hinman, 2011b; Bliddal et al., 2011; Christensen et al., 2007; McKnight et al., 2010; Wang et al., 2012). There is opportunity for interventions geared toward younger adults with OA, in order to enable better management of knee symptoms, limit progression of OA, and delay the need for more costly interventions such as surgery. However, given the limited research, there is too inadequate of an understanding of how younger adults manage knee symptoms to even begin to develop interventions which address their needs earlier in life. I aimed to address this gap and explore how adults age 35-65 years respond to and manage their knee symptoms.

5.3 Methods

5.3.1 Study Design

A qualitative study was conducted based on the principles and methods of constructivist grounded theory including iterative data collection and analysis and constant comparative analysis. Grounded theory uses an inductive approach which aims to describe, explain and predict complex processes and represent the perspectives of the person (Corbin & Strauss, 2008). The researcher’s role is recognized in the shared construction of the meaning of the accounts told by participants who live day-to-day with knee symptoms.
5.3.2 Sampling and Data Collection

Individuals in the Greater Toronto Area were recruited using advertisements in a community paper, an acute hospital and community centres. Interested individuals called the study phone number and were screened for eligibility using a screening questionnaire. Individuals aged 35-65 who self-reported a diagnosis of knee OA or who reported that they had knee symptoms (i.e. pain, aching or stiffness) on most days of the past month were included, recognizing younger adults may not have a formal diagnosis or perceive their symptoms to be OA. The knee symptoms screening question was based on a widely used survey question on joint pain (Centres for Disease Prevention and Control, 2013). Participants who had a knee injury, or had knee pain referred from the low back were excluded as symptoms were unlikely to be related to OA. People with other types of arthritis (e.g. inflammatory arthritis), who were waiting for, recommended or had undergone TJR, or who had other chronic physical health conditions that affected their mobility (e.g. multiple sclerosis, stroke, Parkinson’s Disease) were excluded. Qualitative research focuses in depth on relatively small samples, selected purposefully (Patton, 1990). Purposive sampling was used seeking variation across age and males and females. Data collection was stopped at the point of saturation, when the authors agreed that further data gathering and analysis added little to the conceptualization (Corbin & Strauss, 2008).

Data were collected using focus groups. Group interactions may accentuate members’ similarities and differences and give rich information about the range of perspectives and experiences (Lambert & Loiselle, 2008). Focus group methodologists advocate bringing together participants that share some similar characteristics (Lehoux et al., 2006). Participants were grouped together in focus groups based on age (35-49 years and 50-65 years) to create groups with similar characteristics. I acted as moderator. A second individual kept a speaker log (participant’s unique identifier and first words spoken) to facilitate transcription and took notes which summarized the participants’ comments and non-verbal
communication. These notes facilitated simultaneous data collection and analysis allowing for emerging themes to be pursued in subsequent interviews. Focus groups were semi-structured using a discussion guide (Table 5.1). Probes were used to elicit further elaboration and clarification. The focus groups lasted 1.5-2 hours and were conducted in private rooms in designated hospital conference space. Focus groups were audi-taped, transcribed verbatim and entered into NVivo 9 software for data management. Field notes were written following each focus group to summarize the data and discuss questions arising from the data. To ensure transparency, an audit trail documented all study decisions (Reynolds et al., 2011).

**Table 5.1 Question Guide: Focus Groups**

<table>
<thead>
<tr>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tell me about what is happening with your knee(s).</td>
</tr>
<tr>
<td>2. We are interested in your experiences with your knee in your daily life. Can you tell me how your knee fits into your daily life?</td>
</tr>
<tr>
<td>3. When you think of yourself 10 or 20 years down the road, what do you think might happen with your knee?</td>
</tr>
<tr>
<td>4. What do you do for your knee?</td>
</tr>
<tr>
<td>5. After having your experience, what advice would you give someone else who has just started to have knee issues?</td>
</tr>
<tr>
<td>6. Do you have anything else you wish to say about living with your knee symptoms?</td>
</tr>
</tbody>
</table>

Participants completed demographic questions and the KOOS to describe the extent of participants' knee symptoms and function. KOOS scores range from 0-100 for each subscale (100 indicating no symptoms and 0 extreme symptoms) (Roos et al.,
The study was approved by the University Health Network Research Ethics Board and University of Toronto Research Ethics Board.

5.3.3 Analysis

Data analysis was conducted concurrently with data collection. A constant comparative method of analysis was used (Corbin & Strauss, 2008). The analysis included open coding the data (a process of breaking down, examining, comparing and conceptualizing and categorizing data) and identifying the main categories and relating categories to each other (axial coding) (Corbin & Strauss, 2008). A core category was generated explaining the basic process of how participants managed knee symptoms. The data were progressively conceptualized into the resulting framework (Figure 5.1). I open coded the transcripts independently and developed a coding scheme. All PAC members reviewed the transcripts and coding scheme and met regularly to discuss the data and ongoing analysis, including alternate interpretations of the data. Analytic memos were constructed to explicate emerging categories, make comparisons across data and identify gaps in the analysis. Diagrams were used to tease out the relationships among categories. Analysis also included multiple readings of the transcripts to shed further light on the meanings and processes central to understanding how people manage knee symptoms. A field diary was written to facilitate reflexivity.

5.4 Results

Six focus groups (three groups aged 35-49 years; three groups aged 50-65 years) were conducted with 41 participants with moderately symptomatic OA based on their KOOS scores (mean domain scores ranged from 43.3 to 67.9) (de Groot et al., 2008). Table 5.2 shows participants’ demographic information and Table 5.3 shows the KOOS scores. The core category, taking action on knee symptoms, explains the main process of managing knee symptoms. An overview of the core category is presented first, followed by a more detailed description of the categories which
encompass this core process (control of symptoms, seeking solutions, active management). Illustrative quotes are presented throughout the text and in Table 5.4 (names are pseudonyms).

Table 5.2 Participant Demographics (n=41)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>50.9 (8.1) (range 38-65)</td>
</tr>
<tr>
<td>Female</td>
<td>26 (63)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>4 (9.8)</td>
</tr>
<tr>
<td>Trades Certificate/Diploma or College Graduate</td>
<td>12 (29.2)</td>
</tr>
<tr>
<td>University Graduate</td>
<td>25 (61.0)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Married/Living as Married</td>
<td>16 (39.0)</td>
</tr>
<tr>
<td>Divorced/Widowed/Never Married</td>
<td>25 (61.0)</td>
</tr>
<tr>
<td><strong>Work</strong></td>
<td></td>
</tr>
<tr>
<td>Currently Working</td>
<td>34 (82.9)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>5 (12.2)</td>
</tr>
<tr>
<td>Retired</td>
<td>1 (2.4)</td>
</tr>
<tr>
<td>Student</td>
<td>1 (2.4)</td>
</tr>
</tbody>
</table>
Table 5.3. Knee Symptoms and Function

<table>
<thead>
<tr>
<th>KOOS Subscales</th>
<th>Scores (mean, SD)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms</td>
<td>61.8 (15.8)</td>
</tr>
<tr>
<td>Pain</td>
<td>62.0 (17.6)</td>
</tr>
<tr>
<td>Function in Daily Living</td>
<td>67.9 (18.0)</td>
</tr>
<tr>
<td>Function in Sport and Recreation</td>
<td>50.8 (27.4)</td>
</tr>
<tr>
<td>Knee Related Quality of Life</td>
<td>43.3 (19.9)</td>
</tr>
</tbody>
</table>

*KOOS scores range from 0-100 for each subscale with 100 indicating no symptoms and 0 extreme symptoms

Table 5.4 Illustrative Quotes by Category: Taking Action on Knee Symptoms

**Control of Symptoms**

It’s a never-ending process, yeah. I guess we want a fast fix for everything. That’s the way society is. It’s unfortunate. I think most people have reflected that, that that’s the wish to keep it well-maintained. (Idelle, age 46, FG06)

I would say maintenance and prevention at the same time as in maintenance in keeping mobile through fitness; and prevention in knowing my limitations. (Marta, age 44, FG02)

So for me, I’d like to enjoy activity, be capable of it and have that consistency where there’s no peaks [in pain]. (Peter, Age 57, FG01)

I would love it if there were some way to halt the progress of it. If this were as bad as it was going to get, I can handle it. (Jean, age 65, FG 01)

But then if my knee totally gave out and I couldn’t walk around, I wouldn’t be opposed to going and having it replaced. But I’d like to do everything I can to avoid that or prolong it as long as possible. (Laila, age 60, FG03)
We don’t want that at all. We’re all looking for solutions to avoid surgery. (Donna, age 56, FG03)

**Seeking Solutions**

**Informal Learning**

So it’s research and doctors and word of mouth. If you have the money, you can use that money wisely to different places that will help you out (Marta, age 44, FG02).

I did a lot of research on the internet, WebMD and a few others. You know, I can’t even remember them exactly, but I did a lot of research to see what would work, what wouldn’t work, and some of it was just through trial and error. I knew that the bike would probably work because really the muscles that you’re using are your quad muscles, which are up here, and you’re not putting as much strain on your knee, you’re putting the strain on your quads and your hips. (Samantha, age 40, FG04).

I find that we talk. We talk to your friends, you talk to other people that have maybe had similar symptoms. What did your doctor say? What did you do? I read magazines, you know, I go to the internet and you have to kind of make sure that you’re not being a little bit discriminating in what you’re reading and not just taking everything there about, they’ll try to sell you anything on the internet. (Rachel, age 55, FG01)

Actually, it was recommended by the sports medicine friend of mine in Turkey. He’s in the research part of it. They have like several people who have knee problems, you know, the injury, like a knee or tendons, tendonitis and that kind of stuff and it worked for the sauna. It helps with the toxins. (Eser, age 44, FG02)
**Trial and Error**

I think we take the best from everywhere, what works. And you try many things and find what works well. I would rather eat types of foods that are anti-inflammatory. I pay attention to that stuff and try and include a lot of those foods in my diet. (Laila, age 60, FG03)

It’s trial and error, some of it. And thinking very clearly about what caused this today. What hurt my knee today? What did I do wrong today? (Bill, age 61, FG03)

So okay, there’s so many different schools of thought, different views, that it’s really an individual where you go through life and what path you chose. But, yeah, it’s a lot of trial and error (Helen, age 41, FG02).

**Help-Seeking from Health care providers**

Yeah, stress. I don’t find any supporting hand from my physician. Whenever I complain about my pain to my physician, first of all she did not take it seriously. (Safa, age FG04, Age 38)

No, listen. You have to go in there prepared now, and they tell you this. When you see your physician. This is my knee pain. Okay, can I get physio done? Can I get, like she’s saying, can I get a chiropractor? (Brent, age 45, FG04)

Well, I think more people are becoming … Just listening around this table, all the different things, alternative things people do. I think people are becoming much more aware that there’s other ways. And that you almost have to start to take responsibility for your own health. (Laila, Age 60, FG03)

I keep asking the doctor, because I still see him because he works in the same office as my family doctor. I keep seeing him and I’m like, when can I get the surgery on my knee? He goes, I’m not. It’s like, please. It’s getting to the point. (Wilson, age 41, FG06)
I just go to my doctor’s. When I went through arthritis with my mom, who’s 94 now, I’ve been to numerous of her arthritis appointments, it’s always the same thing. We can’t do anything. I can give you cortisone shots. And it’s 50% whether it helps or not helps. She was getting acupuncture for herself years ago, before anybody else I knew was getting it and that gave her some relief. And then various on Celebrex until her doctor told her not to take it anymore. So I thought well what’s the point? (Jean, age 65, FG01)

I don’t want to use, you know, any prescription medicine because I was also told that it, it could be it needs to be operated, but I don’t want to be operated because they didn’t give me any warrantee. Maybe it’s going to get worse or, you know, it’s a 50/50 chance. So, so I don’t want to get anaesthesia, general anaesthesia. So right now I’m just managing to control like all all the symptoms that I am having. (Eser, age 44, FG02)

I don’t think doctors are preventative enough these days. I think they’re too treatment oriented. So you kind of have to approach them with a problem and then they just want to medicate it or they want to tell you that you’ve sort of imagined it and it’s not quite as bad and kind of walk away from it. (Janet, age 49, FG02)

Active Management

This is sort of a recurring theme, but I made a conscientious effort to do three times a week an exercise regimen more consistent than I had been previously. That has not made it any worse that’s for sure. It seems like I feel a lot better in general health to begin with, whether it’s psychological or not, but I also think it has helped keep any kind of pain from occurring. (Ken, age 48, FG06)

It’s one of the things where I’ve pretty much always known, where I’ve always experienced the pain. I was heavier. I’ve lost like 100 pounds, and the main reason I did lose the 100 pounds was because it was very painful on the knee.
And with the weight loss. And to start off the weight loss, I figured, with the pain, this adjusted like to pull up with it and swimming to help me lose the weight. So, with part of the weight loss I did that, but then the weight loss sort of stopped so the pain with the knees had gotten better, so I did the elliptical and I’ve gone onto the treadmill. (Isabel, age 48, FG04)

Yeah, I use a knee brace, one of those elastic jobs. You can find them in the drug store sort of thing. I spend a lot of time not just on the exercise bicycle but on the treadmill. And there have been days when the 25 minutes that I’m supposed to be on the treadmill turns into 7 or 8 because I’m just pounding way too hard. But the next day, I can come back with the knee brace on and I can go the full distance. (Bill, age 61, FG03)

What I found out was that I started natural, holistic nutrition because I don’t want all this unnecessary conventional treatment. And I know when I apply peanut oil, it’s an antidote for any kind of arthritis or any kind of pain muscle, I was as good as new too. (Jennie, age 63, FG03)

So she’s given me exercises and then every month she increases the exercises more to increase the strength of the inner leg and strengthen the knee. So, that’s where I am at the moment. I stopped losing my balance and the locking and all that happens rarely. I do feel pain and stiffness if I sit for more than an hour. I can’t get up. That’s still there, but at least the severe pain while walking and falling down has gone. So, I just keep working at it and hope it becomes fine. (Savine, age 50, FG05)

I work in a lab. I work in two labs actually. It is a workbench that I’m on. With some benches I need to actually stand a lot. So actually, because of my knee, I actually have to sit. Get a stool and sit okay for a bit. Otherwise I just cannot do my job anymore. (Sarah, age 57, FG03)
5.4.1 Core Category: Taking Action on Knee Symptoms

Taking action on knee symptoms explains the active process by which people work to control knee symptoms and disease progression (Figure 5.1). Participants responded to their knee symptoms by "seeking solutions". That is, people used informal learning (e.g. doing their own research), trial and error and/or sought help from health care providers to find ways to manage their knee symptoms. In some instances, one or a combination of these methods helped participants find strategies they perceived to work (e.g. exercise, weight loss). Strategies were then actively incorporated into management of their knees on an ongoing or as needed basis (active management). Some strategies were only used temporarily, then given up and the search for other ways to manage resumed. Management was constructed as a "never ending" process of "trying" to find solutions and maintain active management. This process entailed significant physical and mental work and personal resources such as time and money.

Figure 5.1 is a visual representation of the process of managing symptoms illustrating that a participant’s approach to management was not an orderly, linear process but rather moved back and forth within and between seeking solutions and active management. The overlapping circles indicate that these also happened concurrently, whereby people actively managed their symptoms using certain strategies but indicated they were still on the lookout for new management strategies. “Control of Symptoms” refers to the intent underlying this active management process. It is placed at the bottom of the figure to indicate that it underpins the management process.

While the data were analyzed for patterns in younger and older age groups, the process of managing knees was generally similar for participants of all ages. When age was interpreted to influence participants’ experiences with management, this is described in the results. The process of managing knees was generally similar for men and women.
5.4.1.1 Control of Symptoms

Participants’ actions were driven by a desire to control knee symptoms, such as pain, aching and stiffness. Some participants remained hopeful of finding a “fix” to regain their former symptom free bodies. One participant stated: “It’s too tempting to think that there is a fix… In my mind, I haven’t resigned myself to staying like this for the rest of my life.” (Mark, age 46) However, most participants indicated they were learning that a “silver bullet” didn’t exist, which meant that they believed there was unlikely to be one solution for everyone. More commonly, participants’ accounts suggested that their motivation for working to control immediate symptoms was to remain active in social and physical activities that they perceived to be
important. Some participants also sought to control progression. They constructed their knee problem as something that might “degenerate further” and sought to slow or halt progression through preventative actions, such as exercise. Participants often expressed a desire to prevent or delay the need for invasive interventions such as TJR. For instance, Samantha discussed her goal to “stave off” OA progression and surgery: “I know eventually that will happen, but the exercise I’m doing now will probably keep it at bay for a little while” (age 44).

5.4.1.2 Seeking Solutions

Seeking solutions refers to the cognitive and physical efforts that participants used to find ways to manage their knee symptoms.

Informal learning

Participants recounted using informal learning processes to find solutions to their knee problems. This entailed intentional learning through social interactions and doing their own research. Participants sought to confirm what was happening to their knee and find appropriate management strategies. They compared their experiences to others with knee problems to make sense of what was going on (e.g. parents, friends) and sought informal advice from peers. They did their own “research” which entailed consulting websites, books, magazines or other resources to help them understand and manage their knees. Some participants talked about evaluating the trustworthiness of information they encountered. For example, one participant explained: “You get it from people who know, like I don’t believe anything until I hear it three times” (Peter, age 57).

Trial and Error

Participants recounted the use of trial and error to find a solution to their knee symptoms. They employed a strategy and considered the effects of it to decide
whether to use the strategy over the long term. For instance, a participant described how she was using trial and error to see how weight loss impacted her knee: “I’ve set up a thing where I’m bringing my weight down. I want to lose ten pounds in the next four months and then we’ll look at that and see, well does that play a part in it” (Debbie, age 48).

**Help Seeking from Health Care Providers**

The majority of participants visited their primary care doctor and many consulted various health professionals (e.g. physiotherapists, chiropractors). Generally, participants felt that their role was to ask questions, engage into a dialogue with their health care providers, ‘push’ for what they need while being an advocate for one’s self. Participants conveyed a need to be persistent and if one avenue was unsuccessful, they perceived it was their responsibility to seek answers elsewhere.

Participants depicted the doctor’s role as instrumental in getting a diagnosis. Their accounts suggested that a professional diagnosis had an important role in legitimizing the problem and guiding management. A few participants, often in the younger age group, conveyed they did not understand what was happening to their knee or did not feel that their complaints were “taken seriously” by care providers. This resulted in frustration and struggles to find ways to manage. For instance, one participant, who stated he did not understand his knee situation very well, tried a range of health care options in his search for a solution, including some he described were experimental procedures (e.g. injection of platelet enriched plasma).

Participants recounted experiences with medical care and portrayed that there were few medical options available, except TJR. They invoked examples to illustrate the shortcomings of current medical treatments. They alluded to recalls of arthritis drugs and their understanding that some interventions only had a 50% chance of being effective. Others commented that “conventional” medicine was too focused on pharmaceuticals, failing to support alternative therapies and not providing them with
enough preventative options. One participant reflected: “*When I went for my last appointment at [hospital], they said, chondroitin and glucosamine, it’s just hogwash. Well, how often does surgery work? You know, the allopathic medicines, the Celebrex or Vioxx… As a Canadian consumer, what are my choices?*” (Nigel, age 61) Participants also recounted instances in which they had not received enough guidance on how to manage (e.g. what to do and not to do).

When participants experienced a lack of health care options and advice, it often resulted in them feeling upset or frustrated. These feelings were more prominent in focus groups with adults age 35-49 years. For instance, Tiana (age 49) expressed frustration over her medical care: “*I guess what I’m really frustrated with is my physician has not really given me any direction as to what could I do or what shouldn’t I be doing?*” Unsatisfactory health care experiences prompted participants to consult other health care providers or resume using informal learning and/or trial and error as they continued to seek a solution.

5.4.1.3 Active Management

Active management refers to the ongoing use of strategies as part of a regular routine of health practices or as needed. The purposive strategies participants recounted were many and varied (e.g. exercise, weight loss, supplements, orthotics, acupuncture). While participants mentioned medications, discussions focused on non-pharmacologic strategies. The strategies participants regularly used reflected their perspectives about health more generally. For example, people engaged in physical activity for varied reasons such as the perceived benefits for their overall health, perceived benefits for their knee or social interaction. Other participants preferred “natural” treatments which they perceived to be healthier than “conventional” medical management.

Some of the strategies participants consistently used were adaptive behaviours integrated within their daily life such as restriction or limitation of certain activities,
planning of activities in advance or modification or substitution of behaviours. For instance, one participant commented: “I avoid stairs. I will walk a lot to avoid a big flight of stairs. Because when I’m going up and down the stairs, it’s as if it’s bone on bone and it’s just a really uncomfortable feeling” (Laila, age 60).

Participants expressed concerns about the challenges involved in maintaining efforts to manage knee symptoms. Management sometimes competed with other demands for their time, (e.g. employment) and monetary issues. Participants used their own money in a myriad of ways to control knee symptoms (e.g. private health care). One participant commented: “I don’t think we mentioned also how much it costs you for your pocket money, that you had your knee problem…” (Marta, age 44) Regardless, most participants conveyed active management was what they should be doing. For example, one participant reflected: “…it’s a long process and I’m not regular with my exercises which I should be” (Savine, age 50).

5.5 Discussion

By exploring how people aged 35 to 65 years respond to and manage knee symptoms, this study provides novel insights that may help us to better support OA management earlier in life. Taking action on knee symptoms explicates the complex process in which people try to find solutions and maintain active management to control knee symptoms and prevent disease progression. Our findings highlight that participants were proactive in working to manage their knee symptoms. In contrast, they perceived that medical care was often more reactive, with little to offer them other than TJR. Participants expressed interest in earlier intervention to support management or halt or delay OA progression and delay interventions such as TJR. Yet, there is currently a gap in providing such supportive conditions within the health care system. I suggest that a shift in how we conceptualize and deliver health care is needed to help people effectively manage symptoms earlier in life.
While research into new treatments that address symptoms and progression is critical, there are non-pharmacologic strategies, such as exercise, which have been shown to be effective in improving pain and function (Bennell & Hinman, 2011b; Bliddal et al., 2011; Christensen et al., 2007; Fransen et al., 2015; Hochberg et al., 2012; McAlindon et al., 2014; McKnight et al., 2010; Wang et al., 2012). Our findings highlight the need for changes in health care delivery to support use of such strategies. Most importantly, more nuanced information is required to tailor advice to individual symptoms within the context of peoples' lives. Like other studies of managing chronic disease, participants conveyed they were already working hard to self-manage (Corbin et al., 1988; Newbould et al., 2006; Ong et al., 2011). They were aware of, and had tried many known best practices for OA. However, participants often recounted that guidance from health care providers on how to manage symptoms was limited. Other studies have reported limited provision of advice on non-pharmacologic interventions for OA (e.g. exercise) in primary care and that physicians lack confidence in musculoskeletal management (Ganz et al., 2006; Glazier et al., 1996a; Li et al., 2011; Matheny et al., 2000). Rather than broad statements on best practices, this study highlights that people may require more personalized help from health care providers to use strategies in effective ways, including how to use them, how often and what outcomes to expect. Studies in older adults have also recommended improvements in the provision of management advice (Jinks et al., 2007; Maly & Krupa, 2007; Mann et al., 2011) including better information on management soon after OA diagnosis (Mann & Gooberman-Hill, 2011). Others highlighted missed opportunities for providing management advice when older individuals don’t seek care, recommending a targeted and integrated approach between health care providers and health planners for primary and secondary prevention (Jinks et al., 2007).

A professional diagnosis had an important role in legitimizing symptoms and guiding management, particularly for younger adults. Other research has shown that people wish to have symptoms acknowledged to be genuine by health professionals and peers. A diagnosis can also enable people to access information and treatments
(Nettleton, 2006). This study points to the need for health professionals to recognize early symptoms and risk factors for OA to facilitate a timely diagnosis.

Participants portrayed themselves as being responsible for their health, reflecting evolving societal views that individuals have a responsibility or moral obligation to pursue health (Cheek, 2008; Frank A, 1997; Townsend et al., 2006). Findings suggest this generation already conceptualizes their role as being “active” and “informed”, as promoted in chronic disease models (Wagner, 1998). While participants often conveyed that maintaining active management was what they should be doing, they suggested it was challenging. Currently, OA is often not conceptualized as a chronic disease requiring long term support. Single consultations may be insufficient to help people manage across the life course, particularly in ways that could have the potential to prevent deterioration. Mechanisms for long-term support for knee symptoms are needed. Routine regular follow-up with a primary health care provider may be beneficial for some individuals. For others, it may be sufficient to use community based programs (e.g. exercise classes) and have the option to re-access the health care system for consultation as needed. In a study of older adults with OA, patients indicated that they would value the support provided by regular follow-up (Mann & Gooberman-Hill, 2011). Further research is needed to determine the best mechanisms for follow-up for younger adults with knee symptoms.

Support for OA self-management has mainly been provided through lay led self-management programs. While outcomes are generally favorable, research suggests these programs tend to have older female participants with more advanced disease (Buszewicz et al., 2006; Lorig et al., 2005; Warsi et al., 2003). Moreover, younger adults without a diagnosis may be less likely to attend an arthritis program. While prior research on older adults found that people normalized OA as a part of aging and did not seek professional help (Ong et al., 2011; Sanders et al., 2002), participants in this study typically sought health care. Others have recognized that primary health care providers have an important role in providing support for self-
management of chronic conditions (Health Council of Canada, 2012; Johnston et al., 2011; Jordan et al., 2008). This role is not yet a routine part of primary health care in Canada (Health Council of Canada, 2012). This study raises crucial questions as to how best to provide management advice and support to people with knee symptoms across the spectrum of age and disease. Further research is needed to understand more about people’s needs, gaps in health care interventions and how people prefer to have assistance provided earlier in life.

While the role of age was considered in the analysis, the management process was generally similar across the age range. It is telling that people are working hard to manage knee symptoms even at relatively young ages. These data are unable to disentangle potential relationships between age, stage of disease and approach to management. However, prior quantitative research shows that once you have arthritis, there is little difference in outcomes by age (Khanna et al., 2011).

The study has limitations. I relied on self-report diagnosis of OA or chronic knee symptoms. While I was unable to determine if participants reporting symptoms have OA, I based the question on a widely used survey question on joint pain (Centres for Disease Prevention and Control, 2013) and careful exclusion criteria to recruit participants more likely to have OA. The majority of participants lived in an urban area and was working, potentially facilitating access to health care resources and insurance. This sample was also highly educated which may have influenced the findings that participants were proactive in management. While the study was conducted in a large multicultural centre, I didn’t sample based on ethnicity. Future research is warranted to understand the role of culture on management.

5.6 Conclusion

This study adds to our understanding of the complex process people engage in as they manage knee symptoms earlier in life. In particular, I shed light on the mismatch between the participants’ proactive approach and the health care system
which they perceived to be more reactive. This study highlights opportunities for future research and provides guidance on important issues that need to be addressed in the health care system to support management of knee symptoms particularly in younger age groups.
Chapter 6: A Qualitative Study of the Consequences of Knee Symptoms: “It’s like you’re an athlete and you go to a couch potato.”
6.1 Chapter Overview

This chapter explores the perceived consequences of knee symptoms on the lives of people aged 35-65 years. Data analyzed for this chapter were collected from focus groups and one-on-one interviews conducted with adults with knee symptoms. This chapter has been modified from the following peer-reviewed publication:

MacKay C, Jaglal SB, Sale J, Badley EM, Davis AM. A Qualitative Study of the Consequences of Knee Symptoms: “It’s like you’re and athlete and you go to a couch potato. BMJ Open 2014; (4)10. (MacKay et al., 2014b)

6.2 Introduction

Osteoarthritis is a common chronic condition resulting in pain, fatigue, functional limitations, increased health care utilization and high economic costs to society (Badley, 1995; Bitton, 2009; Creamer et al., 1997; Litwic et al., 2013; Murphy et al., 2012; Power et al., 2008). The burden of OA is projected to increase, due in part to obesity and population aging (Lawrence et al., 2008; Nguyen et al., 2011; Sharma et al., 2006). While the prevalence of OA increases with age (Kopec et al., 2007; Losina et al., 2013), there is a growing recognition that OA affects people at younger ages. Recent data from the US demonstrated that half of people with symptomatic knee OA are diagnosed by age 55 (Losina et al., 2013). Health care systems are dealing with the increasing rates of TJR for younger patients, particularly those aged 45 to 64 years (Canadian Institute for Health Information, 2009; Losina et al., 2012). There are calls for a paradigm shift in OA management to focus on persons at high risk of developing, or with, early disease in which structural changes may be preventable or reversible (Hunter, 2011; United States Bone and Joint Initiative, 2012). Screening and treating people earlier may help to alter disease progression and reduce the considerable costs to the health care system (United States Bone and Joint Initiative, 2012). To facilitate earlier intervention, a greater emphasis on disease prevention and management in younger adults is critical. A prerequisite to
delivering accessible and acceptable care is an understanding of the effects of disease on people’s everyday lives (Murray et al., 2009). As such, an important first step in developing effective interventions to support early management in younger adults is understanding the consequences of knee symptoms on peoples’ lives.

Research has shown that living with chronic illness leads to a variety of consequences and has highlighted the need to put the subjective experience of the patient at centre stage (Bury, 1982; Charmaz, 1983; Lawton, 2003; Pierret, 2003; Sanders et al., 2002). Studies of different chronic illnesses have also shown that the experience of chronic illness varies by age (Atkin & Ahmad W, 2000; Pierret, 2003; Sanders et al., 2002). Research in OA has focused largely on older persons with end stage disease (Atkin & Ahmad W, 2000; Guccione et al., 1994; Sanders et al., 2002). Studies in older adults with OA have highlighted the disruptive nature of symptoms in people’s daily life including functional limitations and psychological distress (Atkin & Ahmad W, 2000; Guccione et al., 1994; Sanders et al., 2002). The consequences of OA in younger adults have been largely neglected. One study of younger Taiwanese adults with knee OA reported that people experienced difficulties with exercise and a reduction of work (Kao & Tsai, 2012). However, there is a general lack of understanding of how OA symptoms affect younger people in their daily lives. The consequences of symptoms in younger adults may be underappreciated given OA is often perceived to be a disease of older people, even by health care providers (Alami et al., 2011; United States Bone and Joint Initiative, 2012). As such, it remains unclear how best to provide effective and relevant support earlier in life. This study aimed to fill this gap and explore the perceived consequences of knee symptoms on the lives of people aged 35-65 years who had diagnosed knee OA or symptoms that were consistent with knee OA. Since not all participants had a diagnosis of OA, I use the term knee symptoms rather than OA when describing the study.
6.3 Methods

6.3.1 Study Design

This study used qualitative methods, comprising focus groups and one-on-one interviews. The principles and methods of constructivist grounded theory guided data collection and analysis (Charmaz, 2009; Charmaz, 2006). This approach seeks to understand the participants’ beliefs and actions from their perspectives and views researchers as co-creators of the data.

6.3.2 Sampling and Data Collection

Participants were recruited from advertisements in a community paper, an acute care hospital and community centres in the Greater Toronto Area. Individuals were included if they were aged 35-65 and self-reported a diagnosis of knee OA or reported that they had knee symptoms (i.e. pain, aching or stiffness) on most days of the past month, recognizing that younger adults may not have a diagnosis or perceive their symptoms to be OA. Participants who had a knee injury, knee pain referred from the low back, other types of arthritis (e.g. inflammatory arthritis), who were waiting for, recommended or had undergone TJR, or who had other chronic physical health conditions (e.g. stroke) that affected their mobility were excluded. People who were waiting for TJR were excluded as they are more likely to have end stage OA with substantial pain and disability. Sampling was purposive, initially seeking variation across age and sex. As data collection and analysis progressed, I continued to seek variation in age to explicate the categories being developed. Data collection continued until data saturation was reached (Coyne, 1997). The study was approved by the University Health Network and University of Toronto Research Ethics Boards.

Multiple sources of data have been recommended in qualitative research (Lambert & Loiselle, 2008; Tracy, 2010). I used focus groups and interviews as research has
shown that focus groups are useful at examining the range of participants' experiences, while individual interviews contribute to the detailing of experiences (Lambert & Loiselle, 2008). First, six semi-structured focus groups (n=41) were conducted in hospital boardrooms. Participants were grouped by age (35-49 years and 50-65 years) to create homogeneous groups. I moderated the focus groups while a second individual kept a speaker log and took notes summarizing verbal and non-verbal communication. A focus group guide facilitated discussions (Table 6.1). Participants were encouraged to share their experiences, even if they differed from others’ experiences. Discussion amongst the group (e.g. questioning one another and commenting on others’ experiences) was encouraged and facilitated by the moderator. For instance, the moderator would ask the group, “Has anyone else had a similar or different experience?” Following the focus groups, 10 semi-structured interviews were conducted with new participants at the hospital or the participant’s workplace. The focus group guide was refined for the interviews based on preliminary analyses (Table 6.1). I conducted all the interviews and used prompts to clarify or elaborate responses. Focus groups lasted 1.5-2 hours and interviews lasted approximately one hour. Field notes were written following each focus group/interview to summarize data and reflect on analytic topics being developed.
# Table 6.1. Question Guides: Focus groups and Interviews

<table>
<thead>
<tr>
<th>Focus Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tell me about what is happening with your knee(s).</td>
</tr>
<tr>
<td>2. We are interested in your experiences with your knee in your daily life.</td>
</tr>
<tr>
<td>Can you tell me how your knee fits into your daily life?</td>
</tr>
<tr>
<td>3. When you think of yourself 10 or 20 years down the road, what do you think</td>
</tr>
<tr>
<td>might happen with your knee?</td>
</tr>
<tr>
<td>4. What do you do for your knee?</td>
</tr>
<tr>
<td>5. After having your experience, what advice would you give someone else who</td>
</tr>
<tr>
<td>has just started to have knee issues?</td>
</tr>
<tr>
<td>6. Do you have anything else you wish to say about living with your knee</td>
</tr>
<tr>
<td>symptoms?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tell me about the problems you have been having with your knee(s).</td>
</tr>
<tr>
<td>2. How did your knee problems develop?</td>
</tr>
<tr>
<td>3. Has your knee changed things for you in your life? How?</td>
</tr>
<tr>
<td>4. What is your knee like on a day to day basis?</td>
</tr>
<tr>
<td>5. a) Tell me about a day when you don’t require much from your knee.</td>
</tr>
<tr>
<td>b) Tell me about a day when you require a lot from your knee.</td>
</tr>
<tr>
<td>6. Tell me about how you feel about your knee?</td>
</tr>
<tr>
<td>7. Thinking about your knee, what do you think about the future?</td>
</tr>
<tr>
<td>8. Do you have anything else you wish to say related to your knee?</td>
</tr>
<tr>
<td>Is there anything else you’d like to raise that we didn’t talk about today?</td>
</tr>
</tbody>
</table>
All focus groups/interviews were audio-recorded, transcribed verbatim and entered into a qualitative software program, NVivo9, to facilitate data management and analysis. Participants completed the KOOS to describe the extent of participants’ symptoms and function. KOOS scores ranged from 0-100 for each subscale (100 indicated no symptoms, 0 indicated extreme symptoms) (Roos & Lohmander, 2003).

6.3.3 Analysis

A constant comparative analysis was used, in which comparisons constituted each stage of analysis (e.g. comparing data with data, data with category, category with category) (Charmaz, 2006). Data analysis was conducted concurrently with data collection to allow developing themes to be pursued in subsequent focus groups/interviews. The analysis had three main steps: open coding, axial coding, and constructing a core category which explained the central theme of the data (Corbin & Strauss, 2008). I open coded the data and developed a coding scheme which was reviewed by my PAC. Content of codes, including specific quotes, were presented and discussed at regular meetings and codes were subsequently further refined. My supervisor read all transcripts and discussed interpretations of the data with me at regular meetings. My PAC read the majority of the transcripts and met regularly to discuss the data and ongoing analysis, including alternate interpretations of the data. Use of a reflexive diary and group discussions also provided an opportunity to consider how my assumptions and beliefs might impact interpretation of data. Memos were written to make comparisons across data and explicate developing categories. Analysis included multiple readings of the transcripts to understand the consequences of knee symptoms in participants' lives.

This study integrated recommended principles to enhance quality in qualitative research (Reynolds et al., 2011; Tracy, 2010) including a systematic approach to designing, conducting and analyzing the study, maintaining an audit trail (collection of study documentation including decision making), a field diary to promote reflexivity, and use of thick description (e.g. in-depth illustration and abundant detail).
and quotations. Strategies recommended for quality in grounded theory (concurrent data collection and analysis, constant comparative analysis, memoing) were also incorporated (Charmaz, 2006; Elliott & Lazenbatt, 2005; Reynolds et al., 2011).

6.4 Results

Fifty-one individuals with moderately symptomatic OA based on KOOS scores (de Groot et al., 2008) participated (Table 6.2: demographics; Table 6.3: KOOS scores). The core category is presented first, followed by a detailed description of the categories subsumed under the core category. Illustrative quotes are presented throughout the text and in Table 6.4 (pseudonyms are used).

6.4.1 Core Category: Disruption and Change

The core finding, disruption and change, illustrated the consequences of knee symptoms on peoples’ lives (Figure 6.1). Symptoms resulted in disruption and change in two main categories: 1) Disrupted physical, emotional and social life, and 2) Altered way of thinking about the body and self. The first category referred to the disruption described by participants in three aspects of their lives: physical disruption (disruption in one’s ability to carry out physical activities), emotional disruption, and social disruption (disruption in social interactions and social roles in leisure/social activities, work, and family life). In the second category, participants described three changes in the way they thought about their bodies and selves: a new awareness, lack of trust in their knee, and an altered sense of self. Within each of the two main categories, consequences could influence each other. For example, physical disruption, such as giving up sports, could influence social disruption (e.g. loss of social interactions). Moreover, consequences within one category could influence consequences in the other category (e.g. social disruption could influence one’s sense of self). Personal context (e.g. gender, age, stage of life, social roles) shaped how people experienced consequences within their lives. Examples of the influence
of personal context are provided within the following descriptions of the consequences of knee symptoms.

Table 6.2 Participant Demographics (n=51)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>49</td>
</tr>
<tr>
<td>Minimum</td>
<td>37</td>
</tr>
<tr>
<td>Maximum</td>
<td>65</td>
</tr>
<tr>
<td>Interquartile range</td>
<td>(44, 58)</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td>31 (60.8)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>5 (9.8)</td>
</tr>
<tr>
<td>Trades Certificate/Diploma or College Graduate</td>
<td>16 (31.4)</td>
</tr>
<tr>
<td>University Graduate</td>
<td>30 (58.8)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Married/Living as Married</td>
<td>21 (41.2)</td>
</tr>
<tr>
<td>Divorced/Widowed/Never Married</td>
<td>30 (58.8)</td>
</tr>
<tr>
<td><strong>Work</strong></td>
<td></td>
</tr>
<tr>
<td>Currently Working</td>
<td>40 (78.4)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>7 (13.7)</td>
</tr>
<tr>
<td>Retired</td>
<td>3 (5.9)</td>
</tr>
<tr>
<td>Student</td>
<td>1 (2.0)</td>
</tr>
<tr>
<td><strong>Diagnosis of OA/OA-like symptoms</strong></td>
<td>26 (51.0)/25 (49.0)</td>
</tr>
</tbody>
</table>
Table 6.3 Knee Symptoms and Function

<table>
<thead>
<tr>
<th>KOOS Subscales</th>
<th>Scores*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms</td>
<td>67.02 (14.08)</td>
</tr>
<tr>
<td>Pain</td>
<td>63.69 (18.01)</td>
</tr>
<tr>
<td>Function in Daily Living</td>
<td>68.78 (18.26)</td>
</tr>
<tr>
<td>Function in Sport and Recreation</td>
<td>52.05 (27.86)</td>
</tr>
<tr>
<td>Knee Related Quality of Life</td>
<td>43.0 (19.22)</td>
</tr>
</tbody>
</table>

*KOOS scores ranged from 0-100 for each subscale; 100 indicated no symptoms, 0 indicated extreme symptoms.

Table 6.4 Illustrative Quotes by Category: Consequences of Knee Symptoms

**Physical Disruption**

I used to run, skipping, jumping. I used to play badminton, tennis. I used to be able to kick over my head. My mom wanted me to be a dancer; skinny, very physically active, constantly. And when that happened it was like … All your exercises and all your routines and everything you can’t do anymore. So it’s just a whole new lifestyle. (Emma, age 42, interview)

So, I had to change my, I stopped playing squash about seven/eight years ago. I stopped jogging at the same time. (Chata, age 65, interview)

Well, if I could just say, it’s definitely slowed me down. I’m way less active than I used to be. (Laila, age 60, focus group 3)

It gets worse when I exercise more, so I don’t do those particular exercises. (Davis, age 61, focus group 5)
**Social Disruption**

I’ve been out with her and other friends and they’ll be two blocks ahead of me and I can only walk as fast as I can walk and they don’t turn around to look... and I’m left out. (Audrey, age 63, interview)

I used to play hockey with him [son]. I can’t do it. Ball hockey, now I’d break my neck you know. But I can’t run around and do the ball hockey and soccer and stuff so it’s kind of discouraging and my husband’s gone a lot with his work so I’m the one that plays sports with him. (Anna, age 50, focus group 1)

So what happens is I work for my family business in fruits and veggies and then the truck comes in. There’s a least two guys have to be unloading and just stack it up in the back. And when I know the pain’s going to come, I get extra people. I put two more people. So that’s definitely a change. (Max, age 48, focus group 2)

Focus group 4:
Safa (age 38): My gym friends, I used to go and work out with them. I stopped going there, so they are not [friends] anymore. We don’t have connections at the same thing.
Moderator: Anyone else have an example?
Isabel (age 48): Unfortunately, my family is not that active...They want to get together but they want to rest and socialize. They don’t say, let’s go for a walk, let’s go for a run, let’s go be active.

**Emotional Disruption**

I got quite depressed. Suddenly I was overwhelmed with this feeling of I’m only 60-whatever-I-was at the time. We’re very long-lived in my family, oh my god, is this the beginning of the next 30 years? (Jean, age 65, focus group 1)

I feel out of shape and I feel that I’ve put on extra weight that I normally wouldn’t have. I’m not as active as I’d like to be. And I feel like now I’m 42 and I feel like this is the time in my life when I need to be doing these things and yet I’m having
trouble doing them. So I almost feel a bit cheated, like this is not the right time to get this. (James, age 42, interview)

**Altered Way of Thinking about Body and Self**

**Altered Sense of Self**

I pretend I don’t have a knee problem. People ask me, I’m fine. And I’ll go I’ll hobble and then people say Nigel, are you limping? No, I’m fine. So I want to be in denial because my job, my day job requires that I be performing and you can’t show this potential weakness. (Nigel, age 61, focus group 3)

I’m a bad mom because I can’t look after my kids the way I want to when my leg was really bad. (Rebecca, age 37, interview)

I would not be seen in any of my dancing clothes with this extra 70 pounds on because it just doesn’t feel right. I used to love getting dressed up and wearing a nice pair of heels and wearing a nice outfit and going out and you know, kicking up my feet. (Susan, age 47, interview)

**A New Awareness**

I may have to think about going up a ladder, whereas before, I used to go ‘up’ a ladder... It’s changed my way of thinking, more than trying to reduce the activity because I still think I can do it. (Adam, age 54, interview)

And, when I’m walking or if I have to run for any reason, I’ll take shorter strides. I feel that if, I read somewhere if you take long strides, it’s putting a lot of tension on the knee because of where you’re striking. So I’ll make a mental effort to not stretch my strides out too much. (James, age 42, interview)

**Lack of Trust in the Knee**

I’m nervous sometimes. I’m scared to take a step because I’m like what if it just bends in half the other way and I’m just stuck here? (Lynn, age 43, focus group 6)

Standing up first thing in the morning when I get out of bed, I have to push myself up because I don’t trust my knees. (Davis, age 61, focus group 5)
**Figure 6.1 Core Category: Disruption and Change**

**Figure Legend:** Figure 6.1 represents the core category, disruption and change. Under the core category, two main categories of disruption and change were generated: 1) Disrupted physical, social and emotional life, which includes three aspects of disruption: physical disruption, emotional disruption and social disruption; and 2) An altered way of thinking about the body and self, which includes changes in how people thought about their bodies (a new awareness and a lack of trust in their knee) and an altered sense of self. The arrows indicate the potential reciprocal influences within categories and across these categories. The role of personal context is indicated by situating the categories within the person’s individual context.
6.4.1.1 Disrupted Physical, Social and Emotional Life

**Physical Disruption**

A common consequence described by participants was the effect of symptoms on their physical activities. The physical disruption was varied and contingent on participants’ symptoms and the role of physical activity in their lives. Some participants gave up demanding physical activities, such as soccer or running, which they often represented as a loss in their life. One participant who gave up running explained: “I ran almost seven days a week for a good ten years, pretty much 5k a day every day. And there’s nothing more in the world that I like more than doing that… And to have it cut off like that…” (Mark, age 46, focus group 2) Others were able to maintain their physical activities, depending on the demands of the activity they valued participating in. Some participants struggled with whether and when to give up activities. For instance, some participants expressed concern for their knee but were unclear what activities they should avoid. Other participants wished they had given up activities they perceived had caused damage to their knee, such as running, “collision” sports or squash, or changed activities earlier to prevent or reduce their current knee symptoms.

Whether or not participants gave up activities, most reported changes to how physical activities were performed, the amount of activity and/or the speed at which they performed the activity. Some participants reported being less active than they had been and that symptoms had “slowed” them down. For example, Adam (age 54, interview) reported: “I may not be able to do them to the extent that I did do them before.”

Participants reported varied reasons for the physical disruption in their lives. Some participants indicated that they gave up or changed their physical activity due to the symptoms, such as pain, that they experienced while doing the activity. Another reason some participants gave for changing physical activity was their perception
that certain demanding physical activities, such as running, might cause further “damage” or joint degeneration in their knee or even accelerate the need for surgery. James (age 42, interview) reported both of these reasons for changing his physical activities. While reflecting on his attempt to return to running, he recounted: “But I had too much pain, right away, so then I quickly stopped again.” Later, when discussing why he turned down an invitation to do a long bike ride, he reflected: “I thought what possible further damage am I going to do long-term.”

**Social Disruption**

Changes in physical activities could also affect leisure and social life. Giving up activities (e.g. squash, dancing) linked to social interactions was often represented as a social loss in their life. Some participants felt isolated from peers when they couldn’t physically participate or keep up with friends. One participant explained: “I have a couple of girlfriends, who were walking regularly, and then I really hurt my knee bad and then I couldn’t join them. I am socially isolated because of it”. (Susan, age 47, interview) Participants who maintained activities or did not link social life to physical activity did not report such consequences.

Some participants discussed the repercussions of their knee symptoms on their family life. In particular, younger participants who were parents to young children described consequences of the symptoms on their role as a parent. They reported challenges playing with children on the floor or being active with their children. For example, Wilson (age 41, focus group 6) commented: “Most of us that have kids, having the problems with your knee are not able to get down on the ground to play with them.” Another participant described her responsibilities as a parent of teenaged children and an only child to aging parents. As a result of her knee symptoms, the physical activities that sometimes accompanied these roles (e.g. walking long distances, heavy lifting) were challenging to perform.
While symptoms did not cause disruption at work for all participants, it did have significant consequences for some individuals, depending on the demands of the job. A couple of participants reported not working due to their symptoms. For example, one woman who worked in food services and retail stopped working due to difficulty with prolonged standing. More commonly, participants recounted changes at work. These often came in the form of modifications they made to reduce the disruption to work life, such as working from home, delegating activities, or adapting their work environment.

**Emotional Disruption**

Participants described a wide range of emotional responses to symptoms. While some participants expressed frustration and annoyance at having symptoms, others described feeling depressed by symptoms and the impact on their lives. For example, Emma (age 42, interview) recounted: “I was running and doing all kinds of sports and very skinny so it’s caused a little bit of depression trying to manage everything and not being able to do everything I used to.”

Participants also expressed concerns about the future. They worried about knee symptoms getting worse. Older adults expressed concerns about maintaining independence as they aged. Participants also expressed concerns about how changes in their physical activity would affect their general health. For example, a participant who reported she had decreased her activity and gained weight due to her knee, commented: “If I can’t get this weight off, it’s a real threat that I may end up insulin dependent, and with that comes all kinds of other associated risks.” (Susan, age 47, interview)
6.4.1.2 Altered Way of Thinking about the Body and Self

Altered Sense of Self

Participants described changes in the way they viewed themselves. They talked about the physical changes which made them feel they were no longer “infallible”. Men, in particular, recounted that they once felt “strong” and “capable”, but knee symptoms made them feel less capable. For instance, Peter (age 57, focus group 1) stated: “All of sudden you start thinking, I can’t do this anymore, and you extrapolate from the physical to the other things…You start to think that … you’re not as good as you used to be.” Some women also reported that symptoms undermined their view of themselves as active and independent.

The effect of symptoms on aspects of participants’ lives, such as social roles, influenced participants’ appraisals of themselves. For instance, some participants’ view of themselves as parents changed. This change was more commonly recounted by mothers. One participant stated she was a “bad mom” because she couldn’t take care of her children the way she wanted to. Another woman explained that she was not a good role model to her children as she wasn’t leading a physically active lifestyle.

Changes in appearance were also linked to sense of self, particularly for women. A common example recounted by women was not being able to wear “nice” shoes. While this was often downplayed as a minimal consequence, it was disheartening to participants and threatened their identity. For example, Rebecca (age 37, interview) commented: “It makes me feel like crap. I can never be cute… I can’t wear shoes and definitely not high heels…” Another woman described the weight gain she associated with her knee symptoms as “a huge blow to my self-esteem.” (Susan, age 47, interview)
The visibility of symptoms, or lack thereof, affected how participants believed others perceived them. Some participants spoke of not wanting to appear “disabled” or “weak” to others and recounted trying to hide their knee symptoms. Max (age 48, focus group 2) explained: “You don’t want to be seen as a nearly handicapped or a not fully physically functioning individual, so you want to sometimes try to avoid these social situations.” In contrast, other participants spoke of the invisibility of symptoms as a challenge because people underestimated the consequences of symptoms. For example, one woman recounted feeling that work colleagues didn’t understand why she had special considerations such that she could work from home.

**A New Awareness**

Participants indicated they had a new awareness of their body as a consequence of having knee symptoms. Universally, participants recalled not thinking about their knees prior to having symptoms. After the onset of symptoms, their knee came to the fore of their consciousness and they became very aware of having a knee. Some participants reported that their knee seemed to always be on their mind. One woman recounted: “It’s just that I am constantly aware, thinking twice with every activity… Everything now has now a new think to it.” (Gail, age 60, focus group 5) With this new consciousness, participants recounted being more deliberate and cautious in moving their legs. They reported that they thought about if and how to perform movements. One participant explained: “I have to be more conscious and think about how I’m moving and speed of changing direction and how I use my legs.” (Oscar, age 59, interview) Performing activities that were once taken for granted, unconscious acts often became more conscious movements. Other conscious acts included avoiding activities, planning activities ahead or “slowing” down.

While some participants indicated that the heightened awareness of their knee became more subconscious over time, most indicated that this awareness persisted to some extent.
Lack of Trust in Knee

Participants recounted unpredictable symptoms of pain, giving way and locking. As a result of the perceived lack of control, they reported that they didn’t trust their knee, sometimes characterizing it as a “liability”. They indicated that the knee had let them down or “betrayed” them. For example, during an exchange between participants in a focus group, Laila (age 60, focus group 3) stated: “So I don’t trust that I could go jogging anymore or anything like that…because I don’t think I’d make it. I think that knee would go.” Another participant responded: “I have that feeling too. If I was coming home and it was dark and somebody was following me down the street, could I peel out of here…? Could I trust my knees to do that?” (Donna, age 56, focus group 3)

6.5 Discussion

This paper illustrates the significant and varied consequences knee symptoms had on the lives of adults who were relatively young with mild to moderate knee symptoms. While previous studies reported disruption in the lives of older adults with OA, often over age 60, little was known about the consequences of knee symptoms in younger adults. This study found that younger adults experienced a range of significant disruptions and changes, shaped by their personal context. Participants reported disruption and change in their physical, social and emotional life as well as an altered way of thinking about their body and selves. Our findings underscore the importance of recognizing the consequences of knee symptoms in younger adults in order to develop health and community based supports to address peoples’ complex needs. These findings also provide insight into the findings which were presented in Chapter 5 which show that people with knee symptoms were proactive in working to manage symptoms. People may have been motivated to work hard to find ways to manage symptoms due to the significant disruption and change that resulted from symptoms (e.g. disruption in physical activity).
In the current sample, a common consequence discussed by participants was change in physical activities. In other research, findings demonstrated that people with arthritis were less likely to be physically active than those without arthritis (Hootman et al., 2003). I found that participants gave up demanding physical activities and changed how, or how much, they performed activities. Changes in physical activity had important consequences for participants’ well-being. Moreover, reduced physical activity could have long term effects on participants’ health and well-being as they age. Physical activity has been associated with reduced risk of chronic disease and premature death, with some research showing that mid-life physical activity increased healthy aging, disability-free survival and self-reported health (Sun et al., 2010). Recent research also found that people with OA had an increased risk of cardiovascular disease, which may in part be related to activity levels (Rahman et al., 2013).

Participants experienced a myriad of disruptions in their social life (leisure, work, family), highlighting the consequences knee symptoms had on activities and relationships that enrich lives and have been shown to predict well-being (Umberson et al., 2010). Disruptions to social life have been reported in other research in chronic disease (Bury, 1982) and with older adults with OA, who described changes in social interactions, recreation, work and travel (Maly & Krupa, 2007; Ong et al., 2011; Sanders et al., 2002; Turner et al., 2002). Research in younger adults with OA is limited but others have also reported an effect on work (Gignac et al., 2006; Kao & Tsai, 2012) and social activities (Gignac et al., 2006). In a study with a sample of younger people with OA who were mainly labourers, participants reported a reduction in work and family income (Kao & Tsai, 2014). In comparison, our sample had few participants who were working in manual labour, which may have underestimated the potential consequences on work as participants may have been less likely to give up work.

Sociological literature has highlighted the ‘loss of self’ experienced with chronic conditions (Bury, 1982; Charmaz, 1983). Research in older adults with OA indicated
that peoples’ self-worth was reduced as they felt less valuable physically (Maly & Krupa, 2007). Studies of former athletes with OA found people reported changes in identity from the loss of athletic roles and physical changes (Keysor et al., 1998; Turner et al., 2002). Similarly, in my study when changes conflicted with participants’ expectations of themselves, people experienced an altered sense of self. Underlying the changes was a loss of part of their identity. Future work is needed to understand how people cope with these changes and how health care professionals can best provide support to individuals.

This study also extends findings from previous research on how people think about their knee. In my study, participants recounted a new awareness and lack of trust in their knee. In previous research, Maly and Cott indicated that younger adults with knee symptoms engaged in “being careful”, a process aimed at avoiding knee damage during physical activity (Maly & Cott, 2009). My findings suggest that people had a new way of thinking about the knee that permeated their lives and influenced actions. One can view these changes through Gadow’s conceptualization of embodiment (Gadow, 1980). Gadow described the lived body as the experience of unity between the body and self when people do not think about their body. After an injury/illness, there is a stage of disunity between body and self, object body, in which there is a heightened awareness of the body part (Gadow, 1980). My participants described this transition from taking their knee for granted to being very conscious of their knee. In Gadow’s theory, people move on to learn to live with their injury/illness and even find meaning in their body (Gadow, 1980). While my participants recounted adaptations to live with their knee, a heightened awareness of their knee persisted.

Participants indicated that part of “a new awareness” was thinking about how to perform movements and being more deliberate in moving their legs. Whether people changed the way they moved is less clear and the implications of any conscious changes in movement patterns for the knee or other joints are unknown. Other researchers have postulated that biomechanical aberrations that persist over time
may have important consequences for structural changes in the joint (Roos et al., 2011). For instance, disruption of normal gait mechanics (e.g. with trauma, weight gain) can shift the loading patterns during weight-bearing activity to cartilage regions not well adapted for those loads (Andriacchi et al., 2004; Andriacchi et al., 2009; Vincent et al., 2012). It is postulated that at some point the cartilage can no longer adapt to the altered ambulatory loading and begins to degrade, increasing the rate of OA progression (Andriacchi et al., 2006). While more research is needed to understand how peoples’ heightened awareness of their knee affects movement, our findings indicate that people may benefit from support to regain confidence in their knee and to ensure that people are making appropriate adaptations to address symptoms that do not increase risk for joint deterioration.

These findings have implications for policy and practice. First, given the consequences of knee symptoms on physical activity, interventions are needed to help younger adults with knee symptoms remain physically active in valued activities by appropriately modifying their actions when needed and by facilitating exercising in ways that prevent excessive joint stress. Engaging in appropriate physical activity can reduce knee symptoms (Bennell & Hinman, 2011b; Conn et al., 2008; Roddy et al., 2005a; Roddy et al., 2005b), and may delay disease progression and affect peoples’ health more generally by preventing comorbidity. Second, participants’ accounts revealed that consequences extended beyond the physical to social life and how one views him/herself. These consequences deserve increased attention and support in clinical practice. Finally, our findings suggest symptoms and their consequences cannot be separated from other aspects of the person in the context of their life. I found variation in experiences within categories based on participants’ personal context, such as gender, timing (age, stage of life), priorities (e.g. type/value of activities), and the nature of social roles (e.g. demands of work, family). There is a need for clinicians to tailor advice and support to an individual’s needs considering their symptoms, the consequences of symptoms on their lives and their personal context.
The findings of this study need to be considered within the limitations of the work. I used a self-report diagnosis of OA or OA-like knee symptoms. I based our joint symptoms question on a widely used survey question on joint pain (Centres for Disease Prevention and Control, 2013) and used carefully selected exclusion criteria to recruit participants who were more likely to have OA. Prior research indicates that knee pain is often the first sign of knee OA and is a predictor of future radiographic OA (de Klerk et al., 2012; Thorstensson et al., 2009). Moreover, OA often co-exists with other knee conditions (Hill et al., 2003; Hinman et al., 2014; Picerno et al., 2013). For instance, recent research found that underlying radiographic OA was highly prevalent in middle-aged and older adults with a clinical diagnosis consistent with chronic patellofemoral pain (Hinman et al., 2014). However, I acknowledge that there is a chance that some participant’s knee symptoms could have been the result of conditions other than OA. The majority of participants in the sample were working, had a post-secondary education, and lived in an urban area. It is possible these factors influenced their experience with symptoms. Participants were not sampled based on ethnicity and future work is needed to explore the role of culture in understanding the consequences of knee symptoms. In addition, I conducted the focus groups and interviews and coded the data. There is the potential that this could limit alternative interpretations of the data and competing explanations. To mitigate this, all PAC members were involved in interrogating the data when reviewing the transcripts and participating in regular group discussions. Finally, qualitative methods allowed me to develop concepts that helped me to understand individuals’ experiences with knee symptoms. Further work would be needed to investigate the transferability of our findings to the population of adults aged 35-65 years with knee symptoms.

6.6 Conclusion

While OA has often been thought of as an “old” person’s disease and clinical practice has focused on older adults, this study illuminates the significant disruption and change experienced by 35-65 year olds with knee symptoms. The range of
consequences experienced by younger adults with knee symptoms was similar to consequences reported in the literature on older adults with OA; yet, these consequences in younger adults with knee symptoms may be underappreciated in clinical practice. These findings support calls for a paradigm shift in OA management towards early intervention. They also draw attention to the need for approaches in the health care system or community which support the diverse needs of the individual in the context of their lives. In particular, support is needed to help people remain physically active as they age. Future research is needed to examine how to best support younger adults with OA symptoms and address the consequences of symptoms on their lives.
Chapter 7: Discussion
7.1 Overview

The aim of this thesis was to understand the perceptions and experiences of adults aged 35-65 years with knee symptoms. Participants did not view knee symptoms as normal and indicated they wanted to control symptoms and prevent progression of symptoms. Participants made efforts to manage symptoms. This involved a complex process of searching for solutions which often took time and money. Participants consulted health care providers to get help for their knee symptoms but often perceived that medical care offered limited options and guidance. Moreover, participants indicated that knee symptoms had a myriad of significant consequences on their lives. Taken together, these findings indicate there is an opportunity for earlier intervention to provide guidance and support to adults aged 35-65 years with moderate knee symptoms. This research has important implications for practice and policy, providing critical insights which can help support the development of interventions to prevent OA and help younger adults with knee symptoms manage symptoms and potentially control progression.

In this chapter, I will begin by discussing the key findings of the research in the context of the literature. I will then discuss policies and services currently available in Canada for OA and highlight evolving developments in OA care internationally. Following from these contexts, I will discuss the implications of this research for policy and practice, the plan for knowledge translation, the strengths and limitations of the study and future directions for research. Throughout the chapter, concepts related to prevention and chronic disease management will be discussed.

Prevention and management of chronic diseases include a continuum of initiatives to: prevent diseases from occurring; identify disease at its earliest stage so that prompt and appropriate management can be initiated; and, reduce the consequences of a disease through chronic disease management (e.g. halt or delay disability) (Institute of Medicine, 2010). While definitions of what constitutes chronic disease management vary, common elements include: a systematic approach to planning care, utilization of multiple treatment modalities with a focus on self-
management support, use of coordinated care across health-care providers and sectors, and/or use of multidisciplinary teams (Brand et al., 2014).

7.2 Contributions of the Research to the Literature

The importance of understanding lay perspectives of illness in order to improve health care delivery and enhance communication between patients and health care providers is increasingly recognized (Donovan, 1991). Previous research in other chronic conditions has illuminated peoples’ experiences of chronic illness, the ways in which they make sense of and explain their illness, and how they cope with their illness (Newbould et al., 2006; Pierret, 2003). While there is a small body of research which explored the perspectives and experiences of older adults with OA, few studies have considered the perspectives and experiences of adults aged 35-65 years with earlier knee symptoms. Overall, this study adds depth to our understanding of the perceptions and experiences of adults living with knee symptoms at a younger age. This study also highlights that lay perspectives on the meaning of symptoms, how people respond to and manage symptoms, and the consequences of knee symptoms on peoples’ everyday lives all provide important contributions to our overall understanding of knee symptoms and have important implications for practice and policy. In the remainder of this section, I will discuss specific contributions of the research to the literature.

Findings of my research illuminated how people aged 35-65 years with knee symptoms perceived their symptoms. As noted in the literature reviewed at the beginning of the thesis, I found that most studies of older adults indicated that they perceived OA to be a normal part of getting older (Dickson & Kim, 2003; Gignac et al., 2006; Maly & Krupa, 2007; Sanders et al., 2002; Turner et al., 2007). This is consistent with more general research in older adults which found that older adults were more likely to attribute illness symptoms to age rather than illness regardless of severity or duration of symptoms (Prohaska et al., 1987). Studies including some younger participants with OA reported divergent findings related to perceptions of
cause (Sanders et al., 2002; Turner et al., 2007). However, in this study, participants did not attribute their knee symptoms solely to age. They compared themselves to others and did not perceive symptoms as normal or acceptable for their stage of life. Rather, participants perceived symptoms as potentially preventable and linked symptoms to prior actions (e.g. overuse), incidents (e.g. injuries) or characteristics (e.g. obesity) that are modifiable. Participants’ perceptions of cause often reflected known risk factors for OA (e.g. obesity, knee injuries (Blagojevic et al., 2010; Silverwood et al., 2015; Toivanen et al., 2010)). However, some participants expressed uncertainty about the risk of physical activity, questioning if and when to give up or change activities. This may not be surprising given there have been conflicting results regarding physical activity and the risks of developing OA (Blagojevic et al., 2010; Silverwood et al., 2015). Finally, in research of older adults, participants believed symptoms would inevitably progress (Cedraschi et al., 2013; Ong et al., 2011; Sanders et al., 2002; Turner et al., 2007). In this study, participants often believed that symptoms could progress but indicated they believed they may be able to control progression of symptoms (e.g. delay need for TJR) through their behavior.

In response to knee symptoms, participants were working hard to manage symptoms, and in some cases, prevent progression. This involved a complex process of searching for solutions and trying to actively manage symptoms. They used several methods to search for solutions, including interacting with peers and health care providers as well as trial and error. The strategies participants tried were not all supported by evidence. While they did recognize and try some management strategies that have been found to be effective in improving the pain and disability of knee OA (e.g. exercise, weight loss (Christensen et al., 2007; Fransen et al., 2015; Uthman et al., 2013; Yan et al., 2013)), it is unclear if people were using such strategies as recommended in guidelines. In contrast to research in older adults (Maly & Krupa, 2007; Ong et al., 2011; Sanders et al., 2002), most of the participants indicated they had sought health care. However, some participants indicated that they struggled to get a diagnosis and were given minimal advice and
support for management from health care providers. This is congruent with quantitative studies indicating that quality of care for OA in primary care is suboptimal in older adults (Ganz et al., 2006; Li et al., 2011; McHugh et al., 2007; McHugh et al., 2012). Mann et al. also found that older adults with OA also needed more information on OA and management strategies at the time of diagnosis (Mann & Gooberman-Hill, 2011). This lack of advice and support may be a missed opportunity to improve OA management since research shows that a health professional recommendation is associated with use of exercise and weight management in people with arthritis (O'Donnell et al., 2013).

Participants indicated it was difficult to maintain management strategies, such as exercise, for knee symptoms over time. This is consistent with exercise studies in OA which show that adherence to exercise wanes over time (Bennell et al., 2011a; Bennell et al., 2014; Ettinger et al., 1997; van Baar et al., 2001). It represents a concern for long term management since adherence to exercise is critical for optimal clinical benefits (Bennell et al., 2014). There is a dose-response relationship between exercise and adherence with research showing that improvements in pain and disability increased with increasing adherence to exercise in people with knee OA (Ettinger et al., 1997).

The research findings draw attention to the broad range of consequences of knee symptoms in adults aged 35-65 years. Even at relatively young ages, participants described significant consequences of knee symptoms (e.g. pain, aching, stiffness) on their physical, social and emotional lives and how they viewed themselves. The general types of consequences described by participants were similar to the types of consequences described in studies of older adults with OA which included effects on mobility, leisure and social activities, finances, work and family (Maly & Krupa, 2007; Ong et al., 2011; Sanders et al., 2002; Turner et al., 2002). However, there were also some differences between my findings and research in older adults with OA (i.e. studies in which participants mean ages were typically over 60 years). For instance, in my research participants described consequences related to parenting young
children, which is less commonly described in studies of older adults. Participants also indicated that they had a new awareness and lack of trust in their knee. They reported giving up demanding physical activities, such as running and sports, and changing how they performed these activities. They spoke less about difficulties related to performing activities of daily living and household activities, which is reported in the literature on older adults with OA (Guccione et al., 1994; Maly & Krupa, 2007; Ong et al., 2011; Sugiura et al., 2013). It is possible that consequences such as changes in activities that are physically demanding (e.g. giving up sports or running) and how they viewed their knee are early signs of OA symptoms in this age group. Physically demanding activities, such as sports, require dynamic loading of the joint. While there are no data specifically related to these types of demanding physical activities, there are some studies using quantitative data on knee symptoms and function in older adults over age 60 years which suggest that the first signs of OA are linked to movements with dynamic loading of the joint (Case et al., 2015; Hensor et al., 2015).

In this research, participants indicated that the experience living with knee symptoms could be distressing and frustrating, particularly for younger adults in the sample. This is consistent with findings of prior research which found that younger adults with arthritis reported more psychological distress compared to older adults with arthritis (Gignac et al., 2006; Shih et al., 2006). Data from a Canadian population-based health survey showed that women aged 15-64 years and men less than 44 years of age with arthritis were more likely to report fair or poor mental health than older age groups (Ansari et al., 2010). Gignac et al. found that younger participants with OA were more upset by their OA than older adults and suggested that this was because OA was not viewed as normative in this age group (Gignac et al., 2006). The experience of OA in younger adults may have been perceived as “off-time”, or occurring outside normal parameters of the life course. Adults ages 35-54 years with arthritis were also more likely to be diagnosed with mental health conditions than people without arthritis (Hill et al., 2007). A recently published study in adults aged 20-50 years with hip or knee OA showed that the prevalence of high/very high
psychological distress was four times higher than the general population in this age group (psychological distress was categorized based on Australian Health Survey definitions) (Ackerman et al., 2015).

Overall, there were both similarities and differences between my study findings and those of studies of older adults with OA reported in the literature. Findings suggest that age is important to consider in examining the perceptions and experiences of knee symptoms. These findings are in keeping with previous studies related to the sociology of health and illness which considered the age of participants and the timing of illness in the life course. For instance, Bury drew attention to the younger age of his participants with rheumatoid arthritis as being a potential reason the onset of disease was so disruptive in their lives (Bury, 1982). Similarly, Sanders et al. highlighted the importance of age in her research on older adults with OA, finding that participants perceived symptoms as normal and an inevitable part of their biography (Sanders et al., 2002). This study adds to this body of research which highlights the importance of taking into account the age and stage in the life course at which a person experiences symptoms when examining the meanings given to illness and its consequences (Pierret, 2003).

Concepts from life course theory may help explain some differences between my study participants’ perceptions and experiences of knee symptoms and previous research in older adults with OA. A life course perspective emphasizes a temporal and social perspective, examining an individual’s or a cohort’s life experiences, or comparing across generations, to understand current patterns of health and disease, whilst recognizing that both past and present experiences are shaped by the wider social, economic and cultural context (World Health Organization, 2000). Specifically, this perspective posits that there is an age-graded sequence of roles and events that shape life from birth to death (Hendricks, 2012). Alwin argues that the consequences of events are conditional on the timing of events in life (Alwin, 2012). This concept can be applied to explain the unique findings in this research on the consequences of knee symptoms; younger participants were more likely to
have consequences related to parenting since they were actively engaged in being a
caregiver to a child given the timing of events in the life course.

A life course perspective may also help explain differences between this research
and previous findings in older adults on how people perceived OA symptoms. A life
course perspective acknowledges period or cohort effects in which there are
generational groupings where age and historical time are linked. Hendricks posits
that groups share meanings and look at the world in a similar way due to analogous
experiences at similar ages (Hendricks, 2012). This concept can be used to help
interpret why younger adults in this study perceived knee OA symptoms as
preventable while older participants in previous research perceived symptoms as an
inevitable part of aging. Others have suggested that shifts in how people assign
causation to illness are the result in cultural shifts that occur over time (Hodgetts et
al., 2000). Historically, cultural connotations of aging often symbolized a period of
decay (Sidell, 1995). However, there is a greater emphasis today in the media on
successful and healthy aging (Rozanova, 2010) which may influence peoples’
perceptions of causation.

Similarly, a life course perspective can be used to interpret findings related to how
people manage symptoms. In contrast to research in older adults, participants in
this study recounted seeking help from health care providers. This is consistent with
findings from the literature on chronic illness that shows help-seeking is less
frequently used by older adults (Felton et al., 1987). Previous researchers have
attributed differences in information seeking between younger and older adults with
chronic illness to cohort differences (Felton & Revenson, 1987). Cohort differences
may also play a role in the differences between our findings and previous research
in older adults. In this study, participants portrayed themselves as being responsible
for their health and being proactive to manage knee symptoms. This may reflect
current societal views that individuals have a responsibility or moral obligation to
pursue health (Cheek, 2008; Frank A, 1997; Townsend et al., 2006). Further
research using a life course perspective would be needed to examine potential
cohort differences in the way people perceive and manage knee symptoms over time.

While results from this research were presented in three distinct chapters, findings were interconnected. Of particular note, study findings on the meaning of knee symptoms helped us to understand participants' responses to knee symptoms. In prior research in older adults with OA, researchers suggested participants attributed OA to a normal part of aging and outside their control, which might explain why they did not seek health care (Pouli et al., 2013; Sanders et al., 2002). In this study, participants often attributed the cause of symptoms to a modifiable action or incident and believed the future course of symptoms could be controlled, which may explain why they were being proactive in trying to manage symptoms. Broadly speaking, this reasoning is supported by a variety of theories, which have been developed to explain health behavior and posit that health beliefs or perceptions (i.e. the way and individual views the world) affect health behaviours (Nigg et al., 2002). While a number of theories exist to explain behaviour, such as the widely used Health Belief Model, the concepts developed in my research (i.e. people believed symptoms were preventable both in terms of preventing the onset and controlling the course of symptoms), were most similar to concepts from the Common-Sense Model of Self-Regulation of Health and Illness (CSM). The CSM is a theory which holds that illness representations or lay beliefs enable people to make sense of their symptoms and guide coping strategies. The CSM includes illness representations related to perceived cause, controllability, consequences, identity (the disease label) and timeline (how long the condition is perceived to last) (Hagger et al., 2003). Participants’ accounts in this study suggest that the constructs of perceived cause and course of symptoms (including perceptions about progression and controllability) were particularly relevant illness representations for people with knee symptoms. Yet, these constructs often are not fully explored in other commonly used theories of behaviour change, including the Health Belief Model. Future research would be needed to test whether these perceptions are associated with specific health behaviours.
In sum, this research sheds light on the perceptions and experiences of adults aged 35-65 years with moderate knee symptoms, highlighting that participants perceived symptoms as potentially preventable, that they were working hard to find solutions to their knee problems and that symptoms had a myriad of consequences on participants’ lives. Their proactive approach to management was a stark contrast to their perception of medical care which they believed had had little to offer them. Yet, their accounts conveyed an interest in support to manage knee symptoms and progression. In comparing these findings to the literature which has been conducted primarily in older adults with OA, I found there were both similarities and differences, as indicated above. Overall, the collective findings contribute to our understanding of knee symptoms in younger adults and suggest there may be an opportunity for prevention initiatives and early interventions to support management for this population. To address this opportunity, appropriate policies and services for adults aged 35-65 years with knee symptoms are needed.

7.3 Policies and Services for People with OA in Canada

In this section, I will discuss the policies and services which currently exist to support OA prevention and management in Canada.

7.3.1 Policies Related to OA in Canada

The organization of Canada’s publicly funded health care system is set by the Canadian Constitution, in which roles and responsibilities are divided between the federal and provincial/territorial governments (Health Canada, 2012). The federal government’s roles in health care include setting and administering national principles for the system; financial support to the provinces/territories; and other functions, including funding and/or delivery of services to certain groups of people (First Nations people living on reserves, veterans). The provincial/territorial governments have most of the responsibility for delivering health and other social services. The health care system provides access to universal, comprehensive
coverage for medically necessary hospital and physician services. Funding of other services (e.g. care by other health professionals etc.) are at the discretion of the provinces/territories (Health Canada, 2012). Given this structure, health care policy is set at both a federal and provincial/territorial level. All levels of government (federal, provincial or territorial/municipal) share responsibility for public health policy (Health Canada, 2012).

At the federal government level, there is a dearth of current policies directly addressing OA in Canada. The Public Health Agency of Canada does surveillance on arthritis in the population (Public Health Agency of Canada, 2010; Public Health Agency of Canada, 2015c) and has an Integrated Strategy on Healthy Living and Chronic Disease. However, this has not translated into specific programs addressing OA (Public Health Agency of Canada, 2015b). At the provincial level, OA is generally missing from the policy agenda except in some provinces where it is listed as an example within the umbrella of chronic disease by ministries of health (Davis et al., 2014). For instance, in Ontario arthritis is mentioned as an example of a chronic disease within the government’s chronic disease prevention and management framework (Ministry of Health and Long term Care, 2007). However, this has not resulted in targeted policies or programs for OA. This is in stark contrast to other chronic diseases such as diabetes. For example, the Ontario government has developed Ontario’s Diabetes Strategy to educate the public; support patients in managing their disease; improve health care coordination; address gaps in health care; and, monitor performance (Ontario Ministry of Health and Long-Term Care, 2013).

7.3.2 Injury Prevention Initiatives in Canada

There are initiatives in Canada aimed at reducing knee injuries; however, prevention programs are not routinely available. I will discuss two specific projects aimed at reducing injuries in youth participating in sport and recreation activities to provide examples of the types of initiatives available in Canada. One example of knee
injury prevention in Canada is Canada Sport for Life’s *Active and Safe for Life – Physical Literacy* project, conducted with support from the federal government (Canada Sport for Life, 2011). Physical literacy has been defined as the motivation, confidence, physical competence, knowledge, and understanding to maintain physical competence, knowledge, and understanding to maintain physical activity throughout the life course (Whitehead M, 2007). According to Canada Sport for Life, physically literate individuals may be able to reduce injuries because it improves body mechanics and increases awareness of the activity environment (Canadian Sport for Life Physical Literacy, 2015). This program aims to enhance the skills, knowledge and attitudes of children and youth so they can avoid injury when participating in sport and recreational activities. To date, there is a lack of evidence of effectiveness of this program. Another example is the FIFA 11+ program, which is a complete warm-up program to reduce injuries among soccer players aged 14 years and older. The program should be performed as a standard warm-up before each training session at least twice/week. It consists of 15 single exercises, divided into three parts including initial and final running exercises with a focus on cutting, jumping and landing techniques (parts 1 and 3) and strength, plyometrics, agility and field balance components (part 2) (Steffen et al., 2013b). It has been shown in RCTs to significantly prevent (non-contact) injuries in soccer and with elite basketball players (Bizzini et al., 2015; Longo et al., 2012; Steffen et al., 2013a). Bone and Joint Canada is working with the Ontario Soccer Association to pilot FIFA 11+ program in soccer clubs across Ontario through a train the trainer program (Davis et al., 2014). Recently it was announced that the Public Health Agency of Canada, Canada Soccer, the Federation Internationale de Football Association (FIFA) and Canadian Sport for Life were partnering to implement and evaluate the FIFA-11+ program and *Movement Preparation* (a physical literacy program that uses similar exercises as FIFA 11+ but is geared towards younger soccer players, aged 7-13 years) in soccer clubs across the country (Public Health Agency of Canada, 2015a).
7.3.3 How and Where is OA Managed in Canada?

As findings from the literature review highlighted, there is consistent evidence that exercise and weight management reduce pain and improve function in knee OA (Christensen et al., 2007; Fransen et al., 2015). Self-management interventions are generally recommended (Chodosh et al., 2005; Du et al., 2011; Hochberg et al., 2012; Kroon et al., 2014; McAlindon et al., 2014) and there is also some evidence supporting biomechanical interventions such as knee braces and foot orthoses (Moyer et al., 2015a; Moyer et al., 2015b; Raja & Dewan, 2011). Support for management of OA symptoms is mainly provided in primary health care settings. Most adults in Canada who see a physician for OA see a primary care doctor (Mackay et al., 2010). People can visit other health professionals by referral from a physician or through direct access. A survey of adults with OA in British Columbia (mean age 67 years) found that people used a variety of health services, with visits to physical therapists, pharmacists and chiropractors being the most commonly visited non-physician health care providers (Li, 2008). Physical therapists work in a variety of public and private settings (e.g. outpatient departments in hospitals, private clinics) while pharmacists and chiropractors work mainly in private practice settings.

Access to primary health care providers varies across the country, with data suggesting there are some shortages of health care providers to provide care for arthritis (Davis et al., 2010). Within the provinces of Alberta, British Columbia and Ontario, there was significant variability in the number of primary care physicians, physical therapists, chiropractors and pharmacists per 100,000 population (Davis et al., 2010). Data suggest that 90% of health professionals work in urban centres in spite of Canada having a substantial population living in rural and remote areas (Davis et al., 2010). High costs have also been identified as a barrier to accessing physical therapists and chiropractors for people with OA (Li, 2008). Access to publicly-funded physical therapy is determined by provincial eligibility plans. Research in Ontario suggests that wait times for publicly funded outpatient physical
therapy are long (Passalent et al., 2009). Surveys of physicians in Ontario suggest that physicians believe that wait times for publicly-funded physical therapy are too long and private services too expensive (Cott et al., 2007). One survey of primary care physicians found that physicians were less likely to refer to physical therapy for a chronic condition because it is too difficult for people to access services (Glazier et al., 1996b). With limited access to publicly funded services, people access physical therapy services using private payers or pay out-of-pocket.

In Canada, interdisciplinary team care for OA is not routinely available, even for complex patients with OA (Davis et al., 2014). There are some examples of publicly-funded OA programs which have an interprofessional team to support disease management and provide group-based education in Canada (e.g. The Arthritis Program, South Lake Regional Health Centre, Newmarket, Ontario (The Arthritis Program, 2015)); however these programs are rare. More often people seek care from a range of independent practitioners. The system can be uncoordinated and people may receive duplicate care or insufficient care depending on the service provider available (Davis et al., 2014).

### 7.3.4 Self-Management Interventions

Self-management support from health care providers (actions taken to support a person’s self-management) is not routinely integrated into primary care in Canada (Health Council of Canada, 2012) but self-management programs are available. The Arthritis Society offers a lay led-program, The Arthritis Self-Management Program, in several locations across Canada (The Arthritis Society, 2015b) and Chronic Disease Self-Management Programs are also offered across the country (e.g. programs in British Columbia (Self-Management British Columbia, 2013)). Both programs consist of weekly sessions led by trained lay leaders (often for about 6 weeks). Programs cover topics such as: exercise, appropriate use of medications, and communicating effectively with health professionals (Lorig et al., 1993; Lorig et al., 2001). However, studies have shown that self-management programs tend to
have limited reach as most participants are older, Caucasian, well-educated and predominantly female (Newbould et al., 2006). Most participants have had a diagnosis for some time (Li et al., 2012). Studies also show that accessing self-management programs can be challenging. In studies of other chronic conditions, patients identified problems related to child care, transportation, as well as work hours (Health Council of Canada, 2012). Most arthritis programs are held face-to-face and it may be difficult for those who work full-time to attend a program during the day. Although some programs offer evening sessions, participants may be fatigued (Li et al., 2012) or have other commitments and obligations (e.g. family).

7.3.5 Community-Based Programs

Community-based programs (i.e. programs offered in recreation centres, senior centres, homes) delivered by people who are not trained health professionals have been shown to reduce pain and improve function in people with arthritis (Kelley et al., 2011). Fit and Strong! is a physical activity/behavior change intervention developed for older adults with OA in the US. It is a group-based program that consists of a multiple-component exercise program and group problem solving and education (Hughes et al., 2004; Hughes et al., 2006). Recent research has shown that certified exercise instructors can deliver the program with similar benefits as physical therapists, improving pain, physical function, stiffness, strength and aerobic capacity (Seymour et al., 2009). Another program which can be led by trained exercise instructors and is available in some locations in Canada for people with a form of arthritis is The People with Arthritis Can Exercise program (PACE). PACE is an 8-week land-based program to promote the self-management of arthritis through exercise in community-based settings. Research has shown short-term improvements in symptoms and self-efficacy for exercise at 8 weeks (Callahan et al., 2008). Other programs offered in the community are exercise programs in facilities such as fitness centres. This includes pool-based classes, which may be generic classes or may be geared towards people with arthritis (e.g. Aqua Arthritis (The Arthritis Society, 2015a)).
Overall, community-based programs are often generic and not specific to people with OA. Programs are typically offered to seniors (e.g. PACE (Callahan et al., 2008), Fit and Strong! (Hughes et al., 2014; Hughes et al., 2004)). For younger adults with knee symptoms, access to existing programs which target people with arthritis may be a challenge due to their age and the timing of classes (e.g. classes most often offered during daytime hours (e.g. Arthritis Aquafit (Centre Wellington, 2015)). General fitness classes are more widely available, but fitness instructors may not be trained in how to provide guidance to people with knee symptoms. This is particularly relevant since evidence on knee OA indicates targeted exercise needs to be performed with proper body position and be individually progressed to avoid excessive joint stress (Skou et al., 2012).

7.3.6 Summary

There are few policies supporting OA prevention or management in Canada. This may in part be why initiatives to prevent knee injury are not routinely available. However, with new funding for knee injury prevention programs across Canada (i.e. FIFA 11+ and Movement Preparation), there may be reason for optimism. The majority of health care is provided in primary care but there are challenges in accessing health care services and care is often uncoordinated. There are few designated OA interprofessional programs available. Self-management programs are available but may not be accessible to younger people with knee symptoms. Similarly, community-based programs are geared towards seniors. In the next section, I will review developments in OA management internationally that may have relevance to the Canadian context.

7.4 International Examples of OA Policies and Programs

Internationally, there are examples of governments which have recognized the need for an action plan and service improvements for OA. Some countries are currently investing in OA and developing OA chronic disease management programs (ACI
Musculoskeletal Network, 2015; Deloitte Access Economics, 2014; Thorstensson et al., 2014). Key features of international initiatives include education and support for self-management, individualized exercise programs (often delivered by physical therapists) and registries which collect patient data for monitoring and evaluation (ACI Musculoskeletal Network, 2015; Deloitte Access Economics, 2014; Escape Pain, 2015; Skou et al., 2012; Skou et al., 2014; Thorstensson et al., 2012; Thorstensson et al., 2014). Some of the international initiatives are solely government funded, while others have a combination of payers (patients may need to pay small fees in some programs).

One example of an OA initiative comes from Australia, where the government identified arthritis and musculoskeletal conditions as a national health priority and commissioned the National Arthritis and Musculoskeletal Conditions Advisory Group to develop a national action plan and a national service improvement framework for OA, rheumatoid arthritis and osteoporosis (National Health Priority Action Council, 2006). These resulting documents are high level policy guides; practical implementation strategies are the responsibility of individual jurisdictions (National Health Priority Action Council, 2006). State level projects for the early identification and comprehensive, conservative management of individuals with OA have been developed. For instance, the state of New South Wales has developed an OA chronic disease management model of care, the Osteoarthritis Chronic Care Program. People with knee or hip OA are eligible if they have pain most days of the past month and have a visual analogue score of at least four out of 10. Those who don’t meet criteria are referred to a self-management program or community exercise program (ACI Musculoskeletal Network, 2015). In the early implementation of the program, patients were typically on the TJR waitlist with moderate to severe disease (mainly age 60 and 79 years) (Deloitte Access Economics, 2014). Once in the program, a musculoskeletal coordinator (typically a physiotherapist), in conjunction with the multidisciplinary team of practitioners, assesses individuals and links them with relevant health care providers to support timely and effective care (ACI Musculoskeletal Network, 2015). The program includes exercise, support for
weight loss, psychological management, review of medications and disease management education. The program can be delivered at one site with an interdisciplinary team, access to a team which includes private health practitioner settings, or self-directed interventions (ACI Musculoskeletal Network, 2015). Patient reported outcomes and functional performance measures are routinely collected at 12, 26 and 52 weeks (Deloitte Access Economics, 2014). Evaluation of pilot sites found that clinical outcomes of pain, mobility and function improved in the first 26 weeks, with a subsequent loss in clinical gains over the final 26 weeks. It has been recommended that more patient contact with the teams is needed to support self-management over the second half of the program (Deloitte Access Economics, 2014). Almost 11% of knee patients were taken off the TJR wait list because they no longer required surgery (Deloitte Access Economics, 2014).

In the UK, an intervention funded by the National Health System (NHS) called ESCAPE-knee pain is being implemented in large NHS Trusts, community sites, and is expanding into gyms and leisure centres (Escape Pain, 2015). It is an exercise-based rehabilitation program designed to improve function by integrating exercise, education, and self-management strategies (Hurley et al., 2007; Hurley et al., 2012). Participants can attend 12 supervised sessions twice weekly for six weeks. For 15–20 minutes, the supervising physical therapist facilitates a discussion on a topic, suggesting simple coping strategies. For 35–40 minutes each participant performs an individualized exercise regimen (Hurley et al., 2007; Hurley et al., 2012). Prior to broader implementation, this program was tested in an RCT of 418 people (mean age 67 years) with chronic knee pain (Hurley et al., 2012). The participants in the intervention had large initial improvements in function compared to the control group (mean difference in WOMAC function -5.5 (95% CI: -7.8, -3.2). Improvements decreased over 30 months but they still had better physical function and had a high probability of being cost-effective (Hurley et al., 2012).

Some developments in OA care also have emerged from Scandinavia. In Sweden, The Better Management of Patients with OA program (BOA) combines a minimum of
two physical therapist led theoretical sessions held as group sessions containing information about OA and its treatments and on exercise (e.g. how to incorporate exercises into daily life) (Thorstensson et al., 2012; Thorstensson et al., 2014). A third session is ideally led by a trained OA communicator to talk about his/her lived experience with OA. An individualized exercise program is offered to patients by physical therapists and patients can choose to attend a twice weekly exercise program for six weeks or perform exercises on their own (Thorstensson et al., 2012; Thorstensson et al., 2014). By the end of 2013, about 1800 physical therapists from across Sweden were trained on how to implement the BOA program (Thorstensson et al., 2014). Data are routinely collected for evaluation in a national quality registrar (by June 2014, data from 20,200 patients were available for three month follow-up and 10,400 patients had completed 12 month follow-up) (Thorstensson et al., 2014). Three month data suggest nearly all participants (97%) had taken the theory sessions and 81% had volunteered for the exercise program (Thorstensson et al., 2014). Ninety-four percent of people rated the program as good or very good. Findings suggest 72% of participants used the information at least once a week 12 months after the intervention (Thorstensson et al., 2014).

In Denmark, a program called Good Life with Arthritis in Denmark (GLA:D), was developed using similar elements as the BOA program (Skou et al., 2012). It teaches physical therapists to deliver an evidence-based combined treatment of education and neuromuscular exercise to people with hip or knee OA. The education consists of three 1.5 hour sessions (two led by physical therapists; one by a previous participant of the program) aimed at improving the knowledge of the participants regarding OA and its treatment. There are 12 sessions of individualized neuromuscular exercise supervised by a physical therapist or at home (Skou et al., 2012; Skou et al., 2014). Participants of the program range in age from 18-94, 75% are men and 75% have knee pain as their primary problem (Roos et al., 2014). In a pilot study of 36 participants, the program was shown to be feasible and to reduce pain, improve function and quality of life at 3 months (Skou et al., 2012). In another study of 79 people who completed one year follow-up after the program,
improvements in pain and quality of life at three months were maintained at one year (Skou et al., 2014). By December 31, 2014, 2,290 patients had been evaluated at baseline and three months, and 425 patients had undergone baseline and 12-month follow-up (Roos & Skou, 2014). These data show that 57% of people used pharmacological pain relievers at baseline, and this proportion was reduced to 36% at three months. One out of three people reported increased physical activity levels at three and 12 months. Pain was decreased at three months and further decreased at 12 months (Roos & Skou, 2014).

In sum, there are examples of existing initiatives to improve management of OA through individualized exercise, education and support for self-management in other countries. Evaluation of the programs suggest they have benefits for people with knee OA (Deloitte Access Economics, 2014; Hurley et al., 2007; Hurley et al., 2012; Roos & Skou, 2014; Skou et al., 2012; Skou et al., 2014; Thorstensson et al., 2012; Thorstensson et al., 2014).

### 7.5 Implications for Policy and Practice in Canada

Considering the substantial individual burden of OA (e.g. pain, disability, fatigue, psychological distress, reduced quality of life, and altered participation in leisure and work (Ackerman et al., 2015; Agaliotis et al., 2014; Axford et al., 2010; Badley, 1995; Bieleman, 2014; Corti & Rigon, 2003; Fautrel et al., 2005; Grotle et al., 2008; Guccione et al., 1994; Hawker et al., 2008; Hawker et al., 2010; Salaffi et al., 2005; Wilkie et al., 2014)), the increasing prevalence rates (Nguyen et al., 2011), rising rates of TJR (Canadian Institute for Health Information, 2009; Kurtz et al., 2005; Ravi et al., 2012), and the concomitant economic costs and burden on the health care system (Bitton, 2009; Hunter et al., 2014; Le Pen et al., 2005; Leardini et al., 2004; Loza et al., 2009; March & Bachmeier, 1997), OA represents a public health crisis (White & Waterman, 2012). At the same time, policies and services for people with OA in Canada are lacking. Findings of this research suggest there are opportunities for interventions to support OA prevention and provide guidance and support for
management in adults aged 35-65 years with moderate knee symptoms. In this section, I will discuss implications of the study findings for the development of policies and practices to support adults aged 35-65 years with knee symptoms in Canada. I will focus on opportunities to improve prevention and management by leveraging current resources and drawing on international examples. Achieving improvements in health among adults with knee symptoms will take integrated efforts that span multiple sectors (e.g. health care, education, health and wellness (e.g. fitness professionals), public health, sports and recreation) (Hootman et al., 2012).

7.5.1 Public Policy

Public policy can have a profound influence on health status (Brownson et al., 2009). Development of policies at a national level has led to changes in health care delivery and beneficial outcomes for people with OA elsewhere (ACI Musculoskeletal Network, 2015; Deloitte Access Economics, 2014). Given the dearth of national and provincial policies related to OA in Canada, there is a case to be made for the development of policies which could serve to facilitate the development and evaluation of initiatives for OA in Canada (e.g. public education, community programs, improvements in health care, monitoring and evaluation). In particular, national policies making OA a health priority may facilitate action within the provincial governments which have the capacity to improve health care services and support for OA across the country. To drive such changes in policy and practice in Canada, it may be necessary to first improve public awareness of OA.

7.5.2 Public Awareness

International studies have shown that the public know little about rheumatic conditions and that the consequences of rheumatic diseases are largely undervalued (Badley et al., 1979; Price et al., 1983; Wardt et al., 2000). Findings from my study suggested that some participants did not think much about the risks
of OA when they had a knee injury or engaged in behaviours they perceived had caused their OA. Some participants also indicated they were uncertain about how to manage knee symptoms. These findings suggest there is a need for public health messages that facilitate awareness of OA risk factors and ways to prevent and treat knee injuries and OA symptoms at an early age. In the US, The Arthritis Foundation and Centres for Disease Control implemented a public awareness campaign in 2010 to dispel the myths about OA and improve management through evidenced-based strategies (Caceres, 2010). A Canadian public awareness initiative on OA could draw on the experiences of these organizations to develop public awareness strategies.

### 7.5.3 Prevention

Findings of this research have implications for primary prevention initiatives. Some participants’ accounts suggested that in retrospect they believed their symptoms might have been prevented had they changed their behavior earlier in life. History of knee injury is a major risk factor for the development of OA (Blagojevic et al., 2010; Muthuri et al., 2011; Silverwood et al., 2015). Research has shown that 10 to 20 years after an ACL or meniscus tear approximately 50% of people develop knee OA with associated pain and functional impairment (Lohmander et al., 2004). There is evidence for the effectiveness of proprioceptive/ neuromuscular training in reducing the incidence of acute knee injuries among adolescent and young adult athletes during pivoting sports (Hubscher et al., 2010). There are opportunities to enhance injury prevention in Canadian sports and recreation environments by further dissemination of successful programs. The recent announcement to implement and evaluate the FIFA-11+ and Movement Preparation programs in soccer clubs across the country is a promising first step. There also may be opportunities to bring concepts of physical literacy to community sports and recreation programs through support from provincial ministries responsible for sport, such as Ontario’s Ministry of Tourism, Culture and Sport. While the literature tends to focus on injury prevention in sports, there may also be opportunities for prevention within the provincial
education systems in Canada. For example, through Canadian Sport for Life, physical literacy development has become a priority for provincial and territorial education ministries across Canada (Pan-Canadian Public Health Network, 2013). Given the paucity of research, as physical literacy is integrated into programs, evaluation of the program and the impact on knee injury is warranted.

Once a knee injury is sustained early diagnosis and management to ensure optimization of preventative interventions that may slow disease onset and progression is recommended (Whittaker et al., 2015). However, participants in my study indicated they did not think much about the injury when it occurred. Bennell et al. recommended that after joint injury, clinicians should provide full disclosure about the risk of developing OA and consider recommending a change to low-impact sports and/or exercise, or a reduction in intensity (Bennell et al., 2012a). Researchers also have recommended appropriate involvement in prevention activities, especially neuromuscular exercises, particularly for people returning to sport (Bennell et al., 2012a; Tenforde et al., 2012). Others have suggested that support for weight management should be available for people who have sustained a knee injury. Data from a recent study showed that people 3-10 years post-knee injury were 3.75 times more likely to be overweight/obese than healthy matched controls (Whittaker et al., 2015). This increase in weight may put people at even greater risk of developing OA (Whittaker et al., 2015). To date there is a paucity of evidence supporting the effectiveness of prevention of OA following knee injury. However, the aforementioned recommendations are promising and deserve attention from clinicians who advise people following knee injury.

### 7.5.4 Self-Management Interventions

This study has implications for the delivery of self-management support. Younger adults with knee symptoms were engaged in a range of roles, like parenting and work, which may limit access to typical self-management programs delivered on a weekly basis often during the day. Studies have shown that other modes of delivery
of self-management support interventions have benefits. For instance, the internet Arthritis Self-Management Program for patients with all types of arthritis demonstrated a significant improvement in health distress, pain, activity limitation and global health over 12 months (Lorig et al., 2008). Recent studies have also shown potential for harnessing mobile technologies, like smartphone applications, to support health behaviors (Dennison et al., 2013) and disease management (Free et al., 2013). Further research is needed to determine the best approaches to supporting self-management in this population in Canada.

7.5.5 Health Care Support for People with Knee Symptoms

Findings of this research have implications for management support for people with knee symptoms within primary health care. Participants did not feel they were given adequate advice or support to manage knee symptoms and often perceived that medical care was limited. Internationally, chronic disease management programs for OA, which have shown some benefits have included an education component and individualized exercise programs supported by physical therapists (Deloitte Access Economics, 2014; Hurley et al., 2007; Hurley et al., 2012; Roos & Skou, 2014; Skou et al., 2012; Skou et al., 2014; Thorstensson et al., 2012; Thorstensson et al., 2014). While such programs are not typical in Canada, they could be developed by building on the experience and evidence from international programs. Consideration would need to be given to how and where to deliver such programs given the availability of local resources within communities, such as physical therapists.

Recommendations in chronic disease management models support the use of health care teams and coordination of care among health care providers and across sectors (Brand et al., 2014). Improved communication and coordination among the range of health care providers people with knee symptoms may visit and with professionals working in the health and wellness sector may provide improved support and assistance to people with knee symptoms. For instance, participants in
this research expressed feelings of frustration and depression related to their knee symptoms. Appropriate mechanisms for referrals and support for the mental health consequences of knee symptoms need to be established within teams of health care providers (these may be virtual teams). Another example is the need to establish linkages across sectors such as physical therapists communicating with fitness instructors who may be supporting exercise programs for people with knee symptoms in the community. Connecting services and delivering coordinated and integrated care is a priority for some provincial governments (e.g. Ontario’s Patients First: Action Plan for Health Care (Ontario Ministry of Health and Long-Term Care, 2015)) and these recommendations fit within chronic disease management frameworks which have already been developed by ministries of health across the country (e.g. British Columbia (Population Health and Wellness Ministry of Health Planning, 2003), Newfoundland (Department of Health and Community Services, 2011), Ontario (Ministry of Health and Long term Care, 2007)).

Regular follow-up is recommended for chronic disease management (Wagner et al., 2001). In this study, participants’ accounts suggested it was difficult to maintain management over time. Since people are likely to live with symptoms for a long time, mechanisms are needed for ongoing support. Some people may require more regular follow-up by health care providers (Mann & Gooberman-Hill, 2011) while others with early symptoms may need mechanisms to access health care providers as needed.

7.5.6 Community-Based Interventions

For people with mild-moderate knee symptoms, community-based interventions delivered by professionals working in the health and wellness sector in the community (e.g. fitness instructors) may provide another opportunity to support education and exercise. Research has shown that supervised exercise programs are more beneficial (Juhl et al., 2014) and a meta-analyses found that community-based exercise programs that can be delivered by people who are not health
professionals can improve pain and function in people with arthritis (Kelley et al., 2011). Since existing community-based programs are often not OA-specific and mainly target seniors (e.g. PACE), we need to consider how best to deliver community-based interventions to younger adults with knee symptoms. There may be opportunities to leverage existing community programs by training fitness instructors in gyms or community centres to provide support for education and exercise to people with knee symptoms (Davis et al., 2014). There are examples of using fitness instructors in community centres to deliver exercise classes to people with other chronic conditions. For example, physical therapists in Canada partnered with a municipal recreation provider to develop and evaluate a 12-week exercise program for people with neurological conditions at two community centers. The intervention was found to be safe, feasible and potentially beneficial (Salbach et al., 2014).

7.5.7 Targeting Younger Adults with Knee Symptoms

One of the challenges to improving management of OA symptoms in younger adults is how to target younger people with no diagnosis of OA but with symptoms commensurate with OA. Moving forward, it will be important that primary health care providers detect early knee symptoms in younger adults in order to provide appropriate advice and direct them to appropriate supports (as available). This requires a shift in thinking about OA from an inevitable, trivial disease of older adults to a condition that can begin early in life. When developing programs it also will be important to consider strategies which acknowledge that some people who may be in need of support may not have a diagnosis of OA. For example, criteria for programs may need to be flexible enough to include people with chronic joint symptoms.
7.5.8 Monitoring and Evaluation

Registries for monitoring and evaluation are common in international examples of OA programs (ACI Musculoskeletal Network, 2015; Roos & Skou, 2014; Thorstensson et al., 2012; Thorstensson et al., 2014). If initiatives are developed to support people with mild-moderate knee symptoms in Canada, such routinely collected data on patient outcomes and health care utilization will be critical to understanding if programs and services are effective and for whom.

7.5.9 Summary

This section presented implications of the research and discussed potential ways to enhance OA prevention and management of knee symptoms in younger adults including: development of OA policies, enhancing public awareness, broader implementation of prevention initiatives, improvements in self-management support interventions to target younger adults, development of programs in primary health care to support education and individualized exercise, improved coordination of care, and support for education and exercise in the community. While I have outlined a range of implications for policy and practice, some initiatives may be more of a priority for people currently living with knee symptoms. Participants’ accounts described a range of significant consequences of knee symptoms and highlighted a lack of support and guidance to manage symptoms. As such, priorities for action include developing self-management interventions targeting this population and enhancing support for education and individualized exercise within primary health care and community-based programs.

7.6 Knowledge Translation

In order to support the development of initiatives to improve early intervention for younger adults with knee symptoms as well as public awareness and prevention of OA, findings from this research will be disseminated to a broad range of
stakeholders working at multiple levels (e.g. policy makers and health planners, health care professionals, academics, arthritis-related organizations, people with knee symptoms). Table 7.1 presents some key messages and the specific stakeholder groups that can be targeted for each message. The majority of stakeholder groups in Table 7.1 include knowledge users who are critical to implementing initiatives for people with knee symptoms. Tools for outreach to these groups include brief reports with targeted messages tailored to each stakeholder. In addition, facilitating real change will require bringing key stakeholder groups together to discuss how to move forward to implement initiatives across the country to reduce knee symptoms and control progression in younger adults. To this end, it will be important to engage national organizations with a mandate related to OA and include people living with knee symptoms. For instance, Bone and Joint Canada is a knowledge translation network of people with an interest in the management of conditions affecting bones and joints; their work includes pursuing new initiatives related to care and injury prevention and I have had the opportunity to present the findings of my research at a priority-setting workshop Bone and Joint Canada held with national stakeholders which included policy-makers, clinicians, individuals from the health and wellness sector, professional organizations and non-governmental organizations and patients with OA.
Table 7.1. Knowledge Translation Key Messages

<table>
<thead>
<tr>
<th>Key Messages</th>
<th>Key Stakeholder Groups to Target</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Public Awareness</strong></td>
<td></td>
</tr>
</tbody>
</table>
| Study participants believed that their symptoms may have been prevented if they had changed their behavior earlier in life; however, they also indicated that they did not think much about injuries or actions at that time. Participants also expressed some uncertainty about how to manage knee symptoms. There are opportunities to promote public awareness of risk factors for OA and ways to prevent and treat knee injuries and OA symptoms at an early age. | • Public Health Agency of Canada (mandate to promote health and control disease)  
• Ministries of Health across Canada (policy makers who may have mandate for public education)  
• The Arthritis Society (a national organization whose mandate includes increasing public awareness) |
| **Prevention** | |
| Knee injury is a risk factor for knee OA. More widespread implementation of evidence-based initiatives to prevent knee injury (e.g. FIFA-11+) and evaluation of new initiatives that may support injury prevention (e.g. physical literacy interventions) are needed. | • Public Health Agency of Canada (mandate to promote health and control disease)  
• Ministries of Education (capacity to integrate education and physical literacy into physical education/health curriculum)  
• Bone and Joint Canada (have pilot program on injury prevention)  
• Provincial Soccer Associations (can implement successful programs with coaches/players)  
• Sport for Life Canada (a movement to improve the quality of sport and physical activity in Canada; currently implementing programs related to physical literacy)  
• Health Professional Associations |
<table>
<thead>
<tr>
<th>Key Messages</th>
<th>Key Stakeholder Groups to Target</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some study participants indicated that they did not think much about knee injuries when they occurred. Clinicians can provide education about the risks of knee OA following knee injury and support management to reduce risks (e.g. neuromuscular exercises).</td>
<td>• Health Professional Associations (e.g. Canadian Physiotherapy Association)</td>
</tr>
<tr>
<td></td>
<td>• Academics who teach the orthopaedic curriculum within health professional training programs (to ensure appropriate content in training programs)</td>
</tr>
<tr>
<td><strong>Self-Management Interventions</strong></td>
<td></td>
</tr>
<tr>
<td>Younger adults with knee symptoms may have commitments (e.g. work, family) that make regular attendance at self-management programs difficult. Programs need to consider how to reach younger people with early knee symptoms who may benefit from self-management support (e.g. on-line programs).</td>
<td>• The Arthritis Society (delivers the Arthritis Self-Management Program across Canada)</td>
</tr>
<tr>
<td></td>
<td>• Ministries of Health across Canada (some provincial governments are involved in funding/delivery of chronic disease self-management programs)</td>
</tr>
<tr>
<td><strong>Health Care Support</strong></td>
<td></td>
</tr>
<tr>
<td>The study found that participants were working hard to find solutions to their knee symptoms but were often uncertain about how to manage symptoms. They perceived they were given minimal advice and support for knee symptoms. To address this, there are opportunities to build on international chronic disease management programs which use physical therapists to deliver education and exercise programs to people with knee OA.</td>
<td>• Ministries of Health across Canada (provide leadership in delivering health care)</td>
</tr>
<tr>
<td></td>
<td>• Regional health authorities within provinces which may have authority to plan, integrate and fund health care</td>
</tr>
<tr>
<td></td>
<td>• Health care providers through professional organizations (e.g. Canadian Physiotherapy Association)</td>
</tr>
<tr>
<td></td>
<td>• Identify and target local champions who may be able to support development of such programs</td>
</tr>
<tr>
<td>Participants with knee symptoms experienced a broad range of consequences on their lives (e.g. physical, social, and emotional disruptions, an altered way of thinking about their bodies and themselves). As such, some people may need</td>
<td>• Ministries of Health across Canada (provide leadership in planning and delivering health care)</td>
</tr>
</tbody>
</table>
### Key Messages

- Access to a range of services. Improved coordination of care across the health care system and across sectors is needed to improve support for the myriad of consequences people may experience.

### Key Stakeholder Groups to Target

- Regional health authorities within provinces which have authority to plan, integrate and fund health care
- Target existing arthritis programs and health care providers through health professional organizations

### Community-Based Interventions

- Existing community-based programs are mainly geared towards older adults with OA and may be less accessible to younger people with knee symptoms. Community-based interventions to support education and exercise for younger adults with mild-moderate knee symptoms are needed.

### Monitoring and Evaluation

- As programs are developed it will be key to build in data collection systems to evaluate the outcomes of interventions.

### Related Stakeholders

- The Arthritis Society (who currently delivers the PACE program)
- Recreation facilities/gyms who may be interested in learning how to support people with knee symptoms within their current programs and services
- Organizations training and certifying fitness instructors (and may have role to play in training to support people with knee symptoms)

- Public Health Agency of Canada (mandate related to health surveillance; able to support national level monitoring system)
- Ministries of Health across Canada (mandate includes monitoring performance of the health care system)
7.7 Strengths and Limitations

This research focuses on younger adults aged 35-65 years with early knee symptoms, a largely neglected population. Detailed descriptions of the study limitations have been discussed in chapters four to six. However, one key methodological issue will be highlighted here.

To guide the inclusion criteria for the study, I used a self-report diagnosis of OA or knee symptoms. The joint symptoms question was based on a widely used survey question on joint pain (Centres for Disease Prevention and Control, 2013) and exclusion criteria were used to recruit participants who were likely to have OA. While I acknowledge there is the possibility that some participants’ symptoms may not be the result of OA, this definition was necessary to ensure we captured younger adults who may or may not have a diagnosis. Previous research on people with early OA did not use criteria for clinical or radiographic OA, arguing that the onset of symptoms was most applicable (Holla et al., 2014).

7.8 Future Directions

There are a number of potential future directions for research which build upon the findings of this study. In this section, I will highlight some future directions for research exploring the perspectives of people living with knee symptoms, clinical research, epidemiological studies and implications for theory development.

7.8.1 The Perspectives of People Living with Knee Symptoms

1) This thesis explored the perceptions and experiences of knee symptoms in younger adults who were mainly working, lived in an urban area and were highly educated. Further research is needed to explore how adults with less education, who live in rural communities and who have varied ethnic backgrounds think about and respond to knee OA symptoms.
2) Some of the categories developed in the research may be applicable to adults aged 35-65 years living with other chronic conditions (particularly chronic conditions which are typically associated with aging). Further qualitative research may be conducted with adults aged 35-65 years living with different chronic conditions to develop an understanding of the perceptions and experiences which are similar across chronic conditions and those which are unique to certain conditions.

7.8.2 Clinical Research

1) Research is needed to improve self-management support for people aged 35-65 years with mild to moderate knee symptoms. The first step to developing self-management support which targets younger adults is to conduct further research to determine the best approaches to supporting self-management in younger adults with knee symptoms. This could include exploring peoples’ preferences for the delivery of self-management support (e.g. on-line, in-person, mail etc.) and the content of programs. As programs are developed, it will be critical to examine the short and long term outcomes of these interventions on health outcomes (e.g. pain, disability), health behaviours (e.g. exercise, weight loss) and health care utilization using clinical trials.

2) Few programs and services exist for younger people with mild-moderate OA symptoms. Future directions need to include development of programs and services in primary care and community-based settings. It is critical that research studies be conducted to examine these programs/services including studying their feasibility, determining the impact of programs/services on health behaviours (e.g. exercise, weight loss), health outcomes (e.g. pain, disability), participant satisfaction, health care utilization and cost-effectiveness. Since little is known about how to slow or halt OA progression, long term studies that are able to examine changes over time are critical.
3) Since the majority of health care is provided in primary care settings, further research is needed to understand how to optimize the role of health care professionals in supporting primary and secondary prevention of knee OA. For instance, physical therapists play a role in providing support to people with musculoskeletal conditions in the community and there may be opportunities to enhance their role in providing support for primary and secondary prevention of knee symptoms. However, first we need to understand how physical therapists understand OA prevention and risk factors and what they see as their role in prevention.

7.8.3 Epidemiological Studies

The findings of this study have implications for future research examining the burden of OA symptoms in the population.

1) This study illuminated the myriad of significant consequences experienced by younger adults with moderate knee symptoms. Yet, surveillance of arthritis in Canada is limited to people with diagnosed arthritis, potentially excluding some younger adults with early joint symptoms. A previous version of the Canadian Community Health Survey, a cross sectional survey with a large sample to provide estimates for the Canadian population, asked about chronic joint symptoms. Using these data, Canizares et al. found that 10% of people reported chronic joint symptoms and these people, who were younger than people with arthritis, had similar outcomes to people with arthritis (Canizares et al., 2012). Given the potential individual and societal burden of knee OA symptoms in the population, it seems prudent to include younger people with earlier knee symptoms in research and surveillance efforts. Future work could explore how best to capture people with chronic joint symptoms that are likely to be OA in population surveys.
2) Building on the qualitative findings of this study, future research may examine the perceptions of knee symptoms, management of knee symptoms and consequences of knee symptoms in the population using a survey methodology. The findings of this study can be used to support the development of questions one should ask of younger adults with knee OA symptoms in future research. The following reflections offer some points to consider when developing questions for this population.

a. Since knee symptoms resulted in a range of perceived consequences, quantitative surveys examining the burden of OA symptoms should reflect this broad range of consequences including the consequences on their physical activity, social life (work, leisure, family), and emotions, as well as their perceived sense of self, awareness of their knee and trust in their knee. Findings provided an in-depth understanding of each of the disruptions and changes, which may help when formulating response options in surveys. For instance, when considering physical activity, findings highlighted that people gave up activities, changed how they did activities and/or changed the extent they performed activities.

b. Participants’ accounts of management of their knee symptoms suggested that management is a complex process of searching for solutions to their knee symptoms and engaging in active management. While it may be difficult for any quantitative question to capture the complex reality of how people manage symptoms, careful consideration should be given to how questions seeking to understand management are formulated. For instance, a question asking if people are currently using a particular strategy is unlikely to be sufficient to understand how people manage symptoms. Findings suggest that questions should also consider what people do to find solutions to their
symptoms, who they talk to and consult with, and what strategies they have tried as they looked to find effective management strategies.

### 7.8.4 Implications for Theory Development

1) One of the emotional consequences described by study participants was concern for their future health and independence. The impact of these concerns for the future on their current health and health behaviours is unclear. While this forward thinking about time (often referred to as futurity) is acknowledged in life course theory (Hendricks, 2012), it is often missing in empirical research. More often life course research emphasize linkages between earlier life conditions and future life outcomes (e.g. early life social conditions affecting future health). Future research could further explore this concept and how peoples’ perceptions about the future impact health behaviours.

2) This study explored the meaning of knee symptoms, consequences of symptoms and how people managed symptoms. Taken together, these findings illuminated the individuals’ perspectives on knee symptoms. While the relationship between health perceptions and behaviours has been extensively studied in a variety of conditions, future work is needed to fully tease out the relationships between peoples’ perceptions, management behaviours and the consequences of symptoms.

### 7.8.5 Summary

In summary, there are a number of future directions for research which build on the current study including: qualitative studies to explore the perspectives and experiences of people with knee symptoms who are aged 35-65 years in different socio-economic or cultural groups; clinical research questions to support the development of interventions and examine outcomes of interventions for younger
adults with knee symptoms; research examining the burden of knee symptoms in the population; and research related to the development of theory.

7.9 Conclusion

Findings of this thesis provide novel insights into how adults aged 35-65 years perceived knee symptoms, how they responded to and managed knee symptoms and the consequences of symptoms on their lives. Collectively, this research enhances our understanding of a population that is often neglected in research and clinical practice and, in doing so, highlights opportunities for prevention and early intervention for adults aged 35-65 years with moderate knee symptoms. Future research is needed to provide further evidence on how best to support younger adults with early knee symptoms.
REFERENCES


the pain-depression link in older adults with osteoarthritis. *Arthritis Care Res.(Hoboken.),* 63(10), 1382-1390.


Appendix A. Telephone script (Focus Groups)

Date: _____________________
Respondent’s Name: _______________________________________

[Use if voice mail/answering machine when potential respondent calls us after seeing a poster/advertisement for the study]

Hello, my name is __________ and I am calling from the Toronto Western Research Institute regarding your response to our advertisement about our study looking at people’s experiences living with knee pain. Please give us a call at 1.866.214.2748 and ask for Crystal. Thank you.

[If speaking to a live respondent]

Good morning/afternoon. Thank you for calling to learn more about our research study. My name is Crystal. I’m a doctoral student at the University of Toronto and this study is part of my doctoral thesis. Do you have some time for me to tell you about the research?

Before I begin, may I ask where you heard about our research?_________________________________

Thank you. We’re interested in learning more about peoples’ experiences living with knee pain, aching or stiffness and understanding how people manage these knee symptoms.

The study is funded through my student fellowship from the Canadian Institutes of Health Research. Findings will be communicated to people living with knee pain, health care providers, and the scientific community through scientific papers and presentations.

The study involve participation in a focus group that takes approximately one to two hours and also a short self-administered questionnaire that should take about 5-10 minutes. The focus group includes questions about your knee pain, your experiences living with knee symptoms and any management strategies you might use to manage these symptoms.

We will be arranging a date and time for the focus group that meets the needs of participants. You can provide us with information on the most convenient time of day for you to participate in a focus group. We understand that being involved in our research takes up your valuable time. For this reason, we offer all the people who participate in the study an honorarium in the form of a $20 gift certificate as a small token of our thanks. We will also reimburse you for travel costs incurred to attend the focus group such as parking or public transit.
Confidentiality

All information collected during this study, including your personal health information, will be kept confidential and will not be shared with anyone outside the study. We never use any names when reporting the findings of this study. No one except myself will have access to details of the information collected.

Questions about the Study

This research is overseen by an ethics board at the University Health Network. If you have concerns, the person to call is Dr. Anna Gagliardi who is the Co-Chair of the Research Ethics Board. She is not a part of the study team. As I mentioned she oversees the ethical conduct of research at the hospital including your rights as a research participant. I’ll give you the numbers in a moment.

Do you have any questions about the study?

Do you think that you would be interested in helping us?

☐ No
☐ Yes

[If “no”…] Thank you for considering our request.
I’m sorry that you’re unable to help [insert name of respondent]. Thank you for your time.

[If “yes”…] Thank you very much [insert name of respondent]. Before we complete the focus group, we have to screen people to see if they are eligible to participate. Do you agree to answer some questions about yourself to ensure you are eligible for the study?

☐ No
☐ Yes

If “no” [Unfortunately, we can’t proceed with the study without answering the screening questions. Thank you for your time].

If “yes”… Before we begin the questions, I’d like to give you a few phone numbers. Do you have a pen? You can reach myself, Crystal, at 1(866) 214-2748. If you have concerns about participating in this study, feel free to call Dr. Anna Gagliardi at the Research Ethics office at 416-581-7849.

Proceed to Screening Questionnaire
Appendix B. Telephone script (interviews)

Date: _____________________

Respondent’s Name: ________________________________

[Use if voice mail/answering machine when potential respondent calls us after seeing a poster/advertisement for the study]

Hello, my name is __________ and I am calling from the Toronto Western Research Institute regarding your response to our advertisement about our study looking at people’s experiences living with knee pain. Please give us a call at 1.866.214.2748 and ask for Crystal. Thank you.

[If speaking to a live respondent]

Good morning/afternoon. Thank you for calling to learn more about our research study. My name is Crystal. I’m a doctoral student at the University of Toronto and this study is part of my doctoral thesis. Do you have some time for me to tell you about the research?

Before I begin, may I ask where you heard about our research?_________________________________

Thank you. We’re interested in learning more about peoples’ experiences living with knee pain, aching or stiffness and understanding how people manage these knee symptoms.

The study is funded through my student fellowship from the Canadian Institutes of Health Research. Findings will be communicated to people living with knee pain, health care providers, and the scientific community through scientific papers and presentations.

The study involve participation in an interview that takes approximately one to two hours and also a short self-administered questionnaire that should take about 5-10 minutes. The interview includes questions about your knee pain, your experiences living with knee symptoms and any management strategies you might use to manage these symptoms.

A date and time for the interview can be arranged that best meets your needs. We understand that being involved in our research takes up your valuable time. For this reason, we offer all the people who participate in the study an honorarium in the form of a $20 gift certificate as a small token of our thanks. We will also reimburse you for travel costs incurred to attend the interview if needed.

Confidentiality

All information collected during this study, including your personal health information, will be kept confidential and will not be shared with anyone outside the study. We never use any names when reporting the findings of this study. No one except myself will have access to details of the information collected.
Questions about the Study

This research is overseen by an ethics board at the University Health Network. If you have concerns, the person to call is Dr. Anna Gagliardi who is the Co-Chair of the Research Ethics Board. She is not a part of the study team. As I mentioned she oversees the ethical conduct of research at the hospital including your rights as a research participant.

Do you have any questions about the study?
Do you think that you would be interested in helping us?
☐ No
☐ Yes

[If “no”…] Thank you for considering our request.
I’m sorry that you’re unable to help [insert name of respondent]. Thank you for your time.

[If “yes”…] Thank you very much [insert name of respondent]. Before we complete the interview, we have to screen people to see if they are eligible to participate. Do you agree to answer some questions about yourself to ensure you are eligible for the study?
☐ No
☐ Yes

If “no” [Unfortunately, we can’t proceed with the study without answering the screening questions. Thank you for your time].

If “yes”… Before we begin the questions, I’d like to give you a few phone numbers. Do you have a pen? You can reach myself, Crystal, at 1(866) 214-2748. If you have concerns about participating in this study, feel free to call Dr. Anna Gagliardi at the Research Ethics office at 416-581-7849.

Proceed to Screening Questionnaire
Appendix C. Screening Questionnaire

Let’s begin the screening questions:

What is your age: __________ (If less than 35 years, older than 65, EXCLUDE)

Gender:  □1 Male  □2 Female

1. Have you experienced pain, aching and/or stiffness in your knee most days of the past month?
   □1 NO  □2 YES (If yes, INCLUDE)

2. Have you been diagnosed with any type of arthritis?
   □1 NO  □2 YES

<table>
<thead>
<tr>
<th>Type of Arthritis</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Osteoarthritis (OA) or Degenerative Arthritis</td>
</tr>
<tr>
<td>□1 NO (If no, move to Q2c)</td>
</tr>
<tr>
<td>□2 YES (If yes, move to Q2b)</td>
</tr>
<tr>
<td>b. Osteoarthritis (OA) or Degenerative Arthritis in the knee(s)</td>
</tr>
<tr>
<td>□1 NO □2 YES (If yes INCLUDE)</td>
</tr>
<tr>
<td>c. Rheumatoid Arthritis (RA)</td>
</tr>
<tr>
<td>□1 NO □2 YES (If yes EXCLUDE)</td>
</tr>
<tr>
<td>d. Psoriatic Arthritis</td>
</tr>
<tr>
<td>□1 NO □2 YES (If yes EXCLUDE)</td>
</tr>
<tr>
<td>e. Lupus</td>
</tr>
<tr>
<td>□1 NO □2 YES (If yes EXCLUDE)</td>
</tr>
<tr>
<td>f. Ankylosing Spondylitis</td>
</tr>
<tr>
<td>□1 NO □2 YES (If yes EXCLUDE)</td>
</tr>
<tr>
<td>g. Fibromyalgia</td>
</tr>
<tr>
<td>□1 NO □2 YES (If yes EXCLUDE)</td>
</tr>
<tr>
<td>h. Other (specify) ________________________________</td>
</tr>
<tr>
<td>□1 NO □2 YES (If yes EXCLUDE)</td>
</tr>
</tbody>
</table>

3. In the last year, have you had an injury of your knee:

   □1 No injuries
   □2 Yes, please explain: ___________________________________________
If yes, EXCLUSION CRITERIA

- Ligament injury (e.g. anterior cruciate ligament, poster cruciate ligament)
- Injury to the meniscus or cartilage of the knee
- Knee dislocation
- Fracture to the lower leg
- Other injuries to the knee? (use clinical discretion)

4. Have you been in a car accident in the last year which affected your knee?

- 1 NO
- 2 YES, please explain: _____________________________________________________

If yes, EXCLUSION CRITERIA

- Ligament injury (e.g. anterior cruciate ligament, poster cruciate ligament)
- Injury to the meniscus or cartilage of the knee
- Knee dislocation
- Fracture to the lower leg
- Other injuries to the knee? (use clinical discretion)

5. Do you suffer from pain in your back?

- 1 NO
- 2 YES  If yes:
  - Do you have pain that goes down the leg to or below the knee?  
    - 1 NO
    - 2 YES
      (If yes EXCLUDE)

6. Do you have any illnesses or medical conditions other than your joint problems that affect your daily activities?

- 1 NO
- 2 YES, please explain: _____________________________________________________

If yes, EXCLUSION CRITERIA

- Multiple Sclerosis
- Stroke
- Parkinson’s Disease
- Alzheimer’s Disease
- Polio
- Chronic Lung Disease
- Mental illness, schizophrenia, bipolar disorder
- Epilepsy, controlled with meds
- Depression, controlled with meds
- Polio
7. Have you had total knee replacement surgery?
   - 1 NO
   - 2 YES (If yes EXCLUDE)

8. Are you waiting for total knee replacement surgery?
   - 1 NO
   - 2 YES (If yes EXCLUDE)

9. Have you been recommended total knee replacement surgery?
   - 1 NO
   - 2 YES (If yes EXCLUDE)

For excluded participants: Thank you for your interest in this study. Unfortunately, we’re looking for people with a specific range of knee symptoms and no other chronic health problems for this study. However, we do carry out studies on other types of arthritis. Could I keep your name on file for these studies and possibly contact you in the future?

For eligible participants:

Do you agree to provide your contact information to us for the purposes of arranging the [focus group/interview]. Again this information will be kept confidential and will not be shared with anyone outside the study. We never use any names when reporting the findings of this study. No one except myself will have access to details of the information collected.

- No
- Yes

Verbal consent obtained by: ________________________________ on _________________________________ dd/mm/year

Focus groups:

Contact information

Participant Name: ___________________________ Unique ID number: ____________

Address: ____________________________________________

_________________________________________________________________________
Telephone Number: ( ) ________________________ home
Telephone Number: ( ) ________________________ work
Telephone Number: ( ) ________________________ cell
Is it okay to leave a voicemail? ____________________
Gift Card Preference: ____________________________
Is there a day of the week that works for you?
______________________________________________
Is there a time of day that works best for you?
________________________________________________________________________
I will be in touch again to provide specific details about the time and location of the focus group you will attend.

Thank you very much for your time!

For interviews:

Contact information
Participant Name: ____________________________  Unique ID number: S-__________

Address: _________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Telephone Number: ( ) ________________________ home
Telephone Number: ( ) ________________________ work
Telephone Number: ( ) ________________________ cell
Is it okay to leave a voicemail? ____________________
Gift Card Preference: ____________________________

If convenient for you, we can go ahead and arrange a date and time for the interview. Is there a day of the week that works for you?

__________________________________________________________

If you need to reschedule you can reach me at the number I just gave you.

Thank you very much for your time!

Interview Date: ____________________________  Interview Time: ____________________________
Appendix D: Consent Form (Focus Groups)

Consent Form to Participate in a Research Study

Title: Perceptions, Experiences and Management of Knee Symptoms in Adults Age 35-65 Years – A Qualitative Study

Principal Investigator: Crystal MacKay

Phone Number: 1-866-214-2748

Introduction
You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. Participation in this study is voluntary.

Background/Purpose
The purpose of this study is to understand the perceptions and experiences of adults aged 35-65 years who have knee symptoms such as pain, aching or stiffness. We are also interested in any strategies people are using to manage their symptoms. This study is part of the principal investigator’s doctoral work at the University of Toronto. The research is carried out at the Toronto Western Research Institute. The study is funded by the Canadian Institutes of Health Research.

Procedure
We are asking for your participation in a focus group. A focus group is a form of group interview with 5-8 people. The focus group will take about 1-2 hours of your time. Participants of the focus group will be asked questions about their knee symptoms, experiences living with these symptoms and about what they do about these symptoms. There is also a short questionnaire with some general
questions about you and your knee symptoms that you will be asked to complete. The focus group will be audio recorded. The audio recording will be kept until completion of the study and then be erased. Your participation in the study is very valuable and greatly appreciated.

**Voluntary Participation**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time. You may refuse to answer any question you do not want to answer.

**Confidentiality**

We ask that you keep all information discussed in the focus group confidential in order to respect other participant’s anonymity and privacy. While the researchers will keep all information shared for the study strictly confidential, we can’t guarantee confidentiality from other members of the focus group. The researchers will keep all information collected during this study, including your personal health information, confidential and will not be shared with anyone outside the study unless required by law. Names will never be used in the findings reported from this study. The information that is collected for the study will be kept in a locked and secure area at Toronto Western Research Institute by the study investigator for 5 years. Only the study team or the people or groups listed below will be allowed to look at your records.

The following people may come to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines:

- Representatives of the University Health Network Research Ethics Board.

The information from the focus group will be combined and summarized for presentations to people living with knee pain and health professionals, as well as used for scientific and academic publications. If you decide to leave the study, your information that was collected before you left the study will still be used. No new information will be collected without your permission.
Questions About the Study

If you have any questions, concerns or would like to speak to research team for any reason, please call Crystal MacKay on our study line at 1-866-214-2748.

If you have questions about your rights as a research participant, please call the University Health Network Research Ethics Board (REB) at 416-946-4438. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.

Risks

There are no anticipated risks with this study.

Benefits

You may not receive direct benefit from your participation in the study. However, your participation will assist us in understanding more about peoples’ experiences living with knee symptoms.

Consent

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to take part in this study.

____________________________  __________________________  __________
Print Study Participant’s Name   Signature  Date
(You will be given a signed copy of this consent form)

I would like to receive a final summary report of this study (please indicate):

Yes ☐  No ☐
My signature means that I have explained the study to the participant named above. I have answered all questions.

<table>
<thead>
<tr>
<th>Name of Person</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

Obtaining Consent
Appendix E: Consent Form (Interviews)

Consent Form to Participate in a Research Study

Title: Perceptions, Experiences and Management of Knee Symptoms in Adults Age 35-65 Years – A Qualitative Study

Principal Investigator: Crystal MacKay

Phone Number: 1-866-214-2748

Introduction
You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. Participation in this study is voluntary.

Background/Purpose
The purpose of this study is to understand the perceptions and experiences of adults aged 35-65 years who have knee symptoms such as pain, aching or stiffness. We are also interested in any strategies people are using to manage their symptoms. This study is part of the principal investigator’s doctoral work at the University of Toronto. The research is carried out at the Toronto Western Research Institute. The study is funded by the Canadian Institutes of Health Research.

Procedure
We are asking for your participation in a one-on-one interview. The interview will take about 1-2 hours of your time. You will be asked questions about their knee symptoms, experiences living with these symptoms and about what they do about these symptoms. There is also a short questionnaire with some general questions about you and your knee symptoms that you will be asked to complete.
The interview will be audio recorded. The audio recording will be kept until completion of the study and then be erased. Your participation in the study is very valuable and greatly appreciated.

Voluntary Participation

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time. You may refuse to answer any question you do not want to answer.

Confidentiality

All information collected during this study, including your personal health information, will be kept confidential and will not be shared with anyone outside the study unless required by law. Names will never be used in the findings reported from this study. The information that is collected for the study will be kept in a locked and secure area at Toronto Western Research Institute by the study investigator for 5 years. Only the study team or the people or groups listed below will be allowed to look at your records.

The following people may come to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines:

- Representatives of the University Health Network Research Ethics Board.

The information from the interviews will be combined and summarized for presentations to people living with knee pain and health professionals, as well as used for scientific and academic publications. If you decide to leave the study, your information that was collected before you left the study will still be used. No new information will be collected without your permission.

Questions About the Study

If you have any questions, concerns or would like to speak to research team for any reason, please call Crystal MacKay on our study line at 1-866-214-2748.

If you have questions about your rights as a research participant, please call the University Health Network Research Ethics Board (REB) at 416-946-4438. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.
Risks

There are no anticipated risks with this study.

Benefits

You may not receive direct benefit from your participation in the study. However, your participation will assist us in understanding more about peoples’ experiences living with knee symptoms.

Consent

This study has been explained to me and any questions I had have been answered.

I know that I may leave the study at any time. I agree to take part in this study.

_________________________  ______________________  _________
Print Study Participant’s Name  Signature  Date
(You will be given a signed copy of this consent form)

I would like to receive a final summary report of this study (please indicate):

Yes ☐  No ☐

My signature means that I have explained the study to the participant named above. I have answered all questions.

_________________________  ______________________  _________
Print Name of Person Obtaining Consent  Signature  Date
Appendix F. Participant Questionnaire

QUESTIONNAIRE

Participant Demographic Information

Unique ID Number: __________
Date: _____________________

1. What is your date of birth: □ □ □ □ □ □ □ □
   Day      Month      Year

2. What is your gender: □ 1Male
   □ 2Female

3. What is the highest level of education that you have completed? Choose ONE response.
   □ 1Less than high school
   □ 2High school
   □ 3Trades certificate/Diploma
   □ 4College graduate
   □ 5University graduate

4. What is your marital status? Choose ONE response.
   □ 1Married or living as if married
   □ 2Divorced or separated
   □ 3Widowed
   □ 4Never married

- 1. Currently working
- 2. Homemaker
- 3. Retired (not due to ill health)
- 4. Unemployed or on leave of absence
- 5. Disabled and/or retired because of ill health
- 6. Student
- 7. Other (please specify) ________________
Knee Osteoarthritis and Outcome Score (KOOS)

This questionnaire asks for your view about your knee. This information will help us understand of how you feel about your knee and how well you are able to do your usual activities.

**INSTRUCTIONS:** Answer every question by ticking the appropriate box, only one box for each question. If you are unsure about how to answer a question, please give the best answer you can.

### Symptoms

These questions should be answered thinking of your knee symptoms and difficulties during the last week.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>S1. Do you have swelling in your knee?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S2. Do you feel grinding, hear clicking or any other type of noise when your knee moves?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S3. Does your knee catch or hang up when moving?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S4. Can you straighten your knee fully?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S5. Can you bend your knee fully?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Stiffness

The following questions concern the amount of joint stiffness you have experienced during the last week in your knee. Stiffness is a sensation of restriction or slowness in the ease with which you move your knee joint.

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme</th>
</tr>
</thead>
<tbody>
<tr>
<td>S6. How severe is your knee joint stiffness after first wakening in the morning?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>Never</td>
<td>Monthly</td>
<td>Weekly</td>
<td>Daily</td>
<td>Always</td>
</tr>
<tr>
<td>------</td>
<td>-------</td>
<td>---------</td>
<td>--------</td>
<td>-------</td>
<td>--------</td>
</tr>
<tr>
<td>P1. How often do you experience knee pain?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P2. Twisting/pivoting on your knee</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P3. Straightening knee fully</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P4. Bending knee fully</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P5. Walking on flat surface</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P6. Going up or down stairs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P7. At night while in bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P8. Sitting or lying</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P9. Standing upright</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Function, daily living</th>
</tr>
</thead>
</table>

The following questions concern your physical function. By this we mean your ability to move around and to look after yourself. For each of the following activities please indicate the degree of difficulty you have experienced in the last week due to your knee.
For each of the following activities please indicate the degree of difficulty you have experienced in the **last week** due to your knee.

<table>
<thead>
<tr>
<th>Activity</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1. Descending stairs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A2. Ascending stairs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A3. Rising from sitting</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A4. Standing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A5. Bending to the floor/pick up an object</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A6. Walking on a flat surface</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A7. Getting in/out of car</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A8. Going shopping</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A9. Putting on socks/stockings</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A10. Rising from bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A11. Taking off socks/stockings</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A12. Lying in bed (turning over, maintaining knee position)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A13. Getting in/out of bath</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A14. Sitting</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A15. Getting on/off toilet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A16. Heavy domestic duties (moving heavy boxes, scrubbing floors, etc)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A17. Light domestic duties (cooking, dusting, etc)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Function, sports and recreational activities

The following questions concern your physical function when being active on a higher level. The questions should be answered thinking of what degree of difficulty you have experienced during the last week due to your knee.

<table>
<thead>
<tr>
<th>Activity</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Extreme</th>
</tr>
</thead>
<tbody>
<tr>
<td>SP1. Squatting</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SP2. Running</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SP3. Jumping</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SP4. Twisting/pivoting on loaded leg</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SP5. Kneeling</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Quality of Life

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Monthly</th>
<th>Weekly</th>
<th>Daily</th>
<th>Constantly</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1. How often are you aware of your knee problem?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q2. Have you modified your lifestyle to avoid activities potentially damaging to your knee?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q3. How much are you troubled with lack of confidence in your knee?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q4. In general, how much difficulty do you have with your knee</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G. Research Ethics Board Approvals
Notification of REB Initial Approval

Date: August 26th, 2011
To: Ms. Crystal Mackay
    Rm 10M*324, 10th Floor, Main Pavilion, Toronto Western Hospital, 399 Bathurst St., Toronto, Ontario, Canada, M5T 2S8

Re: 11-0540-BE
    Perceptions, Experiences and Management of Knee Symptoms in Adults Age 35-65 years - A Qualitative Study

REB Review Type: Expedited
REB Initial Approval Date: August 26th, 2011
REB Expiry Date: August 26th, 2012

Documents Approved:
    Protocol Version date: May, 2011
    Consent Form - Interviews Version date: August 19th, 2011
    Consent Form - Focus Groups Version date: August 19th, 2011
    Advertisements Version date: June 1st, 2011
    Poster (Focus Group) Version date: August 19th, 2011
    Poster (Interview) Version date: August 19th, 2011
    Focus Group Guide Version date: June 1st, 2011
    Telephone Script (Interviews) Version date: June 1st, 2011
    Telephone Script (Focus Groups) Version date: June 1st, 2011
    Questionnaires Version date: June 1st, 2011
    Questionnaire - Screening Version date: June 1st, 2011


Best wishes on the successful completion of your project.

Sincerely,

Anna Gagliardi, PhD
Co-Chair, University Health Network Research Ethics Board
Dear Dr. Davis and Ms. Mackay

Re: Administrative Approval of your research protocol entitled, “Perceptions, Experiences and Management of Knee Symptoms in Adults Age 35-65 Years – A Qualitative Study

We are writing to advise you that the Office of Research Ethics (ORE) has granted administrative approval to the above-named research study. The level of approval is based on the following role(s) of the University, as you have identified with your submission:

- Graduate Student research – hospital-based only
- Storage or analysis of De-identified Personal Information (data)

This approval does not substitute for ethics approval, which has been obtained from your hospital Research Ethics Board. Please note that you do not need to submit Annual Renewals, Study Completion Reports or Amendments to the ORE unless the involvement of the University changes so that ethics review is required. Please contact the ORE to determine whether a particular change to the University’s involvement requires ethics review.

Best wishes for the successful completion of your project.

Yours sincerely,

Daniel Gyewu
Research Ethics Board Manager- Health Sciences