Improving chronic illness care: Implementation and evaluation of interdisciplinary and patient-centred care

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List of abbreviations

CCM	Chronic Care Model
CDM	Chronic disease management
FRQS	Fonds de recherche du Québec – Santé
НСР	Healthcare provider
HCIC	Health Care in Canada
ICUF	Ireland Canada University Foundation
IDT	Interdisciplinary team
IOM	Institute of Medicine (USA)
LBP	Low back pain
MCID	Minimal clinically important difference
NHS	National Health Service (UK)
PACIC	Patient Assessment of Chronic Illness Care / Patient Assessment of Care for Chronic Conditions
PCC	Patient-Centred Care
PREMs	Patient-reported experience measures
PROMs	Patient-reported outcome measures
QUAL	Qualitative component of mixed methods
QUAN	Quantitative component of mixed methods
REDCap	Research Electronic Data Capture

Abstract

The prevalence of chronic diseases and conditions is steadily increasing in Canada and globally. According to recent health surveys, more than one in four Canadian adults live with at least one chronic disease, and the number of chronic diseases per person increases with age. Despite the availability of effective therapies, the management of chronic diseases remains far from optimal. Several reports and practice guidelines recommend that care should be patient-centred and delivered by health care teams. These approaches are proposed as means to empower patients to engage in their own care decisions, enhance coordination of care, and make more efficient use of resources, ultimately leading to improved patient outcomes and safety. However, many challenges remain in implementing these approaches, including assessing and accumulating evidence on their effectiveness. The overall aim of this thesis is to contribute to evidenceinformed patient-centred and interdisciplinary team (IDT) care in the context of quality chronic illness care through two interrelated research projects.

Based on a review of the literature, I developed a conceptual framework that described the importance of patient experience for team-based care to achieve the objectives of patient centred care (PCC) to improve quality of care and patient outcomes. Using a population-based survey, the first project assessed the level of support for PCC amongst the Canadian public and among health professionals. Significant associations were identified between support for PCC and support for both team-based care and the use of health information technology. These associations were identified from both the public and health professionals' perspectives. The second project used a convergent mixed methods design to investigate experiences of primary interdisciplinary care for low back pain. For the qualitative component, I employed a phenomenological approach to better understand the delivery and perceived impact of IDT care.

The quantitative component used the Patient Assessment of Chronic Illness Care (PACIC) questionnaire to evaluate change in patient experience and to estimate the impact of patient and process variables on patient experience. The findings from the two components were reviewed for convergence, complementarity and discrepancy.

Findings from project 1 suggest that implementation of health care teams supported by information and communication technologies are needed to deliver PCC. From the perspective of the participants in the qualitative inquiry of project 2, IDT care contributed to effective and patient-centred primary care. The quantitative component showed improved experience of care for the majority of the participants but did not demonstrate significant associations between change in experience of care and patient and process outcomes. Overall, implementing an IDT appears to be an appropriate approach to deliver PCC and improve the quality of chronic illness care. Based on these analyses, I propose strategies to help improve the implementation of IDT programs for low back pain. These recommendations can also inform similar primary care programs for other chronic conditions. Directions for future research include further evaluation of the structure and construct validity of the PACIC, and continued investigation of the relationships between PCC, patient experience, patient factors, and outcomes.

Résumé

Le nombre de cas de maladies et conditions chroniques ne cessent d'augmenter au Canada et dans le monde. Selon de récents sondages sur la santé, plus d'un Canadien adulte sur quatre est touché par une maladie chronique. En outre, le nombre de cas de maladies chroniques par personne augmente à mesure que les personnes prennent de l'âge. Malgré le fait qu'il existe des traitements efficaces, la gestion des maladies chroniques est loin d'être optimale. Dans ce domaine, un certain nombre de rapports et de directives recommandent que les traitements soient axés sur le patient et administrés par des professionnels de la santé travaillant en équipe. Ces approches ont pour objectif de permettre aux patients de participer davantage à la prise de décisions, à la gestion de leur traitement afin de tirer plus de profit des ressources mises à leur disposition. Tout cela permet de faire en sorte que les résultats des traitements des patients et leur bien-être soient de meilleure qualité. Il reste tout de même un certain nombre de défis à relever pour mettre ces approches en place, notamment l'évaluation et l'accumulation de données probantes sur l'efficacité réelle de ces approches. L'objectif de la présente thèse est de contribuer à l'amélioration de l'efficacité des soins administrés par des équipes interdisciplinaires (*IDT* en anglais) et axés sur les patients, grâce à l'analyse des faits dans le cas de traitements de maladies chroniques, au moyen de deux projets de recherche concomitants.

A partir de données recueillies à ce sujet, j'ai développé un cadre conceptuel permettant de saisir l'importance de l'expérience vécue par les patients soignés par des équipes interdisciplinaires axés sur les patients, afin d'aider à améliorer la qualité des traitements et de meilleurs résultats de santé pour les patients. Le premier projet consiste, au moyen d'un sondage mené auprès du public canadien et des professionnels de la santé, à évaluer le niveau de soutien apporté aux soins axés sur le patient. J'ai identifié plusieurs associations entre le niveau de soutien aux soins axés sur le patient et le soutien aux soins dispensés en équipes ainsi que l'utilisation de technologies d'information sur la santé. Ces associations sont identifiées selon les perceptions aussi bien des personnes concernées par ces maladies que les professionnels de la santé. Le deuxième projet consiste en un modèle convergent de recherche à méthode mixte conçues pour évaluer l'expérience vécue par les patients recevant des soins de santé primaires interdisciplinaires pour la douleur lombaire. En ce qui concerne la composante qualitative, j'ai utilisé une approche phénoménologique afin de mieux comprendre l'administration des soins prodigués par les équipes interdisciplinaires (IDT), ainsi que l'incidence que ces soins ont sur les patients. La composante quantitative consiste en un questionnaire portant sur l'évaluation des soins lors de maladies chroniques (PACIC en anglais) afin d'évaluer l'expérience vécue par les patients et d'estimer l'impact des variables dans le cadre du processus de cette expérience. Les résultats de ces deux composantes ont été examinés pour déterminer les critères de convergence, de complémentarité ou de divergence.

Les résultats du premier projet indiquent que l'aide des équipes de soins de santé, ainsi que les technologies d'information et de communication, sont nécessaires dans le cadre des soins axés sur les patients. Selon les patients dans l'étude qualitative du deuxième projet, les soins primaires administrés en équipes interdisciplinaires ont permis de prodiguer des soins axés sur les patients de manière efficace. Les résultats de la composante quantitative ont indiqué une meilleure expérience de soins pour la plupart des patients, mais n'ont pas permis de démontrer une corrélation significative entre l'expérience des soins et les variables du processus de soins et résultats des patients. Dans l'ensemble, l'administration de soins par des équipes

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interdisciplinaires semble être une approche adéquate pour prodiguer de meilleurs soins axés sur les patients atteints de maladies chroniques. Selon ces analyses, je suggère des stratégies permettant d'améliorer les programmes de soins administrés par des équipes interdisciplinaires pour la douleur lombaire. Ces recommandations peuvent également être utiles pour des programmes de soins primaires dans le cadre d'autres maladies chroniques. Les recherches à venir incluent d'autres analyses de la validité de la structure et de la validité conceptuelle de l'évaluation des soins lors de maladies chroniques (*PACIC*), ainsi que la continuation d'investigations sur la corrélation entre les soins axés sur les patients, l'expérience vécue par ces derniers, les facteurs liés aux patients et les résultats obtenus en la matière.

Preface

Statement of originality

My decision to pursue this program of research was determined by my continuing interest in population health and applied health research to effectively contribute to better health care and improved outcomes for individuals living with chronic conditions. While patient-centred care (PCC) and health care teams are recommended to improve the quality of care for chronic illness, many challenges exist in implementing these approaches, measuring them and accumulating evidence on their effectiveness.

In this context, my dissertation includes two areas of original contribution. The first contribution that I made was identifying the determinants of support for attributes of PCC. I identified significant associations between support for PCC and team-based care and the use of health information technology, with the implication that they might help facilitate PCC.

A second original contribution was the investigation that I conducted of experiences of primary interdisciplinary care to inform effective implementation. The use of a phenomenological approach enriched the depth of understanding of experiences of interdisciplinary care and provided a foundation for making recommendations to optimize its implementation. In the quantitative component for the investigation of the experience of care, I obtained permission to use the Team Climate Inventory instrument for my data collection. These recommendations may be used for the implementation of similar primary care interdisciplinary programs for low back pain (LBP) and other chronic conditions. I acknowledge guidance from my supervisors and members of my doctoral committee throughout the research program.

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Contribution of Authors

I am the primary author on all the manuscripts and wrote all the chapters of the dissertation. Under the supervision of Dr. Sara Ahmed, I designed the studies, collected patient interview and questionnaire data, designed the qualitative and quantitative analyses plans, including the definition of new variables. I developed a data collection system using REDCap to support the clinical process for the LBP interdisciplinary program. As co-supervisor, Dr. Matthew Hunt provided qualitative expertise on my supervisory team and is co-author on the qualitative manuscript. He provided me with extensive feedback during all phases of manuscript development and finalisation. I also benefitted from the feedback of my doctoral committee: Dr. Elena Torban, Dr. Richard Hovey, Dr. Gillian Bartlett, Ms. Regina Visca, and Dr. Bernard Burnand. Ms. Marie-France Valois ran the statistical analyses and is co-author on manuscripts 1 and 3. Dr. Gillian Bartlett is co-author and provided feedback on relevance of the background and the structure of manuscripts 1 and 3. Dr. Hovey is co-author on manuscript 2 and provided me with significant guidance in terms of methodology and, in particular, data analysis as an expert in phenomenology and hermeneutics. Ms. Regina Visca of the Centre of Expertise in Chronic Pain is co-author on manuscript 3; she and Dr. Mark Ware contributed to the design of the primary interdisciplinary program, and facilitated communication with the clinics.

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This dissertation is dedicated to...

God Almighty!

St Joseph, the quiet strength

My brother Fr. Achille Dometo, J.C.D. and my father Wilfried Komla,

both in memoriam

My mother Roseline Fiasi

My wife BB Marie-Claire and son Jean-Félix.

"I want to be treated as a human being, not as the owner of a defective breast".¹

1. Introduction

In response to the increasing burden of chronic illness and to improve the quality of care, defined as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge",² the Institute of Medicine's (IOM) *Quality Chasm* report and several practice guidelines recommend care that is patient-centred and delivered by health care teams.³⁻⁷ Indeed, chronic diseases represent the leading cause of death and disability worldwide.⁸ In Canada, more than one in four Canadians report having two or more chronic conditions.⁹

Patient-centredness of care is one of the six dimensions of quality of patient care along with safety, effectiveness, timeliness, efficiency, and equity in the IOM's report.³ Patient-centred care (PCC) addresses the subjective experience of patients in terms of "their perception of illness or well-being and their encounters with health (care) professionals and institutions", and complement the technical aspect of quality of care that is based on the "skill and competence of professionals and the ability of diagnostic or therapeutic equipment, procedures, and systems to accomplish what they are meant to accomplish, reliably and effectively".¹⁰ When missing, patients may feel like they are considered only as a bearer of disease and not acknowledged as a human being, as illustrated by the quotation above. Measuring patients' experience, defined as any combination of assessing satisfaction, expectations and experience,¹¹ has been recognized as an essential component of performance assessment and service improvement, and has been addressed in a range of reports and quality care frameworks.^{3, 11-14}

The provision of team-based care (multidisciplinary, interdisciplinary) is one of the core interventions recommended by different conceptual models developed to guide the delivery of care for chronic conditions. Of these models, the Chronic Care Model (CCM)¹⁵ is the most commonly applied. It defines six elements that are important for improving outcomes for individuals with chronic conditions. One of the six elements of the CCM, delivery system redesign, includes the following components: team care, care management and coordination, proactive follow-up, planned visit and visit system change. However, these goals are difficult to achieve in many settings.

Challenges exist for establishing care that is patient-centred and provided by interdisciplinary teams (IDT), particularly at the primary care level (which has been identified as the optimal setting for taking care of individuals with chronic illness), and in accumulating evidence on the effectiveness of these approaches. These challenges include lack of a consensual definition of PCC, lack of measurement instruments to quantify PCC, and conflicting evidence which limit identification of best conditions and strategies to ensure their effective implementation and the evaluation of PCC. Better understanding of patients' experiences, motivations, and needs in terms of health care professional support is thus key to designing and implementing effective interdisciplinary chronic illness management. To achieve this goal, it will be necessary to develop the capacity of health professionals to implement PCC. As stated in IOM's report, "all health professionals should be educated to deliver PCC as members of an IDT, emphasizing evidence-based practice, quality improvement approaches, and informatics."¹⁶

The overall aim of this thesis is to contribute to evidence-informed patient-centred and IDT care in the context of quality chronic illness care using various methodologies: 1) identifying the determinants of the levels of health professionals' and the public's support for PCC using a national population-based survey (project 1, manuscript 1); 2) evaluating individuals' experience with chronic pain and health professionals' perceptions of the interdisciplinary experience in a primary care low back pain (LBP) program using qualitative methods and a phenomenological approach (project 2, manuscript 2); and 3) evaluating the association between patient experience and outcomes for individuals suffering from LBP who participated in an interdisciplinary primary care program using hierarchical regression analyses (project 2, manuscript 3).

2. Background

This dissertation addresses aspects of quality care for chronic conditions, using low back pain (LBP) as an example. As outlined in chapter 1, approaches recommended to help improve the care for individuals with chronic conditions include team-based and patient-centred care. Thus, this chapter will synthesize the literature on chronic pain management and patient-centred care (PCC) with an emphasis on experience of care, in complement to a previous review on team-based care.¹⁷ In that review, we evaluated published evidence on the effectiveness of team-based care in chronic disease management context in general.

2.1. Chronic disease management

Health care for people with chronic diseases and conditions is far from optimal. At least 40% of individuals who live with a chronic illness report not receiving adequate care to help them manage their condition.^{18, 19}

In response to the increasing burden of chronic illness, chronic disease management (CDM) has emerged as a promising approach to improve the quality of health care and is defined as a system of coordinated health care interventions and communications for populations with conditions in which patient self-care efforts are emphasized.^{8, 9, 20-27} Chronic diseases represent the leading cause of death and disability worldwide.⁸ Chronic diseases account for more than \$90 billion a year in lost productivity and health care costs for Canadian society, with more than one in four Canadians reporting two or more chronic conditions.⁹ Several models exist to inform the development and implementation of CDM programs but the most widely used approach is the Chronic Care Model (CCM)¹⁵ and its variants.²⁸⁻³⁰ The CCM defines six elements important for improving outcomes for individuals with chronic conditions: organizational support, delivery system redesign, decision support, self-management support, clinical information systems, and linkages to community services.^{15, 28} While the effectiveness of CCM has been reported,³¹⁻³⁷ delivery system redesign and self-management support have been shown to have the strongest evidence for effective chronic disease care.³⁷⁻³⁹ Delivery system redesign entails team care, care management and coordination, proactive follow-up, planned visit and visit system change. Self-management support strategies include patient education, patient activation and psychosocial support, self-management assessment, self-management resources and tools, collaborative decision making and availability of guidelines to patients.^{40, 41}

2.2. Chronic pain management

2.2.1. The burden of chronic pain

According to Croft et al., chronic pain is emerging as an important component of the global burden of disability yet recent estimations of global burden of disease underestimate the contribution of chronic pain.⁴² There is considerable variation in estimations of chronic pain prevalence compared to other established public health conditions due to the complexity of case definition.⁴³ The prevalence rates of chronic pain of any type and severity level range from 10.5% to more than 50% of the population worldwide.^{44, 45}

In Canada, more than half of all Canadians suffer from some form of chronic pain during their lives and only 50% of these individuals describe their pain as "controlled". The costs in Canada

for treatment and lost productivity due to chronic pain are estimated to be at least \$10 billion per annum.⁴⁶ These costs are also extremely high in other nations, estimated at \$635 billion and more than €200 billion per annum in the United States and in Europe respectively.^{45, 47-49} Furthermore, chronic pain is associated with poor quality of life. Twenty-one percent of people living with chronic pain in Canada wait two years or more for diagnosis, while only 54% have a treatment plan.⁵⁰

LBP is the most common form of chronic pain in Canada⁵¹ and one of the most common nonspecific chronic pain conditions worldwide. Indeed, LBP is considered as the leading cause of disability worldwide, particularly among individuals with low socioeconomic status.⁵² Factors that contribute to LBP and disability include biophysical, genetic, psychological, social, and comorbidities. It also has a high impact on economic costs and quality of life of affected individuals.^{46,54} Recent clinical guidelines recommend initial non-pharmacological treatments to manage LBP.⁵³⁻⁵⁷. These include advice, self-management support, cognitive behavioural approach, as well as some forms of complementary and alternative medicine; procedures, imaging and surgery are not recommended for patients with non-specific LBP.^{53, 55-57} Pharmacological treatments of LBP include nonsteroidal anti-inflammatory drugs (NSAIDs), muscle relaxants, antidepressants, anticonvulsants, opioids; most for limited use and in selected patients.⁵⁵⁻⁵⁹ The evidence on the efficacy of these treatments on pain relief and function in individuals with LBP ranges from no effect to small to moderate effect.⁵⁹

2.2.2. Gaps in chronic pain management

Several gaps have been identified in chronic pain management particularly at the primary care level where more than half of all patients who have Chronic Non-Cancer Pain primarily receive their care.^{60, 61}

2.2.2.1. Access to care

There are limited services available at the primary care level for effective management of chronic pain patients, including diagnostic and treatment services, and self-management support.⁶² In addition to medical treatment, patients may require psychological services, as well as care by other allied health professionals. These services are often limited or unavailable, however.⁶³

2.2.2.2. Skills and knowledge of healthcare providers to manage individuals with chronic pain

Primary care clinicians lack adequate education and training to provide optimal pain care for individual with chronic pain.^{61, 63-65} In Canada, community-based health care providers in Alberta and Quebec identified significant knowledge gaps related to the diagnosis and treatment of LBP and headache; lack of access to appropriately synthesized clinical practice guidelines and to pain management specialists, and concern about patient drug taking behaviour were the most important barriers identified.⁶⁶ According to Jamison et al., most physicians who participated in their survey study recognized the benefit of guideline-based treatment algorithms, however, many also expressed reluctance to regularly consult them when treating pain.⁶⁷ Adherence to evidence-based clinical practice guidelines' recommendations has been "consistently low in studies of physicians, chiropractors, physical therapists, and other clinicians involved in

managing low back pain".^{68, 69} In addition, there is a lack of a coordinated referral processes to key services across primary, secondary, and tertiary care. These features contribute to poor patient satisfaction with care.⁷⁰⁻⁷³

2.2.2.3. The skills, beliefs, and attitudes of the public

The development of information technology and efforts toward the empowerment of individuals to be actively involved in their health care and decisions contributed to the development of health information seeking behaviour, especially among people living with chronic conditions.^{74, 75} This behaviour is now common and it positively impacts health care delivery. For example, it has been shown that "individuals who prefer an active or collaborative role when making decisions with health professionals are also more active in their search for health-related information".⁷⁶ Predisposing characteristics of individuals (personal and situational factors) are reported to influence what type of and how much information is sought, what sources are used, and how the information is obtained,⁷⁶ as well as whether or not it is shared with health care providers. These factors include sociodemographic characteristics as well as psychosocial variables such as personality traits and individuals' expectations, goals, beliefs, values, attitudes, emotions and moods, skills, and health status.^{74, 76} Respondents to the Health Care in Canada survey identified the Internet as their first source of health information (57% of respondents), followed by primary care providers (53%).⁷⁷

In the context of chronic pain management, beliefs and attitudes play important roles. Some beliefs reported in the literature include emphasis on the risk of postsurgical pain and a perception that there is a lack of training of health care professionals in chronic pain treatment.⁷⁸

Moreover, in addition to the complexity of personal characteristics and health information seeking behaviour, is the difficulty to measure pain. Indeed, "patient reports of pain severity often demonstrate modest associations with objective physical and laboratory finding".⁷⁹ All these factors point to the importance of team-based care and multimodal interventions to provide the necessary treatment and self-management support to ensure patients are treated by the right health professionals, at the right time.

2.2.3. Recommendations for the management of chronic pain

One of the main recommendations to improve the management of LBP is the application of multidisciplinary and interdisciplinary teams in the delivery of care.^{48, 63, 80, 81} Evidence suggests that such teams enhance integration of care and improve provider, patient and managerial satisfaction, thereby improving administrative and clinical processes and patient outcomes.⁸²⁻⁸⁴ Studies have linked team performance to positive patient outcomes.⁸⁵ Although the evidence is inconsistent, there is strong support for team care among health professionals, governments, businesses and public institutions.^{17, 38} An interdisciplinary approach to chronic pain management is also supported by the Canadian clinical practice guidelines for chronic non-malignant pain management.⁶³ These recommendations are summarized in table T1.

Table T1. Facilitators of effective interdisciplinary pain care

Health care system

- Promote access to interdisciplinary pain treatment programs
- Improve remuneration for interdisciplinary care

• Allocate adequate time and space for the provision of care that involves multiple providers, and expedite and encourage communication and opportunities for team interaction

• Provide an interdisciplinary (electronic) records system that permits patient-generated documentation to be shared by all team members

Health care professionals

-Referral providers

• Acknowledge the need and appropriateness of interdisciplinary care for those who are referred

• Communicate importance of interdisciplinary treatment and care for their patients during referral

• Be engaged throughout the process and accept care of the patient after completion of program, with guidance from interdisciplinary pain team

-Team members

- Provide unified and consistent messages to patients
- Promote therapeutic alliance based on mutual respect

• Ensure ongoing communication among team members, with the patient, family, referring providers, and payers (insurance companies, governmental agencies, employers)

Individuals experiencing pain

- Understand why interdisciplinary pain care is appropriate
- Embrace self-management

• Participate as much as possible and give input into the establishment of the treatment plan and outcome goals

Professional organizations

- Advocate for research funding to demonstrate benefits of interdisciplinary pain care
- Educate payers regarding the need to appropriately reimburse for this work

• Provide interdisciplinary education and professional development opportunities that foster communication and networking.

Adapted from^{48, 86}

Receiving a comphrehensive assessment and managing pain is among the recommendations for

patient experience by the NHS National Clinical Guideline Centre and should be assessed in

measures of patient experience.¹² Better understanding patients' experiences and motivations is key to designing and implementing effective interdisciplinary chronic pain management.¹¹

In summary, LBP is a common musculoskeletal condition and is associated with the largest impact on limitations in activities, and the highest consultation rate in general practice. The most common type of LBP is called 'non-specific LBP' and accounts for approximately 90% of cases in primary care settings.⁸⁷ The management of LBP is complex, resulting in suboptimal care and low levels of patient satisfaction. Evidence-based clinical guidelines support the development of an interdisciplinary, patient-centered and integrated model of care at the primary level for these patients.^{69, 87, 88} However, there is a lack of implementation of the interdisciplinary model of care for LBP at the primary care level in Canada. Reasons for this deficiency may be lack of human, financial and organizational support. Other reasons documented in the literature include weak support from physicians and patients, probably due to a perceived insufficiency of evidence on the part of physicians and a lack of interdisciplinary care experience among patients.⁸⁹ The lived experience ("everyday experiences, hopes, expectations, future uncertainty, feelings of loss, feelings of being morally judged, feelings of blame") is one of the main themes identified in the NHS Clinical Guidance Group on patient experience.¹²

2.3. Patient-centred care

Patient-centred care (PCC) is defined by IOM as providing "care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions".³ It is worth noting that there are numerous proposed definitions of PCC which "encompass many of the same core principles, but no globally accepted definition".⁹⁰ Based on the work of Gerteis et al. (1993),¹⁰ was operationalized by seven dimensions: i) respect

for patients' values, preferences, and expressed needs; ii) coordination and integration of care; iii) information, communication, and education; iv) physical comfort (relief of pain and suffering); v) emotional support and alleviation of fear and anxiety; vi) involvement of family and friends; and vii) transition and continuity. These dimensions were renamed the Picker Principles of PCC, with the addition of an eighth dimension, access to care.⁹¹ The recent emergence of the concept of PCC can be attributed to the rising of patient frustration with a dehumanized care in the context of the specialization and sophistication of health professions, and patients looking for a more individualized and humanized care approach as developed and taught in the late nineteenth and early twentieth century by William Osler.⁹² This dissatisfaction is well illustrated by the following quote from a patient with breast cancer: "I want to be treated as a human being, not just as the owner of a defective breast".¹

There is a mixed evidence on PCC in the literature. PCC is reported to increase quality and safety of health care and provider and patient satisfaction, and to decrease costs (e.g. fewer diagnostic tests and referrals); other studies demonstrate higher functional status, improved clinical care, and decreased mortality, emergency department visits, and medication errors.⁹³⁻⁹⁷ The benefits of PCC are even more important in the context of chronic conditions and include improved disease management, patient and doctor satisfaction, patient engagement, adherence to long-term therapies and quality of life, and reduced anxiety.^{90, 93, 96, 98-100} Evidence on PCC is not conclusive for other authors.^{97, 101, 102} In these studies, mostly conducted in inpatient settings, doctor-patient communication was the most common aspect of PCC measured. PCC is supported by several leading organizations worldwide^{90, 103-105} and in Canada,¹⁰⁶⁻¹⁰⁹ in spite of the lack of strong evidence, probably because "without patient-centeredness, [health care] can lose its humane face".¹¹⁰

These organizations and researchers have defined context-specific elements of PCC with some core overlapping elements.⁹³ The models that form the basis for the most widely used definitions in empirical studies, in addition to the above-mentioned Picker principles of PCC, are the models proposed by Stewart et al. and Mead et al. Both of these models were developed based on reviews of the literature. According to Little et al., communication, partnership and health promotion were aspects of PCC that patients wanted in primary care settings.¹¹¹ While the models proposed by Stewart and Mead are physician and primary care oriented, the concept of PCC has been reviewed in other health professions including nursing,¹¹² occupational therapy,¹¹³ and dentistry.¹¹⁴ Yet there remains a lack of interdisciplinary delineation, discussion, and application of the PCC concept,^{115, 116} even though the health care team is seen as the first and immediate health care context within which PCC occurs.¹¹⁷

To evaluate PCC at both individual and population levels, quantitative and qualitative methods can be used. Qualitative methods include one-on-one interviews, focus groups, and observation of clinical visits and discussions. Surveys and self-assessment instruments are used in quantitative evaluation. Yet, these instruments are rare, particularly in the context of ambulatory family practice. Indeed, Hudon et al. identified only two instruments, both of which are based on Stewart et al's model: the Patient Perception of Patient-Centeredness and the Consultation Care Measure.¹¹⁸ In a more global context, particularly for hospital care, the Picker Institute survey and its various modified versions is the most commonly used.¹¹⁹ Approaches and strategies to promote PCC include measuring patient and provider experience of care.

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2.4. Patient-reported experience measures

Measuring patients' experience of health services and care has become an essential element of reporting on the quality of care and defining health policy, and an important component of performance assessment and service improvement.¹²⁰⁻¹²⁷ This measurement can have different purposes, as stated by Pettersen et al.¹²⁸: (i) describing health care from the patient's point of view; (ii) measuring the process of care, thereby both identifying problem areas and evaluating improvement efforts; (iii) evaluating the outcome of care.¹²⁹⁻¹³¹

According to several authors, patient experience measure is preferred to patient satisfaction because there is a fundamental conceptual question of what patient satisfaction actually means and, thus, a need to develop instruments that better capture the ways in which patients want to report their experiences.^{12, 129, 132-141} It is reported that satisfaction measures "do not capture all the elements of health care that patients have said are most important to them and thus, these measures have had limited utility for actually improving the quality of care delivery".¹¹⁹ Moreover, behind the apparent simplicity of using patient satisfaction measures, findings are sometimes difficult to interpret¹⁴²⁻¹⁴⁵ given the vast number of potential underlying dimensions¹⁴⁶⁻¹⁴⁸ or because of the fact that these measures provide nearly always the same results.¹⁴⁹⁻¹⁵¹ Only a small portion (up to 40%) of the variance in satisfaction was explained in several studies measuring patient satisfaction,¹⁵²⁻¹⁵⁴ suggesting important gaps in our understanding of which factors influence patient satisfaction.¹⁵²

There are several patient experience frameworks^{12, 155, 156} and patient-reported experience measures (PREMs). They are principally questionnaires and have been found to provide a more comprehensive and meaningful account of patients' experiences with health care compared to

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satisfaction measures.^{151, 157} Even though many instruments and surveys exist to assess patient experience of health services, they do not cover several important aspects that can influence patients' health status and use of health services including coordination of care, PCC and multi/interdisciplinary care.^{11, 118, 120, 128, 158-160} Most of these measures were designed for assessing inpatient hospital experiences, and so they are not relevant in the context of chronic disease management in primary care. In addition, most PREMs and PROMs are not designed with patient input and very little research on this topic is specific to chronic pain patients.¹⁶¹

Because of these limitations, several authors have recommended that future research devote more attention to qualitative research with patients.^{11, 162, 163} There is a diversity of qualitative methods that can be used to assess patient experience of health and health care.¹¹ The most common approach is the use of in-depth interviews, either in person or by telephone. Another common approach is the use of discussion groups (focus groups, patient panels). Observations are also used, mainly from a professional or organisational perspective (e.g. of patient-provider interactions), as a standalone approach or in complement to interviews. Other methods include detailed patient narratives, patient stories (written or videoed), online feedback through websites and social media, complaints and compliments, and more recently photovoice when patients use photographs and captions to share their experience.

2.5. Provider experience with care

Provider experience of care is an important component in achieving high quality patient care.^{13,} ¹⁶⁴ Its importance is reflected in the expansion of the Triple Aim to the Quadruple Aim by several healthcare organizations. The Triple Aim was a quality care framework developed by the Institute for Healthcare Improvement as an approach to optimizing health system performance by

simultaneously improving population health, improving the patient experience of care, and reducing per capita cost of health care.¹⁴ In 2014, a fourth dimension, improving the work life of healthcare providers, was recommended by Bodenheimer and Sinsky.¹³ However, unlike PREMs for patients, no similar measures have been developed to assess provider reported experiences of care. Among the few validated and published instruments are the Assessment of Chronic Illness Care (ACIC)¹⁶⁵ and, in the context of team care, the Attitudes Toward Health Care Teams Scale¹⁶⁶ and the Team Climate Inventory (TCI).¹⁶⁴ While little evidence is available on these instruments, there are some suggestions that "ACIC correlates positively with ratings of teams' performance outcomes"¹⁶⁵ and that higher TCI scores are associated to better quality of care.¹⁶⁷ Several phenomenological studies have also been published on the lived experience with LBP. Those studies conducted in the context of team care were limited in terms of composition or aspects investigated.¹⁶⁸⁻¹⁷⁵ For example, the study by O'Brien et al. focused only on the collaboration aspect, and only physicians and nurses were interviewed.¹⁷⁶ As emphasized by Frampton et al., healthcare provider experience must also be addressed for a patient-centered approach to succeed.¹⁷⁷

3. Conceptual framework of the thesis

The conceptual framework is based on my previous work and knowledge in CDM and the synthesis of the literature that I presented in chapter 2. It is derived from (1) the CCM that proposes elements on which the health system must focus to achieve high quality chronic illness care; (2) the Quadruple Aim framework that outlines four goals for health care improvement initiatives: population health, experience of care, work life of health care team members, and cost of care; (3) the Donabedian model that conceptualizes three dimensions of quality care: structure (i.e. facilities, equipment, qualifications of providers, administrative structure of the setting), process (i.e. all acts of healthcare delivery), and outcome (i.e. effects on the health status of patients); (4) and from the literature review. It displays the relationship between recommended approaches (team-based care, PCC), patient experience, and outcomes. The framework informed the definition of hypotheses and methodological aspects of project 1 which assessed the determinants of PCC, and project 2 which investigated patient experience and its association with team-based care and outcomes. Its use in these projects is described in the subsequent chapters.



Figure T1. Conceptual framework

4. Statement of objectives, hypotheses and research questions

The overall aim of this research program is to contribute to evidence-informed patient-centred and interdisciplinary care in the context of quality chronic illness care. Based on the conceptual framework for this thesis, team-based care, patient-centred care (PCC) and patient experience are the pillars of improved outcomes for patients with chronic conditions. Low back pain (LBP) is the chronic condition that I am investigating in this research program. The thesis is composed of two projects.

The objective of thesis project 1 was to identify the determinants of PCC from the perspectives of the Canadian public and health professionals. It was hypothesized that respondents who strongly support teamwork will have a high level of support for attributes of PCC, as team care is a key component of one of the elements of the CCM as part of delivery system redesign. Findings from this project are presented in manuscript 1 in chapter 6.

My thesis project 2 was integrated within the interdisciplinary primary care program for patients suffering from LBP as part of a larger strategic initiative aimed at building continuums of care for chronic pain. Given the nature of LBP and to better understand the different degrees of support for interdisciplinary team care among patients and providers, we used a mixed methods approach. The objectives of project 2 were to:

Investigate patient and provider experiences with interdisciplinary care for LBP at the primary care level to inform effective implementation of an interdisciplinary LBP program; This qualitative component addressed the following questions for patients who participated in the research: What are the experiences of living with LBP? What are the experiences of being treated for LBP using an interdisciplinary team care approach and

do they perceive its impact on their health status? Results related to this objective are presented in manuscript 2 in chapter 6.

Evaluate the relationship between patient experiences with an interdisciplinary care program for individuals with LBP, and patient, provider and process variables; It was hypothesized that patients who completed the interdisciplinary care program and had a positive experience will show better outcomes. Results related to this objective are presented in manuscript 3 in chapter 6.

5. Methodological approaches

5.1. Project 1: Survey design

A cross-sectional survey method was used to assess population-based perceptions of patientcentred care (PCC) from the perspective of the public and health care professionals. According to Schuman and Kalton, "asking questions is a remarkably efficient way to obtain information from and about people".¹⁷⁸ For this project, we used data from the Health Care in Canada (HCIC) survey. The HCIC survey is a national population-based survey assessing the perceptions of the Canadian public, as well as physician, nurse, pharmacist and managerial health professionals on a range of healthcare related topics since 1998. HCIC is supported by a broad partnership of professional, patient and commercial organizations working in the health sector, as well as affiliated academic institutions. The questions were developed through an iterative consultation process between Pollara Inc. and HCIC members. I have been involved in the HCIC survey since the tenth edition with the inclusion of questions related to chronic disease management. I also founded and led the McGill HCIC coordination group (http://www.mcgill.ca/hcic-sssc/) that oversees data requests and analyses from national stakeholder groups. Questions on attributes of PCC were introduced in the 11th edition and are used in this study. More details of the method are described in manuscript 1.

5.2. Project 2: Mixed methods design

5.2.1. Theoretical foundation

This project, made up of qualitative and quantitative components, was guided by the pragmatic paradigm. This worldview allows the coexistence of singular (postpositivism) and multiple

realities (constructivism) and "enables researchers to adopt a pluralistic stance of gathering all types of data to best answer the research question".¹⁷⁹ With this paradigm, the research problem is central, and different worldviews and assumptions are considered.¹⁷⁹⁻¹⁸¹ The methods are chosen to match the specific questions. In this study, qualitative and quantitative approaches were used due to the multifaceted and contextual nature of the interdisciplinary program in order to investigate patient and clinician experiences of care.¹⁸² Quantitative (QUAN) data, for example, may be 'objective', but often lack the depth needed to elucidate how and why a program works, and how it is understood and experienced by patients and providers. Qualitative (QUAL) data can enhance understanding of program implementation and operation, but are considered less 'objective'. Mixed methods research has strengths that offset some limitations of both quantitative and qualitative research.^{179, 183} The mixed methods approach for this project can be defined as a convergent parallel design (QUAL+QUAN). It involved concurrently gathering both forms of data for comparison, and to search for congruent or divergent findings (figure T2). It permits researchers to better understand or develop a more complete understanding of the research problem by obtaining different but complementary data.


Figure T2. Diagram of mixed methods design, adapted from O'Cathain¹⁸⁴

5.2.2. Program description

My thesis project 2 is integrated within a larger study entitled 'Implementation and evaluation of an integrated primary care network for prevention and management of chronic pain' (funded by the Ministère de la Santé et des Services Sociaux, Fonds de recherche du Québec –Santé, and Pfizer). This study, in collaboration with the McGill *Réseau Universitaire Intégré de Santé* (RUIS) Centre of Expertise in Chronic Pain, was implementing an interdisciplinary primary care program for individuals with LBP within four *Centres de santé et de services sociaux* (CSSS) from three different health regions (*Montréal, Estrie and Abiti-Témiscamingue*). Based on CCM, the program offers evidence-based treatments including pharmacological therapy, physiotherapy, psychology, and self-management therapy. The interdisciplinary team is composed of a nurse, a psychologist, a physiotherapist and a primary care physician with expertise in pain. Individuals received a 6-month program that included a standardized clinical process with interdisciplinary follow-up at 1.5, 3 and 6 months after their initial visit. Patients who complete treatment with satisfactory outcomes return to their primary care physician for ongoing follow-up. Other patients are referred to other tertiary care facilities, mental health services, or return to work rehabilitation as needed.

5.2.3. Qualitative component

According to a number of authors, qualitative methods are "the most successful way of accurately obtaining information related to patient experience and allow a greater depth and flexibility of responses".^{129, 185} For the qualitative component, I employed a phenomenological approach to help understand the meaning of interdisciplinary team care for patients. As specified by Garza (2007), phenomenological research focuses on the 'lived meaning' of the phenomena it aims to investigate.

Phenomenology is a philosophy and a research approach that is concerned with exploring and gaining a deeper understanding of human experience.^{186, 187} It includes a range of distinct traditions, from Husserl's foundational notion of 'reduction' to the consideration of interpretation as developed by Heidegger. (Appendix T1: representation of summary of reading on philosophy and phenomenology¹⁸⁷⁻²⁰⁵). Through the process of reduction, also known as bracketing, the "researcher must acknowledge and put aside prior beliefs about the phenomenon of interest so as not to interfere with seeing the true essence of the phenomenon".²⁰⁶ A phenomenological approach can help the clinician and the investigator to "enter the world of illness as lived by patients" to explore their experience of illness or of health care.²⁰⁷

The phenomenological inquiry that I conducted in thesis project 2 was guided by Husserl's notion of reduction. I followed best practices in data management, thanks to the experiences gained from a research visit at the Irish Qualitative Data Archive (Appendix T2). Further details of the methodology are described in manuscript 2.

5.2.4. Quantitative component

5.2.4.1. Data collection system: REDCap

As part of my PhD work I developed and implemented a data capture system to support the clinical process of the interdisciplinary primary care program. To do so, I used REDCap²⁰⁸ (Research Electronic Data Capture), a secure, web-based application designed to support data capture for research studies. It provides: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources. The application is fully customizable. For the purpose of this multisite study, we used the following features:

-Longitudinal module: allows for the utilization of data collection forms multiple times for each record. As shown in the figure T3, we developed 16 data collection forms and defined 12-time points or events based on the clinical and evaluation programs.

-Data Access Group: allows users to restrict records to each site; with this feature, the users (clinicians, data entry staff) at each site were assigned to their site and could only view the records of their own patients. In addition, different levels of permission (no access, read only, view and edit) were granted for the data collection forms. The users who were not assigned to any site (members of the core research team) could view all the records.

-Calculated fields: we used this feature to create fields for real-time calculation during the data entry within and between the data collection forms, e.g. age, using date of birth and date of assessment; it also allowed the use of 'branching logic' that permitted the addition of conditional fields.

-Piping: we used this function to carry over information entered in a field into other forms (e.g. age of the patient); this was a request from the clinician users. By default, the application only repeats the record identification number on subsequent forms.

-File repository: allowed us to upload and send sensitive files to users securely.

-Auto-validation: to improve the quality of data entry and to perform data quality control using the data quality module of the application, we defined validation fields, e.g. yes/no, date format, minimum/maximum range.

Data Collection Instrument	Recruit- Referral	Triage- Screening	Baseline- Interdisc	Visit week 1 (4)	Visit week 2 (5)	Visit week 3 (0)	Visit week 4_month1	Visit week 5 (8)	Visit week 6 (9)	Visit month3 (10)	Visit month4_5	Visit month6 (12)
Participant_record	0											
Manage_participant	0											
Nurse_triage												
Nurse			۲	۲	۲	۲	۲	۲	۲	۲	۲	۲
Treatment plan			۲									۲
Medical assessment			0									۲
Medical follow_up form				۲	۲	۲	۲	۲	۲	۲	۲	
Physiotherapy assessment			0									۲
Physic follow_up form				0	0	0	0	۲	۲	۲	۲	
Psychological assessment			۲									۲
Psycho follow_up form				۲	۲	۲	۲	۲	۲	۲	۲	
Opioid tool			۲	۲	۲	۲	۲	۲	۲	۲	۲	۲
RAMS			۲	۲	۲	۲	۲	۲	۲	۲	۲	۲
Patient_scores			۲				۲		۲	۲		۲
Patient_satisfaction												۲
Dashboard			۲	۲	۲	۲	۲	0	۲	۲	۲	۲

Figure T3. Event grid in REDCap

5.2.4.2. Outcome and covariate measures

This section describes the variables used in the quantitative component of the mixed-methods project 2. More details on the methods are provided in manuscript 3.

Response variable: PACIC

The Patient Assessment of Chronic Illness Care (PACIC) was used as a measure of patient experience. It has been described as the most appropriate instrument to measure the experience of people receiving integrated chronic care.²⁰⁹ The original PACIC contains 20 items.²¹⁰ Several versions and translations exist.²¹¹ The 20-item PACIC was completed by the participants at baseline and 6 months, and scored from 1 (none of the time) to 5 (almost always). It measures specific actions or qualities of care experienced by patients. Its test-retest reliability, internal consistency and construct validity have been demonstrated.^{212, 213} The test-retest reliability for the overall PACIC was 0.58, and individual scale reliabilities ranged from 0.47-0.68. For the Internal Consistency, the Chronbach's Alpha was 0.93. While the responsiveness of PACIC has not been fully addressed,²¹⁴ Koley et al. reported a responsiveness of 1.11.²¹⁵ The 20 items are aggregated into five a priori scales. These subscales are Patient Activation (1-3); Delivery System Design/Decision Support (4-6); Goal Setting (7-11); Problem solving/Contextual counseling (12-15); and Follow Up/Coordination (16-20). Overall PACIC is scored by averaging scores across all 20 items.²¹⁰ In recent publications, use of the single score structure has been recommended in order to obtain an overall picture of patients' experiences.²¹⁶⁻²¹⁹

Selection of covariates

The selection of the predictor variables was based on the literature review (table T2). In addition, findings from the QUAL study also informed the selection.

-Team functioning was assessed by the Team Climate Inventory (TCI) and completed by the clinician and non-clinician staff members from the four sites. The 19-item TCI is grouped under four subscales: participative safety and support for innovation score on a 5-point Likert scale, and vision and task orientation that score on a 7-item Likert scale. Higher scores indicate more desirable team climate.^{220, 221} The French version was validated.²²² Sub-scale scores are derived by averaging items within the sub-scale; individual responses to items were summed within teams to create a group level sum for each item.²²⁰ To calculate the score for a respondent, the sum of the scores for all questions is divided by the number of questions completed; to obtain the overall score for each team, individual scores are summed up and divided by the number of team members (permission for TCI, appendix T3).

-New defined variables:

*Adherence to program: given that the minimum number of visits required is 6; Yes, if $n \ge 6$ *Interdisciplinary evaluation: Yes, if same assessment date for the initial visit for ≥ 3 HCPs.

4.2.5. Triangulation

Integration of QUAL and QUAN components is an essential aspect of mixed methods design and can be accomplished through the process of triangulation. As described by O'Cathain et al., triangulation, in the context of mixed methods research, is "a process of studying a problem using different methods to gain a more complete picture".¹⁸⁴ Data were collected and analyzed separately for each component to produce two sets of findings. I adopted a 'reciprocal' approach where elements of QUAN data informed the criterion-based sampling in the QUAL study (e.g. risk stratification tool) and conversely analyses of the interview data informed, along with

findings from the literature, the selection of predictors in the QUAN study as illustrated in figure T2. Finally, I reviewed the findings from the two components for convergence, complementarity and discrepancy.

Author	Type of study and regression model	Conditions	List of covariates	Mean Overall PACIC (SD)	Type of association with Overall PACIC
Jackson, 2008 ²²³	Cross- sectional,	Diabetes	-Race	3.1 (1.1)	+ (non- white)
	PACIC, dependent variable		-Education level -Insurance status -Social support		+ (< high school)
	Multivariate logistic regression (≥3.5 (Yes))		-Difficulty obtaining benefits -Mean blood pressure		
Rosemann, 2008 ²²⁴	Cross- sectional, PACIC-5A Stepwise linear regression	Osteo- arthritis	-Duration of OA -PHQ-9 -AIMS2-SF (impact of OA) -Comorbid conditions -Education level -Age -Marital status	2.79 (0.83) in men 2.67 (0.89) in women	7 + -
Schmittdiel, 2008 ²¹³	Cross- sectional, PACIC, independent variable	Diabetes, chronic pain, heart failure, asthma,	-Use of self- management services	2.7 (1.1)	+

Table T2. Summary of studies on predictors of the 20-item PACIC

Author	Type of study and regression model	Conditions I	list of covariates	Mean Overall PACIC (SD)	Type of association with Overall PACIC
	Hierarchical logistic regression	coronary artery disease	-Performance of self-management behaviors		+
			-Medication adherence		
			-Quality of health care		
			-Quality of life		
			-Adjusted as fixed effects on Age, Sex, Race/ethnicity, Education, Self- reported health, chronic condition cohort		+
			-Adjusted as a random effect on geographic region		
Gensichen,	Cross- sectional, Validation of German PACIC Spearman rank	Major	-Age	3.25	
2011223		PC	-Gender	(0.79)	
			-Education		
			-Number of physical comorbid conditions		
	correlation		-PHQ-9		
Taggart, 2011 ²²⁶	Cross- sectional	Diabetes, ischaemic	-Type of practice	3.07 (1.06)	
	PACIC,	heart disease	-Kural/urban		
	dependent variable	hypertension	-Age		

Author	Type of study and regression model	Conditions	List of covariates	Mean Overall PACIC (SD)	Type of association with Overall PACIC
	Factor analysis,		-Home/car ownership		<u>.</u>
	multi-level regression		-Education		_
	models		-Employment /marital status		
			-Born in Australia		
			-Health or pension card		
			-Health in the last 12 months		+
			-Comorbidity		_
			-Duration of disease		- (with increase years)
Houle, 2012 ²²⁷	Cross- sectional PACIC, dependent variable Linear	Diabetes,	Age (cont)	2.8	
		or chronic	Sex		+
		obstructive pulmonary	Education		-
		disease	-Nb of chronic illness		+
	regression		-Relational continuity		+
			-Interpersonal communication		+
			-usual-provider continuity		
			-Interdisc care (nb of visits with non- physician professionals)		+

Author	Type of study and regression model	Conditions	List of covariates	Mean Overall PACIC (SD)	Type of association with Overall PACIC
			-TQC (technical quality of care)		+
Levesque, 2012 ²²⁸	 ³ Longitudinal (0 to 12 months) PACIC, dependent variable Multilevel model 	Diabetes, heart failure, chronic arthritis, chronic obstructive pulmonary disease	 -Age -Gender -Education -Self-rated physical health -Self-rated mental health -Self-rated mental health -Medical visits -ED visits -ED visits -Hospitalization -PHC types: Solo Group practice FMG Community Specialist -PHC taxonomy: Single Contact Coordination Coord. integrated 	2.48 (0.98) at baseline 2.54 (0.97) at 12 months	- ref - Ref
Rick, 2012 ²¹⁹	Cross- sectional	Long-term conditions (high blood pressure,	-Age (categ) -Gender -Work	2.4 (0.87)	-

Author	Type of study and regression model	Conditions	List of covariates	Mean Overall PACIC (SD)	Type of association with Overall PACIC
	PACIC, dependent variable Linear regression	chest complaints, diabetes, heart problems, chronic kidney disease, stroke, cancer, anxiety and depression, arthritis, stomach or bowel problems, skin conditions, vision or hearing problems, neurological problems, chronic fatigue, thyroid or other problems)	 -Education -Nb of conditions -Most frequently HCP consulted -Nb of primary care consultations -Shared decision making -Quality of care for long-term conditions -Satisfaction with primary care 		- + +
Iglesias, 2014 ²¹⁷	Cross- sectional PACIC (French) Confirmatory factor analysis	Diabetes	-Age -Gender -SES -Insurance -Citizenship -Place of residence -Smoking status		+

Author	Type of study and regression model	Conditions	List of covariates	Mean Overall PACIC (SD)	Type of association with Overall PACIC
			-Weight and heigh	t	
			-Number of comorbidities		
			-Generic and disease-specific health-related quality of life		
			-Diabetes treatment:		
			Insulin		
			-Process of care indicators:		+
			Physical activity recommendation		+
			Diet recommendation		+
			Feet		+
			Eyes		+
			Microalbuminuria		+
			-Self-management education (proposed / attended)		+
			- Glucose self- monitoring		+
			-Overall care satisfaction level		+
Markun, 2014 ²²⁹	Cross-	Age related	-Age	2.4	
	sectional	macular degeneration	-Gender	(median))
			-Visual acuity of better eye		

Author	Type of study and regression model	Conditions	List of covariates	Mean Overall PACIC (SD)	Type of association with Overall PACIC	
	PACIC, dependent		-Diabetes type 2		-	
	variable		-Coronary artery disease			
	Multivariable regression model					
Petersen, 2014 ²³⁰	Cross-	Hypertension	ı, -Sex	2.4 (0.8)		
	PACIC, dependent	metabolism	-Age			
		disorders, chronic LBP	-Education level			
	variable Multilevel	chronic LBP, joint arthrosis, diabetes, etc.	joint arthrosis.	-Autonomy of former occupation		+
	hierarchical model		-Monthly net income			
			-No. of contacts with GP		+	
			-Weighted count o chronic conditions	f		
			-Existence of a DMP disease		+	
			-Geriatric depression scale			
			-IADL			
			-Quality of life		+	
			-Graded Chronic pain scale		+	
			-Self-efficacy			
			-Social support		+	
			-Sex of GP (Female)	+	
			-Years of ownership of practice			

Author	Type of study and regression model	Conditions	List of covariates	Mean Overall PACIC (SD)	Type of association with Overall PACIC
			-Type of practice (solo, group)		-(ref=solo)
			-Practice size		
Kuznetsov,	Cross- sectional,	Diabetes	-HbA1c	2.4 (0.79) in	
2015231	PACIC.		-Age	control	
	dependent		-Sex	2.4	
	variable,		-Education	(0.82) in inter-	
	Linear regression		 -Lifestyle behav- iours [smoking status (non- smoker/ex-smoker or current smoker), alcohol consumption [those who meet the guidelines on alcohol consumption and those who did not -History of angina and/or myocardial infarction and/or stroke (yes/no), -Intake of glucose- ,hypertension- and lipid-lowering drugs and aspirin 	vention	+
Aung, 2016 ²³²	Longitudinal, PACIC, independent variable	Diabetes	-Physical activity -Adherence to self- management support		+

Author	Type of study and regression model	Conditions	List of covariates	Mean Overall PACIC (SD)	Type of association with Overall PACIC
	(dichotomize by median <3 and >3)	d			
Desmedt, 2017 ²³³	Cross-	Multiple	-Age	2.87	
	sectional PACIC, dependent variable Factor analysis, multi-level regression	chronic conditions, including chronic back pain, multiple sclerosis.	-Gender	(0.93)	
			-Educational level		
			-Number of chroni conditions	lic	
		chronic neck pain,	-Duration of home care		
		osteoarthritis	-EQ-5D mobility		
		hypertension	-EQ-5D self-care		
			-EQ-5D usual activities		
			-EQ-5D pain discomfort		
			-EQ-5D anxiety/depressio	n	
+: associated with	higher PACIC sc	ore			
-: associated with	lower PACIC sco	re			

6. Results

6.1. Project 1 - Manuscript 1: Support for Teams, Technology, and Patient Involvement in Decision Making Associated with Support for Patient-Centred Care

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Running title: Support for Patient-Centred Care

Abstract

Objective

Patient-centred care is recommended to transform health care delivery to improve the quality and safety of health care. This study aimed to assess the determinants of support for attributes of patient-centred care from Canadian public and professionals' perspectives.

Design

A national population-based survey, the Health Care in Canada Survey.

Setting

Canada

Participants

1000 Canadian adults, 101 doctors, 100 nurses, 100 pharmacists, and 104 administrators, randomly selected from online panels based on multiple source recruitment.

Intervention

None

Main Outcome Measure

Support for patient-centred care, assessed using a summary score across seven items.

Results

Of 1000 Canadian public adults surveyed, 51% were female, 74% were living with another person, and 62% had at least one chronic condition. Only 18% of health professionals were

working in teams. Multivariable regression models showed that work in teams (0.24, 95%CI:0.20, 0.28), use of e-technology (0.29, 95%CI:0.17, 0.42), and patient older age (0.59, 95%CI:0.32, 0.86) and involvement in decision making (0.42, 95%CI:0.30, 0.55) were significantly associated with higher support for PCC while lower adherence to medications (-0.81, 95%CI: -1.16, -0.47) was associated with a decreased support for attributes of PCC.

Conclusions

The findings confirmed that perceptions of requiring health professionals to work in teams and the use of technology in health care are associated with support for PCC from both the public and health professionals. Programs to accelerate the implementation of health care teams supported by information and communication technologies are needed to deliver PCC, particularly for individuals living with chronic conditions.

Keywords

Patient-centred care, health survey, chronic conditions, quality care, health professionals

Introduction

In order to improve the quality and safety of health care, particularly for individuals with chronic illnesses, there have been calls for the transformation of the health care delivery system [1-3]. In particular, the Institute of Medicine *Quality Chasm's* report recommended a health care system that is safe, effective, timely, efficient, equitable and patient-centred, defined as providing 'care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions' [1].

This definition of patient-centred care (PCC) and the description of its role in quality care by the Institute of Medicine was based on the seminal work of Gerteis et al. (1993) for the Picker Institute/Commonwealth Fund PCC program [4]. Gerteis et al. identified several dimensions of patient-centered care in the inpatient setting: (1) respect for patients' values, preferences, and expressed needs; (2) coordination and integration of care; (3) information, communication, and education; (4) physical comfort; (5) emotional support and alleviation of fear and anxiety; (6) involvement of family and friends; and, (7) transition and continuity. These dimensions were renamed the Picker Principles of Patient-Centred Care, with the addition of an eighth dimension: access to care [5]. According to Gerteis et al., the term 'quality' encompasses two aspects: (1) technical excellence that includes "skill and competence of professionals and the ability of diagnostic or therapeutic equipment, procedures, and systems to accomplish what they are meant to accomplish, reliably and effectively"; and (2) subjective experience, an aspect that patients experience in terms of "their perception of illness or well-being and their encounters with health (care) professionals and institutions". It is this second aspect that is addressed through the concept of PCC. Even though PCC is not a new concept, the recent emergence of the concept coincides with growing patient frustrations with dehumanized care in the context of the

specialization and sophistication of the medical profession and with patients looking for a 'patient-centred care' approach as developed and taught in the late nineteenth and early twentieth by William Osler [6].

Evidence on patient-centred care approach

Some studies, mostly in inpatient settings, showed that applying PCC increases quality and safety of health care and provider and patient satisfaction, and decreases costs including fewer unnecessary diagnostic tests and referrals. Other studies demonstrated higher functional status, improved clinical care, and decreased mortality, emergency department visits, and medication errors [7-9]. Specific benefits for patients with chronic conditions (e.g. diabetes, asthma, chronic pain) include improvement of disease management, patient and doctor satisfaction, patient engagement, adherence to long-term therapies, and quality of life, and reduction in anxiety [7, 9-12]. Other authors, however, found inconclusive evidence of the effectiveness of PCC delivery [13, 14]. It is worth noting that patient-health professional communication, and in particular communication in doctor-patient relationships, was the most common aspect of PCC measured in these studies. Despite this conflicting evidence, PCC is embraced by organizations worldwide [10, 15-17] and in Canada [18, 19] "because without patient-centeredness, [health care] can lose its humane face." [20].

Definition and measure of patient-centred care

Effective measurement of PCC requires an operational definition; however, there is no consensual definition to date. As described by Luxford et al, leading organisations promoting strategies for PCC and researchers have defined context-specific elements of PCC with some core overlapping elements [7]. The models that form the basis for the most widely used definitions supported by empirical studies, in addition to the above-mentioned Picker principles

of PCC, are those proposed by Stewart et al. and Mead et al., (Table 1). Unlike the Picker model which is more health system/policy oriented, Stewart's and Mead's models are physician and primary care oriented, do not include elements such as continuity or access to care. The concept of PCC has been reviewed in other health professions including nursing [21], occupational therapy [22], and dentistry [23]. However, there is a lack of delineation, discussion, and application of the PCC concept in the context of team-based care [24, 25]. Another aspect absent from the literature is the evaluation of the role of technology despite its high potential to facilitate the delivery of most attributes of PCC [26].

Quantitative and qualitative methods have been used to evaluate PCC at both individual and aggregate levels: one-on-one interviews, focus groups, videotaped clinical visits and discussions, and surveys. However, there is a paucity of instruments dedicated to PCC. In their review limited to the context of ambulatory family practice, Hudon et al. identified only two instruments, based on Stewart et al's model to assess patients' perceptions of PCC: the Patient Perception of Patient-Centeredness and the Consultation Care Measure [27]. The most commonly used, particularly for hospital care, is the Picker Institute survey and its various modified versions [28].

Thus, several challenges exist to assess the delivery of PCC and the collection of evidence on its effectiveness. Implementing PCC requires the implication of patients, health professionals and health care organizations. Challenges of the implementation of PCC also imply effective care team coordination and financial and operational resources. In absence of a consensual definition of PCC and given the fact that it is not well known how these actors support the different dimensions of PCC [29-31], understanding their perceptions may inform the operationalization and implementation of PCC and help decision making in resource allocations. This will ultimately contribute to the evidence on PCC.

The Health Care in Canada Survey (HCIC) [32] offer a unique opportunity to assess the views of the public, health professionals, and health system administrators on a range of health care related areas and for its 11th edition, elements of PCC have been introduced. The definition and the selection of these elements were based on an environmental scan [17, 19] and consultation with the members of the HCIC partnership (Appendix A1) in order to cover a variety of elements of existing frameworks of PCC and suitable for a population-based survey. The aim of this study was to assess the determinants of the level of support for PCC from Canadian public and professionals' perspectives. Given the 'health care team' is seen as the first and immediate health care context within which PCC occurs[33], it was expected that respondents who strongly support team care models for chronic illness management will have a high level of support for PCC.

Methods

The Health Care in Canada Survey

The Health Care in Canada (HCIC) Survey is a national population-based survey that has been assessing the perceptions of the Canadian public, as well as physician, nurse, pharmacist and managerial health professionals on a range of healthcare related areas since 1998. HCIC is supported by a broad partnership of professional, patient and commercial organizations working in the health sector, and affiliated academic institutions. This study used the data from the 11th edition of the survey (2013-2014). The list of the members of the partnership involved in this edition is provided in the appendix A1.

The survey was conducted online between November 2013 and January 2014 by Pollara Strategic Insights for the HCIC partnership. The questions were developed through an iterative consultation process between Pollara and HCIC members. The participants were randomly selected within online panels based on multiple source recruitment (active and open) to ensure the panels were balanced prior to the selection process. In addition, a post-stratification weighting was implemented using the 2011 Census data to account for age and sex distributions within regions for the public sample. The final sample was made up of 1000 adult Canadians, 101 doctors, 100 nurses, 100 pharmacists, and 104 administrators. Because of the non-probability nature of the panels, margins of error cannot be calculated (see Appendix A2 for estimated margins of error). Ethical approval was not required as the study relied exclusively on secondary use of anonymous information.

PCC was assessed by asking questions on seven attributes (Table 1). A summary variable, PCC_average, was created as an average over participants with responses to at least 4 items; the 'do not know' choice was considered as missing.

All the questions of the survey that are related to components of the Quadruple Aim framework [34] or may have an association with PCC concept [7-14, 35, 36] were retained for the analysis. These are detailed below. <u>Patient variables</u> were demographic and socioeconomic variables, self-reported health and chronic conditions. Chronic conditions were respiratory, cardiovascular and mental health conditions, arthritis, diabetes, osteoporosis, and cancer. <u>Provider-related variables</u> included type of practice (institution-/community-based), number of years of practice, level of engagement in practice, provision of patients with instructions on prescribed medications. <u>Health system variables</u> included perceived affordability of health care, support for initiatives to improve health care, and for innovations in the health care system. Outcome measures were medication use and adherence, and health services utilization. The definition of adherence to medications was based on four questions on a 5-item scale (Always, Often, Sometimes, Rarely,

Never): taking medications more frequently than prescribed, less frequently than prescribed, a higher dosage than prescribed, or a lower dosage than prescribed. Responses 'always to rarely' were grouped as 'Yes' and coded 1 while 'never' was 'No' coded 0. Finally, adherence was categorized as 'high', 'medium' and 'low' if the sum was 0, 1-2, and 3-4, respectively. Health services utilization was measured by asking hospitalization and emergency department visit due to chronic conditions within the past month to more than two years or never.

Analyses

Multivariable general linear models were used to estimate the association between PCC, the outcome, and all other variables, the predictor variables. Percentages were calculated for predictor variables, using weighted and unweighted data for the public sample. PCC was analyzed as a continuous variable and mean values and standard deviation were calculated. Correlations were performed between the variables. Univariable models were run for each predictor and the dependent variable. Variables with a significant parameter estimate in the univariable linear regression models and those relevant to the study based on the literature were entered in the multivariable linear regression models.

Two separate multivariable regression models were built on the public and professional samples, starting with only demographic variables and subsequently other groups of independent variables, checking the fit at each step. AIC and adjusted R² criteria were used to select the most parsimonious models. The analyses were performed using SAS ver. 9.3 with PROC GLM and R 3.0.3 with generalized linear model function for the regression models. 95% confidence intervals (CI) were provided for the estimates (mean change in PCC_average for each one-unit difference in predictor variables) from the regression models.

Results

The characteristics of public respondents are presented in Table 2. Of 1000 public respondents, 51% were female, 22% (18%, weighted) were 65 years or older, 62% (58%, weighted) reported at least one chronic condition, including cardiovascular diseases (26%) and cancer (7%). All the professional participants had three or more years in practice, 54% were community-based, 65% were involved in team-based disease management programs (Table 3).

The public and the professionals highly supported all the attributes of PCC with the average support ranging from 7.7 to 9.4 out of 10 (Appendix A3). While the averages support that the different groups are not significantly different, nurses seemed to show the highest support for any of the attributes of PCC.

Numerous variables were significantly associated with support for attributes of PCC when examined individually. For example, being female, not being married, living in a rural area, taking at least four different medications, or being a nurse showed a positive association for support of PCC concept. Variables that showed no significant association when examined individually included household income, type of health insurance, self-rated health for public respondents; and years of practice and type of practice for the professional respondents (Appendix A4).

Results of multivariable regression models are shown in Table 4. For the public population sample, 'requiring health care professionals (HCPs) to work in teams' (0.24; 95% CI:0.20, 0.28), 'using technology to enhance communication'(0.20, 95%CI:0.08, 0.32), and 'increase patient involvement in decision making' (0.42; 95% CI:0.30, 0.55) were significantly associated with support for attributes of PCC. Similar results were seen among professional respondents. For the

variables specific to the public population sample, there was a significant age effect with older individuals more likely to support attributes of PCC; lower adherence to medications was negatively associated with support for attributes of PCC (-0.81, 95%CI: -1.16, -0.47).

Discussion

This is one of few studies that provided an empirical estimate of support for PCC from the perceptions of groups of individuals that will need to be actively involved to make PCC happen: the public and health professionals and administrators. Our results showed that support for attributes of PCC is associated with perceptions of support for team-based care and the use of health information technology, and some patient-related variables such age and adherence to medications. The Health Care in Canada Survey data provided a unique opportunity to explore the association between support for the attributes of PCC and a blend of patients and health system related issues from the public and health professionals' perspectives. Such a survey permits the dissemination of population-based perceptions and the generation of research questions and studies to estimate the extent of PCC nationally and inform the development of PCC healthcare programs.

The first interesting finding was the association between support for attributes of PCC and for requiring HCPs working in teams with a stronger association in the public sample. A second team-related variable in the public sample identified by asking 'Do you work with a doctor or a team of health care professionals to manage your condition(s)?' showed a significant association in the univariable analysis. This finding is in line with other studies suggesting teamwork and PCC "enjoy generous overlap in shared concepts" [25] and health care teams are believed to be the immediate and convenient context to deliver PCC in primary care [37]. Team-based care facilitates whole person and comprehensive care; coordination of care (better familiarity of

health care providers with each other, and of patients and families with members of health care teams); improves access to and safety of care [25, 38]. The fact that the perceptions of the public and health professionals on team-based care were associated with their perceptions of important PCC elements provides support for the necessity and validity of these elements reflecting PCC.

The association of attributes of PCC and the use of health information technology (HIT) was another noteworthy finding. Thus, the use of personal health record (PHR)- under the "custodianship of a patient, which may include a family member or caregiver" [39] - and integrated with electronic medical record and electronic health record systems may promote patient-centeredness. Studies investigating the effect of HIT on the PCC approach as a whole are currently nonexistent in the literature, as only some components were examined [40]. HIT allows patients access to their own health care data, facilitates care management (providing patients with reminders and decision support), effective communication between a patient (and family or caregiver) and health care providers, and continuity of care [26, 40, 41]. According to our findings, professionals showed less support for the use of PHR than the public, while supporting patient involvement in decision making more than the public. Patients, on the other hand, want more access to their PHR, but are not ready to fully engage in decision making. Going forward, these competing differences present a conundrum that needs to be addressed by both groups to optimize patient-centred care.

Among socio-demographic variables, only age remained significant in the multivariable analysis with the strength of the association increasing with age. This is in contrast with the suggestion from some studies that older patients and those with serious illness may not prefer a PCC approach, however these studies were based on patients mostly from secondary care settings, were mainly assessing the shared-decision making component of PCC, and were conducted prior

to the 2000s [42, 43]. Other socio-demographic variables such as gender, marital status or living in rural areas showed a positive association with support of the PCC concept when examined individually despite not emerging as significant in the multivariable analyses, but these results cannot be explained and require further investigation.

The association of PCC with treatment adherence was reported previously [9, 36, 44]. We found among the public that higher level of support of the attributes of PCC was significantly associated with higher adherence. This finding adds to a growing body of evidence that one or many components of PCC are positively associated to medication adherence regardless of the definition and measurement used, given that long-term medication regimens are an essential component of the management of many chronic conditions.

For the professionals, being female or being a nurse were positively associated with attributes of PCC. This can be explained not only by the fact that the large majority of nurses were female but also because nursing care, based on Watson's caring theory, seems to share more commonalities with the attributes of PCC than any other health profession [21].

As the interest in PCC is growing, it is important to note the barriers to the implementation of and research on PCC. These include the lack of a consensual definition; the model of care and mode of remuneration that is mainly based on the acute care model; and, ethical dilemmas that health care providers may sometimes face when balancing patient preferences and clinical judgement or evidence-based practice [10, 45].

Our findings open the perspective on further investigations and causal design research, particularly the relationship between PCC and team-based care and the use of e-technology in

health care delivery on the one hand, and on the other, impact of PCC on patient outcomes and quality indicators.

Limitations

Results from this survey were based on perceptions, and some concepts such as 'team' might be differently conceptualized by the public and professional respondents, and even among the professional groups [46], therefore must be used with caution. Surveys based on online panels are subjects to several limitations such as coverage, selection, non-response biases, and lack of information to assess the characteristics of non-responders. Most of these limitations are not exclusive to online surveys [47]. Moreover, the study was not intending to produce precise estimates of population values. Online surveys have some advantages including satisfactory response rates, lower cost, faster responses, less social desirability or measurement error from interviewers, and higher data quality [48].

Conclusion

The findings confirmed that perceptions of requiring health professionals to work in teams, increasing patient involvement in decision making, and the use of technology in healthcare are associated with support for patient-centred care from both the public and health professionals. Programs to accelerate the implementation of health care teams supported by information and communication technologies are needed, particularly for individuals living with chronic conditions.

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| | Picker/Commonwealth ¹ | Mead et al. ² | Stewart et al. ² | HCIC ³ |
|---|----------------------------------|---------------------------|-----------------------------|-------------------------|
| 1 | Respect for patients' | Biopsychosocial | Exploring health, | Care that is provided |
| | values, preferences, and | perspective (on | disease, and the | in a caring, respectful |
| | expressed needs | illness) | illness | context |
| | | | experience | |
| 2 | Coordination and | Patient-as-person | Understanding | Care that is supported |
| | integration of care | (understanding the | the whole person | by the current |
| | | personal meaning of | | research and expert |
| | | the illness) | | opinion |
| 3 | Information, | Sharing power and | Finding common | Care that is guided, |
| | communication, and | responsibility | ground | and transparently |
| | education | (sensitivity to patients' | | communicated, by |
| | | preferences and | | providers |
| | | shared-decision | | |
| | | making) | | |
| 4 | Physical comfort (relieve | Therapeutic alliance | Enhancing the | Care decisions that |
| | pain and suffering) | (developing common | patient-clinician | are made in |
| | | therapeutic goals and | relationship | partnership between |
| | | enhancing personal | | informed patients and |
| | | bond doctor-patient) | | their providers |
| 5 | Emotional support and | Doctor-as-person | | Care and system |
| | alleviation of fear and | (awareness of the | | outcomes that are |
| | anxiety (relieving fear and | influence of the | | measured (evaluated) |
| | anxiety) | personal qualities and | | and presented in a |
| | | subjectivity of the | | manner meaningful to |
| | | doctor) | | most Canadians |

Table 1. Comparison of attributes of patient-centred of HCIC survey and common models

6	Involvement of family and		Care policy that is
	friends		shaped by interaction
			with, and learning
			from, patients
7	Transition and continuity		
8	Access to care		Care that is readily,
			and timely, accessed

¹ Focus on system/policy ² focus on primary care HCIC: Health Care in Canada

³Below is a list of attributes that have been proposed as elements that could help create a culture and practice of patient-centred care. Please indicate to what extent you oppose or support the widespread implementation of each attribute as an effective contribution to enhance patient-centred care using a scale from one to 10, where one means you would "strongly oppose" it and 10 means you would "strongly support" it (attributes were randomized during survey implementation).

Table 2.	Characteristics	of the	public	respondents
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Variables		Unweighted	Weighted	
		N (%)	N (%)	
Age		(n=1000)	(n=1000)	
	≤ 34	186 (18.6)	280 (28.0)	
	35 - 44	171 (17.1)	157 (15.7)	
	45 - 54	216 (21.6)	214 (21.4)	
	55 – 64	212 (21.2)	171 (17.1)	
	≥ 65	215 (21.5)	178 (17.8)	
Sex		(n=1000)	(n=1000)	
	Male	491 (49.1)	486 (48.6)	
	Female	509 (50.9)	514 (51.4)	
Marita	al status	(n=1000)	(n=1000)	
	Single	224 (22.4)	269 (26.9)	
	Common Law/Married	595 (59.5)	566 (56.6)	

	Divorced/Separated	124 (12.4)	108 (10.8)
	Widowed	48 (4.8)	45 (4.5)
	Prefer not to say	9 (0.9)	12 (1.2)
House	ehold income	(n=1000)	(n=1000)
	< \$50,000	270 (27.0)	270 (27.0)
	\$50,000 to \$74,999	355 (35.5)	351 (35.1)
	\$75,000 to \$99,999	138 (13.8)	144 (14.4)
	≥ \$100,000	126 (12.6)	128 (12.8)
	Prefer not to say	111 (11.1)	107 (10.7)
Living	with another person	(n=1000)	(n=1000)
	Yes	740 (74.0)	738 (73.8)
	No	260 (26.0)	262 (26.2)
Privat	e insurance	(n=1000)	(n=1000)
	Yes	511 (51.1)	491 (49.1)
	No	489 (48.9)	509 (50.9)
Place	No of residence	489 (48.9) (n=1000)	509 (50.9) (n=1000)
Place	No of residence Urban	489 (48.9) (n=1000) 827 (82.7)	509 (50.9) (n=1000) 836 (83.6)
Place	No of residence Urban Rural	489 (48.9) (n=1000) 827 (82.7) 173 (17.3)	509 (50.9) (n=1000) 836 (83.6) 164 (16.4)
Place Self-ra	No of residence Urban Rural ated health	489 (48.9) (n=1000) 827 (82.7) 173 (17.3) (n=1000)	509 (50.9) (n=1000) 836 (83.6) 164 (16.4) (n=1000)
Place Self-ra	No of residence Urban Rural ated health Very good / Excellent	489 (48.9) (n=1000) 827 (82.7) 173 (17.3) (n=1000) 443 (44.3)	509 (50.9) (n=1000) 836 (83.6) 164 (16.4) (n=1000) 447 (44.7)
Place Self-ra	No of residence Urban Rural ated health Very good / Excellent Good	489 (48.9) (n=1000) 827 (82.7) 173 (17.3) (n=1000) 443 (44.3) 342 (34.2)	509 (50.9) (n=1000) 836 (83.6) 164 (16.4) (n=1000) 447 (44.7) 345 (34.5)
Place Self-ra	No of residence Urban Rural Ated health Very good / Excellent Good Fair / Poor	489 (48.9) (n=1000) 827 (82.7) 173 (17.3) (n=1000) 443 (44.3) 342 (34.2) 215 (21.5)	509 (50.9) (n=1000) 836 (83.6) 164 (16.4) (n=1000) 447 (44.7) 345 (34.5) 208 (20.8)
Place Self-ra	No of residence Urban Rural Very good / Excellent Good Fair / Poor er of chronic conditions	489 (48.9) (n=1000) 827 (82.7) 173 (17.3) (n=1000) 443 (44.3) 342 (34.2) 215 (21.5) (n=1000)	509 (50.9) (n=1000) 836 (83.6) 164 (16.4) (n=1000) 447 (44.7) 345 (34.5) 208 (20.8) (n=1000)
Place Self-ra	No of residence Urban Rural Ated health Very good / Excellent Good Fair / Poor er of chronic conditions 0	489 (48.9) (n=1000) 827 (82.7) 173 (17.3) (n=1000) 443 (44.3) 342 (34.2) 215 (21.5) (n=1000) 381 (38.1)	509 (50.9) (n=1000) 836 (83.6) 164 (16.4) (n=1000) 447 (44.7) 345 (34.5) 208 (20.8) (n=1000) 418 (41.8)
Place Self-ra	No of residence Urban Rural Ated health Very good / Excellent Good Fair / Poor er of chronic conditions 0 1	489 (48.9) (n=1000) 827 (82.7) 173 (17.3) (n=1000) 443 (44.3) 342 (34.2) 215 (21.5) (n=1000) 381 (38.1) 261 (26.1)	509 (50.9) (n=1000) 836 (83.6) 164 (16.4) (n=1000) 447 (44.7) 345 (34.5) 208 (20.8) (n=1000) 418 (41.8) 254 (25.4)
Place Self-ra	No of residence Urban Rural Very good / Excellent Good Fair / Poor of chronic conditions 0 1 2	489 (48.9) (n=1000) 827 (82.7) 173 (17.3) (n=1000) 443 (44.3) 342 (34.2) 215 (21.5) (n=1000) 381 (38.1) 261 (26.1) 172 (17.2)	509 (50.9) (n=1000) 836 (83.6) 164 (16.4) (n=1000) 447 (44.7) 345 (34.5) 208 (20.8) (n=1000) 418 (41.8) 254 (25.4) 163 (16.3)
Place Self-ra	No of residence Urban Rural Ated health Very good / Excellent Good Fair / Poor of chronic conditions 0 1 2 3	489 (48.9) (n=1000) 827 (82.7) 173 (17.3) (n=1000) 443 (44.3) 342 (34.2) 215 (21.5) (n=1000) 381 (38.1) 261 (26.1) 172 (17.2) 113 (11.3)	509 (50.9) (n=1000) 836 (83.6) 164 (16.4) (n=1000) 447 (44.7) 345 (34.5) 208 (20.8) (n=1000) 418 (41.8) 254 (25.4) 163 (16.3) 100 (10.0)

Туре о	f chronic conditions*	(n=1000)	(n=1000)
	Asthma, bronchitis or emphysema	146 (14.6)	140 (14.0)
	Arthritis	245 (24.5)	220 (22.0)
	Diabetes	127 (12.7)	113 (11.3)
	Heart disease, stroke or high blood	258 (25.8)	222 (22.2)
	pressure		
	Osteoporosis	57 (5.7)	55 (5.5)
	Cancer	74 (7.4)	65 (6.5)
	A mental health condition	156 (15.6)	162 (16.2)
	Any other chronic health condition	205 (20.5)	192 (19.2)
	None	381 (38.1)	418 (41.8)
Adhere	ence	(n=1000)	(n=1000)
	High	245 (24.5)	219 (21.9)
	Medium	167 (16.7)	157 (15.7)
	Low	72 (7.2)	74 (7.4)
	No prescription medication or	516 (51.6)	550 (55.0)
	missing		
CHC c	ancer	(n=1000)	(n=1000)
	No CD	381 (38.1)	418 (41.8)
	Cancer	74 (7.4)	65 (6.5)
	Other CD	545 (54.5)	517 (51.7)
Work v	vith care provider	(n=619)	(n=582)
	Work with Doctor	435 (70.3)	401 (68.9)
	Work with a Team	105 (17.0)	103 (17.7)
	Neither	79 (12.7)	78 (13.4)
Requir	ing HCPs work in teams	(n=1000)	(n=1000)
	Mean (SD)	7.4 (2.2)	7.4 (2.2)

Receive support from HCI	Ps (n=619)	(n=582)
Always	223 (36.0)	195 (33.5)
Often	177 (28.6)	168 (28.9)
Sometimes	145 (23.4)	140 (24.0)
Rarely / Never	74 (12.0)	79 (13.6)

CHC: chronic health condition; CD: chronic disease; HCP: health care professionals *Numbers and percentages add up to more than the totals since participants could have more than one chronic condition

Table 3. Characteristics of the professional respondents

Variables	Doctors	Nurses	Pharmacists	Administrators	Total
	(n)	(n)	(n)	(n)	N (%)
Sex					
Male	82	9	48	43	182 (44.9)
Female	17	91	47	59	214 (52.8)
Prefer not to say	2	0	5	2	9 (2.2)
Type of practice					
Institution-based	35	68	16	69	188 (46.4)
Community-based	66	32	84	35	217 (53.6)
Years in practice					
< 1	0	0	0	13	13 (3.2)
1 – 2	0	0	0	5	5 (1.2)
3 – 5	1	6	6	10	23 (5.7)
6 – 10	5	22	20	17	64 (15.8)
11 – 20	35	25	31	17	108 (26.7)
21 – 30	27	32	23	23	105 (25.9)
> 30	33	15	20	19	87 (21.5)

Level	of	engagement
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	Very good / Excellent	70	68	60	79	277 (68.4)
	Good	23	26	29	15	93 (23.0)
	Fair / Poor	8	6	10	7	31 (7.7)
	Don't know	0	0	1	3	4 (1.0)
Involve	ed in team care (DM)					
	Yes	70	55	78	61	264 (65.2)
	No	31	45	22	43	141 (34.8)
Requir	ing HCPs work in teams					
	Mean (SD)	6.3 (2.6)	8.5 (2.0)	8.0 (2.0)	8.2 (2.1)	7.8 (2.3)
Provid	e patients with instructions					
	Always	60	45	74	32	211 (52.1)
	Often	31	42	24	29	126 (31.1)
	Often Sometimes	31 9	42 11	24 1	29 14	126 (31.1) 35 (8.6)
	Often Sometimes Rarely / Never	31 9 1	42 11 2	24 1 1	29 14 29	126 (31.1) 35 (8.6) 33 (8.1)
House	Often Sometimes Rarely / Never hold income	31 9 1	42 11 2	24 1 1	29 14 29	126 (31.1) 35 (8.6) 33 (8.1)
House	Often Sometimes Rarely / Never hold income < \$50,000	31 9 1 0	42 11 2 0	24 1 1	29 14 29 3	126 (31.1) 35 (8.6) 33 (8.1) 4 (1.0)
House	Often Sometimes Rarely / Never hold income < \$50,000 \$50,000 to \$74,999	31 9 1 0 0	42 11 2 0 11	24 1 1 1	29 14 29 3 19	126 (31.1) 35 (8.6) 33 (8.1) 4 (1.0) 36 (8.9)
House	Often Sometimes Rarely / Never hold income < \$50,000 \$50,000 to \$74,999 \$75,000 to \$99,999	31 9 1 0 0 1	42 11 2 0 11 25	24 1 1 1 6 24	29 14 29 3 19 16	126 (31.1) 35 (8.6) 33 (8.1) 4 (1.0) 36 (8.9) 66 (16.3)
House	Often Sometimes Rarely / Never hold income < \$50,000 \$50,000 to \$74,999 \$75,000 to \$99,999 ≥ \$100,000	31 9 1 0 0 1 77	42 11 2 0 11 25 55	24 1 1 1 6 24 55	29 14 29 3 19 16 51	126 (31.1) 35 (8.6) 33 (8.1) 4 (1.0) 36 (8.9) 66 (16.3) 238 (58.8)

DM: disease management; HCP: health care professionals

Variables	Estimate (95% CI) Public	Estimate (95% CI) Professionals
Age		
≤ 34 (Reference)	1	
35 – 44	0.32 (0.05, 0.59)	
45 – 54	0.42 (0.16, 0.68)	
55 – 64	0.42 (0.15, 0.69)	
≥ 65	0.59 (0.32, 0.86)	
Sex		
Male (Reference)	1	1
Female	0.13 (-0.03, 0.29)	0.16 (-0.06, 0.38)
Prefer not to say	N/A	-0.69 (-1.14, 0.04)
Place of residence		
Urban (Reference)	1	
Rural	0.20 (-0.01, 0.41)	
Access to HCPs		
Requiring HCPs work in teams	0.24 (0.20, 0.28)	0.11 (0.06, 0.16)
Adherence to medications		
High (Reference)	1	
Medium	-0.81 (-1.16, -0.47)	
Low	-0.28 (-0.49, -0.08)	
Improvement of health care and system		
Using technology will help communicate better	0.20 (0.08, 0.32)	0.21 (0.03, 0.39)
Accelerating the use of personal health records	0.29 (0.17, 0.42)	0.06 (-0.09, 0.21)
Increase patient involvement in decision making	0.42 (0.30, 0.55)	0.55 (0.39, 0.71)

PCC: patient-centred care; HCP: health care professionals

Supplemental material

Appendix A1. List of the members of the HCIC partnership

Canadian Cancer Society

Canadian Foundation for Healthcare Improvement

Canadian Home Care Association

Canadian Hospice Palliative Care Association

Canadian Medical Association

Canadian Nurses Association

Constance Lethbridge Rehabilitation Centre (McGill-affiliated)

Care Net Health Management Consulting

Health Charities Coalition of Canada

HealthCare CAN

Institute of Health Economics

Institute of Work and Health

Merck Canada

Pollara Inc

Strive Health Management

Appendix A2. Estimated margins of error

Group of respondents	Estimate
Public sample	±3.1%
Doctors	±9.7%
Nurses	±9.8%
Pharmacists	±9.8%
Administrators	±9.6%

Appendix A3. Mean score of the level of support for the attributes of Patient-Centred Care (PCC)

Attributes of PCC	Public	Doctors	Nurses	Pharmacists	Administrators
	Ν	Ν	Ν	Ν	Ν
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Care that is readily, and timely,	973	101	99	100	104
accessed	8.7 (1.8)	8.9 (1.4)	9.3 (1.3)	8.9 (1.5)	8.9 (1.6)
Care that is supported by the					
current research and expert	956	101	100	100	103
opinion	7.9 (1.9)	8.6 (1.7)	8.8 (1.8)	8.3 (1.7)	8.4 (1.7)
Care that is provided in a caring.					
respectful context	966	101	99	100	104
	8.7 (1.8)	8.9 (1.4)	9.4 (1.4)	8.9 (1.4)	9.0 (1.7)
Care that is guided, and transparently communicated, by	947	101	100	100	104
providers	8.1 (2.0)	8.4 (1.5)	8.9 (1.8)	8.3 (1.5)	8.6 (1.6)
Care decisions that are made in partnership between informed	956	100	100	100	104
patients and their providers	8.2 (2.0)	8.5 (1.6)	9.2 (1.4)	8.4 (1.5)	8.9 (1.5)

Care policy that is shaped by interaction with and learning from	953	100	100	99	103
patients	7.9 (1.9)	7.7 (1.7)	8.4 (2.0)	7.7 (1.88)	8.3 (1.8)
Care and system outcomes that are measured (evaluated) and	936	99	99	100	104
presented in a manner meaningful to most Canadians	8.0 (1.9)	8.1 (1.6)	8.4 (2.1)	7.8 (1.7)	8.2 (1.8)

Appendix A4. Univariable analysis Estimate for a change of 1 unit and 95% confidence intervals (CI) for support for patientcentered care for unadjusted models

	Public respondents		Prov	iders
		1	respon	ndents
	Estimate	95% CI	Estimate	95% CI
Age				
< 34 years old	Ref		NA	
35 - 44	0.54	0.22, 0.86	NA	
45 - 54	0.72	0.41, 1.02	NA	
55 - 64	0.80	0.50, 1.10	NA	
≥ 65	1.16	0.85, 1.46	NA	
Gender				
Male	Ref		Ref	
Female	0.21	0.01, 0.41	0.40	0.16, 0.64
Prefer not to say	NA		-0.88	-1.70, -0.06
Marital status				
Single	Ref		NA	
Common-law/Married	0.20	-0.04, 0.45	NA	
Divorced/Separated/Wid owed/Prefer not to say	0.33	0.02, 0.65	NA	

Household income

Ref		Ref	
0.16	-0.09, 0.41	-0.40	-1.69, 0.89
0.12	-0.20, 0.45	-0.24	-1.50, 1.02
0.00	-0.33, 0.33	-0.50	-1.73, 0.74
-0.15	-0.51, 0.20	-0.46	-1.72, 0.80
	Ref 0.16 0.12 0.00 -0.15	Ref 0.16 -0.09, 0.41 0.12 -0.20, 0.45 0.00 -0.33, 0.33 -0.15 -0.51, 0.20	Ref Ref 0.16 -0.09, 0.41 -0.40 0.12 -0.20, 0.45 -0.24 0.00 -0.33, 0.33 -0.50 -0.15 -0.51, 0.20 -0.46

Currently live with another person

Yes	Ref		NA
No	-0.06	-0.28, 0.17	NA

Private insurance

Yes	Ref		NA
No	-0.04	-0.24, 0.15	NA

Living in an urban or rural setting

Urban	Ref		NA
Rural	0.37	0.11, 0.62	NA

Self-rated health - categories

Good	Ref		NA
Very good/Excellent	0.11	-0.11, 0.33	NA
Fair/Poor	0.02	-0.24, 0.28	NA

Summary of perceived affordability

Did not perceive	Ref		Ref	
affordability has				
worsened (0				
Worsened somewhat	0.35	0.06, 0.63	0.10	-0.31, 0.51
(1 to 3)				

Worsened moderately	0.25	-0.04, 0.54	0.19	-0.22, 0.60
(4 to 6)				
Worsened a lot (7 to	0.31	-0.02, 0.64	0.21	-0.24, 0.67
9)				
Worsened the most	0.32	0.02, 0.62	0.04	-0.42, 0.51
(10 to 11)				

Number of chronic

diseases - 4 categories

0	Ref		NA
1	0.39	0.14, 0.63	NA
2	0.61	0.33, 0.89	NA
<u>></u> 3	0.51	0.23, 0.78	NA

Type of chronic health condition (CHD)

No CHD	Ref	
Cancer	0.34	-0.04, 0.73
Any other CHD	0.50	0.30, 0.71

Hospitalization due to

chronic health condition

(CHC)

Never	Ref		NA
$\leq 1 \text{ month}$	-0.50	-1.32, 0.32	NA
> 1 to \leq 3 months	-0.41	-1.16, 0.33	NA
$>$ 3 to \leq 6 months	0.12	-0.59, 0.83	NA
> 6 to ≤ 12 months	-0.31	-0.83, 0.20	NA
> 12 to ≤ 24 months	0.56	0.10, 1.03	NA
> 24 months	0.25	0.01, 0.48	NA
Missing	NE		NA

ER visit due to chronic

health condition (CHC)

Never	Ref		NA
\leq 1 month	-0.01	-0.73, 0.71	NA
> 1 to ≤ 3 months	-0.75	-1.36, -0.13	NA
$>$ 3 to \leq 6 months	0.02	-0.60, 0.63	NA
> 6 to ≤ 12 months	0.44	-0.06, 0.93	NA
> 12 to ≤ 24 months	0.49	0.08, 0.90	NA
> 24 months	0.38	0.15, 0.61	NA
Missing	NE		NA

Do you work with a doctor or a team of health care professionals to manage your conditions(s)?

Doctor	Ref		NA
Team	0.52	0.21, 0.84	NA
Neither	-0.17	-0.54, 0.19	NA
Missing	NE		NA

G4. Do you receive the support that you need from

health professionals to help you manage your

condition(s)?

Always	Ref		NA
Often	-0.08	-0.34, 0.19	NA
Sometimes	0.00	-0.29, 0.29	NA
Rarely	-0.24	-0.67, 0.20	NA
Never	-0.25	-0.94, 0.45	NA
Missing	NE		NA

Number of prescription medications currently taken

< 1	Ref		NA
2	0.28	-0.06, 0.62	NA
3	0.35	-0.02, 0.71	NA
4	0.54	0.31, 0.78	NA
Missing (answered No			
or missing)	NE		NA

Adherence to medications - High/Medium/Low

High	Ref		NA
Medium	-0.21	-0.51, 0.09	NA
Low	-1.18	-1.59, -0.76	NA
No or Missing	-0.67	-0.90, -0.43	NA

Type of practice

Institution-based	NA	Ref	
Community-based	NA	-0.20	-0.44, 0.04

Years of practice

Less than one	NA	Ref	
From one to two	NA	-0.60	-1.88, 0.68
From three to five	NA	-0.68	-1.53, 0.16
From six to 10	NA	-0.69	-1.43, 0.05
From 11 to 20	NA	-0.58	-1.29, 0.14
From 21 to 30	NA	-0.32	-1.03, 0.40
More than 30	NA	-0.21	-0.93, 0.51

Level of engagement

Very Good / Excellent	NA	Ref	
(8 to 10)			
Good (5 to 7)	NA	-0.32	-0.61, -0.03
Fair / Poor (1 to 4)	NA	-0.57	-1.03, -0.12

Don't know	NA		0.94	-0.28, 2.15
Involved in intervention prog	gram			
Yes	NA		Ref	
No	NA		0.19	-0.07, 0.44
Type of provider				
Doctor	NA		Ref	
Nurse	NA		0.49	0.15, 0.83
Pharmacist	NA		-0.11	-0.45, 0.23
Administrator	NA		0.17	-0.16, 0.51
How often you provide instr	uctions on	prescribed		
medication				
Always	NA		Ref	
Often	NA		-0.18	-0.45, 0.10
Sometimes	NA		0.03	-0.41, 0.48
Rarely / Never	NA		0.06	-0.39, 0.52
To what extent would you su	pport or o	ppose each of th	ne follow	ing policies to
increase access to health professionals using a scale from one to 10, where ones				
means you would "strongly of	oppose" it	and 10 means y	ou would	"strongly
support" it?				
Health professionals	0.33	0.29, 0.37	0.18	0.13, 0.23
work in teams				
Diagnosed with Arthritis				
No	Ref		NA	
Yes	0.31	0.09, 0.54	NA	

Diagnosed with Heart disease, stroke or high blood pressure

No Ref NA	lo	Ref	NA
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0.45	0.23, 0.67	NA
	0.45	0.45 0.23, 0.67

Diagnosed with Any other chronic health condition

No	Ref		NA
Yes	0.40	0.16, 0.64	NA

Below is a list of initiatives that may lead to a better health care system.

Thinking of how effective these might be, indicate the degree to which you support or oppose the implementation of these initiatives.

0.75	0.62, 0.88	0.36	0.21, 0.50
0.84	0.70, 0.97	0.73	0.58, 0.89
	0.75	0.75 0.62, 0.88 0.84 0.70, 0.97	0.75 0.62, 0.88 0.36 0.84 0.70, 0.97 0.73

Technological advancements have created new options for health care delivery.

To what extent do you agree or disagree with each of the following statements?

Using technology will 0.57 0.44, 0.70 0.52 0.34, 0.69 help me communicate better

NA: not applicable; NE: not estimated

6.2. Project 2

6.2.1. Preface to Manuscript 2

In Canada and worldwide, the prevalence of chronic diseases is increasing but the quality of chronic care is far from optimal. Patient-centred care (PCC), one of the six key components of quality care identified by the IOM, and team-based care are among the recommended approaches to help improve quality care. However, there remains uncertainty about how to effectively implement, evaluate and 'accumulate' evidence on the effectiveness of patient centred interdisciplinary care. In addition, implementing these approaches requires the implication of all stakeholders. Using a population-based survey, manuscript 1 (project 1) showed a high level of support for the concept of PCC amongst the Canadian adult population and different health professional groups. More interestingly, this manuscript showed a positive association between support for PCC and support for team-based care as hypothesized. Understanding the perceptions of healthcare stakeholders will inform the operationalization and implementation of PCC and help decision makers who are responsible for resource allocation. Doing so will also contribute to the evidence on PCC.

To further explore the aspects of team-based care that contribute to a positive experience and PCC, we used LBP in project 2 (manuscripts 2 and 3) as an example of a chronic condition to investigate the experience of interdisciplinary care. We used a convergent mixed methods approach and concurrently collected qualitative and quantitative data. The aim of project 2 is threefold: i) identify elements of effective implementation of IDT care; ii) identify constructs that are meaningful for patients to inform effective evaluation; and iii) accumulate more evidence on the effectiveness of IDT care. For the qualitative component (manuscript 2), given

the complexity of chronic pain care, we used a phenomenological approach. This approach is particularly valuable for exploring and gaining a deeper understanding of human experiences.

6.2.2. Manuscript 2: Patients' Experiences in an Interdisciplinary Primary Care Program for Low Back Pain

(submitted to Disability and Rehabilitation)

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Implications for Rehabilitation

- Team-based care has important benefits for the management of low back pain.
- Advantages of interdisciplinary team care identified by patients with subacute and chronic low back pain included having professionals evaluate the patient together and provide a personalized approach.
- Participants characterized recovery as being able to function again.
- Integrating constructs and concerns that are important to patients is essential for efforts to improve the delivery of care.

Abstract

Purpose. One of the main recommendations to improve the management of low back pain (LBP) is the use of interdisciplinary teams in the delivery of care. However, many challenges remain in establishing interdisciplinary care, particularly in community-based primary care settings. The goal of this study was to explore patients' experiences with interdisciplinary care for LBP to inform effective implementation.

Methods. We adopted a phenomenological approach with purposive criterion-based sampling. Semi-structured interviews were conducted with fifteen adults enrolled in a six-month interdisciplinary LBP program as part of an integrated care network. The analysis combined a detailed description of the experiences and an interpretation of their meanings.

Results. The study supports the view that the management of non-specific LBP is complex and that individuals living with LBP experience a long journey to recovery. Advantages of interdisciplinary team articulated by the participants include professionals being seen together and a personalized approach. They characterized recovery as being able to function.

Conclusions. The findings will contribute to our understanding of how to optimise patientcentred care for individuals with chronic pain. Constructs that are identified as being important to patients may inform the development of a patient experience questionnaire for use in interdisciplinary primary care.

Keywords

Patient experience, low back pain, interdisciplinary program, primary health care, phenomenology

Introduction

Healthcare support for people living with chronic health conditions remains far from optimal. Approximately 40% of people with chronic illness report not receiving the care and resources they need to help them manage their condition [1, 2]. This is also the case for individuals living with chronic pain and particularly for those with LBP. Long considered only as the manifestation of an underlying pathology, chronic pain is now acknowledged as a health condition in its own right [3-5]. Furthermore, unlike other common chronic conditions such as asthma or diabetes, the effective management of pain as a chronic condition has not been well documented.

LBP is one of the most common non-specific chronic pain conditions. Up to 85% of these cases cannot be attributed to a specific underlying pathology [3, 6]. LBP is associated with high economic costs, including medical costs, absence from work, disability, and diminished patient quality of life [7, 8]. The management of LBP can be complex and costly, and includes non-pharmacological and pharmacological approaches [3, 9-13]. The guidelines recommend non-pharmacological approaches based on advice and self-management education as first line options, followed by cognitive behavioral and exercise therapies, and some forms of complementary and alternative medicine [9, 10, 12, 14]. They recommend a prudent use of medication, imagery, procedures and surgery. The pharmacological options available for symptomatic relief of LBP include non-steroidal anti-inflammatory drugs, muscle relaxants, opioid analgesics, anticonvulsants and antidepressants [9-12, 15].

One of the main recommendations to improve the management of subacute and chronic LBP is the use of multidisciplinary and interdisciplinary teams in the delivery of care [3, 9, 12, 14]. Research evidence suggests that a healthcare team approach will lead to increased integration of

care and higher patient, provider and managerial satisfaction; as a result, administrative and clinical processes and patient outcomes are improved [16-21].

Chronic pain is one of the top reasons for consultation in general practice [7, 8]. It is estimated that 40% of primary care visits are related to pain [22]. Primary care is associated with better health outcomes and cost control compared to other models of care, with a more equitable distribution of health resources in populations [23-25]. Features of primary care that contribute to these advantages include first-contact access to care, care that is long-term, person-focused, comprehensive, coordinated, and family and community-oriented. Consequently, to increase its effectiveness, the management of LBP should begin in primary care [26] to initiate early prevention thereby mitigating the risk of chronicity and optimizing long-term outcomes.

However, despite the availability of management guidelines, several gaps have been identified in chronic pain management within primary care settings. Across health systems, there are limited services available at the primary care level for effective management of chronic pain patients, including self-management support, psychological services as well as care by other allied health professionals (e.g. physiotherapy and occupational therapy) due to high levels of demand which exceeds available resources in many jurisdictions [27, 28]. At the provider level, primary care clinicians lack adequate education and training to appropriately diagnose, treat and manage individuals with chronic pain to provide optimal pain care [22, 27, 29, 30]. Furthermore, with the growing prevalence of opioid use and related health problems [31, 32], it is important to specifically train primary care physicians and educate patients on effective alternative treatment options.

The application of interdisciplinary programs, as recommended by several reports and practice guidelines[3, 26, 27, 33], can be part of the solution. However, many challenges remain in establishing interdisciplinary programs within community-based primary care settings. There are gaps in the knowledge of how to implement effective interdisciplinary team (IDT) programs that meet the patient's needs. Moreover, there are gaps in the measurement of interdisciplinary chronic disease management programs especially in terms of patients' experiences to inform the effectiveness of these kinds of programs [34]. Assessing and managing pain is among the recommendations to improve patient experience of care issued by the NHS National Clinical Guideline Centre [35]. A patient's report [33]. This aspect can be addressed through the concept of patient-centred care which entails the provision of care that is based on respect, needs, and ongoing and transparent information sharing with patients and families [36, 37]. Better understanding of patients' experiences, perspectives and motivations is key to designing and implementing effective interdisciplinary chronic pain management [38].

Several patient experience frameworks [35, 39, 40] and patient-reported experience measures (PREMs) exist which have been found to provide a more comprehensive and meaningful indication of patient experience with healthcare compared to satisfaction measures [41, 42]. However, the many existing instruments and surveys to assess patient experiences of health services and care do not consider several important aspects that can influence health status and use of health services. An important gap is that they do not take into consideration the coordination of patient-centred and interdisciplinary care, features which are highly relevant in

the context of chronic disease management in primary care. This may be the case because most measures were designed for assessing in-patient hospital experiences [38, 43-48]. In addition, most PREMs are not designed with patient input and there is very little research on their use with chronic pain patients [49]. Consequently, because of these limitations, several authors have recommended that "future research devote more attention to qualitative research with patients"[50] in order to better understand their experiences with health conditions and care, and develop questions that are comprehensive and meaningful to them [38, 50, 51].

The lived experience of chronic health conditions is one of the main themes identified by the NHS Clinical Guidance Group on patient experience [35]. Seeking to understand this concern through patient experiences of interdisciplinary care is uncommon. This study was designed with the assumption that gaining a better understanding of these experiences and their relationship with outcomes and measurements will help in designing, implementing and evaluating effective interdisciplinary chronic pain management.

The purpose of this inquiry was to investigate patient experiences with an interdisciplinary program for LBP by exploring the following questions: i) what is the individuals' experience of being treated for LBP using an interdisciplinary team care approach; and ii) how do participants perceive its influence on their health status? The inquiry was conducted in the context of implementing an interdisciplinary primary care program for individuals with LBP, part of a larger strategic initiative aimed at building continuums of care for chronic pain.

Methodology

In order to better understand IDT care, we employed a qualitative phenomenological approach that allowed us to study the lived and prereflective (without any conceptualization) experiences of individuals living with LBP.

Phenomenology is a philosophy of understanding that informs a research approach that is concerned with exploring and gaining deeper insight into human experiences [52, 53]. In this way, "phenomenologists seek to reunite science with life and to explore the relationship between the abstract world of the sciences and the concrete world of human experience" [54]. A phenomenological approach can help the clinician and the investigator to "enter the world of illness as lived by patients" to explore their experience of illness or of healthcare [54]. This inquiry was guided by Husserl's foundational notion of 'reduction' [53]. This notion is articulated in a variety of ways in the philosophical and phenomenological literature [55, 56]. Through Husserl's process of reduction, or bracketing, the "researcher must acknowledge and put aside prior beliefs about the phenomenon of interest so as not to interfere with seeing the true essence of the phenomenon"[57]. Given that patients are referred to the interdisciplinary program by primary care physicians, it is expected that patients will implicitly compare their experiences with the interdisciplinary team with their experiences with primary care physicians or other health professionals in a solo practice or in a group practice not using an interdisciplinary approach. In this inquiry, eidetic reduction allowed us to focus on what is unique in a phenomenon and compare it with other related experiences [55].

Aspects of our pre-understandings of the phenomenon included previous work [18], lower support for team-based care by the public and physicians compared to other health professionals

[58], and the assumption that the particular relationship that exists between patients and physicians might represent a barrier to team-based care.

Participants and Sampling

The research participants were adults, aged 18 to 85 years, 60% female with sub-acute or chronic LBP referred to four clinics delivering a six-month interdisciplinary care program by a nurse, a physician, a physiotherapist, and a psychologist. It is a self-management oriented program aimed at providing participants evidence-based care and skills to better manage their condition. A purposive criterion-based [59] sampling strategy was used [60] with the goal of maximum variation across several characteristics (table 1)[61, 62]. The recommended number of participants for a phenomenological study is at least five participants [63-65] and factors that affect the sample size include the heterogeneity of the population; the number of selection criteria; and the budget and resources available [64, 66]. Based on findings from several studies [64, 65, 67-69] and given the selection criteria, the number of sites, and the richness of data collected, 15 participants were recruited.

Data collection

An interview guide was developed based on a review of the literature, and the objectives of the interdisciplinary care program. It consisted of neutral, open-ended questions and probes, which allowed for elaboration and clarification in order to increase the depth of responses [70]. Participants were asked to describe in detail their experiences [71, 72] of the following dimensions: i) history of their pain; and ii) interdisciplinary team (IDT) care experience (Supplemental Appendix A). The interview was used "as a vehicle to develop a conversational relation with the interviewee about the meaning" of their experience of IDT care [73]. Mock pilot interviews were conducted with two individuals to inform modifications to the interview

process, including one with a Quebec native French speaking person to ensure the clarity of the interview questions once translated into French.

Recruitment was facilitated by the IDT clinics and the data collection and management system, REDCap [74], an electronic data capture tool (hosted at the Research Institute of McGill University Health Centre). Each IDT clinic was contacted to obtain the REDCap IDs for patients scheduled for the 3 and 6 month visits. Once their eligibility was assessed against the selection criteria (table 1), the IDs of selected patients were communicated to the IDT clinic staff. In order to ensure the criterion-based sampling and maximum variation, an additional recruitment procedure was implemented while data collection was ongoing. This strategy involved identifying patient profiles through the REDCap database. The goal was to recruit individuals who were "willing to talk about their experience, and who [were] diverse enough from one another to enhance possibilities of rich and unique stories" [72, 75]. The staff of the clinics contacted the selected patients and confirmed their willingness to participate and their availability for a 30min to 60min interview after their 3 or 6 month visit. Eligible individuals who agreed to participate were interviewed at 3 and 6 month visits (n=8), or at 6-month visit only (n=7), (table 2). Of the 22 participants approached, 15 accepted and were interviewed (ten in French and five in English), 5 declined. Reasons of refusal include no show up/drop out, not wanting to be recorded, lack of time and willingness to be interviewed.

The individual interviews were held immediately after the visit at the clinic because according to Kane et al., "patients are more likely to focus on their present state of health than to consider the extent of improvement they have enjoyed when determining their satisfaction with the care they have received"[76], and to avoid the need for an additional visit and to minimize organizational constraints. Conducting two interviews per participant, when feasible, helped mitigate the time

constraint of the participants while building up their confidence during the interview process. All interviews were conducted by the same interviewer (AG) to ensure consistency and reliability in data collection. Before starting each interview, a short conversation was conducted to assess participants' availability in terms of time and willingness to talk about their lived experience of LBP and the IDT care. For the patients interviewed at the 3-month visit, this conversation helped confirm their acceptance to participate in the 6-month interview. All the interviews were audio-recorded.

Data analysis

Audio recordings were transcribed verbatim by a professional transcriptionist. The interviewer checked the transcripts for accuracy and anonymized them by removing any potentially identifying information (e.g. replacing the names of people and health centres). For those participants who were interviewed twice, the two transcripts were merged to obtain a single file per participant. The anonymized transcript files were entered into Qualrus software to assist with the organisation and manipulation of data during the analysis stage. In this article, names of participants have been replaced with pseudonyms to ensure anonymity yet make the accounts and related quotes more personal.

Although the overall methodological approach in this inquiry was descriptive, the analysis of the transcribed interviews was inspired by the interpretative phenomenological approach, combining description and interpretation [77]. Less emphasis was placed on the particular experience of individual participants because the inquiry was based on the implementation of a program with the ultimate goal to provide recommendations for the stakeholders. The five steps of the analysis are summarized in figure 1. Step 1 permitted us to get a sense of the whole by reading each transcript with and without listening to the audio recordings; significant units of data were

extracted using the computer-assisted qualitative data analysis software at step 2; Step 3 permitted us to formulate meaning observations by answering the question 'What does this sentence / segment reveal about the experience being described?' through an iterative process; the meaning observations were winnowed into essential themes at step 4; and step 5 allowed us to group similar themes generated from the accounts from individual participants into meta-themes. This approach is different from typical thematic analyses [78] because no coding structure was developed and applied to the whole transcript; each participant's account was analysed separately in detail prior to the cross analysis.

Ethics

The implementation study obtained ethical approval from the Research Ethics Board of the McGill University Health Centre and informed consent was obtained from all the participants at their first visit at the start of the program.

Results

The participants described their experience of IDT care as a long journey to recovery. We thus elected to organize our presentation of the results along the trajectory of care within the program. Synopses of the participants are provided to the readers in order to give a sense of each participant's story (table 3). It is worth noting that all the participants were experiencing the IDT care for the first time. Selected verbatim quotes are including to illustrate aspects of the analysis and enrich the narrative account of the findings.

Challenging start: "It's intimidating"

Two participants described their first IDT meeting as an intimidating experience, with all four clinicians in the same room. For example, Michelle reported the following experience: "*Ça avait l'air d'un bureau où on rencontrait des patrons pour se faire engager. Mais c'est correct; ça a*

duré quoi? Une seconde là : le temps de reconnaître les visages, de savoir qui fait quoi là; c'est toujours un peu intimidant là [mais] je n'ai rien de négatif. J'ai aimé l'accueil, je n'étais plus gênée, après ça là, ça a super bien été." ["It looked like an office where you would meet with bosses when applying for a job. But that's okay; it lasted how long? A second: the time it took to recognize the faces, to know who does what; it's always a bit intimidating [but] I've nothing negative to say. I liked that everyone was friendly, I wasn't uncomfortable any more, after that it went really well."]. Two other participants also expressed that they had been nervous. Maurice stated : "J'étais,..., j'étais nerveux un peu. Dans le moment, mais après ça on s'était développé une espèce de... Au début je connaissais pas personne, aucun du groupe des quatre, mais après ça, comme hier, on s'était revus les quatre ensemble, on s'était revus tous ensemble quelque fois pour le groupe des quatre, puis j'étais tout seul avec eux-autres. Ça [n'a] pas été long que ma nervosité est partie. " ["I was,..., I was a bit nervous. At the time, but after that we developed a sort of... At first I didn't know anyone, not one person in the group of four, but after that, like yesterday, we met again the four together, we met again all together sometimes for the group of four, then I was all alone with them. It wasn't long before my nervousness disappeared."].

The presence of all the clinicians and the delineation of their roles in the health care team during the first IDT evaluation helped mitigate these participants' feelings of intimidation and nervousness. "On m'a expliqué le programme, on m'a expliqué chaque personne, la fonction de chaque personne, puis à partir de là j'ai été en confiance" ["They explained the program to me, they explained each person, each person's function, from then on I trusted them."] (Michelle). "Au début, j'étais un peu nerveux mais après ça j'ai compris que c'était un groupe de personnes qui voulaient m'aider, et soigner mon mal" ["At first, I was a bit nervous but after that I understood that it was a group of people who wanted to help me and treat my pain."] (Maurice).

"Usually because I get to know the person, and I get to know what they do, and I know that they're there to help. So that ... makes it a little easier on me." (Helena).

Desire for flexibility: "I don't need it"

In this program, the IDT consists of four different health professionals. While they recognized the importance of all the clinicians, some participants also expressed the desire for some flexibility to 'use' them as needed. For example, the participants expressed divergent views regarding the psychologist. Two participants felt that they did not need the psychologist. "I didn't need as much from the psychologist... I mean, I am still trying to figure out the role of the psychologist in this program" (Debra); "No, I don't need [a] psychologist." (Zachary). Michelle, in contrast, praised the contribution of the psychologist in these terms: "Elle donnait des petits trucs, parce que c'est côté stress aussi; la médecin je n'ai pas eu à m'en server." ["She gave some tips because it's the stress too; I didn't have to see the doctor."]. For Rita, "Moi j'aurai aimé avoir un peu plus de temps avec la physiothérapeute" ["I would have liked to have a bit more time with the physiotherapist."]. The role of the nurse was also not well understood by two other participants: "I don't understand the difference between seeing a physician doctor and a nurse doctor. I don't see a difference, to me they're just health care professionals so I don't know the difference between a nurse and a physician is because they're both there to help you with medical problems." (Helena).

It is worth noting that the participants did not perceive a hierarchy of the roles and professions within the team and its importance. In terms of the composition of IDT, two participants suggested the addition of a nutritionist and alternative medicine specialists (acupuncture, osteopathy).

Better collaboration: "They are all together"

Seven of the participants articulated advantages of having all the clinicians in the IDT working together. They noted benefits such as avoiding misinterpretation, and having input from different providers which facilitated the ability to find alternative solutions when needed. "And with everybody together I mean, uh, I feel so much better. It's - you know, it's wonderful." (Heather). For example, Rachel described what she appreciated about the program : "Moi ce que j'ai aimé, je pense je l'ai dit la dernière fois, ..., c'est qu'ils sont tous ensemble; le premier médecin que je suis allée voir m'a envoyé voir un physio, ils se parlent même pas entre eux autres,..., ils font juste leur job." ["What I liked, I think I said it the last time, ..., it's that they're all together; the first doctor I went to see sent me to a physio, they didn't even talk to each other,..., they just do their own jobs."] (Rachel). Charles even stressed the financial aspect of having all the care providers in the same location and that this arrangement avoided unnecessary costs for patients: "C'est peut-être mieux d'en avoir plusieurs à la même place... C'est parce que, en réalité, ça ne coûte rien. Quand tu vas à des places [différentes], ça n'améliore pas mais ça me coûte des centaines de pièces hein; fait que c'est comme ça que j'ai pu aller dépenser chez des chiro puis des ci et des ça" ["Perhaps it's better to have several at the same place... because in reality it costs nothing. When you go to [different] places, there's no improvement but it costs me hundreds of dollars; ... that's how I came to spend so much on chiropractors, then this and that."]. (Charles).

They helped!

Almost all (twelve) of the participants interviewed felt that they were "*helped*" to better understand their condition, to learn what to do or not to do, or to "*see light again*". There are different ways to analyze (describe) the use of 'help' by these participants. (i) There are

participants who have already accepted their condition before joining the program and thus, who sought help to better manage their pain. For example, Stella stated that "I would like something that would... not cure it [LBP], but that I'm able to cope with it. If there's something like a mix of exercise that I do [to] feel better. You know, learning... You have to learn to cope with something. And I think a lot of things is right here." (Stella). (ii) There is a group of participants who were seeking help to understand their health problem. A participant expressed that in her account: "I appreciate them taking time out of their busy day to help me. They are all very nice, I really appreciate everything they were doing for me, they were able to answer pretty much any question I had to ask them, they always had the answer for me, which I really appreciate. It did help quite a bit, and I would definitely refer, if anybody else had any problems, to come here." (Helena). (iii) There are participants who sought people who would listen to them. Valerie shared this perspective: "En fait c'est, juste de savoir que tu es suivi, que tu peux parler à quelqu'un, si ça va pas bien, déjà c'est comme 50% de la guérison là, parce que si je n'avais pas eu ces genslà, comme j'ai dit 2, 3 fois, je ne sais pas où je serais là." ["In fact, it's just knowing that you are being followed, that you can talk to someone if things aren't going well, that's like 50% of the cure right there because if I hadn't had those people, as I said 2 or 3 times, I don't know where I'd be."] (Valerie). (iv) And finally, a group of participants who expected a friendly relationship with the providers. This is also reflected in the following theme.

Care was personalized

Participants who were satisfied with the IDT described several facets of the program as especially meaningful: being listened to and understood, being asked relevant and individualized questions, being treated kindly, with politeness and attentiveness. This statement from Helena is an example: "They were all very nice to me and answered all my questions and everything." Stella expressed a similar view: "People are always nice and friendly." Stella went further in describing the individualized approach: "I felt that from A to Z, I had very good personalized care. From the people around me, here." (Stella). Samuel echoed Stella's account: "je me sentais jamais comme si on était dans une situation générale... poser les bonnes questions puis si on veut arriver à des conclusions qui semblaient vraiment être ciblées sur moi ; je veux dire je me suis toujours senti comme si on parlait de moi, puis qu'on trouvait des explications, des solutions, des choses améliorées. Dans toutes les interventions je me suis senti comme si c'était toujours centré sur moi, pas général, ... c'était toujours très personnalisé, centré sur moi-même." ["I never felt as if we were in a general situation... ask the right questions then if you want to arrive at some conclusions that seemed to be really focused on me; I mean I always felt as if we were talking about me, that we found explanations, solutions, things improved... In all the interventions I felt as if it was always centered on me, not general, ... it was always very personalized, centered on me"]. Other notions that were expressed by fewer participants were the completeness of care, the sense that the team took sufficient time and did not act hurried, and how IDT care decreases a feeling isolation: "The difference [with usual care] I know is like I'm not alone to fight my problem. That's the first difference." (Debra). Some of the participants described IDT as unique. Heather stated that "You can't compare the difference" between unidisciplinary (physician only) and IDT care. Rachel summed up her experience in the

following way: "Je veux dire le médecin de famille, c'est pas qu'il n'est pas bon mais c'est pas un spécialiste dans le dos... Je le recommande à tout le monde qui a mal au dos là : 'N'allez pas chez votre médecin de famille! Allez à la Clinique' [interdisciplinaire]." ["I mean the family doctor, it's not that he wasn't good but he wasn't a back specialist... I recommend it to everyone who has back pain: 'Don't go to your family doctor! Go to the [interdisciplinary] clinic'."].

Meanings of recovery: "I'm able to function"

Most of the participants viewed IDT care as having worked for them because they could accomplish things as they did before their injury, or to return to work. For the participants, recovery means to regain function, to function normally or function better than before. For example, Valerie reported that: "*Je suis capable de fonctionner ; ce qui n'était pas le cas quand j'étais arrivée ici; je fonctionnais vraiment pas, j'étais à zéro pour le fonctionnement. Puis là je me considère au moins 60% que je fonctionne ; alors c'est beaucoup.* " ["I'm able to function; which wasn't the case when I got here; I really didn't function, I had zero functioning. Now I think that I function at least 60%; that's a lot."]

They also characterized recovery as feeling less pain when doing things or being able to bridle the pain and live with it: "If I have a little less pain, that's recovery to me. I will never be painless, because I've realized that, I'm honest to myself. You know, I'm [a] certain age, I'm overweight, my back carries a lot, and my back is going to be painful." (Stella). Some participants, especially older ones (Charles, Michelle, Rachel, Stella, Thomas; table 3), seemed to have accepted the pain and were looking for means to better live with it. As expressed by Stella: "You know, something that's totally worn can't be cured. It can be calmed, but not cured. It can improve, by exercise, by walking more, by just training. And I think that is... it's like... how can I say... You can't fix an old washing machine. You know, you can try a little bit but you can't really repair it because there is a certain damage that is done. Wear and tear." Others seemed to come to that conclusion because of the role of IDT members during the first and subsequent visits (Bernadette, Helena, Maurice, Samuel, Valerie; table 3). As stated by Valerie : *"Ils m'ont appris à l'apprivoiser ce mal-là puis c'est ça qui est le plus important, c'est de l'apprivoiser puis de vivre avec.*" ["They taught me to manage this pain, that's the most important thing, to manage it and live with it."]. The expectations of these participants appear to have influenced their satisfaction with the IDT care and how they perceived its impact on their health status.

Discussion

The findings add to the growing body of knowledge on the potential benefits of team-based care in the treatment or management of chronic conditions in general, and LBP in particular. They tend to support the view that the management of non-specific LBP is complex and that individuals living with LBP experience a long journey to recovery. Pain, according to Aydede [79], is "the most prominent member of a class of sensations known as bodily sensations." Given its essential subjectivity, pain is a "particularly apt topic" [80] for phenomenological inquiry. It is the case in this inquiry where the use of phenomenological approach enhanced the exploration of the subjectivity of experience with pain and recovery from pain.

Among the participants, those who accepted their condition before joining the IDT program were mostly looking for help to better live with the pain. These participants tended to be older and have had lived with their pain for a longer time. In contrast, the participants who were younger or with a shorter pain duration, sought to gain understanding of the cause of the pain and to be relieved from it. Several participants had tried different treatments in the past (separately), and expressed their limits prior to joining the IDT program.
While the use of multidisciplinary and interdisciplinary treatment is recommended by guidelines, these documents do not describe its optimal composition or content [3, 9, 12]. The composition of the primary care IDT with a physician, nurse, physiotherapist and psychologist seemed to be adequate from the perspective of participants; only two participants suggested the addition of a nutritionist and alternative medicine specialists. However, the role and the importance of the different clinicians in the team were appreciated differently by the participants. Some participants wanted some flexibility in the involvement of clinicians from the different professions.

Being treated by an interdisciplinary team composed of several members is relatively infrequent in the context of ambulatory and chronic disease management settings in Canada and other high income countries [27, 81, 82]. Some participants mentioned the intimidating aspect of their first IDT evaluation. In order to decrease uncertainty and anxiety, it would be helpful to provide information to patients prior to their first visit about who will take part in the program, and the purpose and role of each IDT member, as well as the evaluations that will be conducted. Such tools might include an animated video, an interactive quiz, or a leaflet on IDT care and the role of each team member. Moreover, the presence of all team members at the initial IDT evaluation is warranted to help patients mitigate this feeling and better understand the roles of the different professionals.

The participants in our study insisted on the advantages of IDT care. Having all the care providers in the same location prevented the participants from needing to start over and over to tell their story to each of the clinicians, a practice which might yield divergent patient stories depending on how and which questions were asked. Participants also saw IDT as an opportunity to be heard. "The premise of anyone going to a doctor is that someone will listen to his or her

story"[83] and IDT appears to fulfil this need with the combined contributions of a group of health care professionals (synergistic effect). The desire of being heard was so intense for some participants that sometimes I [the interviewer] found myself thanked for my time during the interview as if I was part of the care team. "C'est fantastique. Vous voyez, j'ai comme un peu envie de pleurer quand je vous dit ça, parce que le avant, le après... oh mon dieu... j'étais une femme très active, moi, avant. Puis là, que je tombe, j'avais de la misère à bouger, qu'est-ce qu'il m'arrive... Puis là, avoir les outils, comprendre mon corps, fonctionner... Pour moi, c'est merveilleux, c'est merveilleux. Vous m'avez aidée terriblement, en tout cas. Merci infiniment." ["It's fantastic. You see, I feel a bit like crying when I say that because before and after... oh my God... I used to be very active before. When I fell, I had difficulty moving, what's happening to me... Then having the tools, understanding my body, functioning... For me, it's marvelous, just marvelous. You helped me tremendously [...]. Thank you very much."] (Rita). This construct was reported in several studies [84-88]. The notion of phenomenological reduction is also relevant to clinical practice. Adopting this approach can help clinicians listen attentively to their patients. By attempting to suspend and set aside pre-conceptions, they can better understand and appreciate the world of illness inhabited by their patients.

Participants also saw IDT as personalized, that is person-centred. This is consistent with the conclusion from Foster et al. that "Patients viewed the combined contributions of a [general practitioner] and other health professionals in team care as thorough and reassuring" [89]. This finding also supports many carative factors of Watson's theory of human caring, including existential-phenomenological-spiritual forces [90, 91]. "The assumption of holism best suits the approach to medical knowledge and practice that includes the patient's illness experience. Rather than striving exclusively for restoration of the patient to a pre-diseased state,

the clinician assists the patient in redefining what the illness means for their life. The outcome is not a physical cure necessarily, as it is healing of wholeness from the fragmentation in the patient's life caused by the illness." [92].

"The importance of understanding the patient's lived experience is fundamental to patientcentred care" [90, 93]. Indeed, several elements of patient-centred care (PCC) [94] emerged from the participants' accounts: the importance of respect for patients' values, preferences and expressed needs; information, communication, and education; and emotional support. The findings seem to support the assumption that team-based care is "seen as the first and immediate health care context within which PCC occurs" [95].

For the majority of the participants, recovering means being able to function again or to function better not because of the total mitigation of the pain but rather as the result of a better understanding of their condition and the acquisition of relevant management skills. For Zhong Hui, the process of recovery begins with self-cultivation [96] (learning about one's condition and taking steps to improve it). In this sense, IDT care helped the participants to better understand their condition. The IDT program appeared to be facilitating, for some participants, a response shift in their expectations from seeking cure to learning to cope with their pain condition. Response shift is defined as a change in the meaning of one's self-evaluation in terms of values, standards of measurement, or redefinition of constructs [97].

Finally, our assumption that the particular patient-physician relationship may constitute a barrier to IDT care was not supported by our participants' accounts. The traditional paradigm of medical care has been based on a dyad of one doctor and one patient. This construction, and associated expectations of clinicians and health professionals, however, does not seem to have been an

impediment to an IDT care approach for our participants. Possible implications for IDT programs, based on our findings and conclusions, are summarized in table 4.

Limitations and strengths

Participants in this inquiry only included individuals who remained in the IDT program. We were not able to conduct in-depth interviews with people who withdrew from the IDT program. Among those participants who withdrew, some might not have felt ready or been interested to participate actively in a self-management oriented program, or were expecting a program that offered a ready-made solution by the team to rid them of their pain; (other reasons based on a brief questionnaire include improvement after a few weeks, lack of time or inappropriate schedule). We also did not compare the experiences of individuals receiving IDT and those with chronic pain not in the program, which would have provided a comparison of experiences. However, this was beyond the scope of this study's objectives.

As documented in the literature [98-102] sex and gender affects pain perception, pain coping, pain reporting, and pain-related behaviors. Although nine of the participants were women, we did not explore the impact of sex on the findings and we did not collect gender specific information. While the analysis was performed by one author (AG), various strategies were used to promote the trustworthiness and credibility of the research findings[103-105]: review of the transcripts to ensure their accuracy, peer examination trustworthiness through continuing conversation with an expert at the stage of development of the interview guide and during the analysis process, maintenance of a reflexive log that facilitated the application of the phenomenological reduction, the modification of the interview guide as the project progressed, including the technique of asking participants to think about a friend or someone with LBP and try to tell her/him how was their experience with the IDT program, as a means to obtain more

detailed accounts. However, as pointed out by van Manen [56], "it should be acknowledged that phenomenological research is always incomplete and tentative because the researcher cannot possibly capture a given experience in its entirety nor describe how all people will experience a particular event."

From the perspective of patients in an IDT program for LBP, interdisciplinary team care contributed to effective and patient-centred primary care. This inquiry to explore patients' experiences with an interdisciplinary care team is part of an integrated and interdisciplinary primary care program for the prevention and the management of LBP. Consequently, the findings may assist clinicians to understand patients' perspectives and help improve the process of care; to inform the design and implementation of IDT programs, and to devise patient and interprofessional education programs on team-based care. Currently, no Patient Reported Experience Measures (PREMs) [27, 106] instruments or surveys offer full coverage of the dimensions that are important to patients in relation to quality of care [107], and no PREM is specifically designed for interdisciplinary care at the primary care level. In this context, the findings may inform the development and the validation of a patient experience questionnaire for use by interdisciplinary primary care teams. Integrating constructs and concerns that are important to patients is essential for efforts to improve the delivery of care and patient health outcomes.

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Declaration of interest statement

No potential conflict of interest was reported by the authors.

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Figure 1. Steps of the analysis



Table 1. Criteria-based selection

Criterion	Justification
Age (<65, ≥65 years)	Prevalence of chronic pain and co-morbidity increases with age [108-110]; age is considered as a yellow flag* [111], determines the employment status and is a predictor of satisfaction [112]
Gender	Gender affects pain perception, pain coping, pain reporting, and pain-related behaviors [99, 100, 102]; female gender considered as a yellow flag [5, 98, 101, 111]
Clinical sites (4 study sites)	There are always variations in the implementation of programs across sites (implementation variation across program sites) [113-122]
Risk (StarT Back Tool) [‡]	The three risk-defined groups (low, medium, high) impact on clinical and economic benefits [123, 124]
Adherence to the program	Participant adherence and responsiveness [115, 116]
Ethnicity	Pain treatment and pain outcomes may vary by race or ethnicity [125-128]

* risk factor for chronicization of acute and sub-acute low back pain and psychosocial barriers to recovery; ‡ physical and psychosocial risk of poor prognosis

Participants	Sex	Age (years)	Highest education	Employmen t status	Risk (STarT Back Tool)*	Pain duration [‡] (weeks)
Debra	F	55-64	College or University	Retired	Medium	14
Heather	F	45-54	College or University	Part-time	Low	14
Zachary	М	65-74	Secondary school	Retired	Medium	52
Samuel	М	35-44	College or University	Unemployed	Low	62
Rachel	F	35-44	College or University	On disability	Medium	104
Valerie	F	55-64	Secondary school	Retired	High	33
Michelle	F	65-74	College or University	Retired	Low	60
Charles	М	75-84	Secondary school	Retired	Medium	68
Hebert	М	45-54	College or University	Full time	High	130
Rita	F	55-64	Secondary school	Full time	Medium	41
Bernadette	F	65-74	Secondary school	Retired	High	10
Stella	F	65-74	College or University	Retired	High	22
Thomas	М	65-74	College or University	Retired	High	9
Helena	F	25-34	Secondary school	Unemployed	Medium	25
Maurice	М	45-54	Primary school	On disability	High	4

Table 2. Characteristics of participants

*low if total score=0-3; high if total score = and subscale=4-5; [†]most recent episode

	Women	Men
Accepted their condition prior to referral to the IDT	Michelle saw the advertisement in the local newspaper about the program and decided to take her chance by requesting her family physician to obtain a referral. Her LBP has impacted her life significantly, especially during acute episodes. She described having difficulty to stand up, to walk, to get in and out of a car, or to do household work. Michelle was not emotionally affected and her condition did not prevent her from going out because she is not a "whiner". Before joining the program, she had visited several medical centres and allied health and alternative medicine professionals (kinesiology, physiotherapy, osteopathy) with no satisfactory outcomes but had to stop because of the cost. She seemed to have accepted her condition -"You have to learn to live with it"- and for her, living as a couple was a facilitator for coping with pain. Rachel was suffering from leg pain, but	Charles was happy to be accepted in the LBP program. He has been living with LBP for more than a decade with recurrent episodes but he was not very affected by his condition when we did the interview, apart from some limitations such as long walking or traveling. "I endure it and that's it" he said but having a mild persistent pain is harmful mentally a little bit. He tried chiropractic and osteopathic sessions, in addition to the medical treatment from his family doctor who does not believe in these alternative medicines. He conceded that his doctor was right because these alternative treatments "give more or less nothing". For Charles, if his pain is around 3 or 4 [on a 10-point pain rating scale], then he is able to tolerate
	was barely affected by her back pain. She thought some level of back pain was normal given the type of work she was doing ("everyone has some kind of pain") and did not take it seriously. She did not hesitate to blame herself for having made some 'absurdities' in the past. Rachel did not like to take medication or visit a health centre: when she decides to go to a physician's office, "it is for a good reason". She has experienced conflicting diagnoses for the leg problem and unsuccessful physiotherapy sessions before joining the program. For Rachel, her pain is chronic and will remain as "a scar".	 it. He admitted that he was not expecting a cure, as his family doctor told him, so his expectation with the program was to stabilise or improve his condition. Thomas was referred to the program for a LBP subsequent to a fall. His x-ray revealed some wear meaning that his condition will last forever that was why he was interested in a program that certainly would give him means to be (live) better. For Thomas, living with the pain was difficult to accept. His LBP prevented him

Table 3. Synopses of participants

	Stella, a retired woman, understood and accepted her condition as an inevitable	trom doing usual things such as taking a long walk, driving for a
	consequence of age and wear and tear	long period or carrying things
	and because the back problem is a family	Even for things that he continued
	thing. The main impact the LBP had on	to do he had to do them
	hor life was proventing for from standing	differently. This resulted in stress
	up and thus all the related activities that	and pogative emotional affects
	up and thus an the related activities that	Thus, he was not expecting a
	like "running a vanium cleaner or	total auro
	like running a vacuum cleaner or	total cure.
	wasning floors, and almost all sports. But	
	she felt blessed to have a husband who	
	does most of the things for her. She did	
	not want to get addicted to medication so	
	she was trying hard to manage her	
	condition without any pills. Stella is not a	
	"complainer": "I'm very hard on myself",	
	she said, and having experienced a lot of	
	pain already in her life helped her.	
Interrogative	Bernadette first experienced LBP when	Maurice was referred to the LBP
(skeptical)	getting out of a car ten months ago. The	program by his family doctor
about their	initial pain was so intense that she	following his work accident. He
condition	described it as "30 out of 10". At that	accepted in order to improve his
	moment, she was not able to do anything.	back because, as he said,
	It was impossible for her to stand up for	medications were good to relieve
	more than a couple of minutes. She could	his pain but their effect was
	not lie down or sleep on her back or left	ephemeral. He was obliged to
	side. She had to walk with a chair on	stop working, and ultimately lost
	wheels. She was emotionally affected	his job by the non-renewal of his
	because she was afraid of staying in this	contract. He was limited in doing
	condition.	everything including moving,
		walking, and driving; referring to
	Helena is a dynamic young lady whose	his pain as "so horrible" at the
	career was broken because of her lower	beginning. He was very stressed,
	back pain. She had to stop because she	including his family, not only
	"was not able to give her patients the	because of the pain but also for
	proper care that they deserve including	the lack of income because his
	doing transfers or lifting them,because	spouse was forced to stop
	that's not fair to the patients". Sometimes	working too. He saw his
	her lower back pain is so intense that she	condition very hard to live, from
	can't even move or walk: "Usually when it	twelve hours working shift to
	gets to the point where it's unbearable. I	nothing. As a consequence, his is
	just try to sit down or lie down and wait	gaining weight that might trigger
	until the pain goes away and slowly try to	other health problems.
	get back up and try to continue what I'm	

doing". So she accepted to participate in the program to find solutions for her back problems with the goal of returning to work. She was very impacted by her condition: anger, frustration, stress. According to Valerie , her LBP was related to a spine surgery that she had a decade ago. She was disappointed at not being given a post-operative action plan by the surgeon or the hospital. Prior to being referred to the program, she had been seen in physiotherapy, osteopathy, and acupuncture with a partial satisfaction. She was disheartened by her persistent pain that preventing her from "doing anything" and was feeling really down so she did not know what to expect from the program.	Samuel joined the program due to his lower back and joint pains, and wanted to understand his pain problems. Prior to the program, he was followed by a family physician and went through several medical consultations and tests (including x-ray, computerized tomography scan, tests with a physiatrist, and tests for rheumatism). Samuel has been living with the back pain for several years and has yet to find answers about why he has these pains, wondering if his LBP was a premature degeneration as a result of heavy physical work or due to a personal fragility. The LBP significantly impacted on his life including poor motivation in playing with his children, working around the house, or doing sports. He has been going through periods of discouragement, increased pain and irritability.
Debra described herself as a proactive person with a strong health-care-seeking attitude. She found out about this program herself and subsequently asked her family doctor for a referral. As a consequence of her LBP she had to reduced her travelling. She used three words to summarise her experience with LBP: manage, care, and support. By "manage," Debra referred to pacing herself in daily activities; by "care", she meant taking steps to look after herself like doing some exercises or wearing appropriate shoes; and by "support" she referred to the possibility of calling professional team members as a back-up plan after completing the IDT program.	Hebert thought that his chronic pain might be related to some difficulty to adapt to the cold weather even though he had some back pain while living in his native country. Before being referred to the program, he tried some complementary and alternative treatments (massage, osteopathy and acupuncture) with ephemeral results, in addition to self-medication with anti-inflammatory and analgesics. He emphasized the impact of the LBP on his income because of work absences. The condition limited his ability to

Heather is an active woman who was referred to the program by her family doctor. As far as she could remember, the only way the back pain had affected her life was in terms of sleep disturbance. However, she experienced this as very challenging: "When you don't sleep you're tired all day" she said. She was not expecting to get rid of her pain just by taking medications but was hoping that the physiotherapy sessions "would remove the pain". She really did not want to take medications so she was very comfortable with the self-management oriented program.

Rita got the information about the program from the physiotherapist she was seeing for her LBP and was very excited upon being accepted. The condition somewhat affected her life especially regarding sports and dancing activities, but she did not "let herself influenced" by the condition. Before the physiotherapist, she had 'shopped' around for chiropractic, massotherapy and osteopathy care which provided her with momentary relief but no explanation of the cause of the pain. Thus, she was in search of understanding.

complete some tasks particularly in a standing position and it negatively impacted his affect to a certain degree. Hebert expressed his frustration with the health care system and how badly it works for him, particularly emergency room visits. Thus, he had no specific expectation before entering the program. He expressed that when you have problems in other areas of life (such as finances or within one's family), this will limit one's capacity to benefit from the program. He stated that, as was the case for him, the people most in need of the program often struggled to adhere to it because attending the program meant a loss of income due missing work.

Zachary was referred to the pain program from another care program. He was limited in all his daily activities as the result of his LBP, including being unable to participate in a group walking program that he used to do. However, according to Zachary, his LBP condition does not interfere with his emotional affects. Because he was already on a polypharmacy regimen, he did not want to take more pills for his pain. He tries to live with his LBP and hopes to be completely free from the pain thanks to the program.

LBP: low back pain

Table 4. Implications for IDT programs

Findings	Possible implications
Two types of participants: those who accepted their condition before joining the IDT program and those who did not	 Assess state of acceptance and readiness for IDT to adapt care approach
Fear/uncertainty experienced at first IDT evaluation Role of clinicians in IDT care not well understood	 Develop information tools (animated video, quiz, leaflet) on IDT care to be disseminated to patients prior to the visit Ensure the presence of all team members at the first IDT evaluation
Team members necessary but not seen as equally important (request for more flexibility)	 Collaboratively agree with patients on necessity to adapt follow-up visits to patient's interests and needs
Lack of other categories of professionals	 Ensure the availability of other key professionals for referral
Interdisciplinary care is person- centred	 Include training on PCC approach and a PCC measurement tool for performance monitoring that include the following main elements: politeness, attentiveness, friendliness, good listening, tailoring of questions and care
Being able to function again or better as main meaning of recovery for individuals with LBP	 Include a measure of functional status alongside pain assessment tools for ongoing monitoring

IDT: interdisciplinary team; PCC: patient-centred care; LBP: low back pain

Appendix A. Patient interview guide

Part 1

Please tell me what brings you to this program (motivation)?

Can you please describe as detailed as (in as much detail as) possible your experiences with living with your lower back pain?

Follow-up questions:

e.g. What has it meant to you to have low back pain? How has it changed your life/affected your everyday life? Family (in the house)? Job? Attending school? Socializing (social activities)? Sport? Trip? Relation with relatives (Emotional affects)? Okay, you've already mentioned some of them, what about...?

What does it mean for you to live with low back pain?

What kind of impact has it had on your life?

Part 2

What the interdisciplinary team care means to you? How do you define/describe interdisciplinary clinic/team care?

Please tell me about your overall experience with being part of the interdisciplinary clinic, as detailed as possible.

Follow-up questions:

e.g. What was the difference between other clinical experiences (care received) and the interdisciplinary care?

What recovering means to you?

After completing the program, would you describe yourself as having recovered from your low back condition?

-When/How did you know you had recovered? *or* When you think about your recovering, what comes to mind? What had changed in your situation (condition)?

-If no, what would have to change/can be done to allow you to recover from your low back pain? If you think complete recovery isn't possible, what could be better?

What were the three most important things to you:

-about the physical setting,

-about the healthcare providers,

-about facility used for the interdisciplinary program?

What did you learn about ways to manage your back pain that you found the most useful? Which ones were the least valuable or helpful to you?

What would you recommend (or not recommend) about this program?

Is there anything we should have talked about today that we haven't?

Do you have any questions about the project and the research?

6.2.3. Preface to Manuscript 3

In manuscript 2, we employed a phenomenological approach to explore patient experiences with primary interdisciplinary care for LBP. This inquiry was the qualitative component of the mixed methods approach that we employed in Project 2. Participants perceived interdisciplinary team care as contributing to effective and patient-centred primary care. The findings permitted us to identify constructs important to patients that should be taken into account when developing instruments and to propose recommendations to improve implementation of IDT care.

These findings also informed the selection of predictor variables in manuscript 3 in which we present the quantitative component of our mixed methods approach. We used PACIC to assess patient experience of care with the IDT and defined functional status as the main predictor.

6.2.4. Manuscript 3: Determinants of patient experience with low back pain interdisciplinary care

(Formatted to be submitted to The Journal of Pain)

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Running Title: Determinants of low back pain patients' experience

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Abstract

Measuring patients' experience of health services has become an essential part of quality of care reporting and identifying opportunities for improvement. This study aimed to evaluate change in patient experience in an interdisciplinary primary care program, and to estimate the impact of sociodemographic, function, pain and general health status, resource utilization, and process variables on patient experience. A six-month interdisciplinary care program for individuals with low back pain (LBP) was implemented at 4 primary care settings and evaluated using an observational pre/post study design. The change in patient experience was evaluated using the Patient Assessment of Chronic Illness Care questionnaire (PACIC) completed at baseline and 6 months post-intervention (n=132). The mean overall PACIC score at 6 months was higher than the numbers reported in other studies suggesting a better patient experience. The experience of care improved for 62% of the participants based on the minimal clinically important difference (MCID). No significant determinants of overall PACIC change score were identified in the multivariable regression models. The lack of association of hypothesized determinants requires further examination of the properties of the PACIC and with a larger sample. Future investigation is needed on the relationship between improved patient experience and outcomes.

Perspective

Measuring patients' experience of care is important to identify problems areas and evaluate improvement efforts and outcomes of care. Using PACIC as measure of experience of a primary interdisciplinary care, this study found that the experience of care improved based on MCID, however no significant determinants of overall PACIC change score were identified. **Key words:** Interdisciplinary care, low back pain, patient experience, PACIC, primary care.

Introduction

Low back pain (LBP) is one of the most common non-specific chronic pain conditions, and up to 85% of the cases cannot be attributed to any specific underlying pathology [1]. LBP is associated with high economic burden on individuals and societies, disability with low levels of physical activity, impaired quality of life and the highest consultation rate in general practice [2-4]. Clinical guidelines for LBP now recommend non-pharmacological approaches as first line treatment options. These include advice and education supported by self-management, cognitive behavioural approach, as well as some forms of complementary and alternative medicine; procedures, imaging and surgery are not recommended for patients with non-specific LBP [5-8]. Pharmacological treatments are recommended for selected patients and for limited use, and include nonsteroidal anti-inflammatory drugs (NSAIDs), muscle relaxants, antidepressants, anticonvulsants, opioids; most for limited use and in selected patients [6-10]. Given the complexity and suboptimal management, one of the main recommendations to improve the management of LBP is the use of multidisciplinary and interdisciplinary teams in the delivery of care, with the expectation that teams will enhance integration of care and improve provider, patient and managerial satisfaction, thereby improving administrative and clinical processes and patient outcomes [11-13]. Considerable attention has been focused on the effectiveness of multidisciplinary and interdisciplinary teams, and studies have linked team performance to positive patient outcomes [14, 15]. For chronic pain management, improved outcomes across a range of domains including pain severity and interference, and functioning have been reported [16-19].

Interdisciplinary care can be distinguished from multidisciplinary treatment in that not only do health professionals with different backgrounds work in concert with the patient, but they also

organize meetings to discuss cases, making collective therapeutic decisions, use one record system and, most importantly, often employ a uniform approach to patient management [20, 21]. There is a growing body of evidence suggesting health care teams can have beneficial impact on clinical and health resource endpoints, and on patient and provider experience [17]. Patient experience of health and health care is defined as any combination of satisfaction, expectations and experience [22]. Measuring patients' experience of health services has become an essential part in reporting on the quality of care and defining health policy and an important component of performance assessment and service improvement [23-29]. This measurement can have different purposes: (i) describing health care from the patient's point of view; (ii) measuring the process of care, thereby both identifying problem areas and evaluating improvement efforts; (iii) evaluating the outcome of care [30-33].

Studies that have examined the relationship between patient experience and health outcomes are very scarce and yielded mixed results [22, 34-37]: some studies found positive association [38-40] while others found null or negative association [41-44]. In a recent systematic review of 55 studies, Doyle et al. concluded that patient experience is positively associated with clinical effectiveness and patient safety but did not assess the strengths of positive associations in different studies [45]. Building on Doyle et al. review and focusing on Consumer Assessments of Healthcare Providers and Systems (CAHPS) surveys to measure patient experience, Anhang Price et al. showed associations between positive patient experiences and clinical processes, patient safety, and unnecessary utilization of health services [34]. Yet, these studies were based on the acute care model, which is different from the long-term care model. Tan et al. showed a significant association between patients' ratings of services and outcome measures for chronic pain in a multidisciplinary outpatient clinic at a tertiary teaching hospital but they used a non-

validated satisfaction measure [46]. In addition, previous studies were cross-sectional and on conditions other than LBP.

This study aimed to investigate the association between change in patient experience of care of individuals with LBP participating in an interdisciplinary care program and patient and process variables. Specific objectives were to evaluate change in patient experience after a 6-month period of participating in a primary interdisciplinary care program, and to estimate the relationship of sociodemographic, functioning, pain and general health status, resource utilization, and process variables with change in patient experience.

Methods

Study design

This paper is based on a larger pre/post multiple time series study design. Individuals attended the program for 6 months and completed questionnaires at baseline, 6 weeks, 3 and 6 months post program initiation, depending on the type of data and instruments used.

Participants and the Interdisciplinary Program

Based on the framework of the chronic care model (CCM), the primary care interdisciplinary program was developed by the Centre of Expertise in Chronic Pain (Quebec, Canada) and integrated elements of needs of patients and clinicians and evidence-based guidelines. The composition of the interdisciplinary team was determined by the assessment of the needs for individuals suffering from LBP and included a nurse, a physician, a physiotherapist and a psychologist. Relevant assessment tools were identified through literature review and validation by clinician experts and health system decision-makers. The model included referral criteria, a treatment algorithm; standardized clinical process and assessment tools for the interdisciplinary team; provision of self-management support for patients; and defined administrative and clinical

indicators supported by an electronic data collection and management system for the clinicians and for evaluation. Primary care physicians referred individuals with subacute and chronic LBP to the program implemented at four *centres de santé et de services sociaux* (CSSS). Participants received an interdisciplinary evaluation at the start of the program and individualized evidencebased treatments including pharmacological, physiotherapy and psychological therapies, and structured self-management support. Data were collected on socio-demographic status, impact of pain, physical and mental health, function, and quality of life using self-report and standardized questionnaires.

Outcome and covariates measures

PACIC

The main outcome variable of this study is patient experience with care, measured by the Patient Assessment of Chronic Illness Care (PACIC); the most appropriate instrument to measure the experience with aspects of care associated with the CCM [22, 47-49].

Participants completed the 20-item PACIC at baseline and 6 months, and scored from 1 (none of the time) to 5 (almost always). It measures specific actions or qualities of care experienced by patients in the delivery system. Its test-retest reliability, internal consistency and construct validity have been demonstrated in varied chronic condition patient populations including hypertension, depression, diabetes, asthma, and chronic pain [47, 50]. The PACIC is scored by averaging scores across all 20 items [51]; the single score structure is recommended by recent research in order to obtain an overall picture of patients' experiences [48, 52-54].

Patient Covariates

The selection of the predictor variables was based on the literature review and findings from the qualitative study on patient experience conducted by our team, particularly the themes related to

the effect of interdisciplinary care including 'togetherness of the clinician team members/varied professionals' and 'meaning of recovery' [55]. The construct of functional ability, the most important recovery 'item' mentioned by the participants was the main predictor variable and was measured using the Oswestry Disability Index (ODI), the most commonly used outcome measure for LBP. The ODI is divided into 10 sections of 6 statements, each section scored on a 0-5 scale (higher values represent greater disability), with a test-retest reliability of 0.83-99 and an internal consistency (Cronbach α) of 0.71 – 0.87 [56, 57].

The association between pain outcomes and socio-demographic, depression, anxiety, and healthrelated quality of life has been shown in previous studies [20, 58]. Thus, other predictor variables included baseline socio-demographic variables: age, sex, marital status, level of education, employment status, social assistance, private insurance, ethnicity; Start Back, a risk (low, medium, high) stratification tool – a risk of delayed recovery [59]; anxiety measured by the Hospital Anxiety and Depression scale (HADS) with score ranging from 0 (no distress) to 21 (highest distress) [60]; depression using the Patient Health Questionnaire (PHQ-9) with score ranging from 0 to 27 (the higher the more severe);[61] general health status (physical and mental) measured by the SF-12 and ranging from 0 to 100 with higher scores meaning a better health-related quality of life [62]; and pain severity measured by the Brief Pain Inventory (BPI) and ranging from 0 to 10 with higher scores meaning severe pain [63, 64].

Staff and process covariates

Team functioning was assessed by the Team Climate Inventory (TCI) and completed by the clinician and non-clinician staff members from the four sites. The 19-item TCI [65] is grouped under 4 subscales: participative safety and support for innovation score on a 5-point Likert scale, and vision and task orientation that score on a 7-item Likert scale. Sub-scale scores are derived

by averaging items within the sub-scale; to obtain the overall score for each team, individual scores are the summed up and divided by the number of team members. Higher scores indicate better desirable team climate [66, 67].

Other variables include the total number of visits with health professionals over the 6-month program (physician, nurse, physiotherapist, psychologist); number of months since implementation of the program; adherence to the program: given that the minimum number of visits (with the nurse/physiotherapist) required is 6, adherence is coded Yes, if the number of visits ≥ 6 , and No otherwise; and interdisciplinary evaluation: Yes, if the date of assessment for the initial visit is the same for ≥ 3 health professionals.

Data collection

Study data were collected manually and electronically and managed using an electronic data capture tool, (Research Electronic Data Capture or REDCap) [68] hosted at the Research Institute of McGill University Health Centre (MUHC). REDCap is a secure, web-based application designed to support data capture for research studies, providing: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources. For this multisite study, the use of the Data Access Group feature allows to restrict records to each site.

Sample size

Because no minimal clinically important difference (MCID) for PACIC was found in the literature, we used an estimate of 0.5*SD, equivalent to a moderate effect to estimate sample size [69, 70]. Findings from studies on patients with chronic illness showed SD ranging from 0.8 - 1.1 [47, 50, 71]. Based on a MCID of 0.5 and SD = 1, using an alpha of 5% and a power of 80%

the minimum required sample size is 63 subjects, increased with an additional 10 subjects for every additional variable that is included in the multivariable analysis.

Analyses

For all variables, mean values and standard deviation were calculated for the continuous variables while frequencies and percentages were calculated for categorical variables. Pearson correlation matrix was calculated to investigate collinearity. We calculated the mean overall PACIC score for all the patients who completed at least 10 items at baseline and 6 months; the PACIC score representing the score of all completed questions. To determine the proportion of patients whose experience has improved, we categorized PACIC variable as improved, stable and worsened based on MCID (= 0.5*SD) and calculated the proportion for each category; improved if the difference (6 month - Baseline) > 0.5; stable if the difference is comprised between - 0.5 and 0.5; and worsened if the difference is < - 0.5. We conducted multivariable regression to evaluate the relationship between patient and staff and process covariates and the change score of PACIC as the outcome. We first estimated univariate models, and all significant covariates (95% confidence interval does not include the null value) in the unadjusted models were included in the multivariate model. Patient socio-demographic covariates were entered in the model first, followed by patient health status, and staff and process variables. The analyses were performed using SAS ver. 9.3. (SAS Institute, Cary, NC, USA) and R ver. 3.3.

Ethical consideration

Ethical approval was obtained from the Research Ethics Board of the McGill University Health Centre (#MP-CUSM-12-220 GEN). Informed consent was obtained from the participants at their referral to the program. Consent from staff members was also obtained.

Results

Sociodemographic and health characteristic of the study population

The sample, based on patients who were recruited from December 2012 until November 2016 completed the 6-month visit (by June 2017) and answered at least 10 PACIC questions at baseline and 6-month, was 132. The average patient age was 57 (\pm 14) years of age and the majority were female (53 %). Men were slightly older on average (58 (\pm 14)) compared to women (55 (\pm 15)). Thirty percent of the participants were categorized as high risk while 34% and 29% were categorized as medium and low respectively according to the Start Back Tool. The anxiety score ranged from 1 to 18 (8.4 (\pm 3.7)) out of 21, and the depression from 0 to 25 (7.4 (\pm 6.0)) out of 27 at baseline. All the characteristics of the participants are shown in table 1. *Distribution of PACIC completion and mean change scores*

Of the 132 patients who completed at least 10 items at baseline and 6 months, 84% and 78% answered all the 20 questions at baseline and 6 months respectively (table 2). The average overall PACIC was 2.6 (SD: 1.1) at baseline and 3.6 (SD: 0.9) at 6 months; men and women had similar scores at baseline (2.6 vs 2.7) and 6-month (3.4 vs 3.7). The distribution of PACIC score by category of risk (measured by the StarT Back tool) was similar even though the mean PACIC score appeared to increase with the level of risk at baseline (2.4, 2.7, 2.7) and at 6-months (3.4, 3.6, 3.6) for low, medium, and high respectively (table 3). At the end of the 6-month program, the experience of care for 62% of the patients improved (table 4).

Potential determinants of PACIC change score

Sociodemographic variables such as age and employment (retired) and environmental variables (site and number of months of implementation) had a significant regression coefficient in the univariate models; statistically nonsignificant variables included sex, level of education, social
assistance, private insurance, ethnicity, StarT Back risk category, anxiety, depression, functional status, health status, pain severity, team climate inventory, and interdisciplinary evaluation (supplementary table A1). None of the variables included in the multivariable regression models remained significant; age was of borderline statistical significance with an average change in PACIC score of -0.021 (-0.046, 0.004) for 1 year increase (table 5, and supplementary table A2).

Discussion

In this study, we used PACIC as a measure of patient experience with a primary interdisciplinary program for the management of LBP, implemented at 4 sites in the province of Quebec. We found that the experience of care improved for the majority of the participants based on the MCID. However, no significant determinants of overall PACIC change score were identified in the multivariable regression models. Some variables selected as predictors of patient experience of care in this study were based on constructs identified as important by patients who participated in a previous qualitative study [55] such as functional ability or interdisciplinary evaluation. None of these were found to be significantly associated with change in patient experience. The absence of significant association of the overall PACIC change score with sites may indicate a negligible impact of implementation variation across program sites. Our mean overall PACIC score at 6 month was higher than the numbers reported in other studies regardless of the type of chronic conditions, setting, or design (cross-sectional, longitudinal) [30, 50, 54, 72-78]. The higher PACIC scores obtained in our study suggest better patient experience. This may be due to the unique characteristics of the IDT program implemented and/or the study population (LBP). Additional data obtained from the implementation of similar IDT programs within LBP population will be needed to support these hypotheses.

Similar to previous findings [72, 75, 79, 80], no significant association with potential determinants of PACIC were found. Other authors reported some significant associations. For example, having a degree/diploma, being retired, having a greater duration of disease had negative effects on the total PACIC in a type 2 diabetes population from a cross-sectional design [78]. In our study, only being retired was negatively associated with overall PACIC in univariable regression models. Interdisciplinarity and team functioning were not significant, even in univariable models while Houle et al. reported a significant association with IDT care; however, IDT care was assessed as "the number of visits with non-physician professionals at the clinic during the previous 2 years, as abstracted from the medical chart" [73]. This is an indicator but not a comprehensive or direct measure of effective implementation of IDT care. To our best knowledge, this is the first study using PACIC as a measure of patient experience of interdisciplinary care for individuals living with LBP in a longitudinal design. Thus, the association of PACIC with some variables such as Start Back risk category and team climate inventory have not been explored to allow comparison. The rate of completion of all 20 PACIC questions in our sample was relatively high (84% and 78% at baseline and 6-month respectively) compared with nearly 75% in studies in multiple chronic condition populations [50, 78]. This finding may be indicative of a better adaptability of PACIC questions for the LBP population. The absence of significant association between PACIC and potential determinants is common in the literature and puts into perspective the notion of the best instrument to assess patient experience, particularly in the context of primary interdisciplinary care. The PACIC was developed for individuals with chronic illness to measure specific actions or qualities of care congruent with the CCM [51], and most recent analyses of PACIC supported the use of the overall summary score [48, 52-54, 81, 82]. However, the fact that we did not find strong

associations with hypothesized predictors raises potential questions regarding the five-dimension structure of the PACIC. It may be that in the context of team-based chronic illness care a modified and improved version of PACIC would be needed to capture aspects of interdisciplinarity patient-centred care including the role of other professionals (or the role of professionals other than doctors and nurses) to reflect on team-patient relationship, the quality of communication and listening, the use of technology in decision making and care coordination. Further evaluation of the factor structure of the PACIC, for example, using rash analyses, will help evaluate the domain structure of the PACIC and whether there are sufficient items to measure each domain.[53, 83].

It is worth noting that the results, based on data from patients who completed the PACIC questionnaire at baseline and 6 months (two-time points), a subsample of the interdisciplinary program, should be interpreted with caution given the small sample size and the absence of control that may positively affect patient experience results. Existing studies on the natural history of LBP focused on pain and function outcomes so do not offer comparison for patient experience outcomes [84-86].

In conclusion, the IDT program appears to have improved the experience for the majority of individuals living with LBP. The lack of association of hypothesized determinants requires further examination of the properties of the PACIC and with a larger sample. Future investigation is needed on the relationship between improved patient experience and outcomes, and to determine whether patient experience plays a mediation role in the relationship between team-based/patient-centred care and improved outcomes.

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		deviation) (range) or proportion
.ge (years)	132	56.7 (14.3) (23 – 87)
ex		
Female	70	53.0 %
Male	62	47.0 %
evel of Education		
College or University	79	59.8 %
Secondary School	29	22.0 %
Primary School or None	3	2.3 %
Other	7	5.3 %
Missing	14	10.6 %
Iarital Status		
Married or Common Law	78	59.1 %
Divorced or Separated	22	16.7 %
Never Married	15	11.4 %
Widowed	2	1.5 %
Other	2	1.5 %
Missing	13	9.8 %
mployment		
Full time	49	37.1 %
Part-time	8	61%
Retired	36	27.3 %
On disability	8	61%
Other	19	14 4 %
Missing	12	91%
ocial Assistance	12	J.1 70
No	107	81.0 %
Ves	107	7.6%
Missing	15	11 / %
rivate Insurance	15	11.7 /0
Vec	70	59.8 %
No	36	27 2 %
Missing	50 17	179%
thnicity	1 /	12.7 /0
Coucasian	<u>80</u>	60.6 %
Diask	0U 5	
	3 6	J.O 70 1 5 0/
Asian Uisponio	0	4.J 70 0 8 0/
nispanic Other	1 12	0.0 70
Other Missing	15	9.8 %0 20.5 0/
Missing	27	20.3 %
tart I Back	20	
Low	38	28.8 %
rivate Insurance Yes No Missing thnicity Caucasian Black Asian Hispanic Other Missing tartT Back Low Medium	15 79 36 17 80 5 6 1 13 27 38 45	11.4 % 59.8 % 27.3 % 12.9 % 60.6 % 3.8 % 4.5 % 0.8 % 9.8 % 20.5 % 28.8 % 34.1 %

Table 1. Baseline characteristics of the study population

High	39	29.5 %
Missing	10	7.6 %
Functional status (ODI, 0-100)	132	31.3 (13.5) (6.0-70.0)
Pain_Severity (BPI, 0-10)	119	4.4 (1.8) (0.8-8.0)
Pain_Interference (BPI, 0-10)	122	4.4 (2.2) (0.0-10.0)
Health status_Physical(SF-12, 0-100)	113	35.9 (9.2) (15.2-56.2)
Health status Mental (SF-12, 0-100)	113	47.9 (11.3) (19.0-67.5)
Anxiety (HADS, 0-21)	128	8.4 (3.7) (1.0-18.0)
Depression (PHQ-9, 0-27)	122	7.4 (6.0) (0.0-25.0)

ODI: Oswestry Disability Index; BPI: Brief Pain Inventory; HADS: Hospital Anxiety and Depression Scale; PHQ-9: Patient Health Questionnaire

Table 2. Distributio	n of PACIC	completion at	t baseline and	six months
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Item responded	Baseline N (%)	6 months N (%)
All 20 items	111(84.1)	103 (78.0)
15-19	20 (15.1)	27 (20.5)
10-14	1 (0.8)	2 (1.5)
5-9	0 (0)	0 (0)
1-4	0 (0)	0 (0)
None	0 (0)	0 (0)

	Mean (SD)	Mean (SD)	Mean (SD)
Sex			
Female	2.68 (1.16)	3.70 (0.90)	0.94 (1.17)
Male	2.56 (1.04)	3.40 (0.93)	1.02 (1.16)
Site			
А	2.72 (1.11)	3.48 (0.96)	0.76 (1.10)
В	2.66 (1.14)	3.54 (0.88)	0.88 (1.15)
С	2.11 (0.83)	3.87 (0.84)	1.75 (1.25)
D	2.62 (1.19)	3.60 (0.94)	0.97 (1.20)
StarT Back			
Low	2.39 (0.90)	3.41 (0.95)	1.03 (1.12)
Medium	2.69 (1.16)	3.63 (0.89)	0.94 (1.27)
High	2.73 (1.22)	3.61 (0.92)	0.88 (1.09)
Anxiety (HADS)			
Minimal	2.52 (0.97)	3.53 (0.84)	1.01 (1.15)
Mild	2.89 (1.30)	3.67 (1.10)	0.78 (1.07)
Moderate	2.70 (1.13)	3.54 (0.90)	0.84 (1.26)
Severe	2.31 (1.12)	3.35 (0.88)	1.04 (1.54)
Depression (PHQ-9)			
No depression	2.43 (1.06)	3.40 (0.91)	0.97 (1.31)
Minimal	2.77 (1.01)	3.66 (0.89)	0.89 (0.99)
Mild	2.78 (1.11)	3.60 (1.02)	0.81 (0.94)
Moderate	2.62 (1.32)	3.39 (1.05)	0.77 (0.82)
Severe	2.31 (1.19)	3.69 (1.11)	1.38 (1.97)

Table 3. Distribution of PACIC mean change scores

HADS: Hospital Anxiety and Depression Scale; PHQ-9: Patient Health Questionnaire

	Improved	Stable	Worsened
Total (n=132)	82 (62%)	39 (30%)	11 (8%)
Sex			
Female (n=70)	43 (61%)	21 (30%)	6 (9%)
Male $(n=62)$	39 (63%)	18 (29%)	5 (8%)
Site			
A (n=70)	38 (54%)	25 (36%)	7 (10%)
B (n=27)	17 (63%)	7 (26%)	3 (11%)
C (n=16)	13 (81%)	3 (19%)	0 (0%)
D n=19)	14 (74%)	4 (21%)	1 (5%)
Adherence Program Nurse			
Yes	11 (13%)	3 (8%)	0 (0%)
No	71 (87%)	36 (92%)	11 (100%)
Adherence Program PT			
Yes	64 (78%)	32 (82%)	11 (100%)
No	18 (22%)	7 (18%)	0 (0%)
Interdisciplinary evaluation			
Yes	65 (79%)	36 (92%)	7 (64%)
No	17 (21%)	3 (8%)	4 (36%)

Table 4. Distribution of PACIC change scores based on MCID

MCID: minimal clinically important difference; PT: physiotherapist

Variables	Regression	95% CI
Patiant pradisposing factors	coefficient	
A ge (years)	0.021	0.046.0.004
Age (years) Morital Status	-0.021	-0.040, 0.004
Married or Common Law	Deference	
Diversed or Separated		0 771 0 472
Never Married	-0.149	-0.771, 0.472
	0.303	-0.528, 1.158
Widowed	0.359	-1.396, 2.114
Other	0.479	-1.529, 2.48/
Missing	-1.679	-4.269, 0.911
Employment		
Full time	Reference	
Part-time	-0.142	-1.078, 0.794
Retired	-0.008	-0.796, 0.779
On disability	0.104	-0.990, 1.199
Other	-0.368	-1.208, 0.472
Missing	1.472	-1.084, 4.027
Ethnicity		
Caucasian	Reference	
Black	0.047	-1.326, 1.419
Asian	-1.209	-2.488, 0.071
Hispanic	NE	-
Other	-0.192	-0.977, 0.593
Missing	0.139	-0.621, 0.899
Environmental factors		,
Site		
A	Reference	
B	0.177	-0.560.0.913
C	0.986	-0.821, 2.793
D	0.335	-0 758 1 427
Adherence Program Nurse	0.555	0.750, 1.127
No	Reference	
Vec		-1 864 1 262
Number of months implementation	0.025	-1.00+, 1.203
Dationt health status	0.023	-0.44/, 0.42/
Haplth status Dhysical (Dasalina)	0.039	0.216 0.202
NE ant articute 1	0.030	-0.210, 0.292

 Table 5. Multivariable association of potential determinants with change PACIC score

Supplementary

Variables	Regression coefficient	95% CI
Age (vears)	-0.025	-0.038, -0.011
Sex		,
Female	Reference	
Male	-0.174	-0.579, 0.231
Level of Education		,
College or University	Reference	
Secondary School	0.136	-0.372, 0.644
Primary School or None	0.108	-1.269, 1.485
Other	0.577	-0.347, 1.500
Missing	0.085	-0.594, 0.764
Marital Status		,
Married or Common Law	Reference	
Divorced or Separated	-0.118	-0.666, 0.431
Never Married	0.638	-0.002, 1.278
Widowed	0.234	-1.393, 1.860
Other	2.023	0.397, 3.649
Missing	-0.130	-0.811, 0.550
Employment		,
Full time	Reference	
Part-time	-0.275	-1.159, 0.610
Retired	-0.544	-1.053, -0.036
On disability	-0.325	-1.209, 0.559
Other	-0.472	-1.099, 0.154
Missing	-0.359	-1.105, 0.388
Social Assistance		,
No	Reference	
Yes	-0.604	-1.370, 0.162
Missing	-0.103	-0.741, 0.535
Private Insurance		
Yes	Reference	
No	-0.160	-0.628, 0.309
Missing	0.113	-0.510, 0.736
Ethnicity		,
Caucasian	Reference	
Black	0.508	-0.538, 1.554
Asian	-1.003	-1.963, -0.043
Hispanic	2.593	0.310, 4.875
Other	0.054	-0.624, 0.733
Missing	0.144	-0.360, 0.649

Table A1. Univariable analysis

StartT Back		
Low	Reference	
Medium	-0.085	-0.601, 0.431
High	-0.145	-0.679, 0.389
Missing	-0.251	-1.083, 0.582
Functional status (ODI, change of 10 units)		
Baseline	-0.114	-0.261, 0.034
Difference (6 month - Baseline)	-0.086	-0.214, 0.043
Pain Severity (BPI, change of 1 unit)		-
Baseline	0.011	-0.100, 0.122
Difference (6 month - Baseline)	-0.006	-0.116, 0.105
Pain Interference (BPI, change of 1 unit)		-
Baseline	-0.002	-0.097, 0.093
Difference (6 month - Baseline)	-0.022	-0.120, 0.076
Health status Physical (SF-12, change of 10 units)		
Baseline	0.080	-0.159, 0.320
Difference (6 month - Baseline)	0.249	0.029, 0.470
Health status Mental (SF-12, change of 10 units)		,
Baseline	0.109	-0.084, 0.303
Difference (6 month - Baseline)	-0.026	-0.250, 0.197
Anxiety (HADS, change of 1 unit)		,
Baseline	-0.028	-0.082, 0.027
Difference (6 month - Baseline)	-0.058	-0.121, 0.005
Depression (PHO-9, change of 1 unit)		,
Baseline	0.003	-0.032, 0.039
Difference (6 month - Baseline)	-0.018	-0.058, 0.022
Site		,
А	Reference	
В	0.125	-0.387, 0.637
С	0.995	0.368, 1.621
D	0.214	-0.371, 0.799
Number of visits Nurse (change of 1 unit)	0.044	-0.089, 0.176
Number of visits Physician (change of 1 unit)	0.096	-0.058, 0.250
Number of visits Physiotherapist (change of 1 unit)	0.078	-0.137, 0.293
Number of visits Psychologist (change of 1 unit)	0.093	-0.019, 0.206
Number of months implementation (c. of 12 units)	-0.247	-0.453, -0.040
Team climate inventory (TCI, change of 1 unit))	-0.165	-1.007. 0.677
Adherence Program Nurse		
No	Reference	
Yes	0.768	0.123. 1.413
Adherence Program Physiotherapist		···, ·····
No	Reference	
Yes	0.206	-0.722. 0.310
	-0.200	
Interdisciplinary evaluation	-0.200	0.722, 0.010
Interdisciplinary evaluation No	-0.200 Reference	0.722, 0.810

|--|

Variables	Model a	Model b	Model c
	Coef. (95% CI)	Coef. (95% CI)	Coef. (95% CI)
	N=116, R ² =0.115	N=110, $R^2 = 0.124$	$N=92, R^2=0.073$
Patient predisposing factors			
Age (years)	-0.017 (-0.038, 0.004)	-0.016 (-0.037, 0.006)	-0.021 (-0.046, 0.004)
Marital Status			
Married or Common Law	Reference	Reference	Reference
Divorced or Separated	-0.078 (-0.620, 0.464)	-0.150 (-0.697, 0.397)	-0.149 (-0.771, 0.472)
Never Married	0.442 (-0.252, 1.135)	0.533 (-0.188, 1.255)	0.305 (-0.528, 1.138)
Widowed	0.490 (-1.141, 2.121)	0.427 (-1.233, 2.087)	0.359 (-1.396, 2.114)
Other	1.205 (-0.490, 2.900)	0.535 (-1.293, 2.363)	0.479 (-1.529, 2.487)
Missing	-1.719 (-4.064, 0.626)	-1.581 (-3.980, 0.819)	-1.679 (-4.269, 0.911)
Employment			
Full time	Reference	Reference	Reference
Part-time	-0.276 (-1.129, 0.577)	-0.075 (-0.957, 0.807)	-0.142 (-1.078, 0.794)
Retired	-0.119 (-0.790, 0.552)	-0.107 (-0.785, 0.570)	-0.008 (-0.796, 0.779)
On disability	-0.157 (-1.004, 0.690)	-0.133 (-0.978, 0.722)	0.104 (-0.990, 1.199)
Other	-0.432 (-1.115, 0.251)	-0.412 (-1.093, 0.270)	-0.368 (-1.208, 0.472)
Missing	1.259 (-1.114, 3.633)	1.424 (-0.990, 3.837)	1.472 (-1.084, 4.027)
Ethnicity			
Caucasian	Reference	Reference	Reference
Black	0.351 (-0.736, 1.438)	0.413 (-0.697, 1.523)	0.047 (-1.326, 1.419)
Asian	-0.837 (-1.791, 0.117)	-0.690 (-1.669, 0.289)	-1.209 (-2.488, 0.071)
Hispanic	2.589 (0.271, 4.907)	2.792 (0.462, 5.121)	NE
Other	-0.151 (-0.859, 0.557)	-0.112 (-0.834, 0.610)	-0.192 (-0.977, 0.593)
Missing	0.309 (-0.341, 0.959)	0.182 (-0.505, 0.870)	0.139 (-0.621, 0.899)
Environmental factors			
Site			
Α		Reference	Reference
В		0.151 (-0.490, 0.792)	0.177 (-0.560, 0.913)
С		1.173 (-0.352, 2.697)	0.986 (-0.821, 2.793)
D		0.243 (-0.738, 1.224)	0.335 (-0.758, 1.427)
Adherence_Program_Nurse			
No		Reference	Reference
Yes		-0.427 (-1.709, 0.856)	-0.301 (-1.864, 1.263)
Number of months_implementation		-0.004 (-0.422, 0.413)	0.025 (-0.447, 0.497)
Patient health status			
Health status_Physical (Baseline)			0.038 (-0.216, 0.292)

NE: not estimated

6.2.5. Comparison of findings from manuscripts 2 and 3

The second project (manuscripts 2 and 3) of this dissertation used a mixed methods approach. The comparison of QUAL and QUAN yielded convergences and discrepancies.

6.2.5.1. Convergence

The majority of the participants interviewed expressed a positive experience with the interdisciplinary care program, and the QUAN study found that the experience of care, assessed by PACIC instrument, improved for the majority of participants. Analysis of the QUAL enabled us to elucidate features that underlie this finding: being listened to and understood, being asked relevant and individualized questions, being treated kindly, with politeness and attentiveness, and being able to function again/better.

6.2.5.2. Divergence

While a theme of the QUAL analysis was that participants perceived that having all the clinicians in the IDT working together was a strength of the program, the variable interdisciplinary evaluation (having at least three healthcare providers at the initial visit evaluation) was not significantly associated with PACIC. In QUAL, the physiotherapist was the clinician whose role and intervention were mostly praised by the participants for the number of visits and the exercises provided. Another theme in QUAL, in relation to the meaning of recovery was "to be able to function". Thus, I was expecting some correlations between both the variables 'adherence to the program' based on number of visits with physiotherapists and 'functional status' (ODI) and experience of care (PACIC) in QUAN. This was not the case. However, the absence of correlations may not be truly discrepant given the limitations described in manuscript 3, including the sample size and the appropriateness of the structure of PACIC and some of its psychometric properties.^{214, 216-219, 234}

7. Conclusions and implications for practice and research

This dissertation aimed to contribute to the body of evidence in patient-centred and team-based care to improve chronic illness care. In this final chapter, I summarize the key findings from the two interrelated research projects. Then I present the strengths as part of the significance of the work, as well as methodological challenges and limitations. Finally, I discuss the implications for practice and policy directions for future research.

7.1. Summary of research findings

Patient-centred and team-based care are recommended by several guidelines and reports as means to help improve the quality of care. However, implementing these approaches or accumulating evidence on their effectiveness remains challenging. The aim of this dissertation was to contribute to evidence-informed implementation and evaluation of interdisciplinary and patient-centred care to improve quality of chronic illness care.

Thus, chapter 2 reviewed and synthesized the literature. Based on my review of the literature and previous work, I introduced a framework which presents the relationships among the concepts of team-based care, patient-centred care (PCC), provider and patient experience of care, and how they relate to improved outcomes (chapter 3). Patient experience seems to play a central role in the pathway from team-based and PCC to improved outcomes. The three manuscripts included in this dissertation explored these relationships from different stakeholder (patient, public, healthcare provider, and health system administrator) perspectives, and using a variety of research designs and sources of data.

7.1.1. Support for, and predictors of patient-centred care

Implementing PCC requires the implication of patients, health care providers, and health care organizations. Using a population-based survey, the Health Care in Canada (HCIC) survey, the first manuscript evaluated the level of support for elements of PCC among the Canadian adult population, and among health care providers and managers. It showed a high level of support for PCC, with slightly higher support among nurses. The results are consistent with the hypothesis of a positive association between high support for PCC and for team-based care from both the public and health professionals' perspectives.²³⁵ Furthermore, it also showed significant association between support for PCC and support for the use of health information technology. Socio-demographic factors do not seem to influence support for PCC. The HCIC survey assessed the level of attributes of PCC but not the dimensions that are currently being implemented in the healthcare system or those that respondents perceived to be most lacking. I will suggest additional questions to address these limitations in subsequent editions of the HCIC survey.

7.1.2. Understanding experience of interdisciplinary care and its association with outcomes

Two manuscripts in chapter 6 reported the qualitative and quantitative components of a mixed methods inquiry of the experience with an interdisciplinary team (IDT) for low back pain (LBP). Using a phenomenological approach, manuscript 2 explored the experience with an IDT care program for individuals living with LBP. From the perspective of the participants, IDT care contributed to effective and patient-centred primary care. The desire to be "heard" emerged as an overarching topic, particularly among participants who were living with chronic LBP. This notion was reported in previous studies but suggestions for healthcare providers to improve listening/hearing skills were lacking or vague.²³⁶⁻²⁴⁰ Some suggestions include more training in communication skills,²³⁸ asking physicians to "work to make sure patients feel listened to".²³⁹ I

propose that the integration of phenomenological approaches in the training of clinicians including interprofessional education and the use of bracketing (attempt to put aside prior beliefs about the phenomenon of interest so as not to interfere with seeing the true essence of the phenomenon) in clinical interviews can help improve these skills. Feeling intimidated during the IDT evaluation was another theme that emerged from the account of the research participants. While previous studies on team-based care or interprofessional collaboration reported that some team members 'may' feel intimidated due to traditional hierarchy and strong (dominant) personality factors, none considered this form the perspective of patients. ^{176, 241, 242} Thus the importance of the intimidating aspect of IDT evaluation for patients, in the context of outpatient/chronic illness care, was uniquely reported in this study and suggestions for mitigating this situation are outlined in table 4 of manuscript 2. An assumption prior to conducting this research was that the particular patient-physician relationship might constitute a barrier to IDT care. However, this was not supported by the findings.

The QUAN component, presented in manuscript 3, showed improved experience of care (assessed by PACIC) for the majority of the participants. We also found that the mean overall PACIC score at 6 months was higher than the numbers reported in other studies suggesting a better experience. While some sociodemographic variables (age, employment) and environmental variables (site, number of months of implementation) had a significant regression coefficient in the univariate models, no significant determinants of overall PACIC change score were identified in the multivariable regression models.

7.2. Strengths

7.2.1. Health care in Canada survey

It is a representative population-based survey and unique in Canada by assessing the perception of public and health professionals. Serial surveys like the HCIC are important in disseminating population-based perceptions and generating research questions or hypotheses.

7.2.2. Phenomenological approach

The use of a phenomenological approach enhanced the exploration of the subjectivity of experience with pain and recovery from pain, but also the complexity of the management of non-specific LBP in particular, to better understand the delivery and perceived impact of IDT care. By researching the prereflexive meaning of experience, a phenomenological approach was especially effective for illuminating the complexity of understanding LBP and how participants perceived the uniqueness of IDT care and the meaning of recovery.

7.2.3. Mixed methods approach

Given the multifaceted and contextual nature of the IDT program and the nature of the chronic condition (LBP), adopting a mixed methods approach, and integrating qualitative and quantitative data collection and analysis, enabled me to develop a more comprehensive understanding of experiences of care in the context of interdisciplinary care for LBP. I adopted a 'reciprocal' approach: elements from QUAL informed steps in QUAN, and vice versa. For example, the concomitant collection of QUAN data facilitated effective criterion-based sampling in the QUAL with maximum variation; findings from QUAL data informed the definition of new variables used in the analyses of QUAN data.

7.2.4. Research Electronic Data Capture

REDCap facilitated effective recruitment of the participants to QUAL (criterion-based sampling) as described in manuscript 2 (data collection section). The system ensured high-quality data management throughout the research project as described in chapter 5 (e.g. password-protected, audit trails for tracking data entry and manipulation and export procedures, secured file sharing).

7.3. Methodological challenges and limitations

7.3.1. Challenges

The use of a mixed methods approach constitutes a challenge in project 2. In particular, it is a challenge to reconcile two worldviews in designing the mixed methods study: a phenomenological approach which is basically constructivist and a quasi-experimental approach which is positivist, and how to balance the weight of each component. In this study, I adopted a pragmatic stance and no *a priori* weight was given to the components. Thus, I was attentive to method-specific rigor criteria for conducting QUAL and QUAN research, and data collection and analysis methods were chosen accordingly.^{180, 243, 244} It can be argued that there was common ground in terms of data collection as the QUAL component relied upon the participants' views and the QUAN component upon PREMs/PROMs where all the outcomes measured come from the participant-generated answers.

The conduct of the phenomenological interview requires directing the participant (having the participant speak to the phenomenon of interest identified by the researcher) instead of leading the participant (attempting to get the participant to say certain specific things that the researcher is seeking in the data). Thus, the need for a high level of concentration and focused listening to

be able to follow up/probe interesting topics as they arose prevented me from taking notes during the interviews. I was also confronted with the risk of loss of control, particularly with my first patient interview. My skills in phenomenological interview improved as the study progressed. The phenomenological inquiry was guided by Husserl's notion of reduction or bracketing. As noted by Giorgi,¹⁹⁴ there is no a priori way of guaranteeing that one has bracketed successfully. Bracketing was incomplete during the interview and the analysis steps given my previous work and my involvement in the design of the IDT care program. Regardless of its completeness or not, I can acknowledge that the process of bracketing helped me to develop a description of experience as experienced by the participants themselves, and facilitated the emergence of other perspectives.

7.3.2. Limitations

Several limitations of this research should be noted. In the QUAL study in project 2, no in-depth interviews were conducted with people who withdrew from the IDT program. We made this decision for practical and logistical reasons but recognize that their perspectives would have offered another valuable point of view on our phenomenon of interest. In the QUAN study, where the change in experience of care was categorized as improved, stable or worsened, the small size of some categories prevented us from using the proportional odds ordinal regression to investigate potential determinants of PACIC and thus estimate direct effect of improved patient experience on outcomes. Other specific limitations are presented in the different manuscripts in chapter 6. A broader consideration related to the scope of the project is that provider experience data were not analyzed in this dissertation. However, we have interview data from clinicians of the IDT and these data that will be analysed in subsequent work to add to the recommendations made from the analysis of patients interview data.

7.4. Implications for practice and policy

The following points present some recommendations, particularly in relation to elements of CCM, for healthcare stakeholders.

-Health care organization

In quality care improvement, a measurement system for performance monitoring is recommended.²⁴⁵ Based on findings from project 2, we suggest the integration of a PCC measurement tool that includes the following main elements: politeness, attentiveness, friendliness, good listening, and tailoring of questions and care.

-Delivery system design

Health care should be a 'team sport', particularly in chronic illness care. Findings from project 1 suggest that implementation of health care teams supported by information and communication technologies are needed to deliver PCC. The high level of support for attributes of PCC among all stakeholders may facilitate the implementation of PCC. It may be helpful to assess the state of acceptance and readiness for IDT to adapt care approach.

-Decision support

In complement to clinical expertise and evidence, patients' beliefs and preferences should be taken into account. To this end, listening/hearing skills of health care professionals should be improved.

This inquiry in project 2 is part of an integrated and interdisciplinary primary care program for the prevention and management of LBP. Consequently, the findings will assist clinicians to

better understand patients' perspective and help improve the process of care. Further, it will help local and regional health managers involved in the program improve implementation by considering patient and provider perspectives. Specific recommendations are presented in table 4, manuscript 2. The overall recommendation is interdisciplinary care should be implemented in order to deliver PCC and improve quality of chronic illness care.

7.5. Directions for future research

The lack of a globally accepted definition of PCC is a hindrance to effective measurement and evaluation of PCC. Thus, projects like the ISPOR systematic literature review on definitions of PCC and patient engagement^{246, 247} are worth noting. These projects should attempt to integrate patient organization, healthcare organization, and researcher-generated definitions of PCC, or to operationalize the definition of PCC according to these different perspectives. Findings from the QUAL (chapter 6) suggested, for some participants, a response shift in their expectations from seeking cure to learning to cope with their pain condition that requires further investigation. The 'complex' relationships between PCC, patient experience, patient factors, and outcomes, as presented in the conceptual framework, requires continued investigation. For example, structural equation modelling can be used to test the mediation role of patient experience between teambased care and PCC and improved patient outcomes. Moreover, identifying which factors have the greatest effect on outcomes may inform effective implementation of these approaches. This work also highlighted the issue of measurement of patient experience and PCC, particularly in the context of team-based care. In particular, there is a need for more evaluation of the structure and construct of PACIC used to assess patient experience, and its adaptation to team-based care supported by information and communication technologies.

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Appendices

Appendix T1: Representation of summary of reading on philosophy and phenomenology



Note: The qualitative inquiry on patient experience was guided by Husserl's notion of reduction. This diagram, based on my reading, represents the place of Husserl in the world of philosophy and phenomenology.

Appendix T2: Report on a research visit at the Irish Qualitative Data Archive (with permission from ICUF)

Developing an archiving system for qualitative research data

By Amédé Gogovor (amede.gogovor@mail.mcgill.ca)

Introduction

On December 22nd of 2015, I received the notification from the Ireland Canada University Foundation (ICUF)'s executive that I was one of the awardees of the inaugural James M. Flaherty Research Scholarships (JMFRS). This scholarship program was set up to support short research visits to Irish host institutions for Canadian graduates, and vice versa.

Briefly, I am currently pursuing a doctoral program at McGill University, using a mixed methods approach to investigate patients' and providers' experiences with the management of low back pain. A mixed methods approach is a research methodology that involves integrating qualitative and quantitative data collection and analysis to provide a better understanding of research problems (1). While using interviews to collect qualitative data, I was pleasantly surprised by the wealth of the content of certain interviews, and I wondered how these could be archived to be consulted by other researchers and the public. A quick internet search on the topic yielded a report on National Data Archive Consultation, commissioned by the Social Sciences and Humanities Research Council of Canada (2) but none of the recommendations seemed to be implemented.

It was during the application process of the JMFRS that I discovered the existence of the Irish Qualitative Data Archive (IQDA). So I am very grateful to Dr. Jane Gray and Dr. Aileen O'Carroll for having accepted to host my visit to IQDA.

Setting of the visit and Facilities

My two-week research visit took place at IQDA, Maynooth University Social Sciences Institute, *National University of Ireland Maynooth. I was provided with all the necessary facilities including an office in the* Iontas building where IQDA is located and an access card for the library. Regarding internet connectivity, given that the eduroam wireless network is one of the two primary networks on Maynooth Campus, I was able to access the network using my McGill credentials.

Objective

The purpose of the visit was to discover the development and functioning of an existing qualitative research data archive system and to find out how the lessons learned can be applied in Canada at local and national levels.

Methods

My first week was dedicated to documentation review and data collection and included:

- Access to the websites of IQDA, Digital Repository of Ireland (DRI), and UK Data Archives;
 IQDA is a member of the DRI, a national digital preservation repository for humanities and social sciences data that was launched in 2011. IQDA is currently using the DRI infrastructure to manage and ingest data into the repository;
- Consultation of policy documents, guidelines and other tools developed by IQDA, DRI, and UK Data Archives;
- Interviews conducted with the Program Leader and Policy Manager of IQDA;
- Literature search based on references from the above-mentioned points.

During the second week, I attended a seminar organised by DRI on digitising material for a digital repository. The seminar took place in the Royal Irish Academy.

My other activities included:

- Hands on experience on the anonymization process;
- Development of the logic model of IQDA, using the data gathered in the first week;
- Literature search on the current state of research data archive in Canada.

All these findings were integrated in a presentation that I made before the IQDA staff and their post-doctoral researchers for feedback.

Results

1. Logic model of IQDA

The elements of the Logic Model are objectives, resources, activities, outputs, outcomes (change between a pre- and post-activity condition), and contextual factors.

-*Objectives*. Founded in 2008, the objectives of IQDA(3) were to archive all qualitative social science data generated in or about Ireland and to promote best practice in data management.

-Resources.

- Staff: Project leader, Policy Manager
- Financial: initial 4 –year research project, other project specific monies; no current direct funding
- Material: website, DRI infrastructure, forms, training material

Partnerships & Collaborations: Maynooth University Social Sciences Institute (MUSSI), Maynooth University Sociology Department, Irish Social Sciences Platform (ISSP), Irish Social Science Data Archive (ISSDA), Digital Services Infrastructure for Social Sciences and Humanities (DASISH), Tallaght West Childhood Development Initiative (CDI), UK Data Archives, and Finnish Social Science Data Archive (FSD).

-Activities.

- Advice for data preparation
- Data access management
- > Face-to-face training in methods for re-use of qualitative data
- Development of tools and teaching resources

-Outputs.

- > Online catalogue of academic qualitative research
- > Research reports
- Number and types of requests
- > Number of presentations, seminars, workshops, etc.
- Number of projects based on re-use of data

-Outcomes.

- Increase the number of collections
- Increase data re-use

-Contextual factors

- Increase the number of collections
- Absence of core funding, the
- Data protection legislation (European/National)
- Research Ethics Boards' policies
- Guidelines of the Sociological Association of Ireland, Attitudes in research community.

2. Current status of research data archive in Canada

The policy regarding the ethical conduct of research and the archiving of research data in Canada is defined by federal and provincial research funding agencies.

At the federal level, it is the Tri-Agency, namely the Natural Sciences and Engineering Research Council of Canada (NSERC), the Canadian Institutes of Health Research (CIHR), and the Social Sciences and Humanities Research Council of Canada (SSHRC). In the province of Quebec, where McGill University is situated, it is the Fonds de recherche du Québec with its three sectors (Nature and Technology, Health, Society and Culture).

Even though some policies exist (SSHRC's Research Data Archiving Policy, CIHR data deposit policy with certain types of data -bioinformatics, atomic, and molecular coordinate data), Canada does not have a national data archive and the Canadian National Archives does not house academic research data (2). While various reports have been produced on research data archives (4), the recommendations have yet to be put into practice.

The implementation of these recommendations can be facilitated by some existing structures including the Canadian Research Data Centre Network of University campuses, in partnership

with Statistics Canada's Research Data Centre Program, for quantitative social, economic, and census data and the digital collection of research outputs by the Canadian Association of Research Libraries.

Next steps and future collaborations

Establishing a qualitative research data archive is a long process. It entails not only the availability of appropriate infrastructure, but also the skills necessary for data preparation, curation, and dissemination. These will include:

- Report on qualitative data archive
- Development of appropriate consent forms
- Implementation of Best Practice in Archiving Qualitative Data at research group level
- Training on qualitative data management
- Discussion with Research Ethics boards
- Principles of qualitative data archive in Canada
- Awareness on the existence of qualitative data archive to promote access and use from both countries
- Development of training course and material.

Conclusion

My research visit at Maynooth University gave me the opportunity to learn about the qualitative research data archive developed for social data and to meet researchers and staff members of IQDA and DRI. It is worth noting that there is currently no digital repository for qualitative

health research data in Ireland, based on the electronic contact that I made with the Irish Health Research Board. IQDA has currently no core funding which threatens its sustainability and on the rebound the quality of future collaboration. Nevertheless, I am confident that the contacts I made during this visit will remain to devise collaborative work in the next steps in Canada.

Acknowledgments

This research visit has been made possible by the awarding of a James M Flaherty Research Scholarship from the Ireland Canada University Foundation, with the assistance of the Government of Canada. I would particularly like to thank Mr. James Kelly and Mrs. Amanda Hopkins, respectively Chief Executive Officer and Program Manager of ICUF.

I am very grateful to Dr. Jane Gray and Dr. Aileen O'Carroll, respectively Program leader and Policy Manager of IQDA, for having welcomed me to IQDA. Thanks to their post-doctoral researchers Dr.Kerry Gallagher, Dr. Niall Gilmartin, and Dr. Cliona Rooney.

I would also like to thank Dr. Sara Ahmed from McGill University who encouraged me to apply for this scholarship and who provided me with the letter of recommendation, as well as Dr. Terrence Montague.

I hope that the JMFRS program which is also opened to scholars, will contribute to establish or strengthen collaboration between Irish and Canadian researchers and research institutions.

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Appendix T3: Permission to use Team Climate Inventory

RE: Request for licence West, Michael [m.a.west@lancaster.ac.uk] Sent:August 18, 2014 2:13 PM To: Amede Gogovor

I am very happy for you to use the Team Climate Inventory in your research Amede. I hope it is successful.

Best wishes

Michael

Michael West

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