Avoidable hospital use in community-dwelling persons living with dementia: impact of health service interventions, and primary care continuity

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Abstract

Persons with dementia have twice the acute hospital use (Emergency Department (ED) visits and hospital admissions) as older persons without dementia. This hospital use dramatically impacts their health and quality of life. A share of this hospital use might be avoidable with appropriate ambulatory care, including primary care. Reducing avoidable hospital use and improving healthcare services for persons with dementia are global healthcare priorities. However, to date, we do not know how to reduce these potentially avoidable hospital use. At least, two avenues have been explored in the literature to reduce avoidable hospital use: 1) designing and implementing health service interventions; and 2) increasing primary care continuity. The aim of this PhD thesis was to investigate how avoidable hospital use of community-dwelling persons with dementia could be reduced, especially by measuring the impact of health service interventions or primary care continuity on potentially avoidable hospital use. Addressing this overarching aim was accomplished in four articles.

The first article aimed at measuring the impact of health service interventions on potentially avoidable hospital use in community-dwelling persons with dementia. In the first article, I conducted a systematic literature review and meta-analysis to synthesize available evidence on the impact of health service interventions on hospital use in dementia compared to usual care. Despite a comprehensive systematic literature review and meta-analysis, including predominantly unpublished data, no health service intervention beyond usual care was found to reduce hospital use in community-dwelling persons with dementia.

The three remaining articles aimed at measuring the impact of primary care continuity on potentially avoidable hospital use in community-dwelling persons with dementia.

In the second article, I conducted a descriptive study of hospital use of community-dwelling persons living with dementia in Quebec, over the last 15 years using the Quebec provincial administrative database. I estimated that around 40 and 60 per 100 person-year of community-dwelling persons with dementia had at least one hospitalization and one ED visit during the year of diagnosis, respectively. In those hospitalized, the average length of hospital stay in the year of diagnosis was around 1.5 months. Between 20 and 30% of those hospitalized, depending on the indicator, had a potentially avoidable hospital use, with average length of Alternate Level of Care (ALC) stay of more than 4.5 months. Most indicators remained constant over the 15 years.

In the third article, I described in a Method Brief, for a non-expert audience how advanced statistical methods can be used to strengthen causal inference from observational data, especially with propensity scores; the method I am using in the fourth article.

In the fourth article, I measured the association between high primary care continuity and potentially avoidable hospital use in community-dwelling persons with dementia in Quebec. I estimated, using an observational 4-year retrospective cohort, with inverse probability of treatment weighting using the propensity score, that high continuity with a primary care physician was significantly associated with fewer potentially avoidable hospitalizations (Ambulatory Care Sensitive Conditions (ACSC) hospitalization and 30-day readmission). In addition, high primary care continuity was significantly associated with fewer ED visits and hospitalizations. The relative risk reduction for Ambulatory Care Sensitive Condition hospitalization (general population definition) in those exposed to high primary care continuity was 0.82 (95% confidence Interval (CI) [0.72;0.94]; P=.004) compared to the unexposed. The relative risk reduction for Ambulatory Care Sensitive Condition hospitalization (older population definition) was 0.87 (CI [0.79;0.95]; P=.002). The relative risk reduction for 30-day hospital readmission was 0.81 (CI [0.72;0.92]; P<.001). The relative risk reduction for hospitalization and Emergency Department visits were 0.90 (CI [0.86;0.94]; P<.001), and 0.92 (CI [0.90;0.95]; P<.001), respectively.

In this PhD thesis, I generated evidence that could ultimately inform healthcare policies aiming at reducing avoidable hospital use in community-dwelling persons with dementia. I generated evidence in support for a call for action to develop evidence-based policies to reduce avoidable hospital use in community-dwelling persons with dementia. I showed that, to date, no health service intervention beyond usual care was found to reduce hospital use in community-dwelling persons with dementia. I showed a negative, large, and statistically significant association between primary care continuity and hospital use, especially potentially avoidable hospital use. I proposed several avenues to increase

primary care continuity in the care of persons with dementia. Throughout this thesis, robust evidence was generated by using advanced statistical methods and rigorous approaches in health service research.

Résumé

Les personnes vivant avec une démence ont deux fois plus d'utilisation de l'hôpital (urgences ou hospitalisation) que les personnes âgées sans démence. Ces utilisations retentissent dramatiquement sur l'état de santé des personnes, et leur qualité de vie. Une partie de ces utilisations serait évitable avec des soins ambulatoires appropriés. Réduire ces utilisations évitables et améliorer les soins et services aux personnes ayant une démence sont des priorités mondiales de santé publique. Cependant, les moyens de les prévenir sont encore controversés. L’objectif général de mon projet de recherche doctoral était d’explorer les moyens de réduire ces utilisations évitables. J’ai répondu à cet objectif général en quatre articles.

Dans le premier article, j’ai conduit une revue systématique de la littérature avec méta-analyse. J’ai synthétisé l'impact des interventions d'organisation des services de santé sur les utilisations de l'hôpital des personnes vivant avec une démence. Malgré l'exhaustivité de cette revue, incluant principalement des données non publiées, aucune intervention n’était associée à une réduction des utilisations de l'hôpital chez les personnes avec démence.

Les trois articles suivants visaient à mesurer l’impact de la continuité des soins en première ligne sur les utilisations évitables de l’hôpital.

Dans le deuxième article, j’ai réalisé une étude descriptive de l'utilisation de l’hôpital des personnes atteintes de démence vivant à domicile au Québec, au cours des 15 dernières années, en utilisant la base de données administratives provinciale du Québec. J'ai estimé qu'environ 40 personnes par 100 personnes-années avec démence vivant à domicile étaient au moins une fois hospitalisées au cours de l'année du diagnostic. J'ai estimé qu'environ 60 personnes par 100 personnes-années avec démence vivant à domicile avaient au moins une visite à l’urgence au cours de l'année du diagnostic. Chez les personnes hospitalisées, la durée moyenne d’hospitalisation au cours de l'année du diagnostic était d'environ 1,5 mois. Entre 20 et 30 % des personnes hospitalisées, selon l'indicateur, avaient une utilisation de l’hôpital potentiellement évitable, avec une durée moyenne de séjour en Niveau de Soins Alternatif (NSA) de plus

de 4,5 mois dans l’année du diagnostic. La plupart des indicateurs demeuraient constants au cours des 15 années.

Dans le troisième article, j’ai décrit, à l'intention d'un auditoire non spécialisé, comment les méthodes statistiques avancées peuvent être utilisées pour renforcer l'inférence causale à partir de données observationnelles, en particulier les scores de propension, la méthode que j'utilise dans le quatrième article.

Dans le quatrième article, j’ai mesuré l'impact de la continuité des soins en première ligne sur les utilisations évitables de l'hôpital chez les personnes vivant avec une démence au Québec (Canada). J'ai estimé, à l'aide d'une cohorte rétrospective observationnelle de quatre ans, et d’une analyse de pondération inverse sur la probabilité de traitement basée sur les scores de propension, qu'une continuité des soins élevée en première ligne était associée de façon significative à moins d'hospitalisations potentiellement évitables (hospitalisation pour des maladies propices aux soins ambulatoires (*Ambulatory Care Sensitive Conditions*; ACSC) et réadmission dans les 30 jours). De plus, une continuité élevée des soins en première ligne était associée de façon significative à moins de visites à l'urgence et d'hospitalisations.

Dans cette thèse de doctorat, j'ai produit des données probantes qui peuvent éclairer les politiques de santé visant à réduire les utilisations évitables de l’hôpital chez les personnes atteintes de démence vivant à domicile. Elles appuient un appel à l'action visant à élaborer des politiques pour prévenir les utilisations évitables de l’hôpital par les personnes atteintes de démence vivant à domicile. J'ai montré qu'à ce jour, aucune intervention de services de santé n'a permis de réduire l'utilisation de l’hôpital chez les personnes atteintes de démence vivant dans la communauté. J'ai montré une association négative, importante et statistiquement significative entre la continuité des soins en première ligne et l'utilisation de l’hôpital, en particulier l'utilisation potentiellement évitable de l’hôpital. J'ai proposé plusieurs avenues pour accroître la continuité des soins de première ligne dans les soins aux personnes atteintes de démence. Tout au long de cette thèse, l'utilisation de méthodes statistiques avancées et d'approches rigoureuses a permis de produire des données solides.

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List of Abbreviations

ACSC = Ambulatory Care Sensitive Condition; *maladies propices aux soins ambulatoires*

ALC = Alternate Level of Care; *Niveau de Soins Alternatif (NSA)*

CASFM = Committee on Advancing the Science of Family Medicine

CARDI = Centre for Ageing Research and Development

CCNA = Canadian Consortium for Neurodegeneration and Aging

CHSLD *Centre d'hébergement et de soins de longue durée* = Québec residential and long-term care centre

CI = confidence interval

CIHI = Canadian Institute for Health Information

CIHR = Canadian Institutes of Health Research

CLSC *Centre local de services communautaires* = Quebec local community service centre

DSM = Diagnostic and Statistical Manual of Mental Disorders

DOSA = Direction des orientations des services aux aînés

ED = Emergency Department

EPOC = Effective Practice and Organization of Care Cochrane Group

FMG = Family Medicine Group – *Groupes de Médecine de Famille*

IC/ES = Institute for Clinical Evaluative Sciences

INSPQ *Institut national de santé publique du Québec* = The Quebec Public Health Institute

IPTW = Inverse Probability of Treatment Weighting

LTC = Long-Term Care

MED-ECHO = *Fichier des hospitalisations*

MSSS *Ministère de la santé et des services sociaux* = Quebec Ministry of Health and Social Services

QICDSS = Quebec Integrated Chronic Disease Surveillance System, SISMACQ

Qc = Quebec

RCT = Randomized Controlled Trials

RECORD = REporting of studies Conducted using Observational Routinely-collected health Data
RSSS *réseau de la santé et des services sociaux* = Health and Social Services Network
ROSA = Research on Organization of Healthcare Services for Alzheimer's
STROBE = Reporting of Observational Studies in Epidemiology
UK = United Kingdom
US = United States of America
WHO = World Health Organization

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Preface

Details Regarding the Manuscript-Based PhD Thesis

This doctoral thesis is a collection of scholarly papers of which I am the first author. Two manuscripts have been published in Plos One and Family Practice, and two are in submission process. The following paragraphs are quoted from the Faculty of Graduate and Postdoctoral studies at McGill University's Guidelines for *Preparation of a Thesis*.

"As an alternative to the traditional format, a thesis may be presented as a collection of scholarly papers of which the student is the first author or co-first author. A manuscript-based doctoral thesis must include the text of a minimum of two manuscripts published, submitted or to be submitted for publication. Articles must be formatted according to the requirements described below. A manuscript-based Master's thesis must include the text of one or more manuscripts.

Manuscripts for publication in journals are frequently very concise documents. A thesis, however, is expected to consist of more detailed, scholarly work. A manuscript-based thesis will be evaluated by the examiners as a unified, logically coherent document in the same way a traditional thesis is evaluated. Publication of manuscripts, or acceptance for publication by a peer-reviewed journal, does not guarantee that the thesis will be found acceptable for the degree sought.

A manuscript-based thesis must:

- be presented with uniform font size, line spacing, and margin sizes (see Thesis Format above);
- conform to all other requirements listed under Thesis Components above;
- contain additional text that connects the manuscript(s) in a logical progression from one chapter to the next, producing a cohesive, unitary focus, and documenting a single program of research - the manuscript(s) alone do not constitute the thesis;
- stand as an integrated whole.

For manuscript-based thesis, each individual chapter/manuscript should be identical to the published/submitted version of the paper, including the reference list. The only change is with respect to the font/size which should be the same as the one used for the rest of the thesis for consistency and homogeneity reasons. So each chapter represents a full manuscript and has its own reference list. Then at the end of the thesis, you have a master reference list which includes all the other references cited throughout the other sections of the thesis, mostly within the general introduction but also from the general discussion.

In the case of multiple-authored articles, the student must be the first author. Multiple-authored articles cannot be used in more than one thesis. In the case of students who have worked collaboratively on projects, it may be preferable for both students to write a traditional format thesis, identifying individual contributions. Consult this page for information on intellectual property and required permissions/waivers.

In the case of **co-first authored articles**, only **one** student can use the article in a manuscript-based thesis and must have a written agreement from the other co-first author student(s)."

Statement of Originality

This work constitutes original scholarship and advances knowledge in the domain of health service research on avoidable hospital use in persons living with dementia, specifically by 1) measuring the extend of the phenomenon in Quebec, 2) measuring the association between health service interventions or primary care continuity with these avoidable hospital use. I was the first to measure the prevalence and trends over time of hospital use and potentially avoidable hospital use in community-dwelling persons with dementia, in Quebec. I was the first to synthesize the impact of any type of health service intervention on hospital use in community-dwelling persons with dementia. I was the first to estimate the association between high primary care continuity and potentially avoidable hospital use, among community-dwelling persons with prevalent dementia in Quebec.

In addition, I contributed to the advancement of the science of family medicine and primary care research. First, I explained, in a Method Brief, in an accessible and didactic format to a non-expert audience (primary care researchers, family physicians, primary care managers), two powerful methods to strengthen causal claims from observational data. Second, I used a conceptual framework to 1) guide my reflections on avoidable hospital use and their prevention, 2) define and measure avoidable hospital use, which is an innovative approach in health service research in community-dwelling persons with dementia. Third, I used rigorous and advanced approaches in health service research, and especially with observational routinely collected data, including: the causal inference, potential outcome, and target trial frameworks, the e value, and prediction intervals.

Even though I received extensive support and highly relevant insights from my Supervisors, my Committee members, and my co-authors, I confirm that I developed the research questions, the study designs, conducted or supervised the analyses, interpreted the findings and wrote the manuscripts and the thesis.

Contribution of Authors

- Manuscript 1: Godard-Sebillotte C, Le Berre M, Schuster T, Trottier M, Vedel I (2019) Impact of health service interventions on hospital use in community-dwelling persons with dementia A systematic literature review and meta-analysis. PLoS One. 2019;14(6):e0218426. doi: 10.1371/journal.pone.0218426. eCollection 2019.
- Manuscript 2.1: Godard-Sebillotte C, Strumpf E, Sourial N, Rochette L, Pelletier E, Vedel I. Hospital use in community-dwelling persons living with dementia: a population-wide descriptive study from Quebec (2000-2015). In Submission process.
- Manuscript 2.2: Godard-Sebillotte C, Karunananthan S, Vedel I (2019) Difference-in-differences analysis and the propensity score to evaluate primary care interventions implemented outside of a randomized experiment. Family Practice 2019;36(2):247-251. doi:10.1093/fampra/cmz003.
- Manuscript 2.3: Godard-Sebillotte C, Strumpf E , Sourial N, Rochette L, Pelletier E, Vedel I. Primary care continuity and potentially avoidable hospitalization in persons with dementia, in Quebec (Canada). In Submission process.

As a doctoral candidate and first author on all the manuscripts included in this thesis, I confirm that I conducted a comprehensive literature review to develop the research questions, I developed the designs to address them, conducted or supervised the analyses, interpreted the findings and wrote the manuscripts and the thesis. The overall scope of this research was determined jointly with my supervisors, Dr. Vedel, and Dr. Strumpf, as well as with members of my thesis supervisory committee: Dr Bergman, Dr Borgès Da Silva, and Dr Pluye. Members of my thesis supervisory committee provided feedback on their respective areas of expertise at the stages of study design, results interpretation, and manuscript revision.

For manuscript 1: I developed the eligibility criteria with Dr. Vedel. I developed the search strategy with Dr. Vedel and Muriel Gueriton, a librarian specialized in health service interventions and meta-analysis. I supervised two students: Miguel Trottier (MT) and Mélanie Le Berre (MLB). I performed the study selection with MT and MLB. I performed the data extraction and quality appraisal with MLB. I supervised the data analysis, performed by MLB. Dr. Vedel participated in every step. Dr Schuster provided direction and specialized statistical expertise in meta-analysis. M Le Berre, T Schuster, M Trottier, I Vedel gave their feedback on the design, participated in interpreting the data, and provided critical input on the manuscript.

For manuscript 2.1: I developed with I Vedel a collaboration with Eric Pelletier, Louis Rochette (INSPQ). The protocol was developed with Nadia Sourial, Dr. Vedel, Dr. Strumpf, Eric Pelletier, and Louis Rochette. I developed, with the input from key stakeholders, two algorithms: 1) an algorithm identifying community-dwelling persons and 2) an algorithm identifying ambulatory care visits in the administrative database. I developed with Nadia Sourial and Dr. Vedel an operationalized framework of indicators to be measured on the database. I supervised the analysis performed by Louis Rochette, statistician at INSPQ. N Sourial, E Strumpf, L Rochette, E Pelletier, I Vedel, gave their feedback on the design, participated in interpreting the data, and provided critical input on the manuscript.

For manuscript 2.2: I and Sathya Karunananthan developed the original idea. I drafted the manuscript. I designed and refined figures. Sathya Karunananthan designed some of the figures and revised the manuscript. Dr Vedel participated in every step. Dr. Erin Strumpf provided helpful advice on the content and organization of this paper.

For manuscript 2.3: The cohort was extracted by Louis Rochette (INSPQ) based on my protocol. I developed the variables (exposure and outcomes) in collaboration with Nadia Sourial, Dr. Vedel, Louis Rochette, Dr. Strumpf. In collaboration with Dr. Strumpf, Dr Vedel and Louis Rochette, I created the statistical programs necessary for analysing data, and I performed the data analysis. I Vedel, N Sourial, L Rochette, E Pelletier, E Strumpf, gave their feedback on the design, participated in interpreting the data, and provided critical input on the manuscript.

The motivating story of the PhD

Madame T. was diagnosed with dementia 4 years ago. She is currently waiting for an evaluation by the local community service centre *("Centre local de services communautaires" "CLSC"*) *to obtain homecare services, as she started having difficulties while bathing and taking her medications. For the past 3 days, she was not feeling well. Her daughter was not able to obtain an appointment with her family doctor. This morning she fell and was unable to stand up again. Her daughter called an ambulance that transferred them to the emergency department (ED), where she was diagnosed with a hip fracture. The story goes on with a long waiting in the ED, complicated by delirium, that after her hip fracture surgery, impeded her chances to walk again.*

Was this ED visit needed? On an individual perspective and in the current healthcare system, certainly "YES". Mme T. required immediate medical attention, and she could not have obtained the care she needed in any other setting.

However, could this ED visit have been prevented in an ideal health care system?

A health care system where she received timely access to supportive care, such as home care, and timely access to primary care, such as her family physician.

Maybe…

This work is dedicated to all the Madame T. that I met in the ED waiting rooms.

1 Chapter 1: Introduction

1.1 Background

The World Health Organization (WHO) recognizes dementia as a global public health priority of the 21st century [1,2]. Dementia, as defined by the WHO, is "a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. […] Dementia results from a variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke." [3] "[Dementia is] characterised by a decline from a previously attained cognitive level, [affecting] activities of daily living or social functioning." [4] Dementia is currently classified as "major neurocognitive disorders" by the Diagnostic and Statistical Manual of Mental Disorders (DSM) 5 [4].

Dementia affects 47.5 million people worldwide and this number is expected to double every 20 years [4]. It is estimated that 564,000 Canadians are currently living with dementia, figures projected to at least double by 2031 as Canadians continue to age [5,6]. In Quebec, it is estimated that 108,865 people aged 65 and over were living with dementia in 2011-2012 [7]. The dementia population imposes a dramatic strain on healthcare systems worldwide [5]. In Canada, "costs for people with dementia are estimated to be five-and-a-half times greater than for those who do not have the condition." [5] "The combined Canadian health care system costs and out-of-pocket caregiver costs [were estimated to amount] to $10.4 billion in 2016. By 2031, this figure is expected to increase to $16.6 billion." [5]

It is estimated that persons with dementia have twice the hospital use as older persons without dementia [8–11]. Each year in the United States of America (US), approximately 40% of community-dwelling persons with dementia will visit the ED and approximately 30% will be hospitalized at least once [9–13]. Higher proportions were found in Ontario and in British Columbia [14,15]. In Ontario, in 2012, in the entire population of community-dwelling home care recipients with dementia: almost 40% and 50% had experienced an hospital admission or an Emergency Department (ED) visit during the previous year [14]. In British Columbia (2001), in the entire population of community-dwelling persons newly diagnosed with dementia, more than 60% had been hospitalized in the year of diagnosis [15]. In addition to straining already overburdened healthcare systems, hospital use impacts patient and caregiver quality of life and is associated with increased risk of delirium, falls, cognitive and functional decline, long-term care admission and death [8–10].

A large proportion of hospital use of persons with dementia may be avoidable with appropriate ambulatory care, including primary care [9,10,16]. A study of a US nationally representative sample of adults aged fifty and older, the Health and Retirement Study from the period 2000–08, estimated that community-dwelling persons with dementia would have up to 74% and 51% higher odds than persons without dementia to have any potentially avoidable hospitalization and any potentially avoidable ED visits, respectively [10]. Reducing avoidable hospitalisation and improving health services for persons with dementia are healthcare priorities, as seen in the 2017-2025 WHO action plan [17].

However, to date, we do not know how to reduce these potentially avoidable hospital use. This PhD thesis will advance our knowledge on avoidable hospital use in community-dwelling persons with dementia and how to reduce them. This will constitute a first step that could ultimately inform healthcare policies aiming at reducing avoidable hospital use in persons with dementia, and better the care offered to this vulnerable population.

At least, two avenues have been explored in the literature to reduce avoidable hospital use: 1) designing and implementing health service interventions; and 2) increasing primary care continuity. By health service intervention, I refer to any intervention aiming at improving practices and organization of care as defined and classified by the Effective Practice and Organization of Care Cochrane Group (EPOC) Taxonomy 2015 [18]. These interventions could reduce avoidable hospital use by different ways: for example, case management could improve coordination of care; self-management could improve caregiver abilities to care for behavioral and psychological symptoms of dementia [19–21]. By primary care continuity, I refer to relational continuity: the relationship between a family physician and a patient that extends beyond specific episodes of illness [22–24]. Primary care continuity could reduce avoidable hospital use, by different ways : for example by improving the management of chronic conditions, or improving the detection and treatment of acute exacerbations [25].

1.2 Objectives and sub-objectives

The objective of this PhD thesis was to investigate how avoidable hospital use of community-dwelling persons living with dementia could be reduced. Addressing this overarching objective was accomplished in four sub-objectives:

The first sub-objective was aimed at measuring whether health service interventions reduced potentially avoidable hospital use.
Objective 1) To synthesize available evidence on the impact of health service interventions on potentially avoidable hospital use in community-dwelling persons with dementia compared to usual care.

The three next sub-objectives were aimed at measuring whether primary care continuity reduced potentially avoidable hospital use.
Objective 2) To measure the impact of primary care continuity on potentially avoidable hospital use in community-dwelling persons with dementia

Objective 2.1. To describe the prevalence and trends in potentially avoidable hospital use in community-dwelling persons with dementia in Quebec from 2000 to 2015
Objective 2.2. To explain to a non-expert audience how advanced statistical methods can be used to strengthen causal inference from observational data
Objective 2.3. To measure the impact of primary care continuity on potentially avoidable hospital use in community-dwelling persons with dementia in Quebec

To answer Objective 1, I conducted a systematic literature review and meta-analysis to synthesize available evidence on the impact of health service interventions on potentially avoidable hospital use in dementia compared to usual care.

To answer Objective 2.1, I conducted a descriptive study of potentially avoidable hospital use in community-dwelling persons with dementia in Quebec, over the last 15 years using the Quebec provincial administrative database.

To answer Objective 2.2, I explained how advanced statistical methods can be used to strengthen causal inference from observational data, especially with propensity scores the method I am using in the fourth sub-objective.

To answer Objective 2.3, I estimated the association between primary care continuity and potentially avoidable hospital use in dementia in Quebec, with inverse probability of treatment weighting using the propensity score.

In the following paragraphs, I present the problem and its importance, and the four knowledge gaps and knowledge translation gaps that the four articles of my PhD thesis address. Then, I present the conceptual framework, I use throughout this PhD thesis. Finally, I present the four articles of this PhD thesis.

2 Chapter 2: Literature review, knowledge gaps and knowledge translation gap

As stated in the previous chapter, it is estimated that persons with dementia have twice the hospital use as older persons without dementia [8–11]. A large proportion of this hospital use may be avoidable with appropriate ambulatory care, including primary care [9,10,16]. Reducing avoidable hospital use and improving health services for persons with dementia are healthcare priorities. However, to date, we do not know how to reduce these potentially avoidable hospital use. At least, two avenues have been explored in the literature to reduce avoidable hospital use: 1) designing and implementing health service interventions; and 2) increasing primary care continuity. In the following chapter, I review the literature on the impact of health service interventions and primary care continuity on potentially avoidable acute hospital use in community-dwelling persons with dementia. Throughout this literature review, I highlight the knowledge gaps that I fill in this PhD thesis.

2.1 Impact of health service interventions on potentially avoidable hospital use in community-dwelling persons with dementia

In the literature on vulnerable elderly very few health service interventions[1] have shown any impact on hospital use, exemplifying the complexity of this endeavour. Reducing hospital use, through a decrease in avoidable hospital use, is a goal shared by many researchers and policy makers. But the way to go is still subject to many controversies and discussions in the scientific community and among policy makers [26]. For example, recent literature synthesis found no impact on hospital use either of case management or of multidisciplinary teams for older persons at risk of hospital admissions

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[1] Health service intervention as defined and classified in the Effective Practice and Organization of Care Cochrane Group (EPOC) Taxonomy 2015 [18].

[26–29]. No intervention reduced hospital use in persons with multimorbidity, even though the authors included any type of healthcare intervention in their meta-analysis [30]. The only interventions that have shown any impact on hospital use, in chronically ill older persons, are transitional care interventions or disease centred interventions (multidisciplinary teams with a condition specialist (specialist clinic) or self-management interventions) [26,29,31–35]. These interventions, achieving a reduction of avoidable hospital use, target specific populations with high risk of avoidable hospital use sharing common causes for avoidable hospital use for which effective strategies to tackle these causes are known.

For the community-dwelling population with dementia, various health service interventions, including memory clinics or case management, have been designed and implemented over the last two decades to improve practices and organization of care [19–21]. However, the evidence on the impact of these interventions on hospital use is scarce and inconclusive. Previous meta-analyses have focused on case management only, and were unable to show any impact on hospital use [21,36–40]. To date, there is no comprehensive evidence synthesis or meta-analysis on the impact of health service interventions on avoidable hospital use in community-dwelling persons with dementia [16].

Gap #1: While health service interventions have been developed to improve practices and organization of care for community-dwelling persons with dementia, to date, there is no comprehensive and rigorous evidence synthesis and meta-analysis on the impact of health service interventions on avoidable hospital use in dementia. An evidence synthesis is essential, to ultimately inform healthcare policies aiming at reducing avoidable hospital use in this population.

In the first study of this PhD thesis (Manuscript 1), I conducted a systematic literature review and meta-analysis of the impact of health service interventions on avoidable hospital use in community-dwelling persons with dementia.

2.2 Impact of primary care continuity on potentially avoidable hospital use in community-dwelling persons with dementia

In the following paragraphs, I review the literature on the impact of primary care continuity on potentially avoidable hospital use in community-dwelling persons with dementia. First, I review the literature and identify a knowledge gap on descriptions of the extent of potentially avoidable hospital use in community-dwelling persons with dementia. Second, I identify a knowledge translation gap. Indeed, the impact of primary care continuity on potentially avoidable hospital use can be measured with observational data using advanced statistical methods, with which many primary care decision-makers, clinicians and researchers are not familiar. Third, I review the evidence and identify a knowledge gap on the impact of primary care continuity on potentially avoidable hospital use in community-dwelling persons with dementia.

2.2.1 Potentially avoidable hospital use in community-dwelling persons with dementia: description of the phenomenon

Most of the literature on avoidable hospital use in persons with dementia stems from the US, and uses Ambulatory-Care Sensitive Condition (ACSC) hospital admission to define and measure avoidable hospitalization [10,11,41–48]. ACSC are conditions, “where appropriate ambulatory care may prevent or reduce the need for admission to hospital” [49]. However, recently (2016), Amjad et al., questioned the relevance and accuracy of ACSC to measure avoidable hospital use in persons with dementia [41]. Indeed, they found conflicting results on the association between continuity of care and ACSC hospital admissions [41]. The authors hypothesise that this measure of avoidable hospitalization might be unsuitable to the population with dementia. One reason could be that ACSC were defined to measure variation in quality of primary care on a population level and not avoidable use on an individual level [41]. One other reason could be the specificities of clinical presentation in dementia. ACSC may “present differently in patients with dementia, as symptoms specific to the ACSC condition may be overshadowed by delirium, and early signs and/or symptoms are missed even with high continuity and a longstanding physician relationship” [41].

In Canada, there is little evidence on potentially avoidable hospital use in persons with dementia [10,11,41–48], and none specifically in the community-dwelling population. No study measured ACSC hospitalization in community-dwelling persons with dementia. Alternate level of care (ALC) hospitalization has been measured in persons with dementia. “ALC is used in hospitals to describe patients who occupy a bed but do not require the intensity of services provided in that care setting. […] ALC identifies a person who has completed the acute care phase of his or her treatment but remained in an acute care bed.” [50]. A share of ALC hospitalizations could be potentially avoidable as I explain in Chapter 3 of this thesis (See Chapter 3: Conceptual framework and avoidable hospital use definition and measures). However, no study measured ALC hospitalization in the community-dwelling population.

Gap #2: To our knowledge, no study worldwide estimated the trends over time of avoidable hospital use in community-dwelling persons with dementia. In Canada, there is little evidence on avoidable hospital use in persons with dementia, and none specifically in the community-dwelling population. In Quebec, there is no evidence on hospital use or potentially avoidable hospital use in community-dwelling persons with dementia. In order to develop evidence-informed policies and programs to reduce avoidable hospital use in community-dwelling persons with dementia, a measure of the extent of the phenomenon, and its trend over time is needed.

In the second study of this PhD thesis (Manuscript 2.1), I described the prevalence and trends in hospital use in community-dwelling persons with dementia in Quebec from 2000 to 2015. I defined avoidable hospital use according to the Gruneir’s conceptual model, presented in the conceptual framework section of this thesis (See Chapter 3). I used four measures of potentially avoidable hospital use: 1) two measures related to the Gruneir’s framework (including ALC hospitalization)(See Chapter 3:), 2) two measures of ACSC hospitalization.

2.2.2 Strengthening causal inference from observational data: advanced statistical methods explained to decision-makers, clinicians and researchers

The impact of primary care continuity on hospital use has been mostly studied with observational data. Observational data used to be considered as not suited to measure impact, especially because of major risks of confounding bias associated with observational data. However, recent development in impact evaluation research known as causal inference and the potential outcome framework offer a solution. The potential outcome framework allows strengthening causal inference from observational data [51]. This is nowadays a recommended approach to assess the impact of healthcare policies on a population level [51].

Gap #3: Evaluation research has been deeply transformed over the last couple of decades by the development of advanced statistical methods strengthening causal inference from observational data [52]. These causal inference methods, including the propensity score, are grounded in the potential outcome framework [52]. However, many decision-makers, clinicians and researchers are not familiar with these methods, and this framework. Addressing this knowledge translation gap is essential to allow decision-makers understand current primary care research findings and develop evidence-based policies.

In the third article of this PhD thesis (Manuscript 2.2), I addressed this knowledge translation gap. I described in a Method Brief, for a non-expert audience, how advanced statistical methods can be used to strengthen causal inference from observational data, especially with propensity scores the method I am using in the fourth article.

2.2.3 Primary care continuity and potentially avoidable hospital use in community-dwelling persons with dementia

In the broader literature on older persons, continuity of care in primary care seems to be one of the features of primary care most commonly associated with reduction of hospital use and avoidable hospital use [25,53–55]. By continuity, I refer to the relationship between a physician and a patient that extends beyond specific episodes of illness [22–24]. For example, in a recent cross-sectional study of United Kingdom (UK) general practices (2017), higher continuity of care in primary care was associated with fewer admissions for ACSC [25]. In multivariable analysis, controlling for demographic and clinical patient characteristics, an increase in the continuity of care index of 0.2 (Usual Provider of Care index) for all patients reduced these admissions by 6.2% (95% confidence interval (CI) 4.9% to 7.6%). The rationale explaining why would continuity of care impact hospital use is the following: "One theory is that continuity might improve the management of long-term conditions by increasing the ability of doctors to respond to patients' needs and preferences and therefore their ability to recommend suitable and acceptable courses of treatment. Continuity might also enable earlier detection and treatment of acute events, or improve the relationship between the general practitioner and patient and thus increase the uptake of preventive interventions such as vaccination or routine drug review, although this relationship is necessarily complex" [25].

In the literature on community-dwelling persons with dementia, there is to date very little available evidence on their primary care patterns of use, and no evidence on the association of primary care continuity and hospital use [56–60]. Two recent studies (2016-2017) examined the association between hospital use and ambulatory care continuity with any physician, including specialists [14,41]. A one-year longitudinal study, from Ontario, found that low continuity of care, during the two years prior, was associated in age-sex adjusted models with an increased risk of total hospital use [14]. However, no significant associations were found in multivariate analysis. The authors did not measure avoidable hospital use. A one-year longitudinal study of the community-dwelling dementia Medicare population in the United States (US), found that higher continuity of care was associated with less total hospital use; both outcome and exposure were measured during the same year. Comparing the highest vs lowest continuity groups, annual rates per beneficiary of hospitalization and ED visits were higher with lower continuity even after accounting for socio demographic factors and comorbidity burden. However, they found no association with potentially avoidable hospitalizations, as measured by hospitalisations for ACSC. To the authors, one hypothesis explaining these conflicting results could be an inaccuracy of the measure of potentially avoidable hospital use, as previously described (See

Paragraph 2.1).

Gap #4: Continuity could be an important determinant of avoidable hospital use in community-dwelling persons with dementia. Recent evidence found conflicting results regarding the association between ambulatory care continuity with any physician, including specialists, and avoidable hospital use in this population [41]. To our knowledge, there is no study of the impact of primary care continuity on avoidable hospital use in this population. Measuring the impact of primary care continuity on potentially avoidable hospital use in community-dwelling persons with dementia is essential, to ultimately inform healthcare policies aiming at reducing avoidable hospital use in this population.

In the fourth study of this PhD (Manuscript 2.3), I measured the association between primary care continuity and potentially avoidable hospital use in community-dwelling persons with dementia in Quebec (Qc), using the Qc provincial administrative database. I used the definition and indicators of potentially avoidable hospital use, I described in the second study, and the method I described in the third manuscript.

2.3 Objectives

The objective of this PhD thesis was to investigate how avoidable hospital use of community-dwelling persons with dementia could be reduced, especially by measuring whether health service interventions or primary care continuity reduce them.

Objective 1. To synthesize available evidence on the impact of health service interventions on potentially avoidable hospital use in community-dwelling persons with dementia compared to usual care.

Objective 2. To measure the impact of primary care continuity on potentially avoidable hospital use in community-dwelling persons with dementia

Objective 2.1. To describe the prevalence and trends in potentially avoidable hospital use in community-dwelling persons with dementia in Quebec from 2000 to 2015
Objective 2.2. To explain to a non-expert audience how advanced statistical methods can be used to strengthen causal inference from observational data
Objective 2.3. To measure the impact of primary care continuity on potentially avoidable hospital use in community-dwelling persons with dementia in Quebec

3 Chapter 3: Conceptual framework and avoidable hospital use definition and measures

3.1 A conceptual framework of health service use to define avoidable hospital use

I chose the "Gruneir's conceptual model illustrating factors that influence ED use by older adults" to guide my reflections on avoidable hospital use and their prevention throughout my thesis (Figure *3.1*) [61]. I chose this model because it was the most appropriate to guide my reflections on avoidable hospital use and their prevention. Indeed, in comparison to the Andersen and McCusker's models presented below, it defines avoidable hospital use in relation to primary care gaps in care. This definition of avoidable hospital use allowed me to restrict the scope of my reflections on avoidable use. In addition, it allowed me to link my reflections to potential interventions in primary care that could reduce these avoidable hospital use. The choice of this framework was thus coherent with my overall objective to deepen our understanding of a phenomenon to ultimately inform healthcare policies aiming at reducing avoidable hospital use in community-dwelling persons with dementia.

The Gruneir's conceptual model was developed and discussed in the light of a literature review on determinants of acute health services use in older persons [61]. The Gruneir's conceptual model is an adaptation of both the Andersen behavioural model of health service use and its modification by McCusker et al. for the specific context of ED visits by older adults [62–64]. In these models, utilization of health service results from the combined effects of need, predisposing, and enabling factors. The Andersen model was initially developed to assess equity in a healthcare system. In addition to the Andersen model, the McCusker's model distinguishes predisposing and enabling factors associated with primary care and other community services use, and ED utilization. In McCusker model, factors that enable primary care use and other community service uses are inversely associated with ED visits [64].

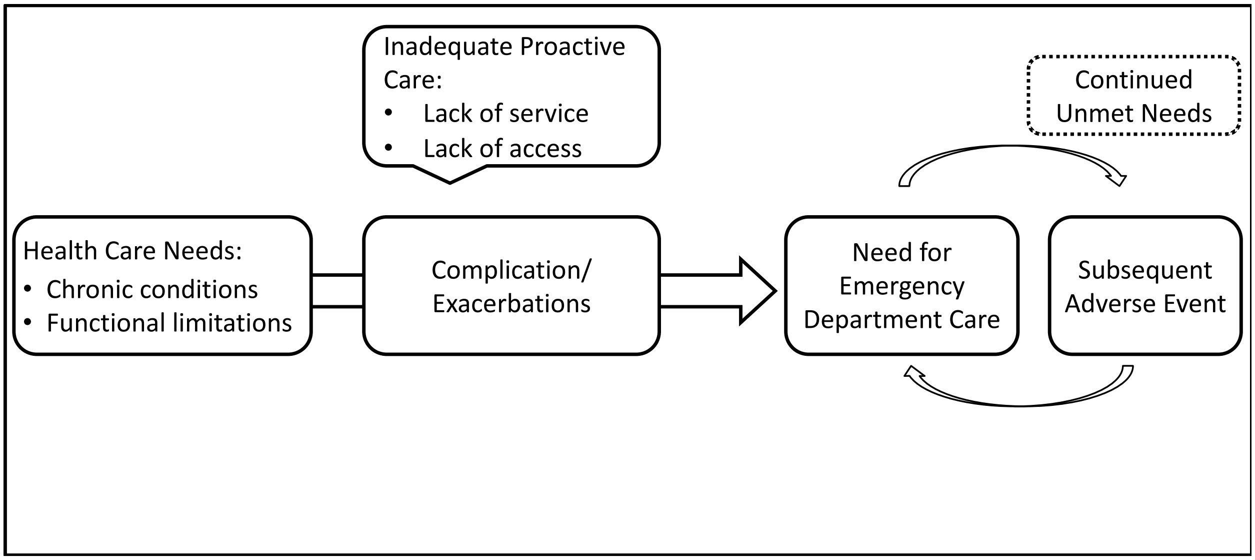

Figure 3.1 : Adapted from Gruneir's conceptual model illustrating factors that influence emergency department use by older adults

Gruneir defines ED use as appropriate when illness acuity required immediate medical attention and no alternative to ED services was available. Gruneir redefines the "need" of service compared to Andersen and McCusker models. Need for care in the ED is a function of i) illness acuity or immediacy with which a person requires acute care services, ii) opportunities to obtain necessary care in alternatives to the ED setting.

Moreover, Gruneir restricts enabling factors, contrarily to Andersen and McCusker, to factors that could prevent ED visit in primary care. To Gruneir, two types of care in primary care could prevent ED visits. They constitute what Gruneir calls pro-active primary care. Pro-active primary care includes both adequate primary care and adequate supportive care.

Gruneir et al. describe adequate primary care and adequate supportive care. Adequate primary care 'should result in management of chronic conditions as well as provide a "safety net" before a health crisis requiring ED care occurs.' [61] Supportive care is not explicitly defined by Gruneir et al. For Gruneir et al., it encompasses home care, and is aimed at supplementing functional impairment "to prevent adverse outcomes such as falls or medication errors." [61] "As such, while age and morbidity may increase use of primary and supportive care services, optimal provision of proactive care should prevent some or much ED use. When proactive care is unavailable, inaccessible, or inadequate, the health care needs of older adults go unmet and the necessity for care in the ED increases. In other words, for older adults, the need for ED care is driven in part by their underlying morbidity as well as access to and availability of primary and supportive care services that adequately manage their underlying morbidity.' [61]

3.2 Definition and measures of avoidable hospital use

3.2.1 Definition of avoidable hospital use

In this PhD thesis, I defined "avoidable hospital use", using the Gruneir's model [61]. I defined a hospital use as avoidable when it could have been prevented by an ideal pro-active primary care, including both timely access to adequate primary care and timely access to adequate supportive care. This choice was coherent with my overall objective to ultimately inform healthcare policies aiming at designing evidence-based policies to reduce avoidable hospital use.

3.2.2 Measures of potentially avoidable hospital use

To measure avoidable hospital use, I used measures of potentially avoidable hospital use. When I refer to the measure, contrary to the definition, I add the adjective potentially. Indeed, even an ideal pro-active primary care system would not prevent every avoidable hospital use. Only a share of potentially avoidable hospital use, as measured in the administrative database, would be prevented by an ideal pro-active primary care system. This choice was also made by other authors on avoidable hospital use in persons with dementia [10,47].

Given my definition of avoidable hospital use, I chose two measures of potentially avoidable hospital use related to the Gruneir's model. In addition, I measured two measures related to ACSC hospitalization; the most widely used concept to measure avoidable hospital use in community-dwelling persons with dementia. Thus, in this PhD, I used four measures of potentially avoidable hospital use. I present first the two measures related to the Gruneir's model and then the two related to ACSC hospitalization.

I used two measures of potentially avoidable hospital use related to the Gruneir's model: 30-day hospital readmission, and ALC hospitalizations. In the following paragraphs I show how these two types of hospital use are potentially avoidable and may be prevented through pro-active primary care as defined by Gruneir: timely primary care access and timely supportive care access.

A share of 30-day hospital readmission may be avoidable, especially through timely primary care access [65,66]. Timely outpatient follow-up after discharge has been identified as one of the strategies that could prevent avoidable 30-day readmission [65]. For example, in Quebec, in elderly or chronically ill persons, Riverin et al. estimated a reduction of 11 percentage point in the risk of 30-day readmission through timely follow-up with a primary care physician [65]. To date, in community-dwelling persons with dementia little is known on 30-day readmission. To our knowledge, only one US study (2013) was published on 30-day readmission in community-dwelling persons with dementia. This study estimated that 18% of the Medicare population with dementia had at least one 30-day readmission in 2013 [67]. No study measured the impact of timely access to primary care on 30-day hospital readmission in community-dwelling persons with dementia.

A share of ALC hospitalizations may be avoidable, especially through timely supportive care access [68]. Timely supportive care access has been identified as one of the strategies that could prevent avoidable ALC hospitalizations and is recommended by the *Ministère de la Santé et des Services sociaux* (MSSS) (Quebec Ministry of Health and Social Services) [68]. In Quebec, one study of a program of integrated care for vulnerable community-dwelling older persons was able to show a 50% reduction in ALC hospitalizations [69]. To the authors, this decrease was attributable to several components of the program including an increased use of community-support services [69]. Persons with dementia are disproportionally at risk of ALC hospitalization, but no study measured ALC specifically in community-dwelling persons with dementia. In 2015-2016, "[Persons] with dementia were 3 times more likely to have ALC days — 1 in 5 seniors with dementia had an ALC component to their stay, versus 1 in 15 [persons] without."[70] No study measured the impact of timely access to support services on ALC hospitalization in community-dwelling persons with dementia.

I measured ACSC hospitalizations as it is done by most authors in the population with dementia, allowing the results of my PhD to be comparable to the literature. Several definitions have been used in persons with dementia. I chose two of them: one developed for the general population, the measure of the Canadian Institute for Health Information (CIHI), and one developed for an older population the measure developed by Walsh and colleagues on dually eligible Medicare Medicaid older persons, previously used in the dementia population by Feng et al. [10,49]. (See operationalized definitions of these measures in Appendix 5.9.2 in Chapter 5).

4 Chapter 4: Impact of health service interventions on hospital use in community-dwelling persons with dementia. A systematic literature review and meta-analysis (Manuscript 1)

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4.1 Preamble

As, described in previous chapters and in particular in Gap # 1, while health service interventions have been developed to improve practices and organization of care for community-dwelling persons with dementia, to our knowledge, no intervention has been shown to reduce avoidable hospital use in this population [16]. To date, there is no comprehensive and rigorous evidence synthesis and meta-analysis on the impact of any health service intervention on avoidable hospital use in dementia [16]. This evidence synthesis is essential, to ultimately inform healthcare policies aiming at reducing avoidable hospital use in this population. In this manuscript, I addressed the following objective: Objective 1) To synthesize available evidence on the impact of health service interventions on potentially avoidable hospital use in community-dwelling persons with dementia compared to usual care.

For this study, I chose to include any type of health service intervention as defined and classified in the Cochrane EPOC taxonomy [18]. Indeed, previous meta-analyses had focused on case management only, and were unable to show any impact on hospital use

[21,36–40]. I wanted as a researcher not to impose a preconception on what would work. This is why I chose wide inclusion criteria that allowed me to look at different health service interventions.

In this manuscript, I tested the following hypothesis: Health service interventions reduce avoidable hospital use and thus reduce total hospital use in community-dwelling persons with dementia. Avoidable hospital use was not measured in randomized controlled trials (RCTs) measuring the impact of health service interventions in community-dwelling persons with dementia. I focused on hospital use.

I performed a systematic review and meta-analysis as it is the best method to synthesize quantitative evidence from RCTs on the impact of interventions and estimate the effect of an intervention on the outcome [71]. I followed an a priori registered protocol (PROSPERO ID: CRD42016046444) [72]. This manuscript was published in PlosOne (Impact factor: 2.776).

During the data collection, I realized that: 1) outcomes were measured and reported in different ways, and at different follow-up times, in each study, 2) that there were very few RCTs testing the impact of health service intervention on hospital use. For this reason I decided to contact 1) every authors of relevant trials measuring impact on healthcare costs to inquire about data on hospital uses, and 2) every corresponding authors of included studies about unpublished data on outcomes at any other time point [73]. This strategy yielded a high response rate (95%), and nearly doubled the number of RCTs, outcomes and participants included in our systematic review. I published a Letter to the Editor of the Journal of Clinical Epidemiology to report my three-stage digital media strategy to obtain unpublished data from trial authors [72].

4.2 Abstract

Background: Persons with dementia have twice the acute hospital use as older persons without dementia. In addition to straining overburdened healthcare systems, acute hospital use impacts patient and caregiver quality of life and is associated with increased risk of adverse outcomes including death. Reducing avoidable acute hospital use in persons with dementia is thus a global healthcare priority. However, evidence regarding the impact of health service interventions as defined by the Effective Practice and

Organization of Care Cochrane Group on acute hospital use is scant and inconclusive. The aim of this systematic review and meta-analysis was to synthesize available evidence on the impact of health service interventions on acute hospital use in community-dwelling persons with dementia compared to usual care.

Methods: Data Sources: MEDLINE, EMBASE, CINAHL and Cochrane CENTRAL (from 01/1995 to 08/2017). Study eligibility criteria: Randomised controlled trials measuring the impact of health service interventions on acute hospital use (proportion and mean number of emergency department visits and hospitalisations, mean number of hospital days, measured at 12 months, and at longest follow-up) in community-dwelling persons with dementia, compared to usual care. Study selection, appraisal and synthesis methods: Reviewers independently identified studies, extracted data, and assessed the risk of bias, with the Cochrane risk of bias tool. Authors of relevant trials were queried about unpublished data. Random effects model was used for meta-analyses. Effect heterogeneity was assessed through prediction intervals, and explored using sub-group analyses.

Findings: Seventeen trials provided data on 4,549 persons. Unpublished data were obtained for 13 trials, representing 65% of synthesized data. Most interventions included a case management or a self-management component. None of the outcome comparisons provided conclusive evidence supporting the hypothesis that these interventions would lead to a decrease in acute hospital use. Furthermore, prediction intervals indicated possible and important increased service use associated with these interventions, such as emergency department visits, hospital admissions, and hospital days. Subgroup analyses did not favour any type of intervention. A limitation of this study is the inclusion of any type of health service intervention, which may have increased the observed heterogeneity.

Conclusion: Despite a comprehensive systematic review and meta-analysis, including predominantly unpublished data, no health service intervention beyond usual care was found to reduce acute hospital use in community-dwelling persons with dementia. An important increase in service use may be associated with these interventions. Further research is urgently needed to identify effective interventions for this vulnerable

population to limit rising acute hospital use, associated costs and adverse outcomes. Systematic review registration PROSPERO CRD42016046444.

4.3 Introduction

The World Health Organization (WHO) recognizes dementia as the global public health crisis of the 21st century [1,2]. Dementia affects 47.5 million people worldwide and this number is expected to double every 20 years [1]. The dementia population imposes a dramatic strain on healthcare systems worldwide, especially acute hospital use (Emergency Department (ED) visits and hospital admissions). It is estimated that persons with dementia have twice the acute hospital use as older persons without dementia [3–6]. Each year, approximately 40% of community-dwelling persons with dementia will visit the ED and approximately 30% will be hospitalised at least once [4–8]. Hospital care is three times more costly for this population compared to older persons without dementia [9,10]. In addition to straining already overburdened healthcare systems, acute hospital use impacts persons with dementia and their caregiver quality of life and is associated with increased risk of delirium, falls, cognitive and functional decline, 30-day readmission, long-term care admission and death [3–5].

Reducing avoidable hospitalisation and improving health services for persons with dementia are healthcare priorities, as seen in the 2017-2025 WHO action plan [11]. Various health service interventions, including memory clinics or case management, have been designed and implemented over the last two decades to improve practices and organization of care for community-dwelling persons with dementia [12–14]. However, the evidence of impact on acute hospital use is scarce and inconclusive. Previous meta-analyses have focused on case management only, and were unable to show any impact on acute hospital use [14–19]. To date, there is no comprehensive evidence synthesis or meta-analysis on the impact of health service interventions on acute hospital use in community-dwelling persons with dementia [20].

We conducted the first meta-analysis of randomised controlled trials (RCTs) measuring the impact of any type of health service intervention, as defined by the Effective Practice and Organization of Care Cochrane Group, on acute hospital use (ED visits / hospital admissions / hospital days) in community-dwelling persons with dementia compared to usual care.

4.4 Methods

This systematic review and meta-analysis were conducted and reported in accordance with the Cochrane Handbook for Systematic Reviews of Interventions and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) [21,22]. We followed an a priori registered protocol (PROSPERO ID: CRD42016046444) [23].

4.4.1 Eligibility criteria

Published articles on RCTs measuring the impact of health service interventions on acute hospital use in community-dwelling persons with dementia were included. **Population:** Community-dwelling persons with dementia or their caregivers or both. **Intervention:** Any health service intervention as defined by the Effective Practice and Organization of Care Cochrane Group (EPOC) Taxonomy 2015: “delivery arrangements”, “financial arrangements”, “governance arrangements”, or “implementation strategies” (Detailed eligibility criteria of interventions in Appendix A) [24]. The definition of self-management applied here was the EPOC definition: “Shifting or promoting the responsibility for healthcare or disease management to the patient and/or their family.” (Detailed definition of self-management interventions in Appendix A). **Comparison:** Usual care. **Outcomes:** Proportion or mean number of ED visits, proportion or mean number of hospital admissions, mean number of hospital days, in persons with dementia. Eligibility was restricted to interventions in high-income countries [25].

4.4.2 Information sources and search

We searched for publications in English or French in four databases: MEDLINE (“In-Process & Other Non-Indexed Citations”), EMBASE, CINAHL, and Cochrane Central Register of Controlled Trials (CENTRAL) from January 1995 (first publications on health service interventions for persons living with chronic diseases (5)) to August 2017. The search strategy was developed by a librarian specialized in health service interventions and meta-analysis (MG), a geriatrician (CGS), and an expert in health service interventions for persons with dementia (IV). The key concepts included in the database search were: dementia, health service intervention, community/primary care and RCT (Medline full electronic search strategy in Appendix B in S1 File). Duplicate publications were removed. The search was expanded using backward citation tracking in the reference list of included articles and recent systematic reviews on the topic [14–20] and forward citation tracking of all included studies using Scopus. Authors of relevant trials measuring impact on healthcare costs were inquired about data on acute hospital uses.

4.4.3 Study selection

Reviewers (CGS, MT, ML) independently assessed all records for eligibility. Disagreements were resolved by consensus or a third reviewer (IV).

4.4.4 Data collection, transformation and imputation

A systematic approach to data collection, transformation and imputation was followed, as recommended in the Data extraction for complex meta-analysis (DECiMAL) guide (Detailed origin, transformation or imputation of reported data in Appendix C and Tables 4.3-4.7 in S1 File) [26]. Two authors (CGS and ML) independently collected data on structured forms. Companion articles were used if needed, to access data on intervention details. To avoid bias due to selective inclusion of trials effect estimates, corresponding authors of included studies were contacted by email about unpublished data on outcomes at any other time point [27]. In cases of non-response, reminder emails and social media messages (ResearchGate, LinkedIn) were sent to corresponding and last authors. Transformation of data consisted of simple algebraic transformation. Data imputation consisted of weighted mean imputation of missing variance estimates. When the sample size in each group was not clearly stated, the randomised number of individuals in the text or flow chart determined the intention-to-treat population. Clustered randomised trials were identified and data adjusted on the clustering effect was collected. If unavailable, unadjusted data were collected.

4.4.5 Quality Appraisal

Risk of bias was rated at the study level by two independent reviewers (CGS and ML), using the Cochrane Collaboration’s tool [28]. Companion articles, especially published protocols, were used to appraise quality. Blinding of participants and personnel was not assessed due to the nature of the interventions. For the six remaining individual domains, studies were classified into low, unclear or high risk of bias according to specific criteria of the tool [28]. As recommended by the Cochrane Handbook for Systematic Reviews of Interventions, studies of low quality were not excluded, but sensitivity analyses were conducted [21].

4.4.6 Summary measures

We pooled estimates for the following five outcomes at two endpoints. We pooled the estimated proportions of persons having at least one ED visit and/or at least one hospital admission, the mean number of ED visits, the mean number of hospital admissions, and the mean number of hospital days on the total sample of participants irrespective of whether participants used the corresponding service. Following the recommendations of the Cochrane Handbook for Systematic Reviews of Interventions on repeated observations on participants, we compiled data available for each outcome at 12 months and at longest follow-up for each study [21].

4.4.7 Synthesis

The statistical software R, and the meta and ggplot2 packages, were used to perform analyses [29]. The unit of analysis was the unique RCT. Random-effects models were employed to allow for varying effect sizes across studies due to heterogeneity of interventions and/or study populations. Risk differences, risk ratio and mean differences were calculated to determine the average relative and absolute effect of the interventions on the dichotomous and continuous outcomes. Not every cluster RCT study had published data adjusting for a potential clustering effect. Mixing unadjusted data from cluster RCTs with data from individual RCTs can lead to artificially narrow confidence intervals [30]. The Cochrane Collaboration recommends performing an “effective sample size” calculation to pool unadjusted data from cluster RCTs and individual RCTs together. As data necessary to perform this ‘effective sample size’ calculation was not available for every cluster RCT, we performed sensitivity analyses excluding unadjusted data from cluster RCTs [30]. Heterogeneity across studies was assessed by calculating the I^2 statistic as well as predictions intervals. Following Cochrane recommendations, our interpretation of the I^2 statistic was that over 40% may represent moderate to considerable heterogeneity [21]. Prediction intervals are another measure of heterogeneity and are easier to interpret and relate to the clinical implication of the observed heterogeneity [31]. Prediction intervals estimate a pre-specified distribution range (here: 95%) of treatment effects that can be expected in future settings. Meta-analysis results were labelled inconclusive if the range of treatment effects consistent with the prediction interval included both positive and negative clinically relevant effects.

Post hoc subgroup analyses were performed to explore heterogeneity for outcomes pooling a minimum of four studies and showing moderate to considerable heterogeneity ($I^2 > 40\%$). Criteria used to perform these subgroup analyses were the types of interventions according to the EPOC taxonomy (either the main component or one of several), country (United States vs. other), and follow-up time. The number of studies included did not allow meaningful application of meta-regression methods.

We conducted several sensitivity analyses to determine the robustness of meta-analysis results. We investigated changes in estimated pooled effects when removing: RCTs with at least one item at high risk of bias, outlying RCTs based on a graphical assessment of the corresponding forest plot, and cluster RCTs that did not properly take clustering into account. We did not generate funnel plots to identify reporting bias, because interpretation would have been questionable since most of the data in the analysis was unpublished. We conducted additional sensitivity analyses investigating changes in estimated pooled effects due to removing unpublished data provided by authors from the analyses 32.

4.5 Results

4.5.1 Studies Characteristics

The systematic literature search resulted in 19 eligible, unique RCTs (Figure 4.1). Two of these were not included as the available data was only on overall healthcare costs (confirmed by study authors) [33,34]. Seventeen unique RCTs were included in the meta-analyses including four cluster RCTs (Table *4.1*). Eight of 17 RCTs were included because unpublished data was provided by authors [13,35–41]. The published data was either only cost data or combined outcomes on use (e.g. long-term care admission and hospitalisation) [13,35–41]. We obtained unpublished data for thirteen trials on five outcomes measured at two endpoints, representing 65% of overall synthesized data (Detailed origin, transformation or imputation of reported data in Appendix C and Tables 4.3-4.7 in S1 File).

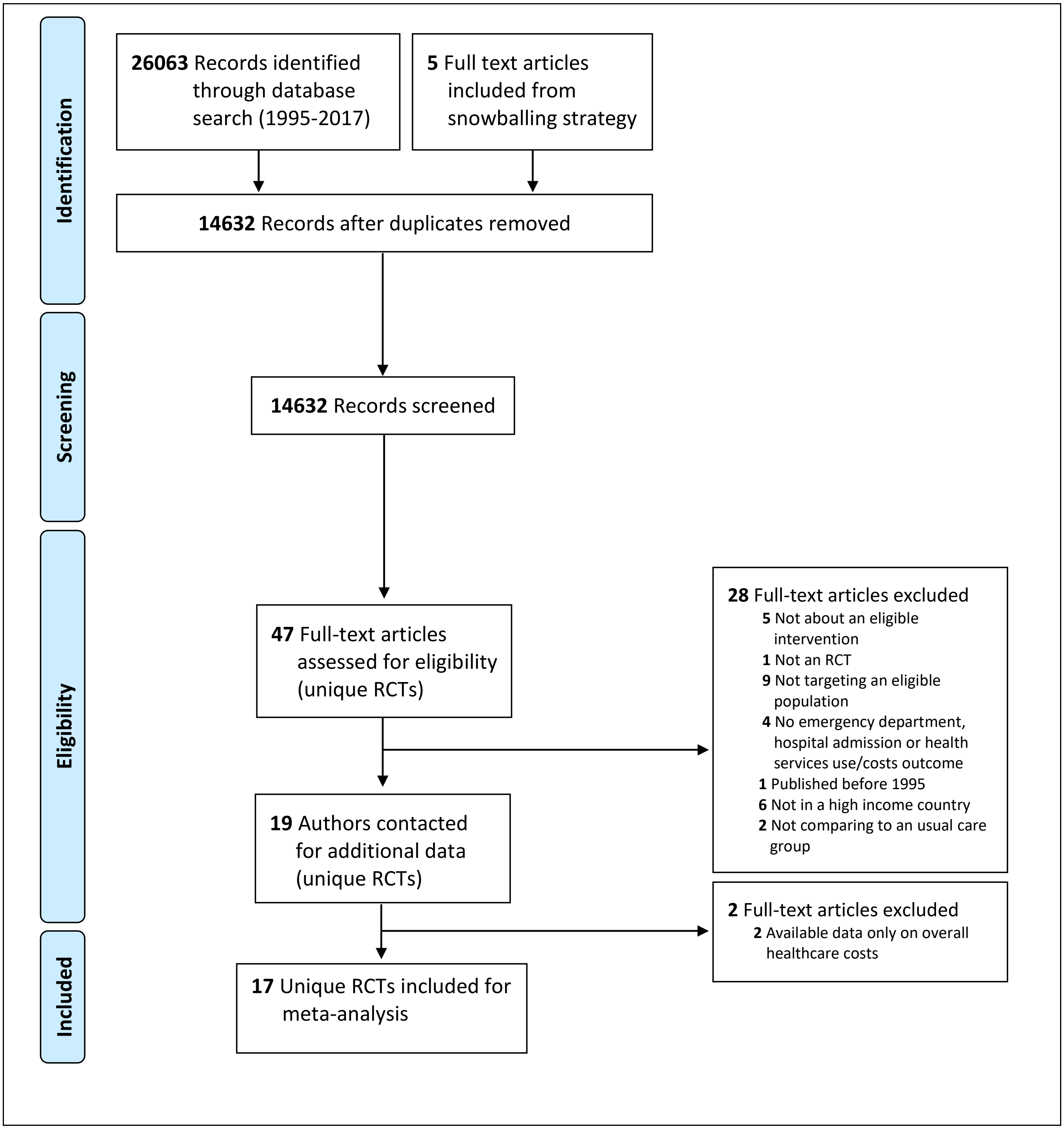

Figure 4.1: Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram of study selection

RCT: Randomised controlled trial

Table 4.1: Studies Characteristics

Authors Publication Date	Country	Intervention type EPOC taxonomy (main component in bold)	Intervention duration	Type of neurocognitive disorder and severity (MMSE if available)	Sample size[a]	Age, Mean (SD)[b]	Female No (%)[b]
Callahan 2006 [42]	United States	**Teams**/case management/self-management/use of information and communication technology	maximum of 12 months	AD; “moderate severity” (mean MMSE: 18)	I: 84; C: 69	I: 77 (6); C: 78 (6)	I: 39 (46); C: 27 (39)
Bass 2003 [43,44]	United States	**Self-management**/case management	12 months	Dementia diagnosis or a symptom code indicating memory loss; severity not reported	I:72; C:48	Not reported	Not reported
Challis 2004 [45]	United Kingdom	**Comprehensive geriatric assessment**	6 months	MMSE lower than 24 (I: 67%; C: 54%); severity not reported	I: 129; C: 127	I: 82 (7); C: 82 (8)	I: 96 (74); C: 92 (72)
Chien 2008 [36]	Hong Kong	**Self-management**/case management	6 months	AD (DSM IV criteria); 80% of the sample at “early (ambulatory) stage"	I: 44; C: 44	Total sample: 68 (7)	Total sample: 38 (43)
Chien 2011 [37]	Hong Kong	**Self-management**/case management	24 months	AD (DSM IV criteria); “mild or moderate” severity (mean MMSE: I:18, C:17)	I: 46; C: 46	I: 68 (7); C: 67 (7)	I: 19 (41); C: 21 (46)
Duru 2009 [46,47]	United States	**Case management**/self-management/use of information and communication	18 months	AD, vascular dementia and other types of dementia; (Blessed-Roth Dementia Scale mean scores: I: 5, C: 6)	I: 238; C: 170	I: 79 (6); C: 80 (7)	I: 94 (55); C: 71 (56)

		technology/educational material and educational meetings (healthcare professionals' education)					
Eloniemi-Sulkava 2009 [40]	Finland	**Teams**/comprehensive geriatric assessment/case management/self-management	24 months	AD, vascular dementia and other types of dementia; "mild", "moderate" and "severe" dementia (mean MMSE: 14)	I: 63; C: 62	I: 78 (7); C: 77 (6)	I: (43)[c]; C: (32)[c]
Joling 2013 [38,48,49]	Netherlands	**Self-management**	12 months	Dementia diagnosis; (mean MMSE: I: 21, C: 22)	I: 96; C: 96	I: 73 (9); C: 77 (8)	I: 30 (31); C: 32 (33)
Laakkonen 2016 [41,50]	Finland	**Self-management**	8 weeks	Dementia diagnosis; "possible", "mild", "moderate" and "severe" dementia (mean MMSE: I: 20, C: 22)	I: 67; C: 69	I: 77 (6); C: 77 (6)	I: 25 (37); C: 26 (38)
Meeuwsen 2013 [51–53]	Netherlands	**Site of service delivery** (memory clinic vs general practitioner)/teams	12 months	AD, vascular dementia, other types of dementia; "very mild" and "mild" dementia (mean MMSE: 23)	I: 87; C: 88	I: 78 (6); C: 78 (5)	I: 54 (62); C: 52 (59)
Menn 2012 [39,54,55]	Germany	**Self-management**/educational material and educational meetings (healthcare professionals' education)/shared care	24 months	Dementia diagnosis; "mild" and "moderate" dementia (mean MMSE: I-groupB: 19, I-groupC: 19, C: 18)	I-groupB: 109 I-groupC: 110 C: 171	I-groupB: 79 (6); I-groupC: 81 (6); C: 81 (7)	I-groupB: (68)[c]; I-groupC: (71)[c]; C: (67)[c]

Nichols 2017 [35,56]	United States	**Self-management**	6 months	AD, Dementia diagnosis or MMSE lower than 24; severity not reported	I: 98; C: 99	I: 80 (8); C: 78 (9)	I: 59 (60); C: 59 (60)
Rubenstein, 2007 [57]	United States	**Case management**/teams	36 months	Cognitive impairment (10-item Geriatric Postal Screening Survey); severity not reported	I: 380; C: 412	I: 75 (6); C: 74 (6)	I: 14 (4); C: 11 (3)
Samus 2014 [58,59]	United States	**Teams**/case management/self-management/use of information and communication technology	18 months	Dementia or "Cognitive Disorder Not Otherwise Specified" (DSM IV criteria); "mild", "moderate" and "severe" dementia (mean MMSE: 19)	I: 110; C: 193	I: 84 (6); C: 84 (6)	I: 73 (66); C:120 (62)
Søgaard 2014 [60–62]	Denmark	**Self-management**	36 months	AD, mixed dementia, or Lewy body dementia; "mild" dementia (mean MMSE: 24)	I: 163; C: 167	I: 76 (8); C: 75 (7)	I: 87 (53); C: 92 (55)
Thyrian 2017 [13,63,64]	Germany	**Case management**/ use of information and communication technology /teams	12 months	Positive screening for dementia (DemTect procedure); "no hint for", "mild", "moderate" and "severe" dementia (mean MMSE: 23)	I: 408; C: 226	I: 81 (6); C: 80 (5)	I: 178 (61); C: 70 (60)
Wray 2010 [65]	United States	**Self-management**	10 weeks	Diagnosis of dementia; "moderate-to-severe" dementia	I: 83; C: 75	I: 78 (7); C: 79 (8)	Not reported

Abbreviations: AD, Alzheimer's Disease; DSM IV, Diagnostic and Statistical Manual of Mental Disorders IV; EPOC, Effective Practice and Organization of Care Cochrane Group; MMSE, Mini-Mental State Examination; I, Intervention Group; C, Control Group

[a] The numbers are the randomised numbers of participants in each group (as reported or calculated).

[b] Denominators are the number of participants with available baseline characteristics. They differ from the randomised numbers of participants for two trials: Thyrian 2017 and Duru 2009. In Thyrian 2017, the numbers of participants with available baseline characteristics are 291 in intervention and 116 in control groups. In Duru 2009, the numbers of participants with available baseline characteristics are 170 in intervention and 126 in control groups.

[c] Only percentages of female participants were reported.

Seventeen unique trials provided data on 4,549 community-dwelling persons living with dementia (study populations ranging from 88 to 792 persons, median randomisation arm size: 96) (Table *4.1*) (13.36–65). These persons had a mean age of 77 years (standard deviation: 4) and 49% were females (proportion ranged from 4% to 74%). Twelve of the seventeen trials reported dementia severity at baseline, ranging from mild to severe: 6/12 mild, 5/12 moderate, 1/12 moderate to severe. None of the trials reported selection of participants based on risk of acute hospital use.

Health service interventions consisted of one or a combination of the following EPOC taxonomy components: case management (9/17), self-management (13/17), comprehensive geriatric assessment (2/17), educational materials/educational meetings (healthcare professional education) (2/17), use of information and communication technology (4/17), teams (6/17), shared care (1/17), site of service delivery (memory clinic) (1/17). None of the interventions involved financial or governance arrangements. Interventions were implemented and evaluated in studies conducted in the USA (7), in Europe (8) and in Hong Kong (2). Duration of interventions ranged from two to 36 months, median duration 12 months.

The sources of the data for each outcome measure included in the meta-analysis are presented in Table *4.2*.

Table 4.2: Intervention types and outcomes included in the meta-analysis for each study

Authors **Publication Date**	**Intervention type EPOC taxonomy** **(main component in bold)**	**Outcomes**				
		Proportion of patients with at least one ED visit	Mean number of ED visits	Proportion of patients with at least one hospital admission	Mean number of hospital admissions	Mean number of hospital days
Callahan 2006 [42]	**Teams**/case management/self-management/use of information and communication technology			✓		✓
Bass 2003 [43,44]	**Self-management**/case management		✓		✓	
Challis 2004 [45]	**Comprehensive geriatric assessment**	✓	✓	✓		✓
Chien 2008 [36]	**Self-management**/case management	✓		✓	✓	✓
Chien 2011 [37]	**Self-management**/case management	✓		✓	✓	✓
Duru 2009 [46,47]	**Case management**/self-management/use of information and communication technology/ educational material and educational meetings (healthcare professionals' education)	✓	✓	✓	✓	
Eloniemi-Sulkava 2009 [40]	**Teams**/comprehensive geriatric assessment/case management/self-management			✓		✓
Joling 2013 [38,48,49]	**Self-management**			✓		✓

Laakkonen 2016 [41,50]	**Self-management**			✓		✓
Menn 2012 [39,54,55]	**Self-management**/educational material and educational meetings (healthcare professionals' education)/shared care			✓	✓	✓
Nichols 2017 [35,56]	**Self-management**	✓	✓	✓	✓	✓
Rubenstein, 2007 [57]	**Case management**/teams			✓		✓
Samus 2014 [58,59]	**Teams**/case management/self-management/use of information and communication technology	✓	✓	✓	✓	✓
Søgaard 2014 [60–62]	**Self-management**	✓	✓	✓	✓	✓
Thyrian 2017 [13,63,64]	**Case management**/ use of information and communication technology /teams	✓	✓	✓	✓	✓
Wray 2010 [65]	**Self-management**				✓	✓

Abbreviations: EPOC, Effective Practice and Organization of Care Cochrane Group.

4.5.2 Impact on acute hospital use

None of the considered outcome comparisons provided conclusive evidence supporting the hypothesis that health service interventions lead to a decrease in service use as measured by ED visits, hospital admission or hospital days (

Figure 4.2 and Figure 4.3, and Figures 4.4-4.49 in S1 File). Furthermore, in every meta-analysis, the estimated 95% prediction intervals indicated that an important increase in service use may be associated with the interventions. Post hoc subgroup analyses did not suggest any systematic dependencies of effects in relation to type of intervention, country or follow-up time.

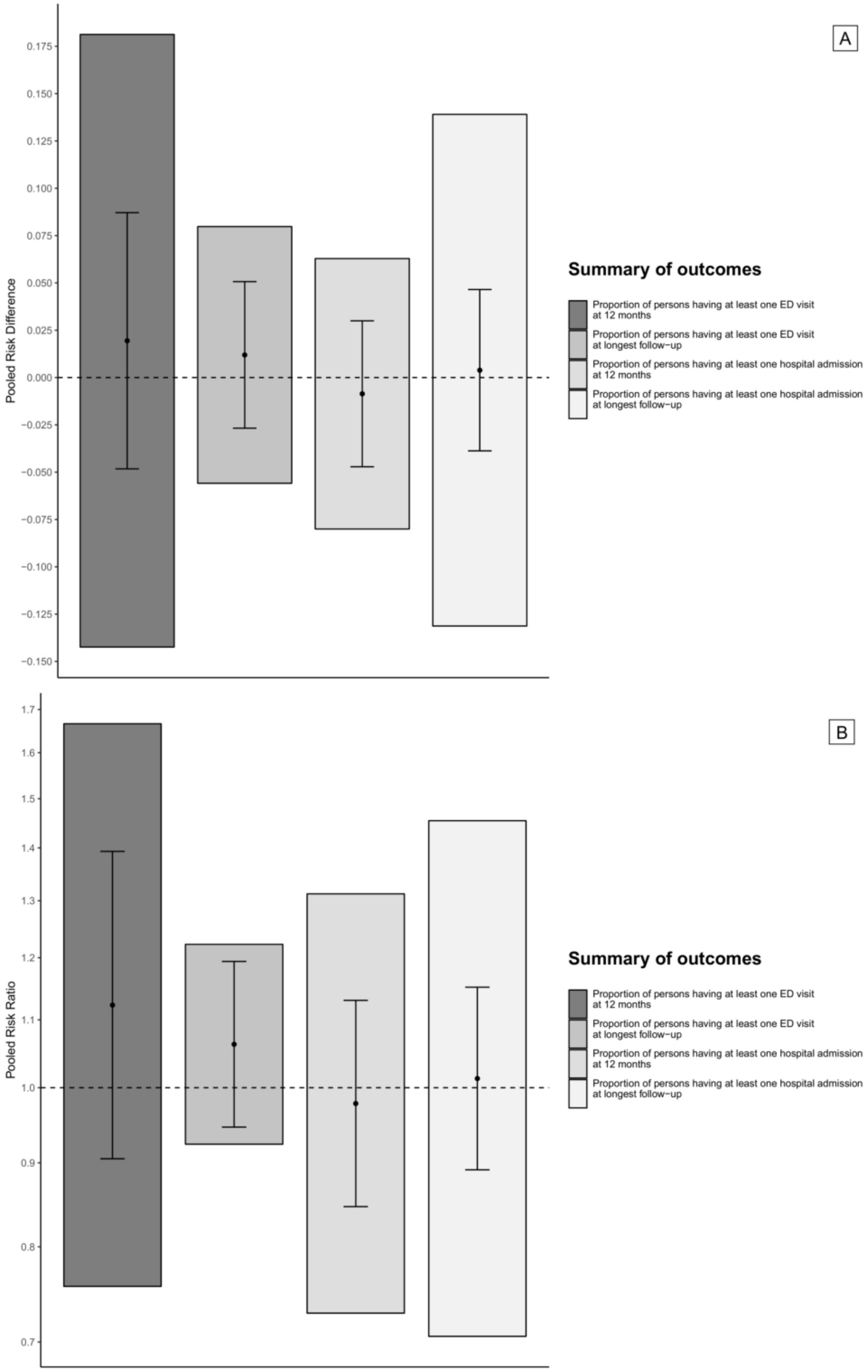

Figure 4.2 : Pooled risk differences (2A) and pooled risk ratios (2B) for dichotomous outcomes (solid dots), 95% confidence intervals (black coloured error bars), and 95% prediction intervals (grey shaded bar plots).
ED : Emergency Department

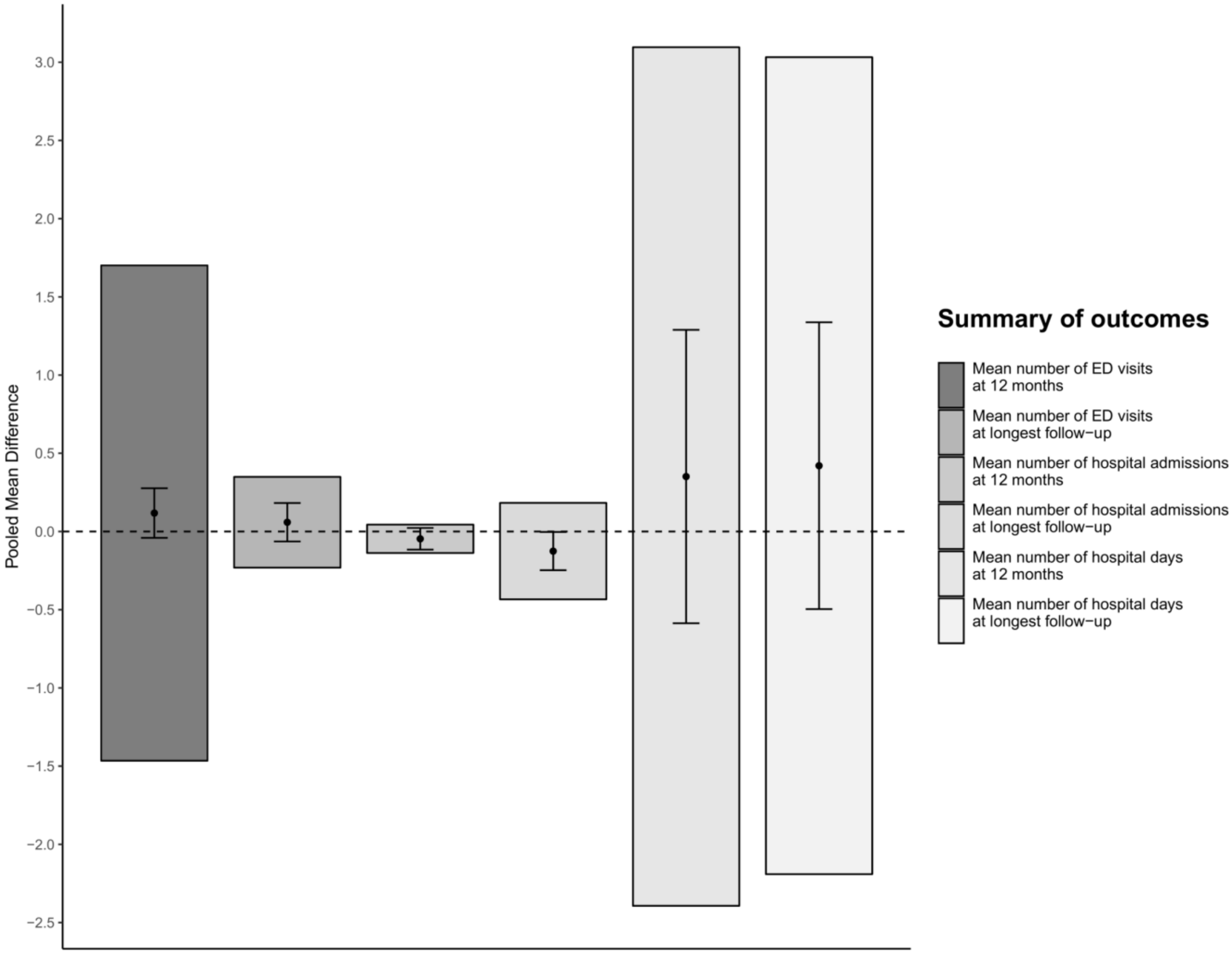

Figure 4.3 Pooled mean differences for continuous outcomes (solid dots), 95% confidence intervals (black coloured error bars), and 95% prediction intervals (grey shaded bar plots)
ED : Emergency Department

4.5.3 Quality and robustness of the evidence

Four of the 17 trials were judged as having at least one area of high risk of bias (Figure *4.9* in S1 File). Eleven trials reported adequate sequence generation, 11 trials properly concealed allocation, 14 trials implemented blinding of outcome assessors, and 15 trials adequately addressed incomplete outcome data. Only eight trials published a study protocol and reported (or provided upon request) pre-specified outcomes.

Sensitivity analyses to determine the robustness of meta-analysis results did not lead to any change in estimated pooled effects that would alter the conclusions. Sensitivity analyses of the impact of unpublished data provided by authors on meta-analysis results did not suggest reporting bias.

Discussion

The results of this systematic review and meta-analysis did not establish superiority of health service interventions over usual care to reduce acute hospital use in community-dwelling persons with dementia. There was no detectable signal favouring any type of health service intervention. Overall evidence had low risk of bias. Sensitivity analyses confirmed the robustness of the results. Furthermore, for every outcome, the estimated 95% prediction intervals indicated that an important increase in service use may be associated with these interventions.

These results are of particular interest to policy makers, persons living with dementia, their caregivers, and healthcare professionals. There is no cure or disease-modifying treatment for dementia and no promising advances in the near future [66]. Improving healthcare delivery remains essential to limit rising acute hospital use and associated costs, improve quality of life of patients and their caregivers, and prevent adverse outcomes for persons living with dementia. The absence of evidence for an impact on acute hospital use of any type of health service intervention is thus highly concerning. The possibility that these interventions may increase acute hospital use is not to be disregarded.

Non-intended effects of health service interventions, such as increase in service use (ED visits, hospital admissions, and hospital days) have previously been witnessed in several contexts, such as self-management interventions. These non-intended effects were associated with either beneficial or adverse outcomes. Some health service interventions, like self-management interventions for caregivers, have led to non-intended beneficial outcomes: increased service use due to increased caregiver awareness of symptoms, diagnosis procedures and treatment options [38,60]. Some health service interventions, such as self-management in patients with chronic obstructive pulmonary disease (COPD), have led to non-intended adverse outcomes. A decreased service use due to patient overconfidence in self-management led to higher mortality [67].

It is essential to better characterize acute hospital use and inappropriate use, so that beneficial and adverse non-intended outcomes can be sorted out. In the trials included in this systematic review and meta-analysis, only total acute hospital use was measured. However, community-dwelling persons with dementia would have a much greater chance of potentially avoidable hospitalizations (74%) or ED visits (51%), than persons without dementia [5]. Definitions and measures of potentially avoidable acute hospital use such as Ambulatory-Care Sensitive Conditions (ACSC) hospital admissions have recently been questioned for inaccuracy in community-dwelling persons living with dementia [68]. Developing accurate measures of potentially avoidable service use in community-dwelling persons living with dementia is essential [68].

Two main reasons could explain the inconclusive results of this evidence synthesis. First, the included RCTs might not have detected an effect because of lack of statistical power. Lack of power could be a consequence of inappropriate specification of the target population. These RCTs did not exclusively consider high-risk populations for acute hospital use. Targeting high-risk populations may be necessary to show measurable reductions in acute hospital use due to health service interventions. To our knowledge, no screening tool is available to identify community-dwelling persons with dementia with high-risk of acute hospital use, so its development is essential [69].

Second, there might be a gap between the focus of the interventions and the actual causes of acute hospital use [20,70]. The interventions may not have effectively addressed the causes of acute hospital use of community-dwelling persons with dementia [20,70,71]. Only a few types of interventions were tested in the 17 trials, mainly case management and self-management. Case management would have been effective if the reasons for acute hospital use were care fragmentation. However, care fragmentation was not identified as a major determinant of crises leading to acute hospital use [70,72]. Since behavioural and psychological symptoms of dementia are not leading causes of hospital admissions, increasing self-management skills for patients and caregivers would not have been effective [3,71].

The literature suggests that physical conditions are a leading cause of acute hospital use in persons with dementia. Most admissions are due to accidents and injuries arising from falls, urinary tract and respiratory infections, or complications of chronic diseases [3,70–72]. Improving access to primary health care and training home-care staff on early detection and appropriate management of the common causes of acute hospital use could reduce avoidable acute hospital use [68,73].

Caregiver availability and caregiver health are other important determinants of acute hospital use. Indeed, caregiver stress, burden, mental health and sudden absence (hospital admission or death) are identified as major drivers of crises [70–72,74]. Offering timely support to caregivers through respite care or temporary home care could reduce avoidable acute hospital use [20].

During the final year of life, nearly 80% of community-dwelling persons with dementia are hospitalized [5]. Some of these hospitalizations may not be the choice of patients and caregivers, who may have preferred to obtain end-of-life care at home [75]. Palliative care in older persons with advanced illness has been shown to double the chances of dying at home [76]. Interventions emphasizing a palliative care approach with discussion of advanced directives and preferences for end-of-life care might reduce undesired acute hospital use.

4.5.4 Strengths and limits

Our study has strengths as well as potential limitations. This is the first systematic review and meta-analysis on the impact of any type of health service interventions on acute hospital use in community-dwelling persons with dementia, and the first to include predominantly unpublished data provided by the authors of included randomised controlled trials. Two main challenges were encountered when retrieving data for this synthesis: i) some evidence was published as cost-effectiveness analysis; ii) outcomes were measured in different ways. We gathered data pro-actively by contacting authors of identified trials, and used a systematic approach for data transformation and imputation. These strategies dramatically increased the range of synthesised evidence and were likely to have decreased potential publication bias impact on our effect estimates [77,78].

Acknowledging the complexity of acute hospital use prevention in this vulnerable population, we included any type of health service intervention as defined and classified in the Cochrane EPOC taxonomy [24]. This is a common approach in Cochrane reviews [79], but might have increased the observed heterogeneity. We computed prediction intervals and performed sub-group analyses to explain possible sources of effect heterogeneity. We used prediction intervals to conservatively interpret the range of expected treatment effects in future studies rather than an average effect composed by a set of different underlying effects. Our sub-group analyses were based on limited descriptions provided in the articles, which limited our understanding of heterogeneity [80]. For example, usual care and primary care access might vary widely between countries, regions, or subpopulations and were rarely described in the studies. Likewise, intervention descriptions were sometimes too limited to classify interventions according to the EPOC taxonomy. We thus looked for protocols and companion articles and performed independent data extraction to reduce subjectivity.

4.6 Conclusion, policy implications and future research

With the data available, it was not possible to establish superiority of any health service intervention beyond usual care to reduce acute hospital use in community-dwelling persons with dementia. In fact, our evidence synthesis findings do not rule out the possibility that the studied health service interventions may be associated with an important increase in service use.

We have no recommendations for health service interventions to be implemented. However, we can propose a research agenda focused on: 1) development of accurate measures of potentially avoidable acute hospital use by community-dwelling persons with dementia; 2) identifying the causes and determinants of potentially avoidable acute hospital use; 3) development of a validated screening tool to target high-risk population; 4) co-design of health service interventions with patients and caregivers that address the causes of avoidable acute hospital use; and 5) rigorous testing of the impact of these co-designed interventions in high-risk community-dwelling persons with dementia.

4.7 Acknowledgments

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4.9 Appendix and supporting information

4.9.1 Appendix A: Detailed eligibility criteria of intervention

Any health services intervention as defined and classified by the Effective Practice and Organization of Care Cochrane Group (EPOC) Taxonomy 2015: “delivery arrangements”, “financial arrangements”, “governance arrangements”, or “implementation strategies” [1.]

Delivery arrangements changes includes, but are not limited to

- changes in where the healthcare is provided and changes to the healthcare environment (e.g. respite care, memory clinic),
- changes in who is providing care and how the workforce is managed (e.g. self-management), coordination of care and management of care processes (e.g.: case management, interdisciplinary team, comprehensive geriatric assessment, care transition, liaison with community organizations (e.g. home care, Alzheimer’s Society), disease management (decision support tools (protocol, algorithm),
- Information and communication technology (e.g.: health information systems, smart home technology, telemedicine).

Financial arrangements changes include, but are not limited to, changes in out of pocket payments, and financial incentives.

Implementation strategies include, but are not limited to, educational meetings, educational materials targeted at healthcare workers, inter-professional education, and local opinion leaders.

As there is currently no consensual definition of what a self-management intervention in dementia is, and to whom should it be delivered: the caregiver or the care recipient, included interventions were those corresponding to the EPOC definition of self-management: “Shifting or promoting the responsibility for healthcare or disease management to the patient and/or their family.” Included interventions of self-management were thus aimed at the caregiver or the patient or both. Reminiscence groups were excluded as they often do not provide group members with new skills in problem solving and goal setting. Therapy (e.g. cognitive behavioural therapy, occupational therapy) directed to the care recipient or the caregiver was also excluded even if these interventions may help coping with caregiving or the disease, since their primary aim is to provide therapy rather than provide skills or social support. We excluded supports groups for the caregiver or the patients, when they were not including any component of a self-management intervention and just providing emotional support.

4.9.2 Appendix B: Medline full electronic search strategy

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily, Ovid MEDLINE(R) and Ovid OLDMEDLINE(R) <1946 to Present>
Search Strategy:
----

1 dementia/ or aids dementia complex/ or alzheimer disease/ or aphasia, primary progressive/ or primary progressive nonfluent aphasia/ or creutzfeldt-jakob syndrome/ or dementia, vascular/ or cadasil/ or dementia, multi-infarct/ or diffuse neurofibrillary tangles with calcification/ or frontotemporal lobar degeneration/ or frontotemporal dementia/ or huntington disease/ or kluver-bucy syndrome/ or lewy body disease/ or "pick disease of the brain"/
2 cognition disorders/ or auditory perceptual disorders/ or huntington disease/ or mild cognitive impairment/
3 ((cogn* adj1 disorder?) or (cogn* adj1 impairment?)).mp.
4 (dementia? or alzheimer*).mp.
5 1 or 2 or 3 or 4
6 patient care management/ or comprehensive health care/ or exp patient care planning/ or case management/ or exp patient-centered care/ or exp critical pathways/ or "delivery of health care"/ or exp after-hours care/ or exp "delivery of health care, integrated"/ or exp health services accessibility/ or exp disease management/ or exp patient care team/ or patient-centered care/ or "quality of health care"/ or exp "outcome and process assessment (health care)"/ or "utilization review"/
7 ((interdisciplin* or multidisciplin*) adj2 team?).mp.
8 (enhanc* adj access*).ti,ab.
9 (memory adj clinic?).mp.
10 ((care adj coordinat?) or (care adj transit?) or (care adj manag*) or (case adj manag*) or (care adj navigator?) or (critical adj pathway?) or (clinical adj pathway?) or (continu* adj1 care) or (disease? adj management)).mp.
11 intervention*.ti,ab.
12 exp Program Development/

13 (program adj (development or evaluation)).mp.
14 self care/ or patient education as topic/ or consumer participation/
15 (self-mangement or "self management" or self?management).ti,ab.
16 exp Geriatric Assessment/
17 Follow-Up Studies/
18 exp Models, Organizational/
19 model*.ti,ab.
20 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
21 Primary Health Care/
22 family nursing/ or family practice/ or general practice/ or home nursing/
23 (primary adj2 care).mp.
24 ((family adj1 practi*) or (general adj1 practi*)).mp.
25 exp Physicians, Primary Care/ or exp Physicians, Family/
26 exp General Practitioners/
27 (physician? adj (family or general)).mp.
28 21 or 22 or 23 or 24 or 25 or 26 or 27
29 community health nursing/ or community mental health services/ or Community Health Centers/ or Community medicine/ or Community psychiatry/ or Home Care Services/ or Community Health Services/
30 (community-based or community?based or "community based").ti,ab.
31 (home-based or home?based or "home based").ti,ab.
32 (community adj3 (health or service? or center? or medicine or psychiatry)).ti,ab.
33 (community-dwelling or community?dwelling or "community dwelling").ti,ab.
34 (homebound or (living adj home)).ti,ab.
35 29 or 30 or 31 or 32 or 33 or 34
36 28 or 35
37 20 or 36
38 5 and 37
39 randomized controlled trial.pt.
40 controlled clinical trial.pt.
41 placebo.ti,ab.

42 randomized.ab.

43 randomly.ab.

44 trial.ti.

45 clinical trials as topic.sh.

46 39 or 40 or 41 or 42 or 43 or 44 or 45

47 exp animals/ not humans.sh.

48 46 not 47

49 38 and 48

50 limit 49 to yr="1995 -Current"

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4.9.3 Appendix C: Detailed origin, transformation or imputation of reported data

A systematic approach to data collection, transformation and imputation was followed, as recommended in the Data extraction for complex meta-analysis (DECiMAL) guide [2].

Data transformation consisted of simple algebraic transformation: addition of two types of admissions representing total hospital admissions, transformation from percentage to fraction, from monthly data over a time period to total data at this time period end point, from standard error to standard deviation, from mean number of event for the subsample that had at least one event to the mean number of event for the total sample irrespective whether participants had any event.

Data imputation consisted of imputation of missing variance from the weighted average of the available variances, weighted by study sample size.

4.9.4 Supplementary Tables

Table 4.3: Origin, transformation or imputation of data for proportions of persons having at least one Emergency Department visit

Studies	12 months	Longest follow-up
Challis 2004 [3]	x	Data published in the article: Challis Age Ageing 2004 and confirmed by the author
Chien 2008 [4]	Additional data sent by the author. Data was given in percentage, numerators were calculated with the denominators given in correspondence	Additional data sent by the author. Data was given in percentage, numerators were calculated with the denominators given in correspondence
Chien 2011 [5]	Additional data sent by the author. Data was given in percentage, numerators were calculated with the denominators given in correspondence	Additional data sent by the author. Data was given in percentage, numerators were calculated with the denominators given in correspondence
Duru 2009 [6,7]	x	Data published in the article: Duru Am J Manag Care 2009. Denominators from the article (Table 2)
Meeuwsen 2013 [8–10]	Additional data sent by the author. Data was given in percentage, numerators were calculated with denominators published in the article	Additional data sent by the author. Data was given in percentage, numerators were calculated with denominators published in the article
Nichols 2017 [11,12]	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.
Samus 2014 [13,14]	x	Additional data sent by author. Denominators from the data published in the article: Amjad Health services Research 2017.
Sogaard 2014 [15–17]	x	Additional data sent by the author. Denominators given in correspondence
Thyrian 2017 [18–20]	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.

Table 4.4: Origin, transformation or imputation of data for mean number of Emergency Department visit

Studies	12 months	Longest follow-up
Bass 2003 [21,22]	Data published in article: Bass The Gerontologist 2003. Denominators calculated from the proportion of individuals randomized in each group from article.	Data published in article: Bass The Gerontologist 2003. Denominators calculated from the proportion of individuals randomized in each group from article.
Challis 2004 [3]	x	Data transformed from the mean number of visits in subsample and rate of visits (from article Challis Age Aging 2004 and confirmed by author), Standard Deviation (SD) imputed from the other SDs for this outcome
Duru 2009 [6,7]	x	Calculated from the monthly data given in article (Duru Am J Manag Care 2009) and the rate. SD imputed from the other SDs for this outcome. Denominators from the article (Table 2)
Nichols 2017 [11,12]	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.
Samus 2014 [13,14]	x	Data published in Amjad Health Services Research 2017. Standard error provided, SD calculated by multiplying by square root of the number of patients in the group. Denominators published in article
Sogaard 2014 [15–17]	x	Data published in article Sogaard Dement Geriatr Cogn Disord 2014. Standard error provided, SD calculated by multiplying by square root of the number of patients in the group. Denominators published in the article
Thyrian 2017 [18–20]	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.

Table 4.5: Origin, transformation or imputation of data for proportions of persons having at least one hospital admission

Studies	12 months	Longest follow-up
Callahan 2006 [23]	Data published in article Callahan JAMA 2006. Data in the article given in percentages, the numerators were calculated from the denominators, with denominators = randomized individuals, as done by the author in correspondence (for additional data for mean hospital days)	Data published in article Callahan JAMA 2006. Data in the article given in percentages, the numerators were calculated from the denominators, with denominators = randomized individuals, as done by the author in correspondence (for additional data for mean hospital days)
Challis 2004 [3]	x	Data published in an article : Challis Age Ageing 2004 and confirmed by the author
Chien 2008 [4]	Additional data sent by the author. Data was given in percentage, numerators were calculated with the denominators given in correspondence	Additional data sent by the author. Data was given in percentage, numerators were calculated with the denominators given in correspondence
Chien 2011 [5]	Additional data sent by the author. Data was given in percentage, numerators were calculated with the denominators given in correspondence	Additional data sent by the author. Data was given in percentage, numerators were calculated with the denominators given in correspondence
Duru 2009 [6,7]	x	Data published in the article: Duru Am J Manag Care 2009. Denominators from the article (Table 2)
Eloniemi-Sulkava 2009 [24]	x	Additional data sent by the author (Pitkala). Denominators in author correspondence. Also corresponds to the denominators found in article (Table 2 – results)
Joling 2013 [25–27]	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.
Laakonen 2016 [28,29]	x	Additional data sent by the author. Intervention and control groups were identified according to the article data (sample of 67 in intervention group and

		sample of 69 in control group – denominators given in article were used)
Meeuwsen 2013 (8–10)	Data published in the article: Meuwsen Plos One 2013. Denominators published in the article	Data published in the article: Meuwsen Plos One 2013. Denominators published in the article
Menn 2012 (30–32)	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.
Nichols 2017 (11,12)	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.
Rubenstein 2007 (33)	Data published in an article: Rubenstein JAGS 20 I07. Denominators taken from the published flowchart of participants for the specific time point	Data published in an article: Rubenstein JAGS 2007. Denominators taken from the published flowchart of participants for the specific time point
Samus 2014 (13,14)	x	Additional data sent by author, denominators from the data published in the article: Amjad Health services Research 2017
Sogaard 2014 (15–17)	x	Additional data sent by the author, denominators given in correspondence
Thyrian 2017 (18–20)	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.

Table 4.6: Origin, transformation or imputation of data for mean number of hospital admission

Studies	12 months	Longest follow-up
Bass 2003 (21,22)	Data published in an article : Bass The Gerontologist 2003. Denominators were calculated from the proportion of individuals randomized in each group written in article.	Data published in an article : Bass The Gerontologist 2003. Denominators were calculated from the proportion of individuals randomized in each group written in article.
Chien 2008 (4)	Calculated from additional data sent by the author (mean number of hospitalizations of the subgroup and rate of hospitalization). SD was imputed from the other SDs for this outcome	Calculated from additional data sent by the author (mean number of hospitalizations of the subgroup and rate of hospitalization). SD was imputed from the other SDs for this outcome
Chien 2011 (5)	Calculated from additional data sent by the author (mean number of hospitalizations of the subgroup and rate of hospitalization). SD was imputed from the other SDs for this outcome	Calculated from additional data sent by the author (mean number of hospitalizations of the subgroup and rate of hospitalization). SD was imputed from the other SDs for this outcome
Duru 2009 (6,7)	x	Calculated from the monthly data given in article (Duru Am J Manag Care 2009) and the rate. SD was imputed from the other SDs for this outcome. Denominators from the article (Table 2)
Menn 2012 (30–32)	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.
Nichols 2017 (11,12)	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.
Samus 2014 (13,14)	x	Data published in Amjad Health services Research 2017. Standard error provided, SD calculated by multiplying by square root of the number of patients in the group. Denominators given in article
Sogaard 2014	x	Data published in article Sogaard Dement Geriatr Cogn Disord 2014. Standard error

(15–17)		provided, SD calculated by multiplying by square root of the number of patients in the group. Denominators published in the article
Thyrian 2017 (18–20)	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.
Wray 2010 (34)	Calculated from the 0-6 months and 6-12 months data on both "acute admission" and "ICU admission" given in article (Wray The Gerontologist 2010). Denominators are the numbers of randomized individuals (no other available data – data from administrative source). SD was imputed from the other SDs for this outcome	Calculated from the 0-6 months and 6-12 months data on both "acute admission" and "ICU admission" given in article (Wray The Gerontologist 2010). Denominators are the numbers of randomized individuals (no other available data – data from administrative source). SD was imputed from the other SDs for this outcome

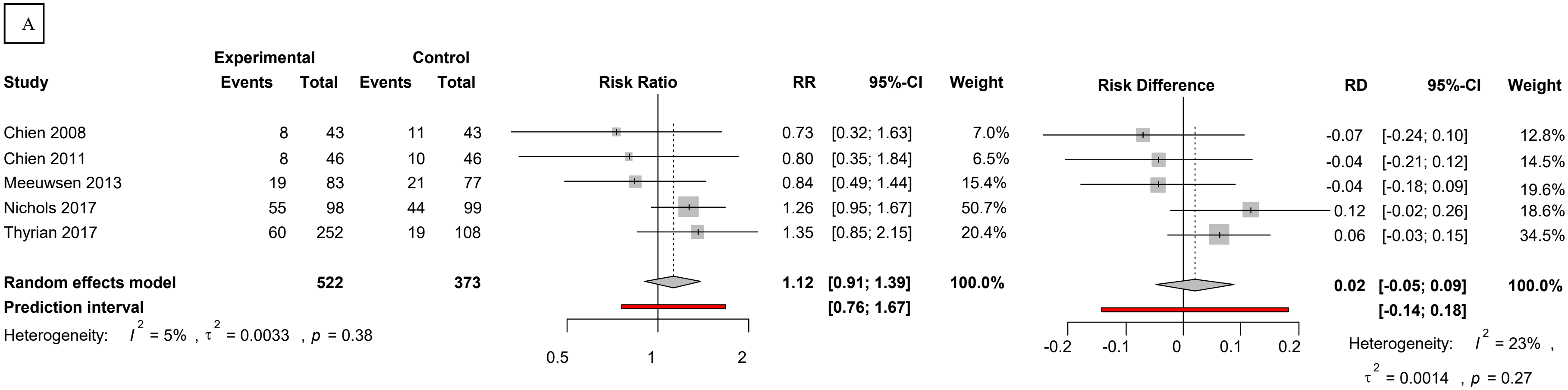
Table 4.7: Origin, transformation or imputation of data for mean number of hospital days

Studies	12 months	Longest follow-up
Callahan 2006 (23)	Data published in the article Callahan JAMA 2006, SD additional data sent by the author. The denominators are the numbers of randomized individuals, as done by the author in correspondence (for additional data for mean hospital days)	Data published in the article Callahan JAMA 2006, SD additional data sent by the author. The denominators are the numbers of randomized individuals, as done by the author in correspondence (for additional data for mean hospital days)
Challis 2004 (3)	x	Data transformed from the mean number of visits in subsample and rate of visits (from article Challis Age Aging 2004 and confirmed by author), SD imputed.
Chien 2008 (4)	Calculated from additional data sent by the author (mean number of hospital days of the subgroup and rate of hospitalization). SD was imputed from the other SDs for this outcome	Calculated from additional data sent by the author (mean number of hospital days of the subgroup and rate of hospitalization). SD was imputed from the other SDs for this outcome
Chien 2011 (5)	Calculated from additional data sent by the author (mean number of hospital days of the subgroup and rate of hospitalization). SD was imputed from the other SDs for this outcome	Calculated from additional data sent by the author (mean number of hospital days of the subgroup and rate of hospitalization). SD was imputed from the other SDs for this outcome
Eloniemi-Sulkava 2009 (24)	x	Additional data sent by the author (Pitkala). Denominators in author correspondence. Also corresponds to the denominators found in article (Table 2 – results)
Joling 2013 (25–27)	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.
Laakonen 2016 (28,29)	X	Additional data sent by the author. Intervention and control groups were identified according to the article data (sample of 67 in intervention group and sample of 69 in control group – these denominators given in article were used).

		Total number of days available in the article.
Meeuwsen 2013 (8–10)	Additional data sent by the author. Denominators published in the article	Additional data sent by the author. Denominators published in the article
Menn 2012 (30–32)	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.
Nichols 2017 (11,12)	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.
Rubenstein 2007 (33)	Data published in an article : Rubenstein JAGS 2007 Denominators taken from the published flowchart of participants for the specific time point	Data published in an article : Rubenstein JAGS 2007 Denominators taken from the published flowchart of participants for the specific time point
Samus 2014 (13,14)	x	Data published in Amjad Health services Research 2017. Standard error provided, SD calculated by multiplying by square root of the number of patients in the group. Denominators given in article
Sogaard 2014 (15–17)	x	Data published in article Sogaard Dement Geriatr Cogn Disord 2014. Standard error provided, SD calculated by multiplying by square root of the number of patients in the group. Denominators published in the article
Thyrian 2017 (18–20)	Additional data sent by the author. Denominators given in correspondence.	Additional data sent by the author. Denominators given in correspondence.
Wray 2010 (34)	Calculated from the 0-6 months and 6-12 months data given on both "acute bed days" and "ICU bed days" in article (Wray The Gerontologist 2010). Denominators are the numbers of randomized individuals (no other available data – data from administrative source). SD was imputed from the other SDs for this outcome	Calculated from the 0-6 months and 6-12 months data given on both "acute bed days" and "ICU bed days" in article (Wray The Gerontologist 2010). Denominators are the numbers of randomized individuals (no other available data – data from administrative source). SD was imputed from the other SDs for this outcome

4.9.5 Supplementary Figures

Figure 4.4: Proportion of persons having at least one Emergency Department visit (Risk Ratio and Risk Difference)

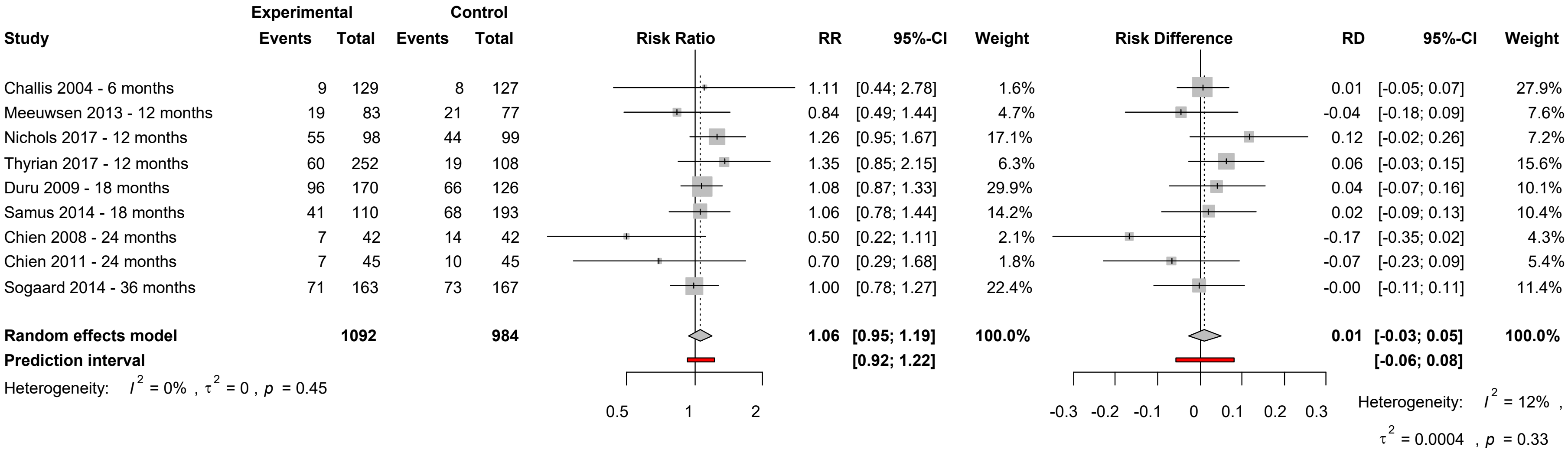


Study	**Experimental**		**Control**		**RR**	**95%-CI**	**Weight**	**RD**	**95%-CI**	**Weight**
	Events	**Total**	**Events**	**Total**						
Chien 2008	8	43	11	43	0.73	[0.32; 1.63]	7.0%	-0.07	[-0.24; 0.10]	12.8%
Chien 2011	8	46	10	46	0.80	[0.35; 1.84]	6.5%	-0.04	[-0.21; 0.12]	14.5%
Meeuwsen 2013	19	83	21	77	0.84	[0.49; 1.44]	15.4%	-0.04	[-0.18; 0.09]	19.6%
Nichols 2017	55	98	44	99	1.26	[0.95; 1.67]	50.7%	0.12	[-0.02; 0.26]	18.6%
Thyrian 2017	60	252	19	108	1.35	[0.85; 2.15]	20.4%	0.06	[-0.03; 0.15]	34.5%
Random effects model		**522**		**373**	**1.12**	**[0.91; 1.39]**	**100.0%**	**0.02**	**[-0.05; 0.09]**	**100.0%**
Prediction interval						**[0.76; 1.67]**			**[-0.14; 0.18]**	

Heterogeneity: $I^2 = 5\%$, $\tau^2 = 0.0033$, $p = 0.38$

Heterogeneity: $I^2 = 23\%$, $\tau^2 = 0.0014$, $p = 0.27$

B

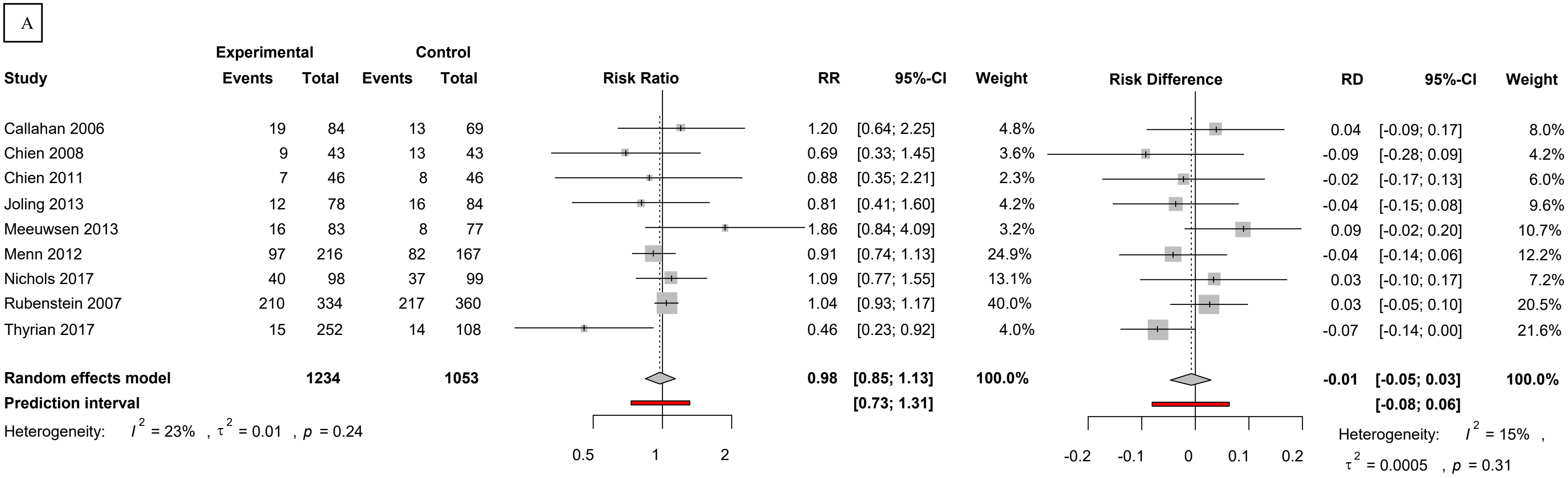


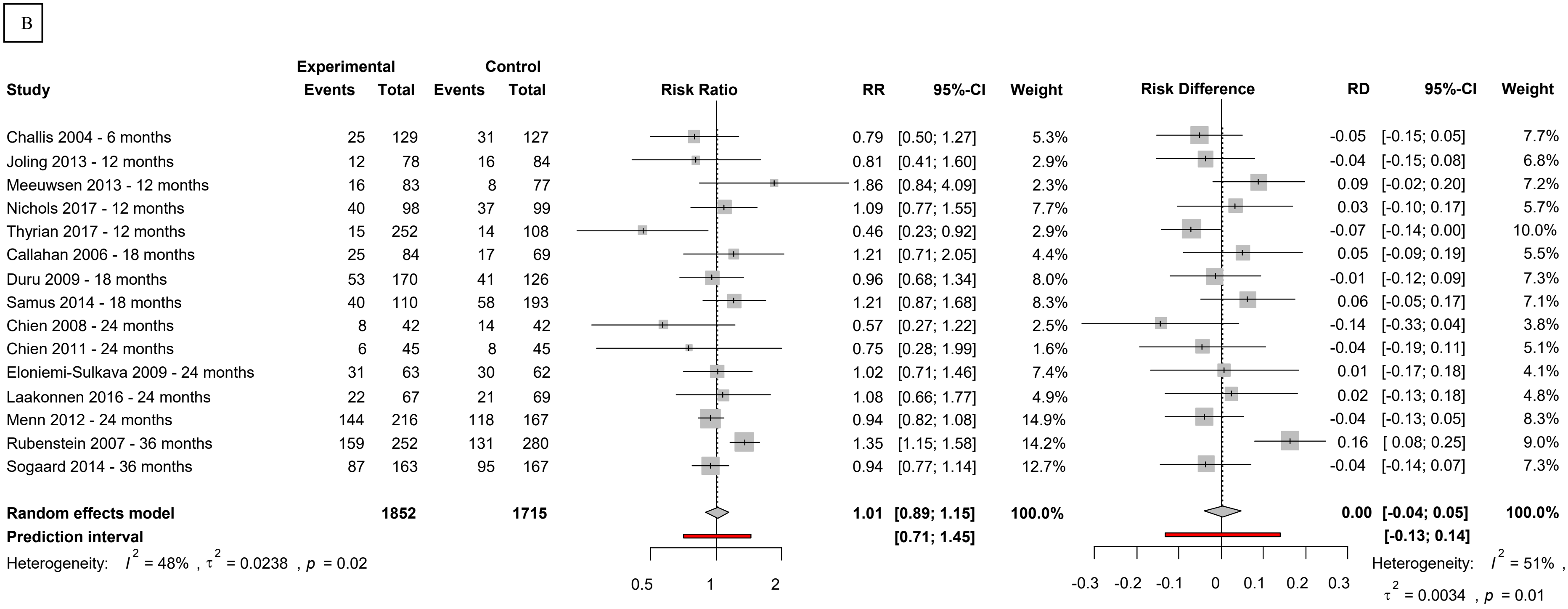
Study	Experimental Events	Experimental Total	Control Events	Control Total	RR	95%-CI	Weight	RD	95%-CI	Weight
Challis 2004 - 6 months	9	129	8	127	1.11	[0.44; 2.78]	1.6%	0.01	[-0.05; 0.07]	27.9%
Meeuwsen 2013 - 12 months	19	83	21	77	0.84	[0.49; 1.44]	4.7%	-0.04	[-0.18; 0.09]	7.6%
Nichols 2017 - 12 months	55	98	44	99	1.26	[0.95; 1.67]	17.1%	0.12	[-0.02; 0.26]	7.2%
Thyrian 2017 - 12 months	60	252	19	108	1.35	[0.85; 2.15]	6.3%	0.06	[-0.03; 0.15]	15.6%
Duru 2009 - 18 months	96	170	66	126	1.08	[0.87; 1.33]	29.9%	0.04	[-0.07; 0.16]	10.1%
Samus 2014 - 18 months	41	110	68	193	1.06	[0.78; 1.44]	14.2%	0.02	[-0.09; 0.13]	10.4%
Chien 2008 - 24 months	7	42	14	42	0.50	[0.22; 1.11]	2.1%	-0.17	[-0.35; 0.02]	4.3%
Chien 2011 - 24 months	7	45	10	45	0.70	[0.29; 1.68]	1.8%	-0.07	[-0.23; 0.09]	5.4%
Sogaard 2014 - 36 months	71	163	73	167	1.00	[0.78; 1.27]	22.4%	-0.00	[-0.11; 0.11]	11.4%
Random effects model		**1092**		**984**	**1.06**	**[0.95; 1.19]**	**100.0%**	**0.01**	**[-0.03; 0.05]**	**100.0%**
Prediction interval						**[0.92; 1.22]**			**[-0.06; 0.08]**	

Heterogeneity: $I^2 = 0\%$, $\tau^2 = 0$, $p = 0.45$

Heterogeneity: $I^2 = 12\%$, $\tau^2 = 0.0004$, $p = 0.33$

Figure 4.5: Proportion of persons having at least one hospital admission (Risk Ratio and Risk Difference)



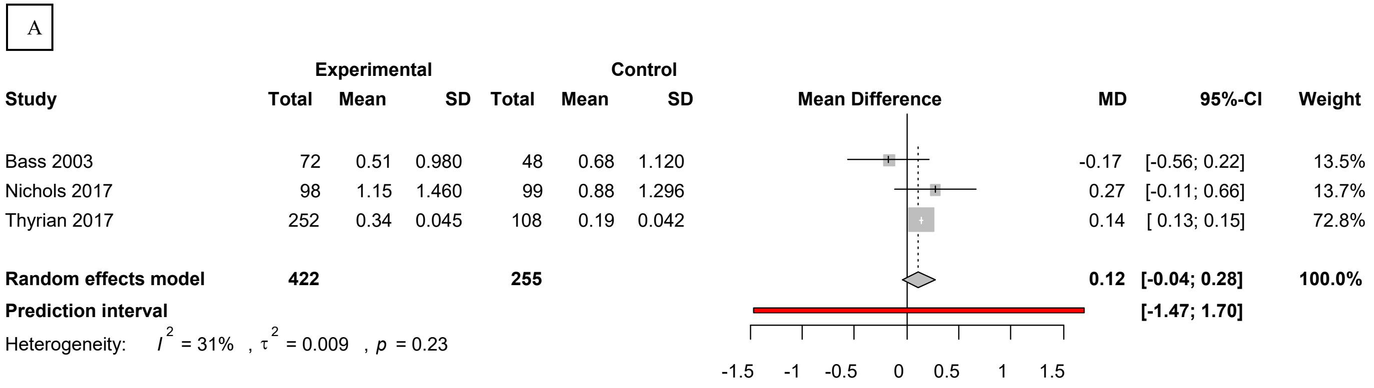


Study	Experimental Events	Experimental Total	Control Events	Control Total	RR	95%-CI	Weight	RD	95%-CI	Weight
Challis 2004 - 6 months	25	129	31	127	0.79	[0.50; 1.27]	5.3%	-0.05	[-0.15; 0.05]	7.7%
Joling 2013 - 12 months	12	78	16	84	0.81	[0.41; 1.60]	2.9%	-0.04	[-0.15; 0.08]	6.8%
Meeuwsen 2013 - 12 months	16	83	8	77	1.86	[0.84; 4.09]	2.3%	0.09	[-0.02; 0.20]	7.2%
Nichols 2017 - 12 months	40	98	37	99	1.09	[0.77; 1.55]	7.7%	0.03	[-0.10; 0.17]	5.7%
Thyrian 2017 - 12 months	15	252	14	108	0.46	[0.23; 0.92]	2.9%	-0.07	[-0.14; 0.00]	10.0%
Callahan 2006 - 18 months	25	84	17	69	1.21	[0.71; 2.05]	4.4%	0.05	[-0.09; 0.19]	5.5%
Duru 2009 - 18 months	53	170	41	126	0.96	[0.68; 1.34]	8.0%	-0.01	[-0.12; 0.09]	7.3%
Samus 2014 - 18 months	40	110	58	193	1.21	[0.87; 1.68]	8.3%	0.06	[-0.05; 0.17]	7.1%
Chien 2008 - 24 months	8	42	14	42	0.57	[0.27; 1.22]	2.5%	-0.14	[-0.33; 0.04]	3.8%
Chien 2011 - 24 months	6	45	8	45	0.75	[0.28; 1.99]	1.6%	-0.04	[-0.19; 0.11]	5.1%
Eloniemi-Sulkava 2009 - 24 months	31	63	30	62	1.02	[0.71; 1.46]	7.4%	0.01	[-0.17; 0.18]	4.1%
Laakonnen 2016 - 24 months	22	67	21	69	1.08	[0.66; 1.77]	4.9%	0.02	[-0.13; 0.18]	4.8%
Menn 2012 - 24 months	144	216	118	167	0.94	[0.82; 1.08]	14.9%	-0.04	[-0.13; 0.05]	8.3%
Rubenstein 2007 - 36 months	159	252	131	280	1.35	[1.15; 1.58]	14.2%	0.16	[0.08; 0.25]	9.0%
Sogaard 2014 - 36 months	87	163	95	167	0.94	[0.77; 1.14]	12.7%	-0.04	[-0.14; 0.07]	7.3%
Random effects model		**1852**		**1715**	**1.01**	**[0.89; 1.15]**	**100.0%**	**0.00**	**[-0.04; 0.05]**	**100.0%**
Prediction interval						**[0.71; 1.45]**			**[-0.13; 0.14]**	

Heterogeneity: $I^2 = 48\%$, $\tau^2 = 0.0238$, $p = 0.02$

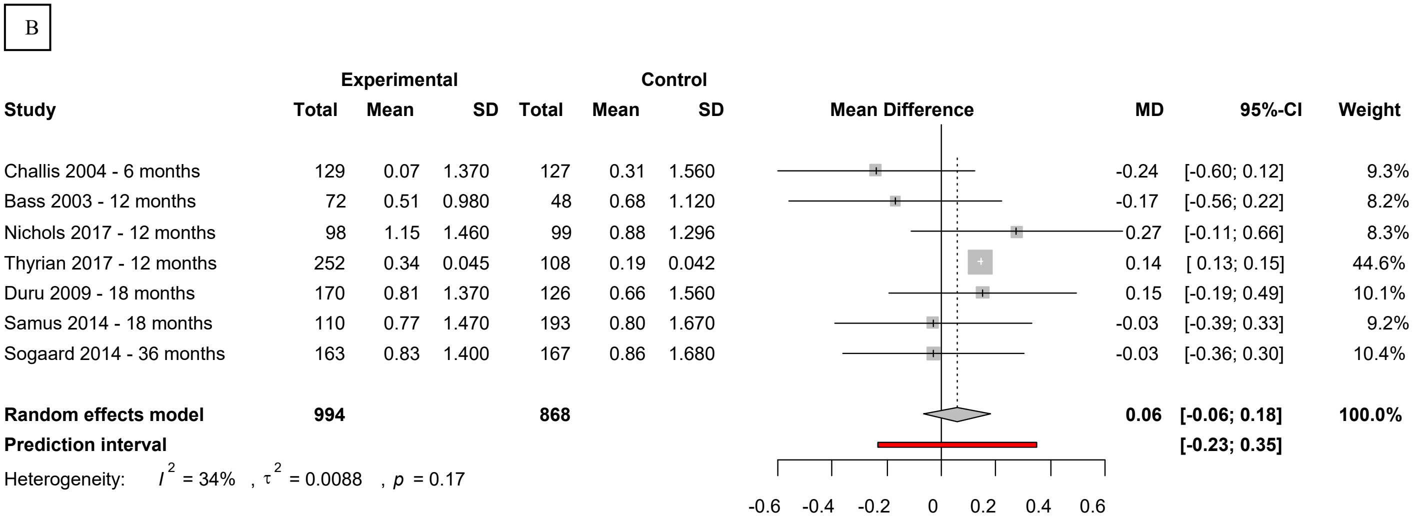
Heterogeneity: $I^2 = 51\%$, $\tau^2 = 0.0034$, $p = 0.01$

Figure 4.6: Mean number of Emergency Department visit (Mean Difference)



Study	Experimental Total	Experimental Mean	Experimental SD	Control Total	Control Mean	Control SD	MD	95%-CI	Weight
Bass 2003	72	0.51	0.980	48	0.68	1.120	-0.17	[-0.56; 0.22]	13.5%
Nichols 2017	98	1.15	1.460	99	0.88	1.296	0.27	[-0.11; 0.66]	13.7%
Thyrian 2017	252	0.34	0.045	108	0.19	0.042	0.14	[0.13; 0.15]	72.8%
Random effects model	**422**			**255**			**0.12**	**[-0.04; 0.28]**	**100.0%**
Prediction interval								**[-1.47; 1.70]**	

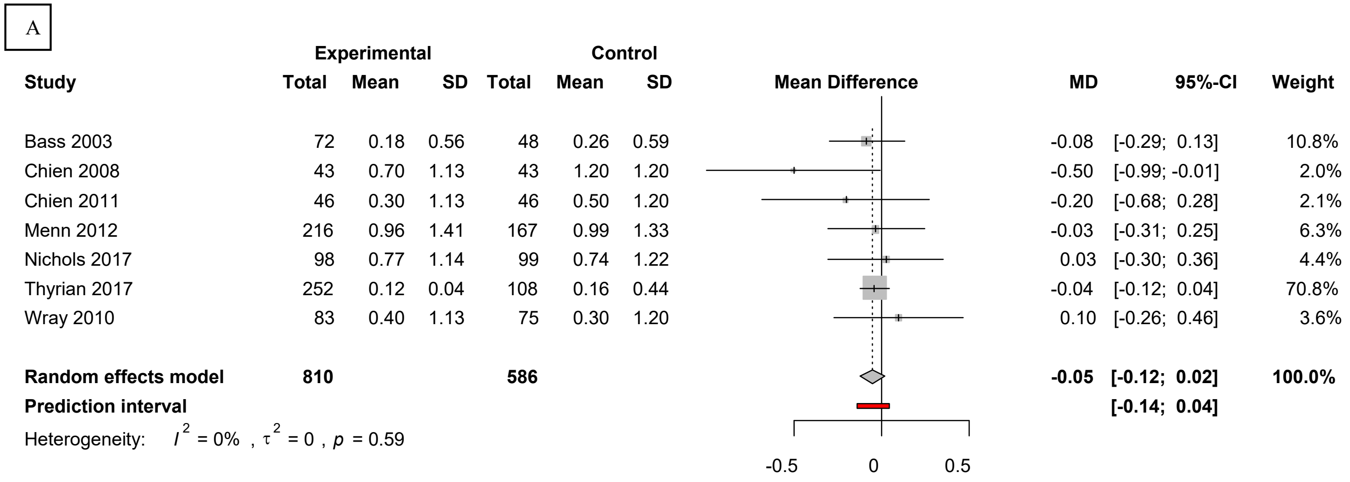
Heterogeneity: $I^2 = 31\%$, $\tau^2 = 0.009$, $p = 0.23$



Study	Experimental			Control			MD	95%-CI	Weight
	Total	Mean	SD	Total	Mean	SD			
Challis 2004 - 6 months	129	0.07	1.370	127	0.31	1.560	-0.24	[-0.60; 0.12]	9.3%
Bass 2003 - 12 months	72	0.51	0.980	48	0.68	1.120	-0.17	[-0.56; 0.22]	8.2%
Nichols 2017 - 12 months	98	1.15	1.460	99	0.88	1.296	0.27	[-0.11; 0.66]	8.3%
Thyrian 2017 - 12 months	252	0.34	0.045	108	0.19	0.042	0.14	[0.13; 0.15]	44.6%
Duru 2009 - 18 months	170	0.81	1.370	126	0.66	1.560	0.15	[-0.19; 0.49]	10.1%
Samus 2014 - 18 months	110	0.77	1.470	193	0.80	1.670	-0.03	[-0.39; 0.33]	9.2%
Sogaard 2014 - 36 months	163	0.83	1.400	167	0.86	1.680	-0.03	[-0.36; 0.30]	10.4%
Random effects model	**994**			**868**			**0.06**	**[-0.06; 0.18]**	**100.0%**
Prediction interval								**[-0.23; 0.35]**	

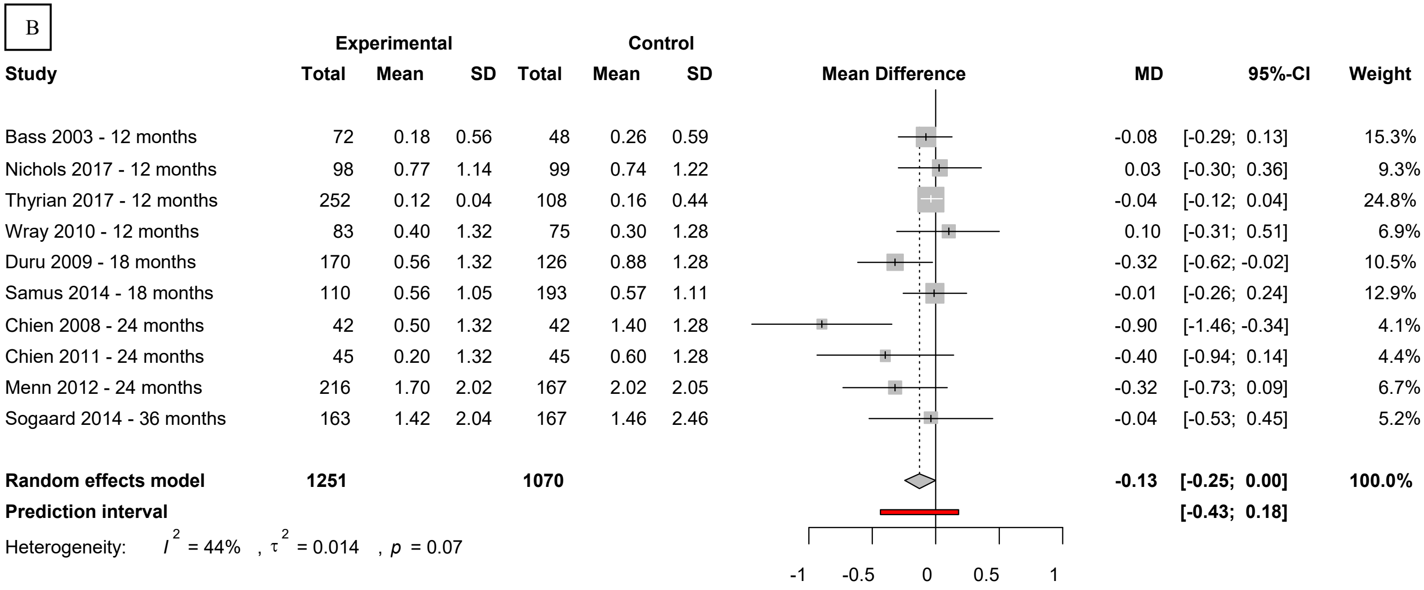
Heterogeneity: $I^2 = 34\%$, $\tau^2 = 0.0088$, $p = 0.17$

Figure 4.7: Mean number of hospital admission (Mean Difference).



	Experimental			Control					
Study	**Total**	**Mean**	**SD**	**Total**	**Mean**	**SD**	**MD**	**95%-CI**	**Weight**
Bass 2003	72	0.18	0.56	48	0.26	0.59	-0.08	[-0.29; 0.13]	10.8%
Chien 2008	43	0.70	1.13	43	1.20	1.20	-0.50	[-0.99; -0.01]	2.0%
Chien 2011	46	0.30	1.13	46	0.50	1.20	-0.20	[-0.68; 0.28]	2.1%
Menn 2012	216	0.96	1.41	167	0.99	1.33	-0.03	[-0.31; 0.25]	6.3%
Nichols 2017	98	0.77	1.14	99	0.74	1.22	0.03	[-0.30; 0.36]	4.4%
Thyrian 2017	252	0.12	0.04	108	0.16	0.44	-0.04	[-0.12; 0.04]	70.8%
Wray 2010	83	0.40	1.13	75	0.30	1.20	0.10	[-0.26; 0.46]	3.6%
Random effects model	**810**			**586**			**-0.05**	**[-0.12; 0.02]**	**100.0%**
Prediction interval								**[-0.14; 0.04]**	

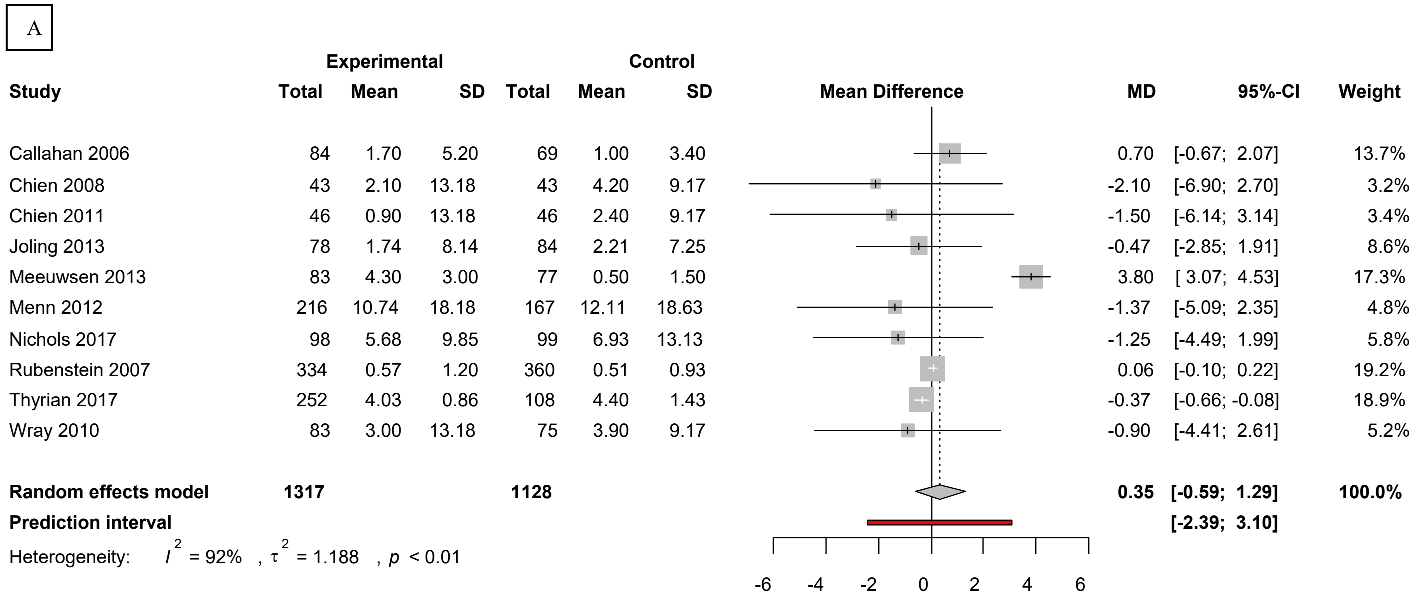
Heterogeneity: $I^2 = 0\%$, $\tau^2 = 0$, $p = 0.59$



Study	Experimental Total	Experimental Mean	Experimental SD	Control Total	Control Mean	Control SD	MD	95%-CI	Weight
Bass 2003 - 12 months	72	0.18	0.56	48	0.26	0.59	-0.08	[-0.29; 0.13]	15.3%
Nichols 2017 - 12 months	98	0.77	1.14	99	0.74	1.22	0.03	[-0.30; 0.36]	9.3%
Thyrian 2017 - 12 months	252	0.12	0.04	108	0.16	0.44	-0.04	[-0.12; 0.04]	24.8%
Wray 2010 - 12 months	83	0.40	1.32	75	0.30	1.28	0.10	[-0.31; 0.51]	6.9%
Duru 2009 - 18 months	170	0.56	1.32	126	0.88	1.28	-0.32	[-0.62; -0.02]	10.5%
Samus 2014 - 18 months	110	0.56	1.05	193	0.57	1.11	-0.01	[-0.26; 0.24]	12.9%
Chien 2008 - 24 months	42	0.50	1.32	42	1.40	1.28	-0.90	[-1.46; -0.34]	4.1%
Chien 2011 - 24 months	45	0.20	1.32	45	0.60	1.28	-0.40	[-0.94; 0.14]	4.4%
Menn 2012 - 24 months	216	1.70	2.02	167	2.02	2.05	-0.32	[-0.73; 0.09]	6.7%
Sogaard 2014 - 36 months	163	1.42	2.04	167	1.46	2.46	-0.04	[-0.53; 0.45]	5.2%
Random effects model	**1251**			**1070**			**-0.13**	**[-0.25; 0.00]**	**100.0%**
Prediction interval								**[-0.43; 0.18]**	

Heterogeneity: $I^2 = 44\%$, $\tau^2 = 0.014$, $p = 0.07$

Figure 4.8: Mean number of hospital days (Mean Difference)



Study	Experimental Total	Experimental Mean	Experimental SD	Control Total	Control Mean	Control SD	MD	95%-CI	Weight
Callahan 2006	84	1.70	5.20	69	1.00	3.40	0.70	[-0.67; 2.07]	13.7%
Chien 2008	43	2.10	13.18	43	4.20	9.17	-2.10	[-6.90; 2.70]	3.2%
Chien 2011	46	0.90	13.18	46	2.40	9.17	-1.50	[-6.14; 3.14]	3.4%
Joling 2013	78	1.74	8.14	84	2.21	7.25	-0.47	[-2.85; 1.91]	8.6%
Meeuwsen 2013	83	4.30	3.00	77	0.50	1.50	3.80	[3.07; 4.53]	17.3%
Menn 2012	216	10.74	18.18	167	12.11	18.63	-1.37	[-5.09; 2.35]	4.8%
Nichols 2017	98	5.68	9.85	99	6.93	13.13	-1.25	[-4.49; 1.99]	5.8%
Rubenstein 2007	334	0.57	1.20	360	0.51	0.93	0.06	[-0.10; 0.22]	19.2%
Thyrian 2017	252	4.03	0.86	108	4.40	1.43	-0.37	[-0.66; -0.08]	18.9%
Wray 2010	83	3.00	13.18	75	3.90	9.17	-0.90	[-4.41; 2.61]	5.2%
Random effects model	**1317**			**1128**			**0.35**	**[-0.59; 1.29]**	**100.0%**
Prediction interval								**[-2.39; 3.10]**	

Heterogeneity: $I^2 = 92\%$, $\tau^2 = 1.188$, $p < 0.01$

B

	Experimental			Control					
Study	**Total**	**Mean**	**SD**	**Total**	**Mean**	**SD**	**MD**	**95%-CI**	**Weight**
Challis 2004 - 6 months	129	6.01	19.14	127	6.10	19.3	-0.09	[-4.80; 4.62]	3.1%
Joling 2013 - 12 months	78	1.74	8.14	84	2.21	7.2	-0.47	[-2.85; 1.91]	8.0%
Meeuwsen 2013 - 12 months	83	4.30	3.00	77	0.50	1.5	3.80	[3.07; 4.53]	15.8%
Nichols 2017 - 12 months	98	5.68	9.85	99	6.93	13.1	-1.25	[-4.49; 1.99]	5.5%
Thyrian 2017 - 12 months	252	4.03	0.86	108	4.40	1.4	-0.37	[-0.66; -0.08]	17.3%
Wray 2010 - 12 months	83	3.00	19.14	75	3.90	19.3	-0.90	[-6.90; 5.10]	2.1%
Callahan 2006 - 18 months	84	2.60	7.90	69	1.50	4.1	1.10	[-0.85; 3.05]	9.8%
Samus 2014 - 18 months	110	2.96	7.24	193	2.80	7.9	0.16	[-1.59; 1.91]	10.7%
Chien 2008 - 24 months	42	1.80	19.14	42	5.50	19.3	-3.70	[-11.91; 4.51]	1.2%
Chien 2011 - 24 months	45	0.80	19.14	45	2.30	19.3	-1.50	[-9.44; 6.44]	1.2%
Eloniemi-Sulkava 2009 - 24 months	63	23.30	42.30	62	28.10	51.2	-4.80	[-21.28; 11.68]	0.3%
Laakonnen 2016 - 24 months	67	8.20	36.70	69	12.90	35.9	-4.70	[-16.91; 7.51]	0.5%
Menn 2012 - 24 months	216	19.88	27.34	167	23.39	29.4	-3.51	[-9.27; 2.25]	2.2%
Rubenstein 2007 - 36 months	252	0.55	1.20	280	0.49	1.0	0.06	[-0.13; 0.25]	17.5%
Sogaard 2014 - 36 months	163	8.48	18.13	167	7.33	15.4	1.15	[-2.48; 4.78]	4.7%
Random effects model	**1765**			**1664**			**0.42**	**[-0.50; 1.34]**	**100.0%**
Prediction interval								**[-2.19; 3.03]**	

Heterogeneity: $I^2 = 88\%$, $\tau^2 = 1.242$, $p < 0.01$

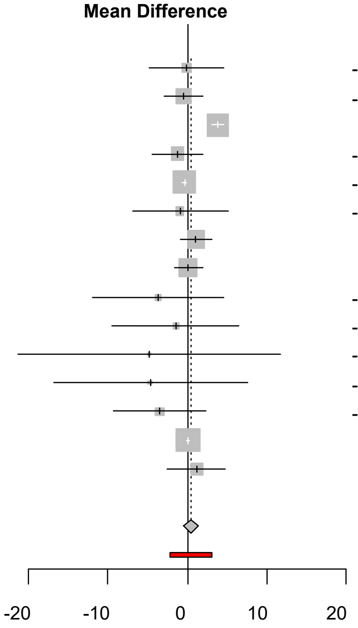
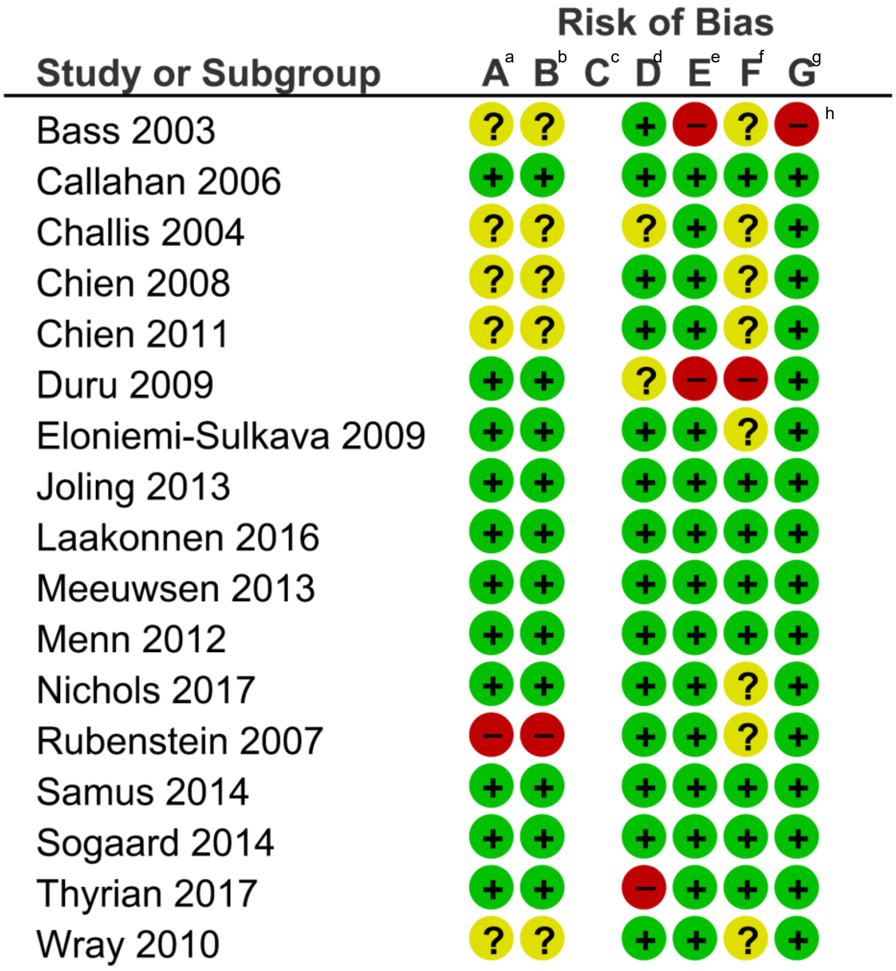


Figure 4.9 Quality Appraisal using the Cochrane Risk of Bias Tool (35)



Risk of Bias

Study or Subgroup	A[a]	B[b]	C[c]	D[d]	E[e]	F[f]	G[g]
Bass 2003	?	?		+	−	?	− [h]
Callahan 2006	+	+		+	+	+	+
Challis 2004	?	?		?	+	?	+
Chien 2008	?	?		+	+	?	+
Chien 2011	?	?		+	+	?	+
Duru 2009	+	+		?	−	−	+
Eloniemi-Sulkava 2009	+	+		+	+	?	+
Joling 2013	+	+		+	+	+	+
Laakonnen 2016	+	+		+	+	+	+
Meeuwsen 2013	+	+		+	+	+	+
Menn 2012	+	+		+	+	+	+
Nichols 2017	+	+		+	+	?	+
Rubenstein 2007	−	−		+	+	?	+
Samus 2014	+	+		+	+	+	+
Sogaard 2014	+	+		+	+	+	+
Thyrian 2017	+	+		−	+	+	+
Wray 2010	?	?		+	+	?	+

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5 Chapter 5: Hospital use in community-dwelling persons living with dementia: a population-wide descriptive study from Quebec (2000-2015) (Manuscript 2.1)

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5.1 Preamble

As stated in previous chapters and in particular in gap #2, to our knowledge, no study worldwide estimated the trends over time of avoidable hospital use in community-dwelling persons with dementia. In Canada, there is little evidence on avoidable hospital use in persons with dementia, and none specifically in the community-dwelling population. In Quebec, there is no evidence on hospital use or potentially avoidable hospital use in community-dwelling persons with dementia. In order to develop evidence-informed policies and programs to reduce avoidable hospital use in community-dwelling persons with dementia, a measure of the extent of the phenomenon, and its trend over time is needed. In this manuscript, I addressed the following objective: Objective 2.1. To describe the prevalence and trends in potentially avoidable hospital use in community-dwelling persons with dementia in Quebec from 2000 to 2015.

In this manuscript, I described the prevalence and trends in hospital use in community-dwelling persons with dementia in Quebec from 2000 to 2015. I conducted this descriptive study with data extracted from the Quebec Integrated Chronic Disease Surveillance System (QICDSS) [74] (See details on the database in the Appendix 1: Presentation of the database and selected variables of interest). I included community-dwelling older adults (aged 65+) with a new diagnosis of dementia between April 1st and March 31st of each year inclusive. The population with dementia was identified through a validated algorithm [75] (See details on the algorithm in the Appendix 2: Algorithm identifying persons living with dementia). I developed an algorithm to identify the community-dwelling population aged 65 +, and long-term care admissions in the database (See details on the algorithm in the Appendix 5: Algorithms identifying community-dwelling populations and long-term care admissions).

I measured hospital use (ED visits and hospitalizations) as routinely performed in the QICDSS (See Appendix 3: Precisions on indicators of service use). I defined avoidable hospital use according to the Gruneir's conceptual model, presented in the Conceptual framework section of this thesis (See Chapter 3: Conceptual framework and avoidable hospital use definition and measures). I used four measures of potentially avoidable hospital use: two related to the Gruneir's model (30-day readmission and ALC hospitalizations) and two related to ACSC hospitalization (general and older population definitions). (See operationalized definitions of these measures in Appendix 5.9.2 in Chapter 5). Hospital use was measured during the follow-up period: one year after the diagnosis date, or death, or admission to long-term care, whichever occurred first. (See details in Appendix 4: Eligibility and computation of events for indicators of hospital use).

In this descriptive study, I chose not to perform time trend tests to describe the trends in indicators, as it has been done in other population-wide studies of health services use [76]. Indeed, in population-wide analyses the large sample size could render small differences statistically significant. Instead of relying on p-values, we adopted a systematic approach to assess and interpret the time-trends. We assessed the trends in indicators of hospital use based on graphical assessment, absolute and relative change from the first to last study year. Following this assessment, we classified the trends as constant, increasing or decreasing. We interpreted the clinical and healthcare significance of the trends based on expert knowledge of over 100 researchers, clinicians, surveillance experts, decision-makers, managers, and knowledge users stemming from the Canadian

Consortium for Neurodegeneration and Aging, the *Institut national de santé publique du Québec*, the *Ministère de la santé et des services sociaux* (MSSS; Quebec Ministry of Health and Social Services), and the Quebec Alzheimer's Plan implementation team.

This manuscript is currently in submission process. This study was part of a larger pan Canadian research project from the Research on Organization of Healthcare Services for Alzheimer's team (ROSA) of 1) the development of a framework of dementia primary care performance and health service use indicators and 2) cross-provincial comparison of these indicators across three provinces (Quebec, Ontario and New-Brunswick). This project led already, in addition to the following manuscript, to the two following articles, that I am a co-author of: "Framework and prioritization of dementia primary care performance and health service use indicators" (Submitted to Annals of Family Medicine) and "Sex differences in dementia primary care performance and health service use: A population-based study" (published in the Journal of the American Geriatrics Association).

5.2 Abstract

Background: Persons with dementia have twice as much hospital use (Emergency Department visits and hospitalizations) as older persons without dementia. A share of this hospital use might be avoidable. Reducing avoidable hospital use in persons with dementia is a global healthcare priority. In Canada, the evidence is scarce on hospital use in community-dwelling persons with dementia. In this study, we described the prevalence and trends in hospital use in persons with dementia in Quebec from 2000 to 2015.

Methods: We conducted a repeated yearly cohort study of hospital use in community-dwelling persons with incident dementia using the provincial health administrative database. We described age and sex standardized rates of hospital use, including potentially avoidable hospital use: Ambulatory Care Sensitive Condition (ACSC) hospitalization (general and older population definitions), 30-day readmission, and Alternate level of care (ALC) hospitalizations.

Results: We included 192,144 community-dwelling persons with dementia. Trends in both types of ACSC hospitalization (general and older population) and 30-day readmission rates remained constant with average rates per 100 person-year: 20.5 [19.9-21.1], 31.7 [31.0-32.4], 20.6 [20.1-21.2], respectively. Rates of ALC hospitalizations decreased from 23.8 [21.1-26.9], to 17.9 [16.1-20.1] (relative change -24.6%).

Interpretation: This study is the first population-wide descriptive study of 15-year prevalence and trends of hospital use in persons with dementia. It sheds light on the importance of the phenomenon and its lack of improvement, for most outcomes, over the years. These figures are a call for action to develop evidence-based policies to prevent avoidable hospital use in this vulnerable population.

5.3 Introduction

Persons with dementia have twice as much hospital use (Emergency Department (ED) visits and hospital admissions) as older persons without dementia [1,2]. In 2015, 25% and 20% of persons with dementia in Canada visited the ED or were hospitalized at least once [3]. They stayed in hospital twice as long as persons without dementia and experienced one-and-a-half times more hospital harm than those without.

A proportion of these hospital uses may be avoidable with appropriate ambulatory care [4–6]. For example, in the United States (US), 20% of hospitalizations of persons with dementia are potentially avoidable, as measured by 30-day hospital readmission or Ambulatory Care Sensitive Conditions (ACSC) hospitalization.

Currently, there are more than 564,000 Canadians living with dementia, a figure projected to at least double by 2031 as Canadians continue to age [7]. Healthcare costs for persons with dementia are estimated to be five-and-a-half times greater than for persons without dementia [7]. Reducing avoidable hospital use in persons with dementia and improving the quality of care they receive is a World Health Organization global healthcare priority and one of the 2019 Canadian national dementia strategy objectives [8–11].

However, in Canada, there is little evidence on avoidable hospital use in persons with dementia [5,12–20], and none specifically on the community-dwelling population. Most of the population with dementia lives in the community, and this proportion is growing [3,21]. In addition, patterns of health care use and available resources differ widely between institutionalized and community-dwelling populations, as well as the policies or programs that could prevent avoidable hospital use [22].

In order to develop evidence-informed policies and programs to prevent avoidable hospital use in community-dwelling persons with dementia, we need to measure the extent of the phenomenon and its trend over time. Quebec accounts for 20% of Canadians with dementia [23], with hospitalization rates among the highest of the Canadian population with dementia [3]. In this study, we describe the prevalence and trends in hospital use in community-dwelling persons with dementia in Quebec from 2000 to 2015.

5.4 Methods

We conducted a repeated cohort study of hospital use in community-dwelling persons with dementia in Quebec. This study was conducted and reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology *(*STROBE) and REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) guidelines [24,25].

5.4.1 Data source

We analysed the Quebec linked, population-based health administrative database held at the *Institut national de santé publique du Québec* (The Quebec Public Health Institute). This database records all services provided via the public universal health insurance system (e.g. medical consultation, hospitalization, prescription drug use) and links these health care services utilization data with individual level demographics and deaths [26,27]. This database covers 99% of the 65+ population of Quebec [26,27]. The database was accessed by LR, who performed the analyses, using SAS Enterprise Guide software, 7.15 version. This study is part of the continuous chronic disease surveillance mandate granted to the *Institut national de santé publique du Québec* by the provincial minister of health and social services and approved by the provincial Ethics Committee of Public Health. In addition, it was approved by the McGill Faculty of Medicine Institutional Review Board.

5.4.2 Study design and population

We analysed repeated yearly cohorts from 2000-2001 to 2014-2015. We included community-dwelling older adults (aged 65+) with a new diagnosis of dementia between April 1st and March 31st of each year inclusive (See details on included population in Supplementary File). A dementia diagnosis was identified through a validated algorithm developed in Ontario by the Institute for Clinical Evaluative Science (ICES) and adopted by the Public Health Agency of Canada [28]. The community-dwelling population was identified as persons with no evidence, in the linked health administrative database, of living in a long-term care facility [29]. The study population was restricted to persons with valid sex and birth date and enrolled in the public provincial health insurance plan for at least 1 day of the studied year.

5.4.3 Outcomes

Outcomes were measured during the follow-up period: 1 year after the diagnosis date, death, or admission to long-term care, whichever occurred first. We measured hospital use: all-causes of ED visits, hospitalizations, and length of hospital stay. (See details on operationalization of variables in Supplementary File). Several measures of potentially avoidable hospital use have been used in populations with dementia [5,12–20]. In order to draw a comprehensive picture, we measured the four most commonly used indicators of potentially avoidable hospital use in persons with dementia: Ambulatory Care Sensitive Conditions (ACSC) hospitalizations (general and older population definitions), 30-day readmission, and Alternate level of care (ALC) hospitalizations. (See details on operationalization of variables in Supplementary File)

ACSC are conditions, “where appropriate ambulatory care may prevent or reduce the need for admission to hospital” [30]. We measured ACSC hospitalizations two ways. First, with a general population definition as defined by *Canadian Institute for Health Information* (CIHI). Second, with an older population definition: the measure developed by Walsh and colleagues on older persons dually eligible for Medicare and Medicaid, previously used in a population with dementia by Feng et al. [5,31]. This definition includes additional conditions that are more specific to an older population like: hypotension, constipation, skin ulcers, or nutritional deficiency. See details on lists of conditions and ICD codes for each definition in Supplementary File.

Alternate level of care (ALC) hospitalization followed the CIHI definition: "patients who occupy a bed but do not require the intensity of services provided in that care setting. […] a person who has completed the acute care phase of his or her treatment but remained in an acute care bed." [32]

5.4.4 Analysis

Indicators of hospital use in each study year were summarized as rates, adjusted for differential person-time. Rates were standardized for differences in the distribution of age and sex over time using direct standardization. The age and sex distribution of the 2011 Canada census data was used as the reference population for the standardization [33].

We assessed the trends in indicators of hospital use based on graphical assessment, absolute, and relative changes from the last to first study year. Following this assessment, we classified the trends as constant, increasing, or decreasing. We interpreted the clinical and healthcare significance of the trends based on expert knowledge of over 100 researchers, clinicians, surveillance experts, decision-makers, managers, and knowledge users stemming from the Canadian Consortium for Neurodegeneration and Aging, the *Institut national de santé publique du Québec*, the Quebec Ministry of Health, and the Quebec Alzheimer's Plan implementation team.

5.5 Results

5.5.1 Study population

From 2000 to 2015, there were 192,144 community-dwelling 65+ persons with a new diagnosis of dementia in Quebec, on average 12,810 persons per year. They accounted for 1.0% to 1.2% of the community-dwelling 65+ persons in Quebec. Overall, their mean age increased by roughly 1 year over the study period (80.3 to 81.6), and the proportion of women decreased by 5 percentage points (66.2 to 61.0). The demographic characteristics of the cohorts are presented in Table 5.1.

Table 5.1: Description of the cohorts of community-dwelling adults 65 years or older with a new diagnosis of dementia in Quebec, Canada, from 2000-2015

	Community-dwelling adults 65 years or older with a new diagnosis of dementia	**Follow-up time**	**Age**	**Female**
	N	**Person-year**	**mean (SD)**	**N (%)**
Diagnostic Year				
2000	9117	7595	80.3 (0.1)	6031 (66.2)
2001	9500	7846	80.5 (0.1)	6272 (66.0)
2002	10102	8424	80.7 (0.1)	6581 (65.2)
2003	10370	8714	80.8 (0.1)	6696 (64.6)
2004	10822	9102	80.7 (0.1)	6962 (64.3)
2005	11282	9660	80.9 (0.1)	7163 (63.5)
2006	12804	10894	81.0 (0.1)	8110 (63.3)
2007	13008	11191	81.1 (0.1)	8232 (63.3)
2008	13525	11685	81.2 (0.1)	8574 (63.4)
2009	14433	12466	81.4 (0.1)	9263 (64.2)
2010	14556	12560	81.4 (0.1)	9288 (63.8)
2011	15519	13505	81.5 (0.1)	9636 (62.1)
2012	15716	13651	81.6 (0.1)	9634 (61.3)
2013	15925	13857	81.7 (0.1)	9747 (61.2)
2014	15455*	13424	81.6 (0.1)	9430 (61.0)
Overall Population	192144	164574	80.3 (0.0)	121619 (63.3)

* The 2014-2015 cohort is incomplete (See Supplementary File). SD: Standard Deviation

5.5.2 Hospital use

From 2000-2015, the rates of at least one ED visit per 100 person-years remained constant at an average of 59.8 (95% confidence interval (CI) [59.3-60.4]) (Table 5.2 and Figure *5.1*)The mean number of ED visits per 1 person-year remained constant at an average 1.4 visits (95%CI [1.4-1.4]).

The rates of at least one hospitalization per 100 person-years decreased from 42.9 (95%CI [40.9-45.1]) to 39.9 (95%CI [38.4-41.5]) (Relative change -7.1%). Among the persons hospitalized, the length of hospital stay in the year of diagnosis per 1 person-year remained constant at an average of 47.3 days (95%CI [47.2-47.4]).

5.5.3 Potentially avoidable hospital use

From 2000-2015, the rates of at least one ACSC hospitalization (general and older population definition) and 30-day readmission per 100 person-years remained constant at averages of 20.5 (95%CI [19.9-21.1]), 31.7 [31.0-32.4], and 20.6 [20.1-21.2], respectively (Table 5.2 and Figure 5.2).

The rates of at least one ALC hospitalization per 100 person-years decreased from 23.8 (95%CI [21.1-26.9]) to 17.9 (95%CI [16.1-20.1]; Relative change -24.6%). Among those with at least one ALC hospitalization, the length of ALC stay, in the year of diagnosis, for 1 person-year remained constant at an average of 4.7 months (95%CI [4.7-4.7]).

Table 5.2: Hospital use (total and potentially avoidable) in the year following diagnosis among community-dwelling adults 65 years or older with a new diagnosis of dementia in Quebec, Canada, from 2000-2015: Age and sex standardized rates with 95% confidence intervals, absolute and relative changes.

Indicator	**2000-2001 Rate (95% CI)**	**2014-2015 Rate (95% CI)**	**2000-2015 Average Rate (95% CI)**	**Absolute change (%)**	**Relative change (%)**
At least one ED visit	59.0 (56.6-61.6)	60.0 (58.1-61.9)	59.8 (59.3-60.4)	+ 0.9	+ 1.6
Mean number of ED visits	1.3 (1.3-1.4)	1.5 (1.4-1.5)	1.4 (1.4-1.4)	+ 0.1	+ 0.1
At least one hospitalization	42.9 (40.9-45.1)	39.9 (38.4-41.5)	41.5 (41.0-41.9)	- 3.1	- 7.1
Length of hospital stay (days)	45.7 (45.2-46.1)	44.3(44.0-44.6)	47.3 (47.2-47.4)	- 1.4	- 3.0
At least one ACSC hospitalization (General population)	21.0 (18.6-23.9)	21.3 (19.3-23.5)	20.5 (19.9-21.1)	+ 0.2	+ 1.0
At least one ACSC hospitalization (Older population)	33.3 (30.2-36.7)	33.2 (30.7-36.0)	31.7 (31.0-32.4)	- 0.1	- 0.2
At least one 30-day readmission	23.7 (20.7-27.0)	21.7 (19.7-24.0)	20.6 (20.1-21.2)	- 1.9	- 8.2
At least one ALC hospitalization	23.8 (21.1-26.9)	17.9 (16.1-20.1)	23.5 (22.9-24.1)	- 5.9	- 24.6
Length of ALC stay (months)	4.2 (4.1-4.3)	4.4 (4.4-4.5)	4.7 (4.7-4.7)	+ 0.2	+ 5.5

The length of hospital stay, Ambulatory Care Sensitive Conditions (ACSC) hospitalizations, Alternate level of care (ALC) hospitalization were measured in the subset of persons with at least one hospital admission during the study period. 30-day readmission was measured in the subset of persons with at least 1 hospital discharge during the study period. Rates are reported as per 1 person-year for length of hospital stay, mean number of ED visits, and length of ALC stay. The remaining indicators are per 100 person years. The census population of Canada in 2011 was used as the standard population for age and sex standardized rates. Absolute and relative change are calculated between the first and last year of the study.

CI: confidence Interval; ED: Emergency Department; ACSC: Ambulatory Care Sensitive Conditions; ALC: Alternate level of care

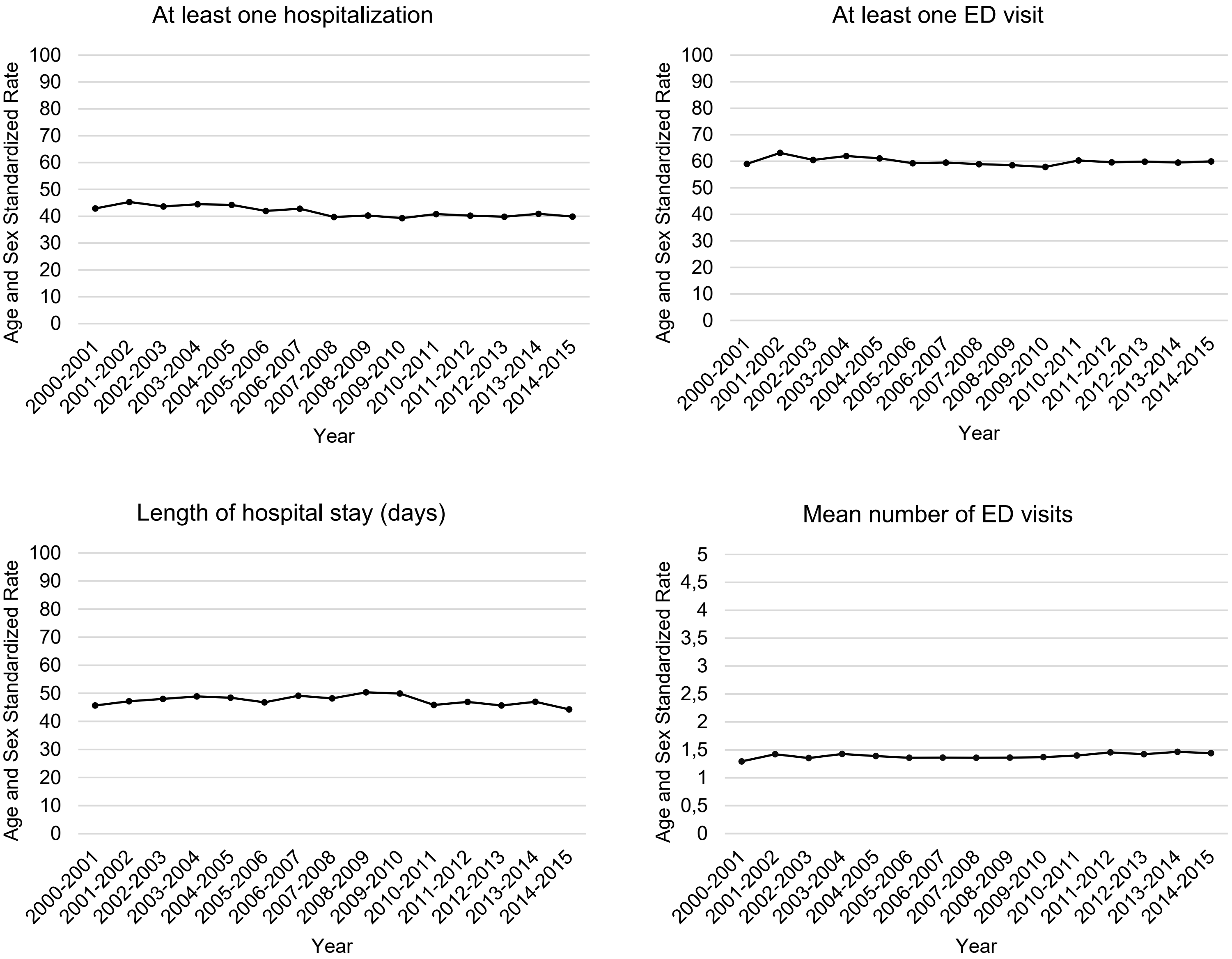

Figure 5.1: Age and sex standardized rates of hospital use in the year following diagnosis among community-dwelling adults 65 years or older with a new diagnosis of dementia in Quebec, Canada, from 2000-2015.

The length of hospital stay was computed as the total number of hospital days during the follow-up period in persons with at least one hospitalization. The rate of at least one Emergency Department visit was computed on the entire cohorts. Rates are reported as per 1 person years for length of hospital stay, and mean number of emergency department visits. The remaining indicators are per 100 person years. Canadian census population of 2011 was used as the reference population for standardization. The 2014-2015 cohort is incomplete (See Supplementary File).

ED: Emergency Department

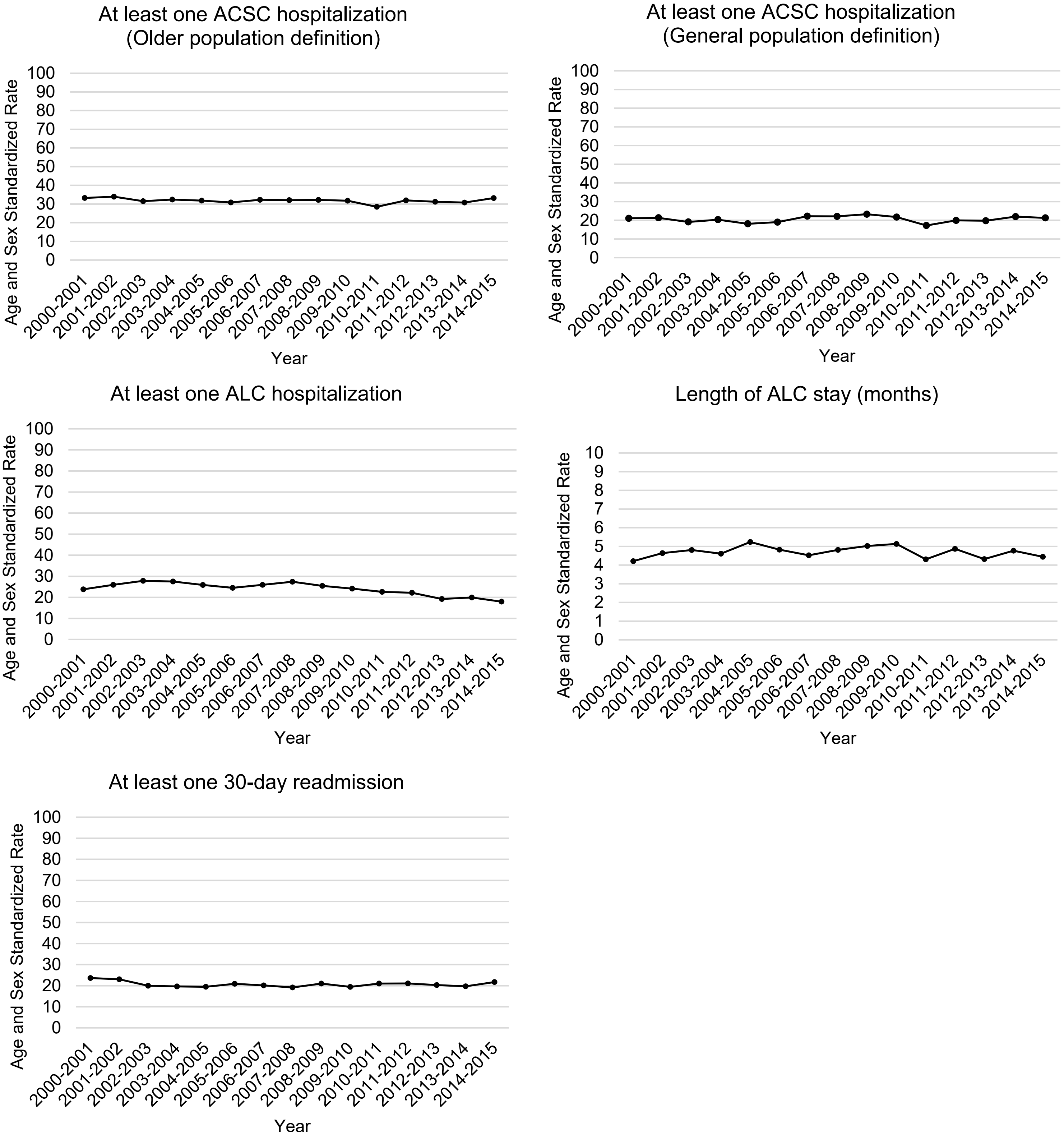

Figure 5.2: Age and sex standardized rates of potentially avoidable hospital use in the year following diagnosis among community-dwelling adults 65 years or older with a new diagnosis of dementia in Quebec, Canada, from 2000-2015.

The rate of Ambulatory Care Sensitive Conditions (ACSC) hospitalizations, and ALC hospitalizations were measured in the subset of persons with at least one hospital admission during the study period. 30-day readmission was measured in the subset of persons with at least 1 hospital discharge during the study period. The length of ALC stay was computed as the total number of ALC hospital days during the follow-up period in persons with at least one ALC hospitalization. Rates are reported as per 1 person years for length of ALC stay. The remaining indicators are per 100 person years. Canadian census population of 2011 was used as the reference population for standardization. The 2014-2015 cohort is incomplete (See Supplementary File). ACSC: Ambulatory Care Sensitive Conditions; ALC: Alternate level of care.

5.6 Interpretation

In this descriptive study, around 40 and 60 per 100 person-year of community-dwelling persons with dementia had at least one hospitalization and one ED visit during the year of diagnosis, respectively. In those hospitalized, the average length of hospital stay in the year of diagnosis was around 1.5 months. Between 20 and 30% of those hospitalized, depending on the indicator, had a potentially avoidable hospital use, with average length of ALC stay of more than 4.5 months. Most indicators remained constant over the 15 years.

To our knowledge, this is the first estimation worldwide of trends in hospital use in community-dwelling persons with dementia. These findings are coherent with the literature on prevalence of hospital use in community-dwelling persons with dementia [34,35]. In Canada, only two studies reported hospitalization rates specifically from the community-dwelling populations. In Ontario (2012), among community-dwelling home care recipients with dementia, around 40% and 50% had a hospitalization or an ED visit during the year [34]. In British Columbia (2001), in the community-dwelling population newly diagnosed with dementia, more than 60% had an hospitalization in the year of diagnosis, with average length of stay in the year of diagnosis, for those hospitalized, of 42 days [35].

Regarding potentially avoidable hospital use, the evidence is scarce in Canada, especially there is no study of ACSC hospitalizations or 30-day readmissions in persons with dementia. Our findings are in line with US estimates. In a 2013 US study, 10% and 18% of the 65+ Medicare population with dementia had at least one ACSC hospitalization or one 30-day readmission during the year [36]. Regarding ALC hospitalization, our results are consistent with the CIHI Report on Dementia in Canada (2015–2016): “One in 5 seniors with dementia had an ALC component to their stay” [3].

Overall, during the entire study period, we did not observe a decrease in most indicators (7/9) of hospital use. This absence of variation is in contrast with the several provincial policies, reforms, and care recommendations that occurred or were released over the 15-year period that could have influenced hospital use. Since 2000, major reforms of primary care delivery occurred in Quebec, including the implementation of multidisciplinary primary care teams, the Family Medicine Groups (FMGs), to enhance primary care access, continuity, and quality [37–39]. In addition, recommendations for dementia care emphasizing the importance of primary care in the care of persons with dementia were regularly issued: the Quebec Alzheimer's Plan (Qc AP) expert report in 2009, the 3rd and 4th Canadian consensus conferences on the diagnosis and treatment of dementia (2006 and 2014) [40–42]. Finally, the Qc AP implementation began in 2014, aiming at improving the quality of care offered in FMGs to persons living with dementia [40,43]. None of these policies, reforms, or care recommendations specifically focused on reducing avoidable hospital use, which might be essential to have a measurable impact.

On the contrary, the rate of ALC hospitalizations decreased over the 15-year period. Since 2006, the Quebec Ministry of Health aimed specifically at reducing the ALC hospitalizations. One of the main intervention was the implementation of the *Relevé quotidien de la situation à l'urgence et en centre hospitalier* (RQSUCH) in 2006, a daily measurement of the number of persons identified as ALC at the hospital level [44]. This measurement is sent daily to all healthcare administrators and hospital managers in the province. While the observed decrease in ALC is promising, we cannot infer causality from this observational study. Formal evaluation of ministerial policies to reduce ALC hospitalizations are needed to inform decision-makers.

Our results call for action to design and implement policies and reforms to specifically target the reduction of avoidable hospital use in community-dwelling persons with dementia. One of the three national objectives of the Canadian national dementia strategy is to improve the quality of life of those living with dementia and their caregivers, especially through an improvement of the quality of care they receive [11,45,46]. Reducing avoidable hospital use in persons with dementia is one way to improve the quality of life of persons with dementia and their caregivers, prevent adverse outcomes for persons with dementia, and minimize rising health care costs.

Improving primary care access, continuity and quality might be powerful avenues to decrease avoidable hospital use. Gruneir and colleagues emphasized the importance of offering timely access to integrated, pro-active primary care that includes community and home care services to prevent avoidable hospital use [47]. Indeed, offering timely access to supportive care was shown to prevent a share of ALC hospitalizations [48]. In addition, offering timely primary care access was shown to prevent a share of avoidable hospitalizations, especially ACSC hospitalizations and 30-day readmissions [49–55]. Experts emphasize the importance of caring for the caregiver, as caregiver absence, burden, and stress are major drivers of crisis leading to avoidable hospitalizations [4,56–59]. Finally, palliative care approaches might be promising avenues, as they have been shown to prevent a large share of non-desired end-of-life hospitalizations in older adults [5,60,61].

Our study has limits. We identified persons diagnosed with dementia with a validated algorithm [28]. As delayed diagnosis is highly prevalent in this population, our findings might represent service use of a subsample of the entire population with dementia, the subsample that is diagnosed. Our estimations are specific to the Quebec context. Further studies in other provinces are needed to inform policy-makers.

Conclusion and future directions

This study is the first population-based descriptive study of the prevalence and trends over 15 years of hospital use in community-dwelling persons with dementia. This study highlights the magnitude of the phenomenon, and for most indicators, their absence of improvement over the period.

As Canada is implementing its federal dementia strategy, and several provinces are conducting Alzheimer’s Plan, these findings are particularly relevant and timely [11]. Knowing the adverse outcomes associated with hospital use in persons with dementia, these figures are a call for action to develop and implement evidence-based policies to prevent avoidable hospital use in this vulnerable population.

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5.9 Supplementary File

5.9.1 Population

We included community-dwelling older adults (aged 65+) with a new diagnosis of dementia between April 1st and March 31st of each year inclusive. A dementia diagnosis was identified through a validated algorithm developed in Ontario by the Institute for Clinical Evaluative Science (ICES) and adopted by the Public Health Agency of Canada [1].

The definition of dementia used to develop the algorithm includes Alzheimer's disease, vascular dementia, dementia in other diseases classified elsewhere (frontotemporal dementia, idiopathic normal pressure hydrocephalus), and unspecified dementia (senile dementia, presenile dementia). The International Classification of Diseases (ICD)-9 and 10 codes used are: ICD-9 (46.1, 290.0, 290.1, 290.2, 290.3, 290.4, 294.x, 331.0, 331.1, 331.5, 331.82); ICD-10 (F00.x, F01.x, F02.x, F03.x, G30.x). The following characteristics were found in a validation study using as reference diagnoses recorded in electronic medical records : sensitivity 79.3% (confidence interval (CI) 72.9–85.8%), specificity 99.1% (CI 98.8–99.4%), positive predictive value 80.4% (CI 74.0–86.8%), and negative predictive value 99.0% (CI 98.7–99.4%) [1]

Persons were considered as diagnosed for dementia if they had at least 1 of the following conditions:

- One dementia diagnosis (primary or secondary) in the hospitalization dataset, since the age of 40;
- OR: At least 3 dementia diagnoses at least 30 days apart in a two-year period in the medical consultation dataset, since the age of 40;
- OR: One prescription of a dementia related drug in the prescription drug use dataset, since the age of 40 (drugs are recorded in the database as of 65 for every person, and for around a third of the population aged 40-64);

The date of diagnosis was the date on which the first of the three criteria became positive. For persons whose algorithm became positive through medical claims, the first medical claim was considered as the date of diagnosis.

It is to be noted, that the last available year of data, as of when we performed the analysis, was 2015-2016. Since the algorithm identifying dementia requires 2 years of data to identify every incident diagnosis, the 2014-2015 cohort is incomplete. As around 75% of the diagnoses are identified within one year, therefore the 2014-2015 cohort might be missing around 25% of incident diagnoses.

5.9.2 Outcomes: detailed definitions

Hospital use:

We measured ED visits (probability of having at least one and mean number), hospitalization (probability of having at least one) and length of hospital stay. All causes were considered. A validated algorithm was used to identify distinct visits to the ED [2]. Day surgeries were excluded from the computation of hospitalizations. The rates of ED visits (at least one and mean number) and hospitalization were computed on the entire cohorts. The length of hospital stay was computed as the total number of hospital days during the follow-up period in persons with at least one hospitalization.

Potentially avoidable hospitalization:

There are several definitions and measures of potentially avoidable hospitalization used in populations with dementia [3–12]. In order to draw a comprehensive picture, we measured, the four most common indicators of potentially avoidable hospital use in persons with dementia: Ambulatory Care Sensitive Conditions (ACSC) hospitalizations (general and older population definitions), 30-day readmission, Alternate level of care (ALC) hospitalizations. ACSC are conditions, "where appropriate ambulatory care may prevent or reduce the need for admission to hospital" [13]. We measured ACSC hospitalizations two ways. First, with a general population definition as defined *by Canadian Institute for Health Information (*CIHI). Second, with an older population definition: the measure developed by Walsh and colleagues on older persons dually eligible for Medicare and Medicaid, previously used in a population with dementia by Feng et al. [7,14]. This definition includes additional conditions that are more specific to an older population like: hypotension, constipation, skin ulcers, or nutritional deficiency. See details on lists of conditions and ICD codes for each definition below. The list of conditions included in the CIHI measure (general population definition) are asthma, cardiac heart failure, chronic obstructive pulmonary disorder (COPD), diabetes, hypertension, angina, seizures. (See Table *5.3*) The list of conditions included in the older population definition are asthma, cardiac heart failure, Chronic obstructive pulmonary disorder (COPD), diabetes, hypertension, hypotension, dehydration, pneumonia, urinary tract infection (UTI), constipation, skin ulcers, weight loss, nutritional deficiency, adult failure to thrive, seizures (See Table *5.4*). 30 day-readmission included any all cause hospital readmission within 30 days after any hospital discharge. Day surgeries were excluded from the computation of 30-day readmission. 30-day readmission was measured in the subset of persons with at least 1 hospital discharge during the study period, while the other indicators of potentially avoidable hospital use were measured in the subset of persons with at least one hospital admission. The length of ALC stay was computed as the total number of ALC hospital days during the follow-up period in persons with at least one ALC hospitalization.

Table 5.3 International Classification of Diseases (ICD) codes for the measures of Ambulatory Care Sensitive Conditions (ACSC) hospitalizations (General Population Definition)

	Hospitalizations with a most responsible diagnosis of	IC9-CM	IC10-CA
Ambulatory care sensitive conditions (ACSC) hospitalization – General Population Definition	Asthma	493	J45
	Cardiac heart failure	428 / 518.4	I50 / J81
	Chronic obstructive pulmonary disorder (COPD)	491 / 492 / 494 / 496	J41 / J42 / J43 / J44 / J47
	Diabetes	250.0 / 250.1 / 250.2 / 250.8	E10.0 / E10.1 / E10.63 / E10.64 / E10.9 / E11.0 / E11.1 / E11.63 / E11.64 / E11.9 / E13.0 / E13.1 / E13.63 / E13.64 / E13.9 / E14.0 / E14.1 / E14.63 / E14.64 / E14.9
	Hypertension	401.0 / 401.9 / 402.0 / 402.1 / 402.9	I10.0 / I10.1 / I11
	Angina	411.1 / 411.8 / 413	I20 / I23.82 / I24.0 / I24.8 / I24.9
	Seizures (Grand mal status and other epileptic convulsions)	345	G40 / G41

Table 5.4: International Classification of Diseases (ICD) codes for the measures of Ambulatory Care Sensitive Conditions (ACSC) hospitalizations (Older Population Definition)

	Hospitalizations with a most responsible diagnosis of	IC9-CM	IC10-CA
Ambulatory care sensitive conditions (ACSC) hospitalization – Older Population Definition	Asthma	493 / 493.01 / 493.02 / 493.10 / 493.11 / 493.12 / 493.20 / 493.21 / 493.22 / 493.81 / 493.82 / 493.90 / 493.91 / 493.92	J45.20 / J45.22 / J45.21 / J44.9 / J44.0 / J44.1 / J45.990 / J45.991 / J45.909 / J45.998 / J45.902 / J45.901
	Cardiac heart failure, Congestive heart failure (CHF)	428 / 518.4 398.91 / 402.11 / 402.91 / 404.11 / 404.13 / 404.91 / 404.93 / 428.0 / / 428.1 / 428.20 / 428.21 / 428.22 / 428.23 / 428.30 / 428.31 / 428.32 / 428.33 / 428.40 / 428.41 / 428.42 / 428.43 / 428.9 / 518.4	I50.9 / I50.1 / I50.20 / I50.21 / I50.22 / I50.23 / I50.30 / I50.31 / I50.32 / I50.33 / I50.40 / I50.41 / I50.42 / I50.43 / J81.0 / I09.81 / I11.0 / I13.0 / I13.2
	Chronic obstructive pulmonary disorder (COPD), Chronic bronchitis	491 / 492 / 494 / 496 466.0 / 466.11 / 466.19 / 490. / 491.1 / 491.20 / 491.21 / 491.8 / 491.9 / 492.0 / 492.8 / 494.0 / 494.1 /	J41.0 / J41.1 / J44.9 / J44.1 / J41.8 / J42 / J43.9 / J47.9 / J47.1 / J20.9 / J21.0 / J21.8 / J40

	Diabetes/Poor glycemic control/ hyper- and hypoglycemia: diabetes mellitus with ketoacidosis or hyperosmolar coma	250.0 / 250.1 / 250.2 / 250.8 / 250.02 / 250.03 / 250.10 / 250.11 / 250.12 / 250.13 / 250.20 / 250.21 / 250.22 / 250.23 / 250.30 / 250.31 / 250.32 / 250.33 / 251.0 / 251.2 / 790.29	E11.9 / E10.9 / E11.65 / E10.65 / E11.01 / E11.69 / E13.10 / E10.10 / E11.00 / E11.641 / E10.641 / E10.618 / E10.620 / E10.621 / E10.622 / E10.628 / E10.630 / E10.638 / E10.649 / E11.618 / E11.620 / E11.621 / E11.622 / E11.628 / E11.630 / E11.638 / E11.649 / E15 / E16.2 / R73.03 / R73.09 / E10.69 / E10.11
	Hypertension	401.0 / 401.9 / 402.0 / 402.1 / 402.9 / / 403.10 / 403.90 / 404.10 / 404.90	I10 / I16.9 / I11.9 / I11.0 / I13.10 / I20.0 / I12.9
	Angina	411.1 / 411.8 / 413	I20.0 / I24.0 / I24.8 / I20.8 / I20.1 / I20.9
	Seizures (Grand mal status and other epileptic convulsions)	345 / 345.01 / 345.10 / 345.11 / 345.2 / 345.3 / 345.40 / 345.41345.50 / 345.51 / 345.60 / 345.61 / 345.70 / 345.71 / 345.80 / 345.81 / 345.90 / 345.91436. / 780.31 / 780.39	G40.401 / G40.409 / G40.311 / G10.411 / G40.419 / G40.A01 / G40.A09 / G40.A11 / G40.A19 / G40.301 / G40.201 / G40.209 / G40.211 / G40.219 / G40.101 / G40.109 / G40.111 / G40.119 / G40.821 / G40.822 / G40.823 / G40.824 / G40.501 / G40.509 / G40.802 / G40.804 / G40.901 / G40.909 / G40.911 / G40.919 / I67.89 / R56.00 / R56.9
	Hypotension	458.0 / 458 / 458.8.1 / 458.21 /458.29 / 458.9	I95.1 / I95.89 / I95.3 / I95.2 / I95.81 / I95.9

Dehydration, volume depletion acute renal failure hypokalemia hyponatremia	276.5 / 276.8 / 584.5 / 584.6 / 584.7 / 584.8 / 584.9 / 588.81 / 588.89 / 588.9 / 276.1 / 276.8	E87.1 / E86.9 / E86.0 / E86.1 / E87.6 / N17.0 / N17.1 / N17.2 / N17.8 / N17.9 / N25.81 / N25.89 / N25.9
Pneumonia (Lower respiratory: pneumonia & bronchitis)	480.0 / 480.1 / 480.2 / 480.3 / 480.8 / 480.9 / 481. / 482.0 / 482.1 / 482.2 / 482.30 / 482.31 / 482.32 / 482.39 / 482.40 / 482.41 / 482.49 / 482.81 / 482.82 / 482.83 / 482.84 / 482.89 / 482.9 / 483.0 / 483.1 / 483.8 / 485. / 486. / 507.0	J12.0 / J12.1 / J12.2 / J12.81 / J12.89 / J12.9 / J13 / J18.1 / J15.0 / J15.1 / J14 / J15.4 / J15.3 / J15.20 / J15.211 / J15.29 / J15.8 / J15.5 / J15.6 / A48.1 / J15.9 / J15.7 / J16.0 / J16.8 / J18.0 / J18.9 / J69.0
Urinary Tract Infection	590.10 / 590.11 / 590.80 / 590.81 / 590.9 / 595.0 / 595.1 / 595.2 / 595.4 / 595.89 / 595.9 / 597.0 / 598.00 / 598.01 / 599.0 / 601.0 / 601.1 / 601.2 / 601.3 / 601.4 / 601.8 / 601.9	N10 / N12 / N16 / N15.9 / N30.00 / N30.01 / N30.10 / N30.11 / N30.20 / N20.21 / N30.80 / N30.81 / N30.90 / N30.91 / N34.0 / N35.111 / N37 / N39.0 / N41.0 / N41.1 / N41.2 / N41.3 / N51 / N41.4 / N41.8 / N41.9
Constipation /fecal impaction/obstipation	560.39 / 564.00 / 564.01 / 564.09	K56.49 / K59.00 / K59.01 / K59.03 / K59.04 / K59.09
Skin ulcers	707.00 / 707.01 / 707.02 / 707.03 / 707.04 / 707.05707.06 / 707.07 / 707.09 / 707.10 / 707.11 / 707.12 / 707.13 / 707.14 / / 707.9 /	L89.90 / L89.009 / L89.119 / L89.129 / L89.139 / L89.149 / L89.159 / L89.209 / L89.309 / L89.509 / L89.609 / L89.819 / L89.899 / L97.909 / L97.109 / L97.209 /

		707.15 / 707.19 / 707.8	L97.309 / L97.409 / L97.509 / L97.809 / L98.419 / L98.429 / L98.499
	Weight loss adult failure to thrive	783.21 / 783.22 / 783.3 / 783.7	R63.4 / R63.6 / R63.3 / R62.7
	Nutritional deficiency	260. / 261. / 262 / 263.0. / 263.1 / 263.2 / 263.8 / 263.9 / 268.0 / 268.1	E40 / E41 / E43 / E44.0 / E44.1 / E45 / E46 / E55.0 / E64.3

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6 Chapter 6: Difference-in-differences analysis and the propensity score to estimate the impact of non-randomized primary care interventions (Manuscript 2.2)

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6.1 Preamble

In this manuscript, I describe to a non-expert audience how advanced statistical methods can be used to strengthen causal inference from observational data. Indeed, as stated in previous chapters, and in particular in gap #3, observational data used to be considered as not suited to measure impact, especially because of major risks of confounding bias associated with observational data. However, recent development in impact evaluation research known as causal inference and the potential outcome framework offer a solution. The potential outcome framework allows strengthening causal inference from observational data [51]. This is nowadays a recommended approach to assess the impact of healthcare policies on a population level [51]. However, many decision makers, clinicians and researchers are not familiar with these methods. As mentioned previously (gap #3), addressing this knowledge translation gap was essential to allow decision-makers understand current primary care research findings and develop evidence-based policies. In this manuscript, I addressed the following objective: Objective 2.2. To explain to a non-expert audience how advanced statistical methods can be used to strengthen causal inference from observational data

This manuscript was written in response to a call for Method Brief to members of the Committee on Advancing the Science of Family Medicine (CASFM) of the North American Primary Care Research Group. This manuscript was published in February 2019 in Family Practice (Impact Factor: 1.986).

6.2 Key Messages

- Primary care interventions are often non-randomized
- Lack of randomization may create bias in the estimation of their impact
- Advanced statistical methods allow estimation of their impact

6.3 Introduction

Primary care delivery has been deeply transformed over the last couple of decades in high income countries [1]. For example, multidisciplinary primary care teams have become widespread in the United States (patient-centered medical homes (PCMH)) and in some Canadian provinces: i.e. Family Health Teams (FHTs) in Ontario, or Family Medicine Groups (FMGs) in Quebec. Evaluating the impact, or causal effect, of these interventions is key to inform evidence-based policies [2]. As most reforms and policies in primary care, these interventions were implemented outside of any randomized experiment [1,3]. Evaluating non-randomized interventions, reforms and policies (referred to as non-randomized interventions hereafter) necessitates overcoming pitfalls of observational studies, like confounding and selection bias [2].

Advanced statistical methods such as the difference-in-differences analysis and propensity scores have been developed to assess the impact of non-randomized interventions [4,5].These two methods are 1) increasingly used to measure non-randomized interventions impact, especially in primary care [6,7]; 2) particularly suited to provide the evidence needed to inform evidence-based policies: estimating the impact of policies on a population-wide scale, in a real-life context [8].

In this method brief, we illustrate the challenges of evaluating non-randomized interventions with an example: the evaluation of the impact of FMGs in Quebec (Canada) on health service use and costs [8].

Impact evaluation of FMGs on health service use and costs in Quebec, Canada

FMGs, multidisciplinary primary care teams, were first implemented in 2000 in Quebec, Canada, to enhance primary care access, continuity and care quality [1]. These FMGs were intended to include 6-12 full-time equivalent family physicians receiving additional funding for nurses, administrative support staff and computer equipment [9]. Family physicians enrollment in these FMGs was voluntary and not associated with major changes in their payment system [9]. Patient enrollment was also voluntary and occurred while registering with a physician practicing in an FMG [8].

There is evidence that physicians and patients that enrolled in the FMGs differed from the general population of Quebec physicians and patients [10]. For example, physicians who enrolled in FMGs had fewer years in medical practice, and a more diverse clinical practice (especially in hospitals) [10]. Patients who enrolled in FMGs had a lower socio-economic status, and greater use of hospital services for total and potentially avoidable causes[10]. These differences between patients and physicians who enrolled in FMGs and those who did not could bias, or confound, the estimation of the impact of FMGs **(intervention)** on health service use and costs, such as emergency department visits **(outcome)** [10], if they are not accounted for. (Figure 6.1) The factors associated with both FMG enrollment and emergency department visits are known as **confounding factors**.

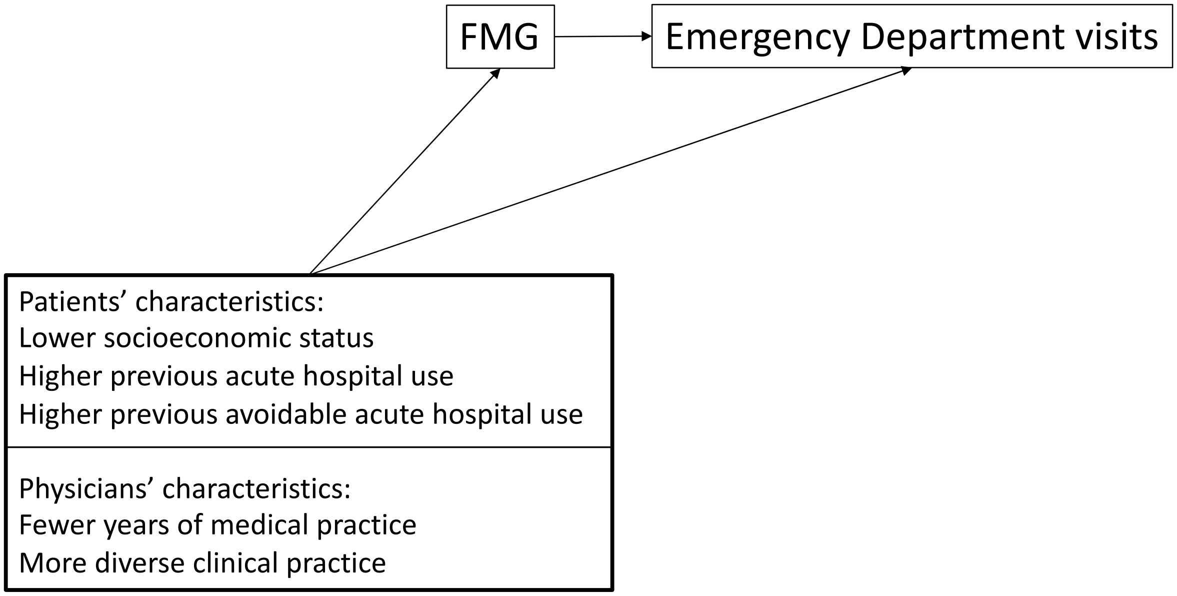

Figure 6.1: Factors associated with both the intervention (Family Medicine Group (FMG) and the outcome (emergency department visits): confounding factors of the impact of the intervention

Impact estimation in randomized controlled trials

An unbiased estimate of the impact of an intervention can be drawn when the intervention group and the control group are comparable or exchangeable [11]. Exchangeability refers to the control group being an adequate substitute for the outcome that would have occurred in the intervention group, had the intervention group not received the intervention [12]. Exchangeability between groups is achieved when groups are similar for all measured and unmeasured confounders [11,12]. The exchangeability condition is also known as “no unmeasured confounding,” [4] and is the focus of this methods brief. Other assumptions, detailed elsewhere, are necessary to estimate impact: positivity and consistency [3,4].

Exchangeability is achieved in well-conducted RCTs thanks to the randomization procedure. As shown in Figure 6.2, as a result of the random assignment, all individuals have the same probability of receiving the intervention, and the intervention and control groups only differ from each other with respect to the intervention of interest. In such cases, the estimation of the impact is not biased by confounding factors. The impact of the intervention on the outcome can be directly estimated by measuring the difference in outcomes between the intervention and control group.

Impact estimation in non-randomized interventions

In non-randomized interventions, the mechanism by which patients come to receive the intervention or not can be much more complex and is often poorly understood. As a result, the intervention and control groups may not be exchangeable (Figure *6.2*). As shown in figure 2B, when intervention and control groups are not exchangeable, estimating the impact of the intervention without taking into account these differences leads to a biased estimate.

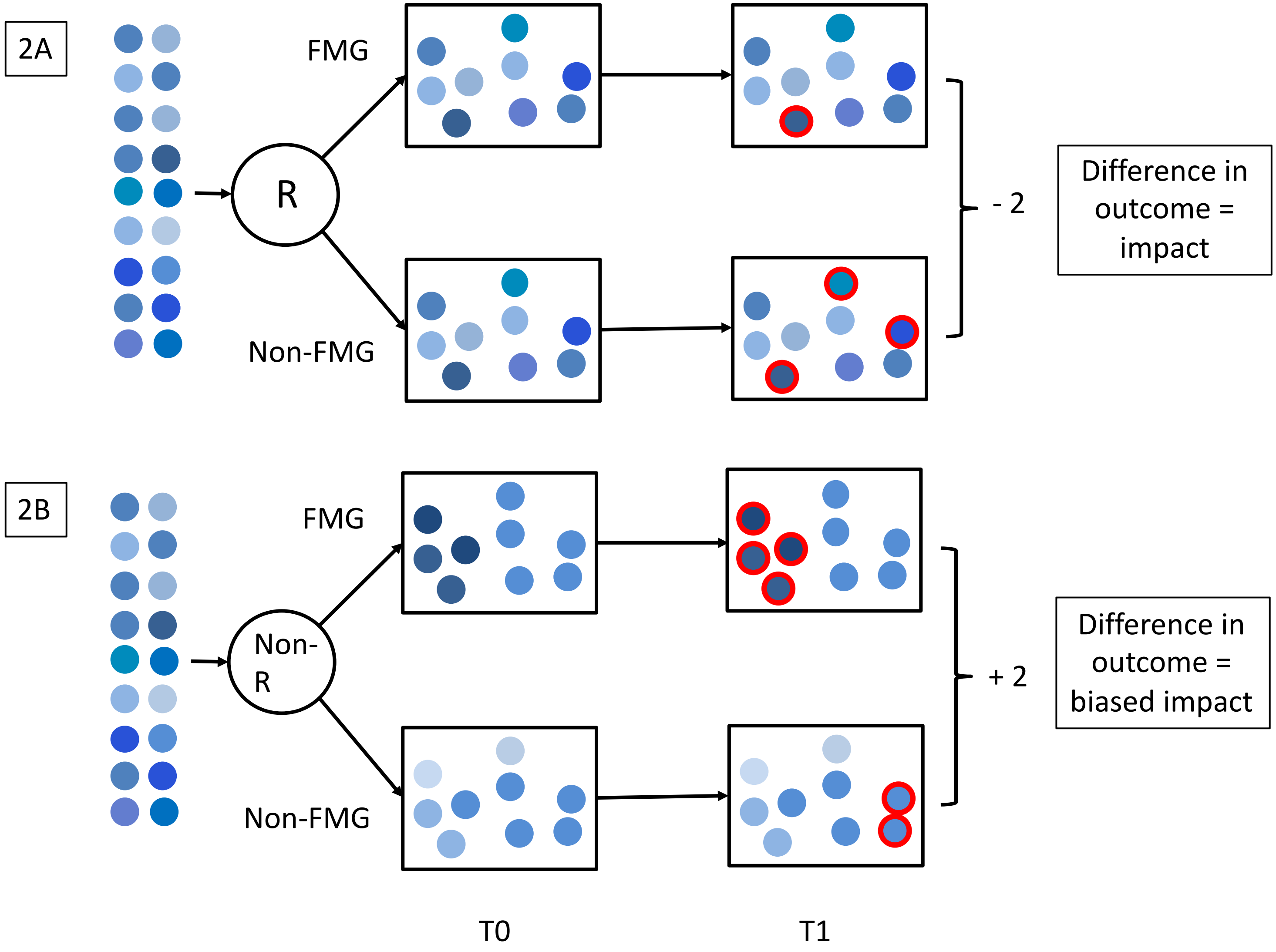

Figure 6.2 : Impact estimation in (2A) randomized controlled trials; (2B) non-randomized intervention

(2A) In a randomized controlled trial, random assignment (R) of the intervention creates exchangeable groups (FMG and non-FMG). Comparison of outcomes between the two groups provides an unbiased estimate of the impact of the intervention on the outcome; Red circles represent patients who experience the outcome: emergency department visits.
(2B) In a non-randomized intervention (Non-R), patients and physicians decide to enroll or not in FMGs, which may create groups that are not exchangeable. Comparison of outcomes between the two groups results in a biased estimate of the impact of the intervention on the outcome. Red circles represent patients who experience the outcome: emergency department visits.

In Quebec, the patients and physicians who enrolled in FMGs systematically differed from those that did not, creating two non-exchangeable groups. A comparison of emergency department visits before and after the implementation of the FMGs between the persons enrolled in FMGs **(intervention group)** and the persons not enrolled in FMGs **(control group)** does not allow disentangling what is caused by the intervention **(FMG)** and: 1) what is related to permanent differences between the control and the intervention groups **(i.e. potential confounding factors);** or 2) what is due to temporal trends (Figure 6.1). For example, higher emergency department visits in the FMG patient population may be attributed to their worse health status, rather than the intervention itself [10]. Moreover, quality of care may have improved over time in Quebec, independently of the intervention, reducing emergency department visits **(temporal trend).** Taking into account these permanent differences between the intervention and control groups **(potential confounding factors)** and **temporal trends** in the outcome is essential to accurately estimate the impact of FMGs.

6.4 The difference-in-differences analysis

The difference-in-differences analysis can be used to estimate the impact of non-randomized interventions. The difference-in-differences analysis allows disentangling the impact of the intervention from 1) permanent differences between control and intervention groups **(potential confounding factors)** and 2) **temporal trends** in the outcome unrelated to the intervention [2]. The impact of the intervention is estimated through the difference between two differences in the outcomes: 1) D1: difference between the pre- and post-intervention periods in the control group, and 2) D2: difference between the pre- and post-intervention periods in the intervention group (Figure *6.3*). This estimate is computed from a regression model, which includes 2 dichotomous variables: the time (before or after the intervention), the group (intervention or control group) and an interaction term between the time and the group [2,6]. The impact is estimated through the coefficient of this interaction term [2,6]. A model, compared to a simple subtraction, allows adjusting for potential confounders, and thus reduces residual confounding. In addition, it allows estimating whether the impact of the intervention is significant, in other words whether the coefficient of the interaction term is significantly different from zero [2,6]. More detailed explanations are provided elsewhere[2,12].

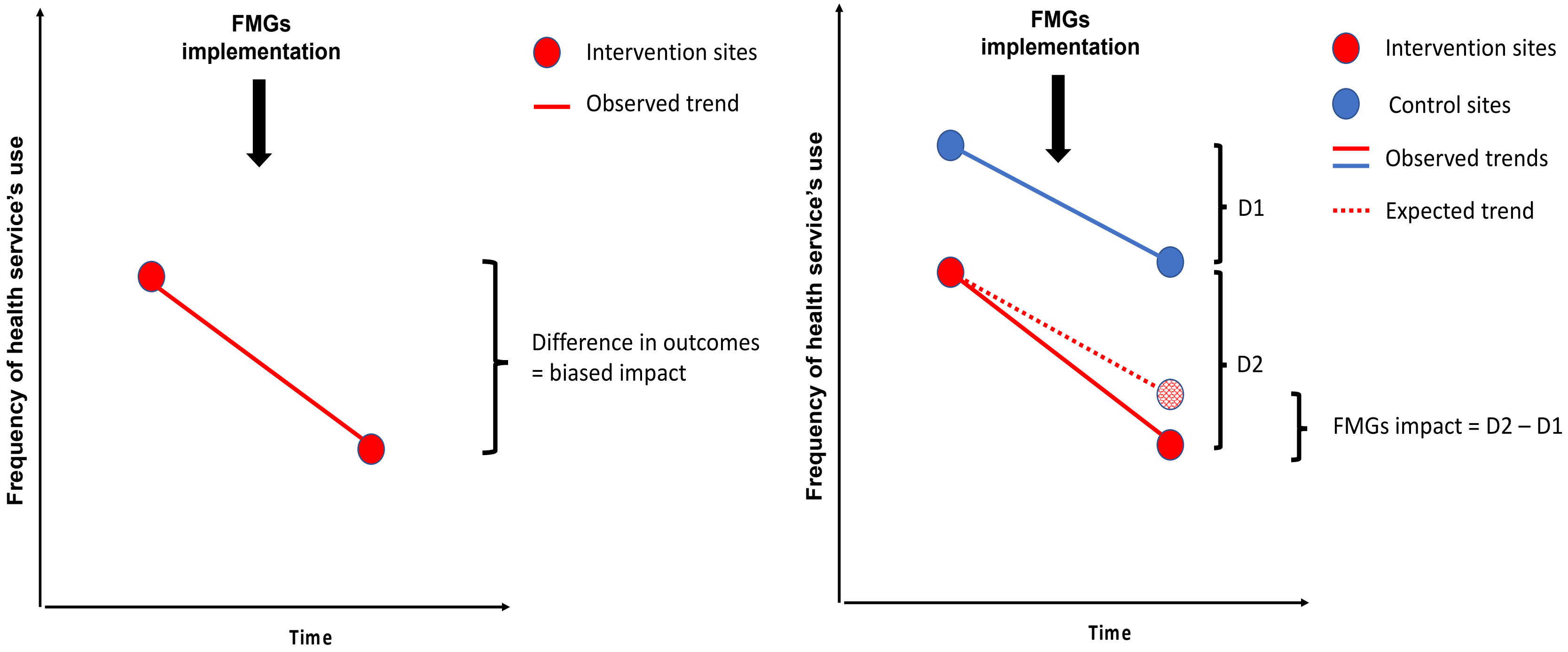

Figure 6.3: Impact estimation with the difference-in-differences analysis

In the difference-in-differences analysis the impact of the intervention is estimated through two differences in the outcomes: 1) D1: difference between the pre- and post-intervention average outcomes in the control group, and 2) D2: difference between the pre- and post-intervention average outcomes in the intervention group.

The difference-in-differences analysis relies on two assumptions:

- the common “shock” assumption”, stating that any events occurring during or after the time the intervention was implemented will equally affect the intervention and control groups [6].
- the “common trend assumption”, stating that the intervention and control group trends would have varied in a similar fashion after the intervention, the intervention group not having received the intervention [6].

These two assumptions cannot be formally tested. However, they guide the choice of an appropriate control group that meets the two assumptions.

The common “shock” assumption” should be questioned through discussion with stakeholders knowledgeable of the context. In our example, the absence of differential exposure between the intervention and control groups to other provincial policies, or major disease-modifying events has to be questioned. For example, did all patients enrolled in FMGs also belong to the same geographic region that was affected by a heat wave that increased emergency department visits?

According to the ‘common trend assumption’, outcomes in the control and intervention groups vary in a similar fashion over time. As such, trends in outcomes observed in the control group correspond to what would have been observed in the intervention group, had they not received the intervention [13]. Plausibility of the “common trend assumption” should be assessed through discussion with stakeholders knowledgeable of the context. In addition, comparability of the trends in the outcome before the intervention, between intervention and control groups, can be assessed graphically and with a formal statistical test.

Several sensitivity analyses may be performed to assess whether the impact estimation is unbiased, and thus whether the impact measured can be attributed to the intervention. The impact of the intervention on placebo outcomes, that should not be affected by the intervention, may be measured. A null effect should be found. The estimated impact of the intervention at a calendar date before the intervention was implemented should also be null. The impact may also be measured using several suitable control groups and should be comparable. Restriction of the study population to the continuously enrolled participants may be considered, taking into account its potential influence on generalizability and study power to detect an impact [13].

In non-randomized interventions where the control and intervention groups are exchangeable, and the above assumptions are met, difference-in-differences provides a reasonably unbiased estimate of the intervention's impact. If however, exchangeability of the control and intervention groups is questionable, one may resort to the use of propensity scores.

6.5 Propensity scores

A propensity score is a balancing score used to construct an analytical sample in which intervention and control groups are exchangeable. By creating exchangeable groups, the impact of non-randomized interventions can be estimated.[14] A propensity score represents each participant's probability of receiving the intervention based on their baseline characteristics, regardless of whether or not they actually received it. In our example, the probability of every participant to enrol in a FMG is modeled. The underlying assumption of using propensity scores is the absence of unmeasured confounders, as the propensity score can only create balance between groups on measured variables. More detailed explanations are provided elsewhere [2,7,14–18].

Propensity scores can be used in different ways (Table 6.1). Propensity score matching is illustrated in the FMG impact evaluation example (Figure 6.4).

Table 6.1: Propensity score (PS) use and impact estimation

PS use	**Impact estimation**
PS matching	Compare outcomes of matched pairs of comparable participants; while taking into account the matched nature of the data
Stratification on PS	Compare participant's outcome within each strata or pooled across strata; strata of participants based on PS values
Covariate adjustment on PS	Include PS as a covariate in impact estimation model
Inverse probability of treatment weighting using the PS	Compare outcomes from intervention and control groups where participants have been assigned weights according to their PS

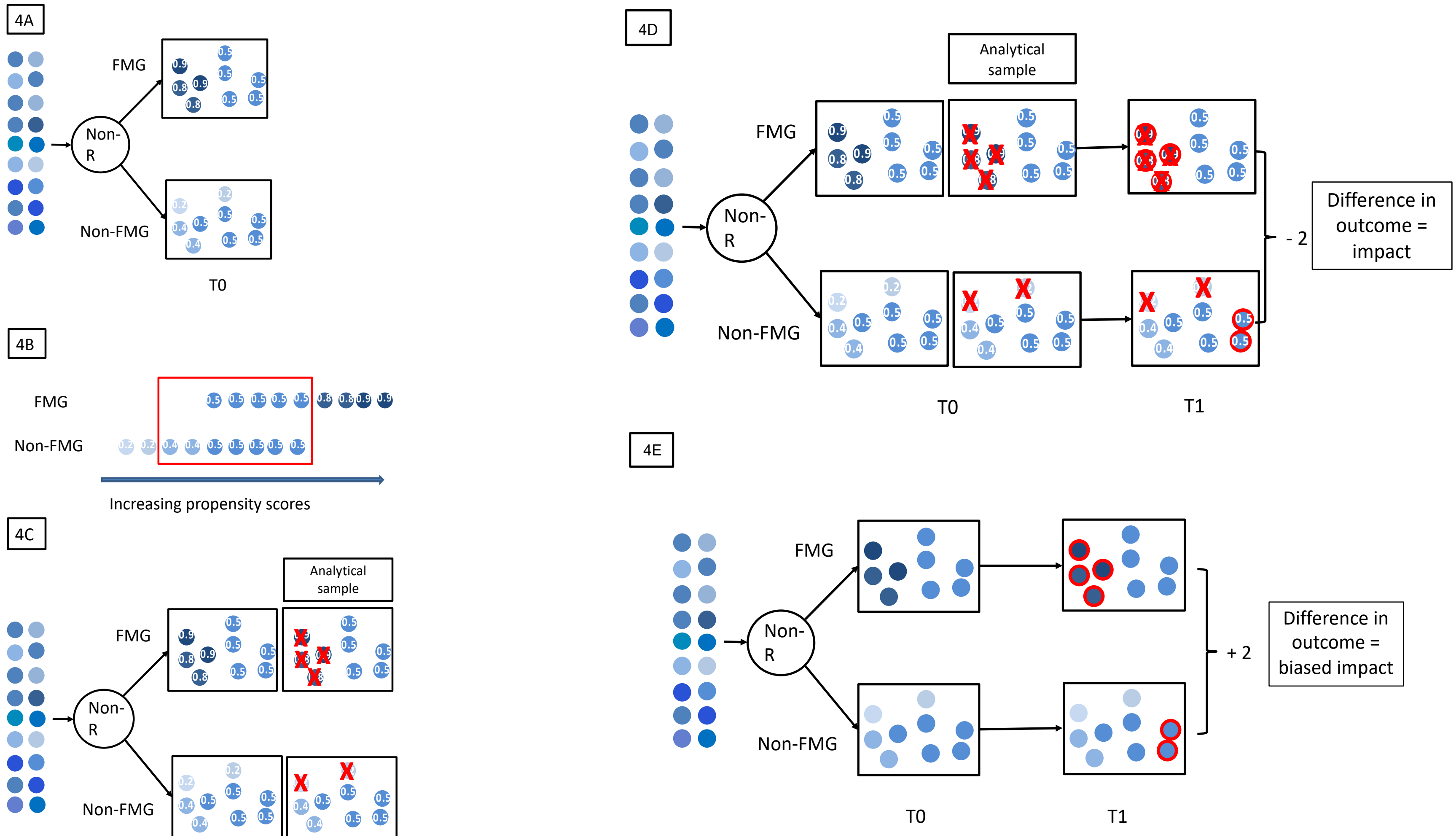

Figure 6.4 : Impact estimation in non-randomized intervention with propensity score: propensity scores assignment (4A), matching (4B), data pre-processing (4C), impact estimation (4D), compared to impact estimation in non-randomized intervention without propensity score (4E).

Preprocessing creates intervention and control groups that are exchangeable, so that the comparison of outcomes between the groups provides an unbiased estimate of the impact of the intervention on the outcome. Red circles represent patients who experience the outcome; Red crosses represent patients who are removed from the analytical sample.

Specification of the propensity score follows an iterative approach until balance of baseline characteristics between intervention and control groups is achieved [14,15]. If balance is not achieved, specification of the propensity score can be improved by using additional predictors[14]. The model is a multiple regression (i.e. logistic regression modeling the probability of being in the intervention group vs control group). Predictors included in the propensity score model are 1) potential confounding factors of the association between the intervention and the outcome or 2) predictors of the outcome. [14] Only variables measured at baseline should be included. Variables affected by the intervention are not included. [14] There is no way to verify that the predicted probabilities reflect the true probabilities. The propensity score is considered correctly specified when balance of baseline characteristics between intervention and control groups is achieved. It is to be noted that balance can only be assessed in measured characteristics. If unmeasured confounders are not balanced between groups, groups will remain non-exchangeable. Presence of unmeasured confounders should be assessed through discussion with stakeholders knowledgeable of the context. The impact of unmeasured confounders can be explored through sensitivity analyses, testing the robustness of the impact estimation to unmeasured confounders[14,16,19,20] . Assessing balance in measured baseline characteristics is usually done with standardized differences [14]. Standardized differences compare the differences in means in units of the pooled standard deviation. A threshold of less or equal to 0.1 is recommended to consider the difference between the two groups negligible [14].

As a result of using propensity scores, the analytical sample of the non-randomized study now mimics an RCT, where participants in the intervention and control groups only differ with respect to whether or not they received the intervention but had the same probability of receiving the intervention (Figure 6.4).

6.6 Conclusion

Most primary care interventions, reforms and policies are implemented outside of randomized experiments. The difference-in-differences analysis and propensity score can provide an unbiased estimation of the impact of these non-randomized interventions.

These methods are therefore key to the evaluation of interventions to inform health policy makers and future policies.

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7 Chapter 7: Primary care continuity and potentially avoidable hospitalization in persons with dementia, in Quebec (Canada) (Manuscript 2.3)

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7.1 Preamble

As stated in previous chapters and in particular in Gap #4, continuity could be an important determinant of avoidable hospital use in community-dwelling persons with dementia. Recent evidence found conflicting results regarding the association between continuity of ambulatory care (primary and specialist care) and avoidable hospital use in this population [41]. To our knowledge, there is no study of the impact of primary care continuity on avoidable hospital use in this population. Measuring the impact of primary care continuity on potentially avoidable hospital use in community-dwelling persons with dementia is essential, to ultimately inform healthcare policies aiming at reducing avoidable hospital use in this population. In this manuscript, I addressed the following objective: Objective 2.3. To measure the impact of primary care continuity on potentially avoidable hospital use in community-dwelling persons with dementia in Quebec.

In this manuscript, I measured the association between high primary care continuity and potentially avoidable hospital use in community-dwelling persons with dementia in Quebec. In the following paragraphs, I, first, present the tested hypothesis, study design and method. Second, I present the database, included population, exposure and outcomes variables.

In this manuscript, I tested the following hypothesis: having high primary care continuity is associated with fewer potentially avoidable hospital use, in community-dwelling persons with dementia in Quebec.

I used the target trial framework and the causal inference framework to design the study, conduct the analyses, and interpret the results. These frameworks allow strengthening causal inference from observational data. These frameworks are the most cutting-edge frameworks allowing producing sound evidence with observational data to ultimately inform evidence-based policies. This type of analysis aims to mimic an intervention with observational data, as it makes as if the exposure was set by the researcher. Using this approach, on provincial-wide data, is coherent with the objective of the thesis, which is to deepen our understanding of the phenomenon in order to, ultimately, inform healthcare policies aiming at reducing avoidable hospital use in this population.

The target trial framework gives a step by step procedure to emulate, with observational data, a hypothetical pragmatic randomized trial to answer a causal question [77,78]. Using the target trial framework allows preventing, among others, immortal time bias, or reverse causality[77,78]. The key element to emulate this hypothetical pragmatic randomized trial is to specify a time zero, on which occur: eligibility assessment, treatment assignment and start of follow-up. [77,78] Thus, I aligned on the same date (Time zero = 31st of March 2015) the eligibility assessment, exposure assignment, and start of the outcome measurement period.

The potential outcome framework allows strengthening causal inference from observational data , as described in Chapter 2.2. of this thesis). In the potential outcomes framework, average causal effect of an intervention can be estimated from the difference in average outcomes from two exchangeable groups [51]. Exchangeability between groups is achieved when groups are similar for every measured and unmeasured characteristic, apart from the exposure of interest [51]. Exchangeability is achieved in well-conducted randomized controlled trials, where the groups only differ from each other for the exposure of interest and where both groups had the same probability to receive the treatment. In non-randomized interventions, both groups are not exchangeable, as there are known and unknown factors associated with both exposure and outcomes. They can be made conditionally exchangeable, for example, using propensity score [51]. A propensity score is a balancing score used to construct an analytical sample in which intervention and control groups are exchangeable. By creating exchangeable groups, the impact of non-randomized interventions can be estimated [79]. A propensity score represents each participant's probability of receiving the intervention based on their baseline characteristics, regardless of whether or not they actually received it.

I used inverse probability of treatment weighting (IPTW) using the propensity score to increase the pre-period comparability of exposed and unexposed to primary care continuity [79]. IPTW creates a weighted sample, in which exposure is independent of measured baseline covariates, which helps to reduce confounding [79]. (See Chapter 6: Difference-in-differences analysis and the propensity score to estimate the impact of non-randomized primary care interventions).

I chose IPTW over other use of the propensity score for several reasons. First, IPTW has been shown to remove systematic differences between exposed and unexposed persons to a comparable or almost comparable degree as propensity score matching [79]. Propensity score matching being the method removing the most systematic differences between exposed and unexposed persons when compared to stratification on the propensity score or covariate adjustment using the propensity score [79]. Second, it is the recommended method when the number of exposed exceed the number of unexposed, which was the case in the study population [80]. Two third of the population was exposed. When the number of exposed exceed the number of unexposed, one wants to prevent bias due to incomplete matching [80]. Bias due to incomplete matching is associated with questions around generalizability, and target population [80].

To conduct this analysis, I used the same database as in Manuscript 2.1 (See details on the database in the Appendix 1). I included community-dwelling persons (aged 65+) with prevalent dementia on March 31st, 2015. The population with dementia was identified with the same algorithm as in Manuscript 2.1 (See details on the algorithm in the Appendix 2). I used a different version of Manuscript 2.1 algorithm to identify the community-dwelling population aged 65 +, and long-term care admissions in the database (See details on the algorithm in the Appendix 5:).

I measured primary care continuity with the Bice-Boxerman index on visits to primary care physicians (See eMethod1 in Online Supplement). I developed an algorithm identifying ambulatory care visits and primary care visits (See Appendix 6: Algorithm identifying ambulatory care visits and primary care visits).

I measured hospital use (ED visits and hospitalizations) and defined avoidable hospital use as in Manuscript 2.1 (See operationalized definitions of these measures in Appendix 7.11.2 in Chapter 7). Hospital use were measured during the follow-up period. Every person was followed from April 1st, 2015 until either death, long-term care (LTC) admission or the end of the study period: March 31st, 2016, whichever occurred first. (See details in Appendix 4: Eligibility and computation of events for indicators of hospital use).

To be noted: on the contrary to Manuscript 2.1, where the indicators of avoidable hospital use are measured on subpopulations having at least one event, in this article, I measure the indicators on the entire populations of exposed and unexposed included in the analytical sample. Indeed, inverse probability of treatment weighting on the propensity scores was used to increase comparability of the exposed and unexposed to primary care continuity. IPTW renders the exposed and unexposed in the analytical sample comparable; but not the exposed and unexposed in the analytical sample with at least one event. This explains the very different proportion of avoidable hospital use reported in Manuscript 2.1 and 2.3: in Manuscript 2.1 the denominator being the sub-population with at least one use, in Manuscript 2.3 the denominator being the entire population.

To be noted: in the submitted article, I chose not to present the results on the association between high primary care continuity and ALC hospitalizations. Indeed, my hypothesis on the association between high primary care continuity and ALC hospitalizations was more exploratory. The direction of the association with primary care continuity could have been both ways. I thus did not formulate a hypothesis to be tested. The results on the association between high primary care continuity and ALC hospitalizations are comparable to the other results in terms of direction of association, but neither in term of statistical significance nor in term of strength of association. They will be presented in another manuscript and are presented in "Appendix 7: Association between high primary care continuity and ALC hospitalizations".

This manuscript is in submission process.

7.2 Key points

Question:

What is the association between primary care continuity and potentially avoidable hospitalization in community-dwelling persons with dementia?

Findings:

In this 4-year retrospective cohort study (2012-2016) from a population-based sample of 22,060 community-dwelling persons with dementia in Quebec (Canada), high primary care continuity was significantly associated with fewer potentially avoidable hospitalizations.

Meaning:

Increasing continuity with the primary care physician might be an avenue to reduce potentially avoidable hospitalization in community-dwelling persons with dementia.

7.3 Abstract

Importance: Persons with dementia have twice as many hospitalizations as older persons without dementia. One out of five of these hospitalizations is potentially avoidable. High continuity with a primary care physician could help reduce these potentially avoidable hospitalizations.

Objective: To measure the association between high primary care continuity and potentially avoidable hospitalization in community-dwelling persons with dementia.

Design: Observational 4-year retrospective cohort (2012-2016), with inverse probability of treatment weighting using the propensity score.

Setting: Population-based study of the Quebec (Canada) health administrative database, recording all services provided via the public universal health insurance system.

Participants: A population-based sample of 22,060 community-dwelling 65+persons with dementia on March 31st, 2015, with at least two primary care visits in the preceding year. Due to missing values, 23 of the 22,060 (0.1%) were excluded. Participants were followed for one year, or until death or long-term care admission.

Exposure: Primary care continuity measured on March 31st, 2015 with the Bice-Boxerman index on visits to primary care physicians during the preceding year.

Outcomes: Primary: Potentially avoidable hospitalization in the follow-up period as defined by Ambulatory Care Sensitive Conditions hospitalization (general and older population definitions), 30-day hospital readmission; Secondary: Hospitalizations and Emergency Department visits.

Results: Among the 22,060 persons, (mean age 81 years, 60% female) 65.8% had high primary care continuity. The relative risk reduction for Ambulatory Care Sensitive Condition hospitalization (general population definition) in those exposed to high primary care continuity was 0.82 (95% confidence Interval (CI) [0.72;0.94]; P=.004) compared to the unexposed. The relative risk reduction for Ambulatory Care Sensitive Condition hospitalization (older population definition) was 0.87 (CI [0.79;0.95]; P=.002). The relative risk reduction for 30-day hospital readmission was 0.81 (CI [0.72;0.92]; P<.001). The relative risk reduction for hospitalization and Emergency Department visits were 0.90 (CI [0.86;0.94]; P<.001), and 0.92 (CI [0.90;0.95]; P<.001), respectively.

Conclusion and relevance: Among community-dwelling persons with dementia in Quebec, high primary care continuity was associated with fewer potentially avoidable hospitalizations. Increasing continuity with a primary care physician might be an avenue to reduce potentially avoidable hospitalizations, the burden on the health care system, and adverse outcomes for this vulnerable population.

7.4 Introduction

In 2019, 5.8 million Americans are living with dementia, and this number is projected to increase by 25% in the next 5 years [1]. In the United States (US), dementia is one of the costliest conditions for society [1]. Persons with dementia have twice as many hospitalizations per year as older persons without dementia and hospital care for them is three times as costly [1]. In addition, hospitalizations in persons with dementia are associated with increased risk of adverse outcomes, including impaired quality of life, delirium, falls, cognitive and functional decline, long-term care admission and death [2–4].

A share of these hospitalizations might be avoidable with appropriate ambulatory care, including primary care [1]. In the US, it is estimated that 20% of hospitalizations of community-dwelling persons with dementia are potentially avoidable [5]. They account for major healthcare system spending, with total Medicare cost per year for these potentially avoidable hospitalizations above $5 billion (2018 US dollars) [5]. Reducing avoidable hospitalization in persons with dementia is a global healthcare priority [6–9]. However, to date, the evidence on effective interventions is scarce [10–17].

Worldwide, high primary care continuity is known to be associated with reduced avoidable hospitalization for the general and older population [18–21]. By primary care continuity, we refer to the relationship between a primary care physician and a patient that extends beyond specific episodes of illness or disease [22–24]. High primary care continuity could improve the management of chronic conditions and the detection and treatment of acute exacerbations [18], and thus reduce avoidable hospitalizations. Primary care continuity might be especially important in the care of persons with dementia, who are mostly cared for in primary care [25]. Increasing primary care continuity might be an avenue to prevent avoidable hospitalizations.

To our knowledge, the evidence on primary care continuity among persons with dementia is scarce. No study has measured the association between primary care continuity and hospital use. Only one study, a cross-sectional study of the Medicare population with dementia, explored the association between ambulatory care continuity with any physician, including specialists, and potentially avoidable hospitalization [26]. This study showed that higher continuity was associated with fewer total hospitalizations, but not with fewer potentially avoidable hospitalizations [26].

There is a need to better understand the link between primary care continuity and potentially avoidable hospitalization in persons with dementia, to ultimately inform healthcare policies aimed at reducing avoidable hospitalizations in this population. In this study, we estimated the association between high primary care continuity and potentially avoidable hospitalization in community-dwelling persons with dementia. Our hypothesis was that high primary care continuity would be associated with fewer potentially avoidable hospitalizations.

7.5 Method

7.5.1 Design

We conducted an observational study, using inverse probability of treatment weights based on the propensity score. We analyzed a 4-year retrospective cohort of community-dwelling persons with dementia in Quebec (2012-2016). We used the target trial and causal inference frameworks to design the study, conduct the analyses, and interpret the results. These methods have been shown to reduce bias in estimates from observational data[27–29]. In addition, we followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) and REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) guidelines[30,31].

7.5.2 Data source and setting

We analyzed the Quebec linked, population-based health administrative database held at the *Institut national de santé publique du Québec* (the National Public Health Institute of Quebec)[32]. Quebec is the second most populated province of Canada, and accounts for 1 out of 5 Canadians with dementia[33]. The provincial database records all services provided via the public universal health insurance system and links five health administrative databases: health insurance registry, hospitalizations, physician claims, drug services and mortality [34,35]. This database covers 99% of the 65+ population of Quebec [34,35]. Data were accessed by LR and CGS, who performed the cohort extraction and the analyses, respectively, using SAS Enterprise Guide software, 7.15 version. This study is part of the continuous chronic disease surveillance mandate granted to the *Institut national de santé publique du Québec* by the provincial Minister of Health and Social Services and approved by the provincial Ethics Committee of Public Health. In addition, it was approved by the McGill Faculty of Medicine Institutional Review Board.

7.5.3 Population

Community-dwelling persons age 65+ with prevalent dementia on March 31st, 2015 were eligible. Persons with dementia were identified through a validated algorithm[36]. The community-dwelling population was identified as persons with no evidence, in the linked health administrative databases, of living in or waiting for admission to a long-term care facility[32]. The population was restricted to persons continuously eligible to the public health insurance system from 2012 to 2015 (Figure *7.1*). In addition, persons living in three very remote northern regions of Quebec were excluded because very small populations live in these regions, with different patterns of health care use.

7.5.4 Exposure

Primary care continuity was measured on March 31st, 2015 with the Bice-Boxerman index on visits to primary care physicians during the preceding year (April 1st, 2014 to March 31st, 2015) (See eMethod1 in the Supplemental File). The population was restricted to persons with at least 2 primary care visits, as continuity of care indices cannot be computed with less than 2 visits. The Bice-Boxerman index was chosen because it is a validated proxy of relational continuity, “the relationship between a single practitioner and a patient that extends beyond specific episodes of illness or disease”22–24. The formula below was used, where ni = number of visits that the patient has with the ith physician and N = total number of visits.

$$(\sum ni2 - N)/N\ (N-1)$$

Because of its distribution, the Bice-Boxerman index was dichotomized (low = [0;1[vs high = [1]). Persons with an index of 1, were labelled as having high primary care continuity. During the preceding year, persons with high primary care continuity had every primary care visit, with the same primary care physician, regardless of the number of visits. Persons with an index of 0, were labelled as having low primary care continuity. During the preceding year, persons with low primary care continuity had primary care visits, with at least two primary care physicians, regardless of the number of visits. Because of its bimodal distribution, modeling the index as continuous would not have added much information.

7.5.5 Outcomes

Outcomes were measured during the follow-up period. Every person was followed from April 1st, 2015 until either death, long-term care (LTC) admission, or the end of the study period: March 31st, 2016, whichever occurred first. We measured, as primary outcomes, the three most commonly-used indicators of potentially avoidable hospitalization in persons with dementia [4,26,37–44]: Ambulatory Care Sensitive Conditions (ACSC) hospitalizations and all cause 30-day readmission. (See eMethod2, Table *7.3* and Table *7.4* in the supplement).

These hospitalizations are considered potentially avoidable in the context of better outpatient care. A 30-day readmission may be avoidable through timely primary care access after discharge[45,46], thus we expected that 30-day readmission may be sensitive to primary care continuity. ACSC are conditions, “where appropriate ambulatory care may prevent or reduce the need for admission to hospital” [47]. We measured two definitions of ACSC hospitalizations: a general population definition and an older population definition [4,47,48]. The list of conditions included in the general population definition are asthma, cardiac heart failure, chronic obstructive pulmonary disorder (COPD), diabetes, hypertension, angina, and seizures. The older population definition includes additional conditions that are more specific to an older population like: hypotension, constipation, skin ulcers, and nutritional deficiency. (See eMethod2, Table *7.3* and Table *7.4* in the supplement).

We measured, as secondary outcomes, all-cause Emergency Department (ED) visit, and hospitalization. (See eMethod2). ED visits may be reduced by better outpatient care and thus be sensitive to primary care continuity[49]. Hospitalization may be sensitive to primary care continuity through a decrease in potentially avoidable hospitalization.

7.5.6 Analysis

7.5.6.1 Construction of the weighted sample

We used inverse probability of treatment weighting (IPTW) using the propensity score to increase the pre-period comparability of exposed and unexposed to high primary care continuity [50]. IPTW creates a weighted sample, in which exposure is independent of measured baseline covariates, helping to reduce confounding [50].

The propensity score modeled the probability of having high versus low primary care continuity on March 31st, 2015. (See eMethod3 in the supplement). Predictors included in the propensity score were potential confounding factors or predictors of the outcomes, all measured before exposure. [50] Predictors were sex, age, small-area level socioeconomic status (Pampalon index of material deprivation [51–53]), rurality, a validated comorbidity index, presence of 16 comorbid conditions, hospital use in 2012-2013 and

2013-2014 (ACSC hospitalization (both definitions), number of ACSC hospitalization (both definitions), 30-day readmission, number of 30-day readmission, delayed hospital discharge, number of days as delayed discharge, ED visit, number of ED visits, hospital admission, number of hospitalization, number of hospital days), ambulatory care use in 2012-2013 and 2013-2014 (number of ambulatory care visits and number primary care visits). Delayed discharge is coded in the administrative database as “a person who has completed the acute care phase of his or her treatment but remained in an acute care bed.” [54]

There were no missing data for the exposure or outcomes. Only 23 persons had missing data for two predictors of the propensity score: the Pampalon index of material deprivation and the indicator of rurality. As it represented only 0.1% (23/22060) of the sample, we restricted the analysis to the persons with no missing data (Figure *7.1*). In addition, we restricted the analysis to the persons whose propensity score was in the common support region (4 persons were excluded) (Figure *7.1*).

7.5.6.2 Association between high primary care continuity and the outcomes

For each outcome, we estimated the risk ratio, risk difference and the number needed to treat to prevent one event in the weighted sample. We estimated the level of significance of the associations with a 2-sided weighted Wald test in an univariable logistic regression model. As the rates of attrition in the exposed and unexposed were comparable, as were the mean and median follow-up time, we did not perform time-to-event analysis (See Table *7.5* in the supplement).

We estimated variances of the estimates with bootstrap-based methods, as recommended by Austin et al. to account for the fact that 1) the propensity score was estimated, and 2) there is lack of independence between persons in the weighted sample because of replications of persons caused by weighting[55]. We corrected for multiple testing using the Bonferroni method, as we had 5 outcomes. Following Bonferroni correction, for a level of significance of 0.05, we set the significance threshold at 0.01.

7.5.6.3 Sensitivity analyses

We performed sensitivity analyses to 1) extreme weights and 2) unmeasured confounders. Extreme weights in IPTW may increase the variability of the estimated exposure effect [56]. We conducted the analysis in a distinct weighted sample where persons with weights less than the 1st percentile or over the 99th percentile were excluded [56].

We performed sensitivity analyses to an unmeasured confounder [57,58]. (See eMethod4, and Table *7.8* in the supplement). We computed E-values, defined by VanderWeele and Ding as "the minimum strength of association, on the risk ratio scale, that an unmeasured confounder would need to have with both the treatment and the outcome to fully explain away a specific treatment–outcome association, conditional on the measured covariates." [57,58]. We interpreted the significance of the E-values according to known strengths of association of potential unmeasured confounders [38,40,59–63].

7.6 Results

7.6.1 Population and weighted sample description

On March 31st, 2015, 41,971 persons were age 65+, community-dwelling, and had a prevalent diagnosis of dementia (Figure *7.1*). A continuity of care index was computable for the 22,060 persons (53%) with at least two primary care visits in the preceding year. The characteristics of these two populations are presented in eTable4 in the supplement. The 22,060 persons with at least 2 primary care visits were younger, more rural, and had more past health service use than persons with less than 2 primary care visits.

In the 22,060 persons, the mean age was 81 years (SD 7.02), 60% were female, and 65.8% had high primary care continuity (Table *7.1* and Table *7.3*). Of these 22,060 persons, the 22,033 without missing values for the predictors of the propensity score and in the common support region were included in the weighted sample (Figure *7.1*).

In the unweighted sample, persons with high vs low primary care continuity were less often living in Montreal and more often living in towns of less than 10,000 inhabitants. They had fewer ED and ambulatory care visits in the two years prior to exposure assessment (Table *7.1*). In the weighted sample, all absolute standardized differences in baseline characteristics between the two groups were negligible (<0.1) (Table *7.1*: Comparison of socio-demographic, health, and service use characteristics of the exposed and unexposed to high primary care continuity in the population of 65+ community-dwelling persons with a prevalent diagnosis of dementia having at least 2 primary care visits between the 1st of April 2014 and the 31st of March 2015 included in the study (unweighted and weighted samples), Quebec, Canada.).

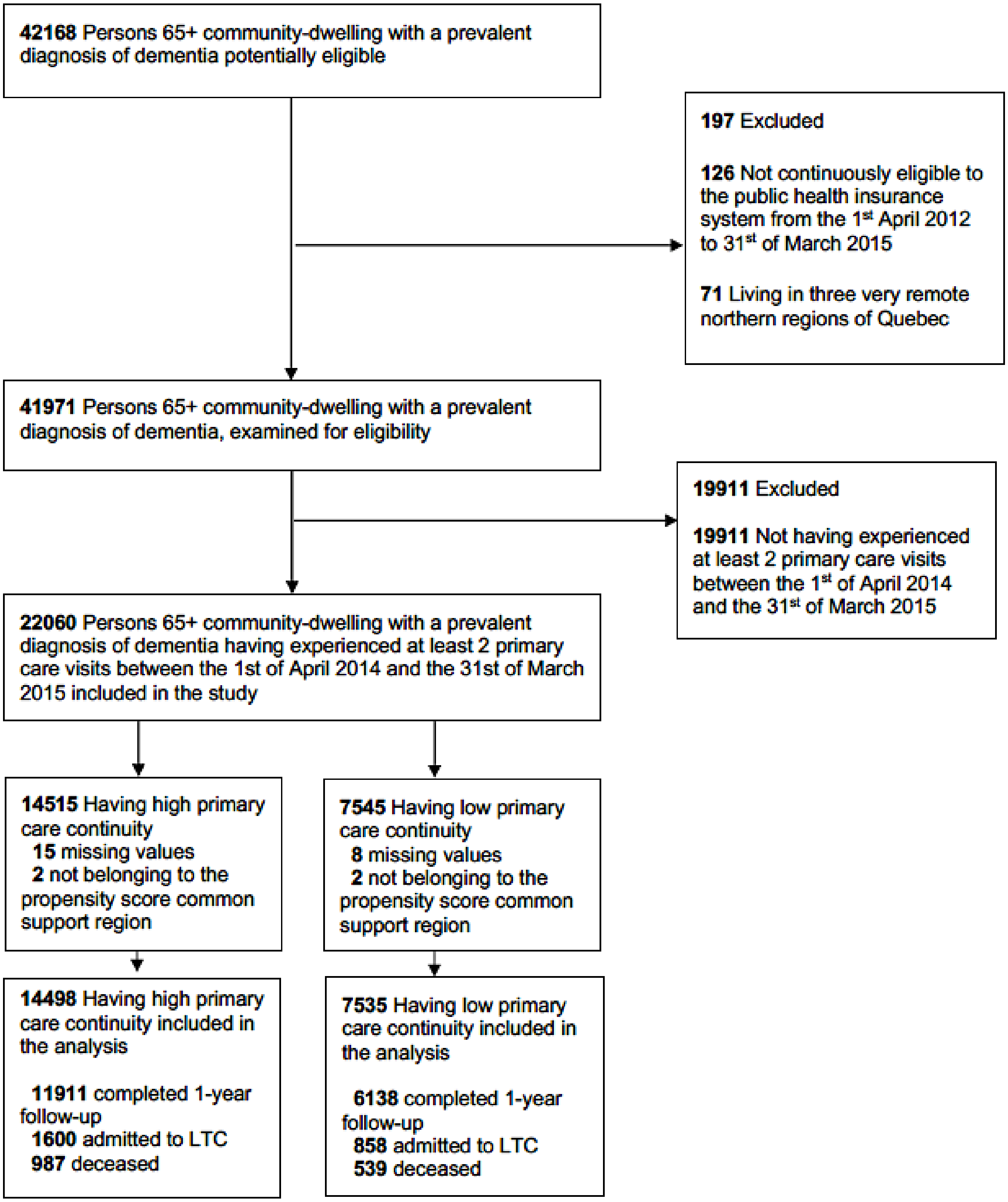

Figure 7.1: Study Population

LTC: Long term care

Table 7.1: Comparison of socio-demographic, health, and service use characteristics of the exposed and unexposed to high primary care continuity in the population of 65+ community-dwelling persons with a prevalent diagnosis of dementia having at least 2 primary care visits between the 1st of April 2014 and the 31st of March 2015 included in the study (unweighted and weighted samples), Quebec, Canada.

	Unweighted			**Weighted**		
	High primary care continuity	Low primary care continuity	Absolute Standardized Differences [a]	High primary care continuity	Low primary care continuity	Absolute Standardized Differences [a]
	N=14515	N=7545		N = 14498 (weight = 14498)	N= 7535 (weight = 14503)	
	No. (%) or Mean (SD)			No. [b] (%) or Mean (SD)		
Sociodemographic characteristics in 2013-2014						
Age	80.47 (7.01)	80.00 (7.04)	0.07	80.47 (7.01)	80.50 (9.75)	0.00
Female	8775 (60.45)	4546 (60.25)	0.00	8764 (60.14)	8722 (60.45)	0.01
Material Deprivation Index	N=14500[c]	N=7537[c]				
Quintile 1= Less deprived	2239 (15.44)	1313 (17.42)	0.05	2239 (15.44)	2224 (15.33)	0.00
Quintile 2	2742 (18.91)	1501 (19.92)	0.03	2741 (18.91)	2776 (19.14)	0.01
Quintile 3	2954 (20.37)	1604 (21.28)	0.02	2954 (20.38)	2985 (20.58)	0.01
Quintile 4	3412 (23.53)	1678 (22.26)	0.03	3412 (23.53)	3402 (23.46)	0.00
Quintile 5 = Most deprived	3153 (21.74)	1441 (19.12)	0.07	3152 (21.74)	3117 (21.49)	0.01
Rurality	N = 14500[c]	N = 7537[c]				
Montreal	4783 (32.99)	3175 (42.13)	**0.19**	4783 (32.99)	4797 (33.07)	0.00
City >100K inhabitants	3358 (23.16)	1670 (22.16)	0.02	3357 (23.15)	3361 (23.17)	0.00
Small cities: 10-99K inhabitants	2369 (16.34)	1164 (15.44)	0.02	2369 (16.34)	2371 (16.35)	0.00
Rural <10K inhabitants	3990 (27.52)	1528 (20.27)	**0.17**	3989 (27.51)	3975 (27.41)	0.00
Health Status in 2013-2014						
Diabetes	4226 (29.11)	2263 (29.99)	0.02	4221 (29.11)	4232 (29.18)	0.00
Hypertension	11084 (76.36)	5725 (75.88)	0.01	11077 (76.40)	11080 (76.40)	0.00

Heart failure	1700 (11.71)	943 (12.50)	0.02	1699 (11.72)	1720 (11.86)	0.00
COPD	3572 (24.61)	2044 (27.09)	0.06	3570 (24.62)	3565 (24.58)	0.00
Comorbidity Index	1.02 (1.90)	1.18 (2.04)	0.08	1.02 (1.90)	1.03 (1.90)	0.00
Service Use in 2012-2013						
At least one ACSC hospitalization (Older population)	536 (3.69)	352 (4.67)	0.05	535 (3.69)	527 (3.63)	0.00
At least one ACSC hospitalization (General population)	294 (2.03)	205 (2.72)	0.05	293 (2.02)	296 (2.04)	0.00
At least one 30-day re-admission	292 (2.01)	198 (2.62)	0.04	292 (2.01)	291 (2.01)	0.00
At least one ED visit	5590 (38.51)	3237 (42.90)	0.09	5584 (38.52)	5596 (38.59)	0.00
Mean number of ED visits	0.78 (1.42)	0.94 (1.66)	**0.10**	0.78 (1.42)	0.78 (1.42)	0.00
At least one hospitalization	2497 (17.20)	1439 (19.07)	0.05	2494 (17.20)	2506 (17.28)	0.00
Mean number of ambulatory care visits	6.50 (5.90)	7.25 (6.95)	**0.12**	6.50 (5.90)	6.49 (5.53)	0.00
Mean number of primary care visits	3.78 (3.42)	3.86 (3.59)	0.02	3.78 (3.42)	3.73 (3.44)	0.01
Service Use in 2013-2014						
At least one ACSC hospitalization (Older population)	659 (4.54)	411 (5.45)	0.04	658 (4.54)	660 (4.55)	0.00
At least one ACSC hospitalization (General population)	354 (2.44)	247 (3.27)	0.05	354 (2.44)	361 (2.49)	0.00
At least one 30-day re-admission	360 (2.48)	264 (3.50)	0.06	357 (2.46)	356 (2.45)	0.00
At least one ED visit	5999 (41.33)	3529 (46.77)	**0.11**	5992 (41.33)	6004 (41.40)	0.00
Mean number of ED visits	0.87 (1.50)	1.08 (1.76)	**0.13**	0.87 (1.50)	0.87 (1.48)	0.00
At least one hospitalization	2955 (20.36)	1707 (22.62)	0.06	2951 (20.35)	2957 (20.39)	0.00

Mean number of ambulatory care visits	6.95 (6.35)	7.91 (7.49)	**0.14**	6.95 (6.36)	6.96 (5.87)	0.00
Mean number of primary care visits	4.03 (3.46)	4.23 (3.75)	0.06	4.03 (3.46)	3.99 (3.51)	0.01

SD: Standard Deviation; COPD: Chronic obstructive pulmonary disorder; ED: Emergency Department; ACSC: Ambulatory care sensitive condition.

[a] Standardized differences less or equal to 0.1 are considered negligible as recommended by Austin et al [50]; [b] Numbers from the weighted sample rounded to the integer ; [c] Total in each group specified because of missing values.

7.6.2 Association between high primary care continuity and potentially avoidable hospitalization

High primary care continuity was significantly associated with potentially avoidable hospitalization in the following year (Table *7.2*). The relative risk reduction for ACSC hospitalization (general population definition) was 0.82 (95% Confidence Interval (CI) [0.72;0.94]; P=.004). The relative risk reduction for ACSC hospitalization (older population definition) was 0.87 (CI [0.79;0.95]; P=.002). The relative risk reduction for 30-day readmission was 0.81 (CI [0.72;0.92]; P<.001).

The number of persons needed to treat with high primary care continuity to prevent one ACSC hospitalization (general population definition), one ACSC hospitalization (older population definition), or one 30-day readmission were 118 (CI [69;356]), 87 (CI [52;252]), 97 (CI [60;247]), respectively.

7.6.3 Association between high primary care continuity and hospital use

High primary care continuity was significantly associated with hospital use in the following year (Table *7.2*). The relative risk reduction for ED visits and hospitalization were 0.92 (CI [0.90;0.95]; P<.001), and 0.90 (CI [0.86;0.94]; P<.001), respectively. The number needed to treat to prevent one ED visit, or one hospitalization were 23 (CI [17;34]) and 29 (CI [21;47]), respectively.

Table 7.2: Estimated association of high primary care continuity and hospital use in the weighted sample (N= 22033)

Hospital use	**Persons exposed to high primary care continuity** N = 14498 (weight = 14498) **No. (%)**[b]	**Persons unexposed to high primary care continuity** N= 7535 (weight = 14503) **No.** [a] **(%)**[c]	**p value**	**Absolute Risk Reduction** **Point estimate [95%CI]**	**Risk Ratio** **Point estimate [95%CI]**	**Number Needed to Treat to prevent one event** **Point estimate [95%CI]**
At least one ACSC hospitalization (general population)	567 (3.91)	690 (4.76)	**0.004**	0.85 [0.28;1.45]	0.82 [0.72;0.94]	118 [69;356]
At least one ACSC hospitalization (older population)	1069 (7.37)	1236 (8.52)	**0.002**	1.15 [0.40;1.91]	0.87 [0.79;0.95]	87 [52;252]
At least one 30-day readmission	648 (4.47)	797 (5.50)	**<.001**	1.03 [0.41;1.66]	0.81 [0.72;0.92]	97 [60;247]
At least one ED visit	7362 (50.78)	8000 (55.16)	**<.001**	4.38 [2.96;5.80]	0.92 [0.90;0.95]	23 [17;34]
At least one hospitalization	4437 (30.60)	4937 (34.04)	**<.001**	3.44 [2.11;4.78]	0.90 [0.86;0.94]	29 [21;47]

CI: Confidence interval; ACSC: Ambulatory Care Sensitive Conditions; ED: Emergency Department.

a = numbers from the weighted analytical sample rounded to the integer;

b = percentage of persons exposed to high primary care continuity with at least one event.

c = percentage of persons unexposed to high primary care continuity with at least one event.

7.6.4 Sensitivity analyses

The results of the sensitivity analysis to extreme weights were comparable to the main analysis in terms of the magnitude of the estimates, their sign, and level of statistical significance. (See Table *7.7* in the supplement).

The sensitivity analysis to an unmeasured confounder showed that the results could be sensitive to an unmeasured confounder. However, the unmeasured confounder would have to be moderately-to-strongly associated with both the exposure and the outcome after having controlled for all observed confounders included in the propensity score. We believe this is an unlikely scenario according to the current literature [38,40,59–63]. (See eMethod4 , Table *7.8* in the supplement).

7.7 Discussion

In the first study on the association between high primary care continuity and potentially avoidable hospitalization in community-dwelling persons with dementia, we show a negative, large, and statistically significant association. High continuity with a primary care physician was significantly associated with fewer potentially avoidable hospitalizations (ACSC hospitalization and 30-day readmission). In addition, high primary care continuity was significantly associated with fewer ED visits and hospitalizations.

Our results are consistent with the broader literature on older persons, where primary care continuity is associated with a reduction in hospitalization and potentially avoidable hospitalization [18–21]. Our results are partly consistent with the only study on the association between ambulatory care continuity (including visits to specialist) and potentially avoidable hospitalization in community-dwelling persons with dementia[26]. This previous study found that higher care continuity was associated with less hospitalization and ED visits, but not with potentially avoidable hospitalizations, as measured by hospitalizations for ACSC[26].

Our results highlight the importance of high primary care continuity among community-dwelling persons with dementia. There are three major reasons that may explain why high primary care continuity is associated with fewer avoidable hospitalization and ED visits. First, high primary care continuity may improve the management of chronic conditions, and the detection and treatment of acute exacerbations [18]. High primary care continuity might be especially important in the care of persons with dementia where persons might be less able to identify and communicate about acute symptoms, and where symptoms of common acute diseases are less typical and often mixed with delirium and behavioral and psychological symptoms of dementia [26,64]. Second, a long-standing primary care relationship might be necessary to assess and address caregiver burden and stress, which are major drivers of crisis, leading to hospital use [17,61,65–67]. Third, a long-standing primary care relationship may ease a palliative care approach with discussion of advanced directives and preferences for end-of-life care. This could prevent undesired hospital use in patients and caregivers, who prefer to obtain end-of-life care at home [4,68,69]. Future research should seek to understand the mechanisms underlying the association between high primary care continuity and hospital use, in order to make informed recommendations. Combinations of qualitative and quantitative data could help understand, for example, the role of caring for the caregiver or palliative care approaches in this relationship.

Reducing avoidable hospitalizations among persons with dementia is a priority and increasing primary care continuity may be a way to work towards that goal. Increasing primary care continuity might be achieved through several actions. First, by sharing these results with policy-makers, primary care physicians, specialists, patients and their caregivers, and the Alzheimer’s society, we could stress the importance of aiming for quality, continuous relationship with one trusted primary care physician. Second, through policies and care organization, we could enable primary care physicians to be available to their patients during acute episodes and for a proactive follow-up to provide high-quality primary care.

7.7.1 Strengths and Limitations

Our study has several strengths and limits. We followed the highest methodological standards to minimize confounding in analyzing routinely collected data [27,28,50]. Even though we took into account a wide range of major potential confounders like past service use or comorbidity, the provincial health administrative database does not record other confounders, like caregiver availability. Sensitivity analyses showed that these results could be sensitive to an unmeasured confounder, though in rather unlikely scenarios according to the current literature [38,40,59–63]. We restricted the study population to persons for whom a continuity of care index was computable. The estimated association is thus only measured in a population with repeated contacts with primary care physicians. Extrapolations should be restricted to similar populations. Finally, in the provincial health administrative database, non-physician primary care clinician (nurse practitioners, registered nurses, and other healthcare professionals) visits are not recorded. Future studies could investigate the role of other primary care clinicians and the continuity with the interdisciplinary primary care team in the prevention of avoidable hospitalization.

7.8 Conclusions and relevant implications for health policy

Increasing primary care continuity might be an avenue to reduce avoidable hospitalization, the burden to the healthcare system, and adverse outcomes for community-dwelling persons with dementia. Further research should seek to understand the mechanisms underlying the association and evaluate the impact of policies or interventions aiming to increase primary care continuity on potentially avoidable hospitalization.

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7.10 References

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7.11 Supplemental File

7.11.1 eMethod1: Exposure: detailed definition

Primary care continuity was measured on March 31st, 2015 with the Bice-Boxerman index based on visits to primary care physicians during the preceding year (April 1st, 2014 to March 31st, 2015).

The population was restricted to persons having had at least 2 primary care visits, as continuity of care indices cannot be computed with less than 2 visits. This choice was a trade-off between representativeness of the included sample and mathematical properties of the Bice-Boxerman index. Indeed, indices of continuity of care are prone to extreme values (0 or 1) in persons experiencing fewer than 4 visits during the period of exposure measurement. In the Quebec community-dwelling 65+ persons with dementia on March 31st, 2015, only around a quarter had four or more visits, and around a third had three or more visits.

Primary care visits included visits to any primary care physician (general practitioner, family physician, community medicine, primary care medicine). The Bice-Boxerman index was chosen because it is a validated proxy of relational continuity, “the relationship between a single practitioner and a patient that extends beyond specific episodes of illness or disease.”[2–4] The above formula was used, where ni = number of visits that the patient has with the ith physician and N = total number of visits.

$$(\sum ni2 - N)/N\ (N-1)$$

Because of its distribution, the Bice-Boxerman index was dichotomized (low = [0;1[vs high = [1]). Persons with an index of 1, were labelled as having high primary care continuity. During the preceding year, persons with high primary care continuity had every primary care visit, with the same primary care physician, regardless of the number of visits. Persons with an index of 0, were labelled as having low primary care continuity. During the preceding year, persons with low primary care continuity had primary care visits, with at least two primary care physicians, regardless of the number of visits. Because of its bimodal distribution, modeling the index as continuous would not have added much information.

7.11.2 eMethod2: Outcomes: detailed definitions

We measured the three most commonly-used indicators of potentially avoidable hospitalization in persons with dementia [4–13]: Ambulatory Care Sensitive Conditions (ACSC) hospitalizations and all-cause 30-day readmission.

These hospitalizations are considered potentially avoidable in the context of better outpatient care. 30-day readmission may be avoidable through timely primary care access after discharge.[14,15] We therefore expected that this may be sensitive to primary care continuity. ACSC are conditions, “where appropriate ambulatory care may prevent or reduce the need for admission to hospital.”[16] We measured two definitions of ACSC hospitalizations: a general population definition and an older population definition.[8,16,17] First, with a general population definition: the measure from the Canadian Institute for Health Information (CIHI). Second, with an older population definition: the measure developed by Walsh and colleagues on dually eligible Medicare Medicaid older persons, previously used in the dementia population by Feng et al.[8,18] The list of conditions included in the CIHI measure (general population definition) are asthma, cardiac heart failure, Chronic obstructive pulmonary disorder (COPD), diabetes, hypertension, angina, and seizures (See eTable 1). The list of conditions included in the measure developed by Walsh and colleagues for dually eligible Medicare Medicaid older persons and applied to the dementia population by Feng [8,17] (older population definition) are: asthma, cardiac heart failure, Chronic obstructive pulmonary disorder (COPD), diabetes, hypertension, hypotension, dehydration, pneumonia, urinary tract infection (UTI), constipation, skin ulcers, weight loss, nutritional deficiency, adult failure to thrive, and seizures (See eTable 2).

30 day-readmission included any all-cause hospital readmission within 30 days after any hospital discharge. Day surgeries were excluded from the computation of 30-day readmission.

We measured all-cause Emergency Department (ED) visits and hospitalizations. ED visits may be reduced by better outpatient care and thus be sensitive to primary care continuity[19]. Hospitalizations may be sensitive to primary care continuity through a decrease in potentially avoidable hospitalization. A previously validated algorithm was used to identify distinct visits to the ED.[20] Day surgeries were excluded from the computation of hospitalizations.

Table 7.3: International Classification of Diseases (ICD) codes for the measures of Ambulatory Care Sensitive Conditions (ACSC) hospitalizations (General Population Definition)

	Hospitalizations with a most responsible diagnosis of	IC9-CM	IC10-C
Ambulatory care sensitive conditions (ACSC) hospitalization – General Population Definition	Asthma	493	J45
	Cardiac heart failure	428 / 518.4	I50 / J81
	Chronic obstructive pulmonary disorder (COPD)	491 / 492 / 494 / 496	J41 / J42 / J43 / J44 / J47
	Diabetes	250.0 / 250.1 / 250.2 / 250.8	E10.0 / E10.1 / E10.63 / E10.64 / E10.9 / E11.0 / E11.1 / E11.63 / E11.64 / E11.9 / E13.0 / E13.1 / E13.63 / E13.64 / E13.9 / E14.0 / E14.1 / E14.63 / E14.64 / E14.9
	Hypertension	401.0 / 401.9 / 402.0 / 402.1 / 402.9	I10.0 / I10.1 / I11
	Angina	411.1 / 411.8 / 413	I20 / I23.82 / I24.0 / I24.8 / I24.9
	Seizures (Grand mal status and other epileptic convulsions)	345	G40 / G41

Table 7.4: International Classification of Diseases (ICD) codes for the measures of Ambulatory Care Sensitive Conditions (ACSC) hospitalizations (Older Population Definition)

	Hospitalizations with a most responsible diagnosis of	IC9-CM	IC10-CA
Ambulatory care sensitive conditions (ACSC) hospitalization – Older Population Definition	Asthma	493 / 493.01 / 493.02 / 493.10 / 493.11 / 493.12 / 493.20 / 493.21 / 493.22 / 493.81 / 493.82 / 493.90 / 493.91 / 493.92	J45.20 / J45.22 / J45.21 / J44.9 / J44.0 / J44.1 / J45.990 / J45.991 / J45.909 / J45.998 / J45.902 / J45.901
	Cardiac heart failure, Congestive heart failure (CHF)	428 / 518.4 398.91 / 402.11 / 402.91 / 404.11 / 404.13 / 404.91 / 404.93 / 428.0 / / 428.1 / 428.20 / 428.21 / 428.22 / 428.23 / 428.30 / 428.31 / 428.32 / 428.33 / 428.40 / 428.41 / 428.42 / 428.43 / 428.9 / 518.4	I50.9 / I50.1 / I50.20 / I50.21 / I50.22 / I50.23 / I50.30 / I50.31 / I50.32 / I50.33 / I50.40 / I50.41 / I50.42 / I50.43 / J81.0 / I09.81 / I11.0 / I13.0 / I13.2
	Chronic obstructive pulmonary disorder (COPD), Chronic bronchitis	491 / 492 / 494 / 496 466.0 / 466.11 / 466.19 / 490. / 491.1 / 491.20 / 491.21 / 491.8 / 491.9 / 492.0 / 492.8 / 494.0 / 494.1 /	J41.0 / J41.1 / J44.9 / J44.1 / J41.8 / J42 / J43.9 / J47.9 / J47.1 / J20.9 / J21.0 / J21.8 / J40

	Diabetes/Poor glycemic control/ hyper- and hypoglycemia: diabetes mellitus with ketoacidosis or hyperosmolar coma	250.0 / 250.1 / 250.2 / 250.8 / 250.02 / 250.03 / 250.10 / 250.11 / 250.12 / 250.13 / 250.20 / 250.21 / 250.22 / 250.23 / 250.30 / 250.31 / 250.32 / 250.33 / 251.0 / 251.2 / 790.29	E11.9 / E10.9 / E11.65 / E10.65 / E11.01 / E11.69 / E13.10 / E10.10 / E11.00 / E11.641 / E10.641 / E10.618 / E10.620 / E10.621 / E10.622 / E10.628 / E10.630 / E10.638 / E10.649 / E11.618 / E11.620 / E11.621 / E11.622 / E11.628 / E11.630 / E11.638 / E11.649 / E15 / E16.2 / R73.03 / R73.09 / E10.69 / E10.11
	Hypertension	401.0 / 401.9 / 402.0 / 402.1 / 402.9 / / 403.10 / 403.90 / 404.10 / 404.90	I10 / I16.9 / I11.9 / I11.0 / I13.10 / I20.0 / I12.9
	Angina	411.1 / 411.8 / 413	I20.0 / I24.0 / I24.8 / I20.8 / I20.1 / I20.9
	Seizures (Grand mal status and other epileptic convulsions)	345 / 345.01 / 345.10 / 345.11 / 345.2 / 345.3 / 345.40 / 345.41345.50 / 345.51 / 345.60 / 345.61 / 345.70 / 345.71 / 345.80 / 345.81 / 345.90 / 345.91436. / 780.31 / 780.39	G40.401 / G40.409 / G40.311 / G10.411 / G40.419 / G40.A01 / G40.A09 / G40.A11 / G40.A19 / G40.301 / G40.201 / G40.209 / G40.211 / G40.219 / G40.101 / G40.109 / G40.111 / G40.119 / G40.821 / G40.822 / G40.823 / G40.824 / G40.501 / G40.509 / G40.802 / G40.804 / G40.901 / G40.909 / G40.911 / G40.919 / I67.89 / R56.00 / R56.9
	Hypotension	458.0 / 458 / 458.8.1 / 458.21 /458.29 / 458.9	I95.1 / I95.89 / I95.3 / I95.2 / I95.81 / I95.9

Dehydration, volume depletion acute renal failure hypokalemia hyponatremia	276.5 / 276.8 / 584.5 / 584.6 / 584.7 / 584.8 / 584.9 / 588.81 / 588.89 / 588.9 / 276.1 / 276.8	E87.1 / E86.9 / E86.0 / E86.1 / E87.6 / N17.0 / N17.1 / N17.2 / N17.8 / N17.9 / N25.81 / N25.89 / N25.9
Pneumonia (Lower respiratory: pneumonia & bronchitis)	480.0 / 480.1 / 480.2 / 480.3 / 480.8 / 480.9 / 481. / 482.0 / 482.1 / 482.2 / 482.30 / 482.31 / 482.32 / 482.39 / 482.40 / 482.41 / 482.49 / 482.81 / 482.82 / 482.83 / 482.84 / 482.89 / 482.9 / 483.0 / 483.1 / 483.8 / 485. / 486. / 507.0	J12.0 / J12.1 / J12.2 / J12.81 / J12.89 / J12.9 / J13 / J18.1 / J15.0 / J15.1 / J14 / J15.4 / J15.3 / J15.20 / J15.211 / J15.29 / J15.8 / J15.5 / J15.6 / A48.1 / J15.9 / J15.7 / J16.0 / J16.8 / J18.0 / J18.9 / J69.0
Urinary Tract Infection	590.10 / 590.11 / 590.80 / 590.81 / 590.9 / 595.0 / 595.1 / 595.2 / 595.4 / 595.89 / 595.9 / 597.0 / 598.00 / 598.01 / 599.0 / 601.0 / 601.1 / 601.2 / 601.3 / 601.4 / 601.8 / 601.9	N10 / N12 / N16 / N15.9 / N30.00 / N30.01 / N30.10 / N30.11 / N30.20 / N20.21 / N30.80 / N30.81 / N30.90 / N30.91 / N34.0 / N35.111 / N37 / N39.0 / N41.0 / N41.1 / N41.2 / N41.3 / N51 / N41.4 / N41.8 / N41.9
Constipation /fecal impaction/obstipation	560.39 / 564.00 / 564.01 / 564.09	K56.49 / K59.00 / K59.01 / K59.03 / K59.04 / K59.09
Skin ulcers	707.00 / 707.01 / 707.02 / 707.03 / 707.04 / 707.05707.06 / 707.07 / 707.09 / 707.10 / 707.11 / 707.12 / 707.13 / 707.14 / / 707.9 / 707.15 / 707.19 /	L89.90 / L89.009 / L89.119 / L89.129 / L89.139 / L89.149 / L89.159 / L89.209 / L89.309 / L89.509 / L89.609 / L89.819 / L89.899 / L97.909 / L97.109 / L97.209 / L97.309 / L97.409 /

		707.8	L97.509 / L97.809 / L98.419 / L98.429 / L98.499
	Weight loss adult failure to thrive	783.21 / 783.22 / 783.3 / 783.7	R63.4 / R63.6 / R63.3 / R62.7
	Nutritional deficiency	260. / 261. / 262 / 263.0. / 263.1 / 263.2 / 263.8 / 263.9 / 268.0 / 268.1	E40 / E41 / E43 / E44.0 / E44.1 / E45 / E46 / E55.0 / E64.3

7.11.3 eMethod3: Specification of the propensity score, construction of the weighted sample, and balance assessment of baseline characteristics between exposed and unexposed in the weighted sample

Specification of the propensity score

Specification of the propensity score followed an iterative approach as described by Rosenbaum and Rubin, until balance on baseline characteristics was achieved.[21,22]

Predictors included in the propensity score model were 1) potential confounding factors of the association between the exposure and the outcome or 2) predictors of the outcome, all measured before exposure.[21] Predictors were sex, age, small-area level socioeconomic status (Pampalon index of material deprivation [23–25]), rurality, a validated comorbidity index, presence of 16 comorbid conditions, hospital use in 2012-2013 and 2013-2014 (ACSC hospitalization (both definitions), number of ACSC hospitalization (both definitions), 30-day readmission, number of 30-day readmission, delayed hospital discharge, number of days as delayed discharge, ED visit, number of ED visits, hospital admission, number of hospitalization, number of hospital days), and ambulatory care use in 2012-2013 and 2013-2014 (number of ambulatory care visits and number primary care visits).

The material deprivation Pampalon index is a composite measure of the level of education, employment, income and family structure of the census dissemination area level.[23–25] The proxy of rurality is categorized into 4 types according to their rurality. The comorbidity index is a combination of the Charlson and Elixhauser indices taking into account 32 conditions, weighted to obtain an individual score.[26] It was validated in the Quebec administrative database to predict 30-day mortality.[26] The 16 comorbid conditions were chosen by Mondor et al. “based on their large economic impact and high prevalence in the general population.”[27] Delayed discharge is coded in the administrative database as “a person who has completed the acute care phase of his or her treatment but remained in an acute care bed.”[28]

Construction of the weighted sample

We used average treatment effect on the treated (ATT) weights to perform the inverse probability of treatment weighting (IPTW). We estimated the effect of high primary care continuity on the persons exposed to high primary care continuity, also referred to as ATT.[21,29] Exposed persons received a weight of one, while unexposed persons received a weight of their odds of being exposed.

We restricted the weighted sample to the region of common support.[30] The region of common support is the region where there is overlap between the distribution of the estimated propensity scores of exposed and unexposed persons. Four persons were excluded (Figure 1). There were no missing data for exposure and outcomes. Only 23 persons had missing data for two predictors of the propensity score: the Pampalon index of material deprivation and the indicator of rurality. As it represented only 0.1% (23/22060) of the sample, we restricted the weighted sample to the persons with no missing data (Figure 1). The 22,033 without missing values on the predictors of the propensity score and in the common support region were included in the weighted sample (Figure 1).

Balance assessment

Balance between baseline characteristics of the exposed and unexposed in the weighted sample was thoroughly assessed, with standardized differences as recommended by Austin and Stuart.[21,31] Standardized differences compare the differences in means in units of the pooled standard deviation. Standardized differences were used to compare 1) the mean and proportions of continuous and binary variables (multilevel categorical variables being coded as a set of binary indicator variables), 2) means of higher-order moments (squares and cubes) of every continuous variables, and 3) interaction between every continuous variables. [21,31] Standardized differences less or equal to 0.1 were considered negligible as recommended by Austin et al. [21] In addition, graphical comparisons of the distribution of continuous variables between exposed and unexposed persons was performed using side-by-side boxplots and empirical cumulative distribution functions in the weighted sample.[31]

Table 7.5: Attrition (long-term care admission and death) in the unweighted sample (N=22060).

	Unweighted		**Absolute Standardized Differences** [a]
	High primary care continuity	**Low primary care continuity**	
	N=14515	**N=7545**	
Attrition during 2015-2016 No. (%), Mean (SD), Median [IQR]			
Long-term care admission	1601 (11.03)	859 (11.39)	0.01
Death	988 (6.81)	541 (7.17)	0.01
Mean follow-up time (days)	333.30 (81.26)	330.23 (85.74)	0.04
Median follow-up time (days)	365.00 [365.00-365.00]	365.00 [365.00-365.00]	na
Total follow-up time (days)	4837784	2491604	na

SD: Standard Deviation; IQR: interquartile range; na: not applicable.

[a] Standardized differences less or equal to 0.1 are considered negligible as recommended by Austin et al [21]

Table 7.6 Socio-demographic, health, and service use characteristics in 2014 2015 of the 65+ community-dwelling persons with a prevalent diagnosis of dementia, Quebec, Canada (N=41971).

	Total population	**Persons with, between the 1st of April 2014 and the 31st of March 2015,**		**Absolute Standardized Differences** [a]
		At least 2 primary care visits	Less than 2 primary care visits	
	Mean (SD) or No. (%)	Mean (SD) or No. (%)	Mean (SD) or No. (%)	
	N = 41971	N = 22060	N =19911	
Socio-demographic characteristics				
Age	81.64 (7.16)	81.31 (7.02)	82.00 (7.30)	**0.10**
Female	25798 (61.47)	13321 (60.39)	12477 (62.66)	0.05
Material deprivation index[b]	N = 41933	N = 22037	N = 19896	
Quintile 1= Less deprived	7142 (17.02)	3600 (16.32)	3542 (17.79)	0.04
Quintile 2	6987 (16.65)	3744 (16.97)	3243 (16.29)	0.02
Quintile 3	8591 (20.47)	4640 (21.03)	3951 (19.84)	0.03
Quintile 4	9371 (22.33)	5106 (23.15)	4265 (21.42)	0.04
Quintile 5 = Most deprived	9880 (23.54)	4970 (22.53)	4910 (24.66)	0.05
Rurality	N = 41933	N = 22037	N = 19896	
Montreal	18737 (44.64)	8282 (37.54)	10455 (52.51)	**0.30**
City >100K inhabitants	8369 (19.94)	5067 (22.97)	3302 (16.58)	**0.16**
Small cities: 10-99K inhabitants	5036 (12.00)	3283 (14.88)	1753 (8.80)	**0.19**
Rural <10K inhabitants	9829 (23.42)	5428 (24.61)	4401 (22.10)	0.06
Health Characteristics				
Diabetes	12050 (28.71)	6489 (29.42)	5561 (27.93)	0.03
Hypertension	31221 (74.39)	16809 (76.20)	14412 (72.38)	0.09
Heart failure	5003 (11.92)	2643 (11.98)	2360 (11.85)	0.00
COPD	10141 (24.16)	5616 (25.46)	4525 (22.73)	0.06
Asthma	4388 (10.45)	2379 (10.78)	2009 (10.09)	0.02
Comorbidity index	1.18 (2.09)	1.24 (2.14)	1.11 (2.02)	0.06
Service use				
At least one ACSC hospitalization (Older population)	2742 (6.53)	1602 (7.26)	1140 (5.73)	0.06

At least one ACSC hospitalization (General population)	1542 (3.67)	919 (4.17)	623 (3.13)	0.06
At least one 30-day re-admission	1589 (3.79)	974 (4.42)	615 (3.09)	0.07
At least one ED visit	19965 (47.57)	11184 (50.70)	8781 (44.10)	**0.13**
At least one Hospitalization	10949 (26.09)	6195 (28.08)	4754 (23.88)	**0.10**
Mean number of ambulatory care visits	5.90 (8.59)	8.08 (6.91)	3.50 (9.57)	**0.55**
Mean number of primary care visits	2.64 (3.34)	4.78 (3.37)	0.27 (0.45)	**1.88**
Attrition during 2015-2016				
Long term care admission	4874 (11.61)	2460 (11.15)	2414 (12.12)	0.03
Death	3014 (7.18)	1529 (6.93)	1485 (7.46)	0.03

SD: Standard Deviation; COPD: Chronic obstructive pulmonary disorder; ED: Emergency Department; ACSC: Ambulatory care sensitive condition.

[a] Standardized differences less or equal to 0.1 are considered negligible as recommended by Austin et al[21];

[b] Total in each group specified because of missing values.

Table 7.7 : Sensitivity analysis to extreme weights: estimated association of high primary care continuity and hospital use in the weighted sample restricted to the observations with weights between the 1st and the 99st percentiles (N=21593).

	Persons exposed to high primary care continuity N = 14498 (weight = 14498)	**Persons unexposed to high primary care continuity** N= 7095 (weight = 13512)	**p value**	**Absolute Risk Reduction**	**Risk Ratio**	**Number Needed to Treat to prevent one event**
Hospital use	**No. (%)^b**	**No. ^{a} (%)^c**		**Point estimate [95%CI]**	**Point estimate [95%CI]**	**Point estimate [95%CI]**
At least one ACSC hospitalization (general population)	567 (3.91)	635 (4.70)	**0.010**	0.79 [0.16;1.38]	0.83 [0.73;0.96]	127 [73;623]
At least one ACSC hospitalization (older population)	1069 (7.37)	1140 (8.44)	**0.005**	1.07 [0.24;1.86]	0.87 [0.79;0.97]	94 [54;415]
At least one 30-day readmission	648 (4.47)	747 (5.53)	**0.000**	1.06 [0.41;1.65]	0.81 [0.72;0.92]	94 [61;245]
At least one ED visit	7362 (50.78)	7417 (54.89)	**<.001**	4.11 [2.59;5.51]	0.93 [0.90;0.95]	24 [18;39]
At least one hospitalization	4437 (30.60)	4601 (34.05)	**<.001**	3.45 [2.03;4.76]	0.90 [0.86;0.94]	29 [21;49]

CI: Confidence interval; ACSC: Ambulatory Care Sensitive Conditions; ED: Emergency Department.
a = numbers from the weighted sample rounded to the integer;
b = percentage of persons exposed to high primary care continuity with at least one event.
c = percentage of persons unexposed to high primary care continuity with at least one event.

7.11.4 eMethod4: Sensitivity analysis to an unmeasured confounder

We performed sensitivity analysis to an unmeasured confounder.[32] We computed E-values as recommended by VanderWeele (see eTable6).[33,34] The E-value is defined by VanderWeele and Ding as “the minimum strength of association, on the risk ratio scale, that an unmeasured confounder would need to have with both the treatment and the outcome to fully explain away a specific treatment–outcome association, conditional on the measured covariates.”[33,34] We computed the E-value, as recommended by VanderWeele and Ding for both the observed association estimates and the limit of the confidence interval closest to the null. [33,34] We interpreted the significance of the E-values according to known strengths of association of potential unmeasured confounders.[6,9,35–39]

The observed risk ratio could be explained by an unmeasured confounder that was associated with both the exposure and the outcome with a risk ratio of 1.39 to 1.77, depending on the outcome, above and beyond the measured confounders. However, weaker confounding could not do so. The confidence interval could be moved to include the null by an unmeasured confounder that was associated with both the treatment and the outcome with a risk ratio of 1.29 to 1.67, depending on the outcome, above and beyond the measured confounders, but weaker confounding could not do so. (See eTable6).

The sensitivity analysis to an unmeasured confounder showed that the results could be sensitive to an unmeasured confounder. However, the unmeasured confounder would have to be moderately-to-strongly associated with both the exposure and the outcome after having controlled for all observed confounders included in the propensity score. We believe this is an unlikely scenario according to the current literature.[6,9,35–39] For example, caregiver availability, a potential confounding factor, is not consistently found to be associated with hospital use in the literature. [9,35,37–39] When an association is found, its magnitude is lower than the estimated E values.[35,36]

Table 7.8: Sensitivity analysis to an unmeasured confounder: E-values for both estimated risk ratios, and limits of their confidence intervals closest to the null.

	Persons exposed to high primary care continuity	**Persons unexposed to high primary care continuity**	**Risk Ratio**	**p value**	**E-value of the Risk Ratio**	**E-value of the limit of the confidence interval closest to the null**
	N = 14498 (weight = 14498)	N= 7535 (weight = 14503)				
Hospital use	**No. (%)**^{b}	**No.** ^{a} **(%)**^{c}	**Point estimate [95%CI]**			
At least one ACSC hospitalization (general population)	567 (3.91)	690 (4.76)	0.82 [0.72;0.94]	**0.004**	**1.74**	**1.67**
At least one ACSC hospitalization (older population)	1069 (7.37)	1236 (8.52)	0.87 [0.79;0.95]	**0.002**	**1.56**	**1.29**
At least one 30-day readmission	648 (4.47)	797 (5.50)	0.81 [0.72;0.92]	**<.001**	**1.77**	**1.39**
At least one ED visit	7362 (50.78)	8000 (55.16)	0.92 [0.90;0.95]	**<.001**	**1.39**	**1.29**
At least one hospitalization	4437 (30.60)	4937 (34.04)	0.90 [0.86;0.94]	**<.001**	**1.46**	**1.32**

CI: Confidence interval; ACSC: Ambulatory Care Sensitive Conditions; ED: Emergency Department.
a = numbers from the weighted sample rounded to the integer;
b = percentage of persons exposed to high primary care continuity with at least one event.
c = percentage of persons unexposed to high primary care continuity with at least one event.

7.11.5 References

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8 Chapter 8: Discussion

8.1 Summary of research results

The aim of this PhD thesis was to investigate how avoidable hospital use of community-dwelling persons with dementia could be reduced, especially by measuring whether health service interventions or primary care continuity reduced them. Addressing this overarching objective was accomplished in four articles.

In the first article, I conducted a systematic literature review and meta-analysis to synthesize available evidence on the impact of health service interventions on hospital use in persons with dementia compared to usual care. Despite a comprehensive systematic literature review and meta-analysis, including predominantly unpublished data provided by the authors of the included studies, no health service intervention beyond usual care was found to reduce hospital use in community-dwelling persons with dementia. Sub-group analyses did not favour any type of health service intervention. An important increase in service use may be associated with these interventions.

The three remaining articles aimed at measuring the impact of primary care continuity on potentially avoidable hospital use in community-dwelling persons with dementia.

In the second article, I conducted a descriptive study of hospital use of community-dwelling persons living with dementia in Quebec, over the last 15 years using the Quebec provincial administrative database. I estimated that around 40 and 60 per 100 person-year of community-dwelling persons with dementia had at least one hospitalization and one ED visit during the year of diagnosis, respectively. In those hospitalized, the average length of hospital stay in the year of diagnosis was around 1.5 months. Between 20 and 30% of those hospitalized, depending on the indicator, had a potentially avoidable hospital use, with average length of ALC stay of more than 4.5 months, in the year of diagnosis. Most indicators remained constant over the 15 years.

In the third article, I described in a Method Brief, for a non-expert audience how advanced statistical methods can be used to strengthen causal inference from observational data, especially with propensity scores; the method I am using in the fourth article.

In the fourth article, I measured the association between high primary care continuity and potentially avoidable hospital use in community-dwelling persons with dementia in Quebec. I estimated, using an observational 4-year retrospective cohort, with inverse probability of treatment weighting using the propensity score, that high continuity with a primary care physician was significantly associated with fewer potentially avoidable hospitalizations (ACSC hospitalization and 30-day readmission). In addition, high primary care continuity was significantly associated with fewer ED visits and hospitalizations.

8.2 Summary of knowledge transfer activities

Throughout my PhD, to inform decision-makers, managers, clinicians, patients, caregivers, and patients and caregivers' representatives, I conducted several knowledge translation activities. First, I expanded the existing Quebec surveillance system of dementia. This surveillance system was providing decision-makers, managers and clinicians figures on the prevalence and incidence of dementia by administrative region. I developed, in collaboration with surveillance experts at INSPQ, 4 new indicators. These indicators are routinely measured and accessible to every professional from the *réseau de la santé et des services sociaux* (RSSS; Health and Social Services Network) across the province, through the 'Info-Centre' interface. These four indicators are: proportion of at least one ED visit, hospitalization, 30-day hospital readmission, and average number of hospital day. These indicators are the first in the 'Info-Centre' interface to be measured for both persons with dementia, and persons without dementia. We plan to 1) offer a webinar on how to use these indicators (Spring 2020), 2) publish an INSPQ report on these indicators and potentially avoidable hospital use in community-dwelling persons with dementia in Quebec (Summer 2020) and 3) further develop indicators at the "Info-Centre" especially the measures of potentially avoidable hospital use I measured in my doctoral work.

Throughout my PhD, in addition to present my results to the scientific community in local, provincial, national and international conferences and in scientific articles, I presented my results several times to 1) researchers and stakeholders of the ROSA team of the Canadian Consortium for Neurodegeneration and Aging (CCNA)): decision-makers, clinicians, managers, persons and caregivers, and persons and caregivers' representatives (Provincial Council June 7th 2019, Annual CCNA Science day and Partners forum from 2015 to 2019), 2) to surveillance experts from the *Institut national de santé publique du Québec*, (September 2019), and 3) knowledge users such as managers and clinicians in specific geographical areas (Conference Midi Montérégie 2017).

Finally, I collaborated closely with the *Ministère de la santé et des services sociaux* (MSSS; Quebec Ministry of Health and Social Services) including with the Quebec Alzheimer's Plan implementation team. Our collaboration entailed repeated exchanges from 2018 to 2019, including three consultations with the Quebec Alzheimer's Plan implementation team of the "*Direction des orientations des services aux aînés en perte d'autonomie*" and the "*Direction des orientations des services aux aînés (DOSA)*" (decision-makers/managers such as Vincent Defoy Director of "*Direction des orientations des services aux aînés en perte d'autonomie*" in the "*Direction générale des programmes dédiés aux personnes, aux familles et aux communautés*" and project managers responsible for the implementation of the Quebec Alzheimer plan). I presented my results and we exchanged on 1) their interpretation of the results in the Quebec context and especially the Quebec Alzheimer's Plan implementation context, and 2) future avenues to be explored. I was invited by the *Ministère de la santé et des services sociaux* (MSSS; Quebec Ministry of Health and Social Services) to present at their first "*Journée d'échange plan d'action ministériel sur les troubles neurocognitifs majeurs : rétrospective et perspective _ conjuguer nos efforts et développer une vision commune*", that convened over 100 decision/policy-makers, managers, clinicians, patients and caregivers, patients and caregivers' representatives.

8.3 Implications for Health Service Research

My research contributes to the advancement of the science and practice of health service research in several ways.

First, I used a conceptual framework, the "Gruneir's conceptual model" to guide my reflections on avoidable hospital use and their prevention throughout my thesis [61]. I chose this model because it defines avoidable use in relation to primary care gaps in care. I defined "avoidable hospital use", according to this framework. I measured indicators of potentially avoidable hospital use related to this framework. These indicators were thus related to gaps in primary care and potential primary care interventions [61]. This choice was coherent with my overall objective to ultimately inform healthcare policies aiming at designing evidence-based policies to reduce avoidable hospital use in this population. This approach is innovative in health service research in community-dwelling persons with dementia, where most authors refer to the concept of ACSC hospital admission when defining avoidable hospitalizations. Very few authors refer to a conceptual framework, or gaps in care or potential interventions to prevent these ACSC hospital admissions [10,11,41–48,67]. My work thus exemplifies how the use of a framework helps in the selection of appropriate indicators in health service research for persons with dementia.

Second, I used rigorous and cutting-edge methods in health service research, and especially with observational routinely collected data. I followed the Strengthening the Reporting of Observational Studies in Epidemiology *(*STROBE) and REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) guidelines. [81,82] I used the causal inference and potential outcome frameworks, to strengthen causal inference with observational data. I used the target trial framework, for the first time in health service research for community-dwelling persons with dementia. The target trial framework has been proposed by Miguel A. Hernan and colleagues in 2016 and has, to date, mostly been used in pharmaco-epidemiology research. I performed quantitative sensitivity analysis to unmeasured confounders. I used the e-value for the first time in health service research for community-dwelling persons with dementia. The e-value was developed by VanderWeele and Ding in 2017. For the meta-analysis, I used cutting-edge methods. I computed prediction intervals to conservatively interpret the range of expected treatment effects in future studies rather than an average effect composed by a set of different underlying effects. Prediction intervals were first described in 2009 [83]. In 2016, a plea for routinely presenting prediction intervals in meta-analysis was published in the BMJ Open Journal [84]. My work thus exemplifies how cutting-edge methods and frameworks can strengthen causal inference with observational data in health service research for persons with dementia.

Third, I contributed to the advancement of the science of family medicine and primary care research. I explained, in a Method Brief, in an accessible and didactic format to a non-expert audience (primary care researchers, decision-makers and clinicians), two powerful methods to strengthen causal claims from observational data. I co-developed a 3-hour workshop to present these methods to a non-expert audience, that I have already presented at two international conferences. My work thus contributes to the advancement of the practice of family medicine and primary care research in introducing primary care researchers, decision-makers and clinicians to the use of advanced causal methods in primary care research.

8.4 Implications for practice and policy

My research has several implications for practice and policy.

First, I generated evidence in support for a call for action to develop evidence-based policies to reduce avoidable hospital use in community-dwelling persons with dementia. Indeed, the descriptive study of prevalence and trends of hospital use in persons with dementia shed light on the importance of the phenomenon and its lack of improvement, for most outcomes, over the years in Quebec. I argued that developing such policies was urgent knowing the negative outcomes associated with hospital use in patients, caregivers, and the burden of these hospital use on the healthcare system as a whole.

Second, I exemplified the importance to attaching a sound evaluation to the implementation of any policy or intervention. Indeed, in the systematic literature review and meta-analysis, using prediction intervals, I measured the extent to which interventions might have unintended effects, such as increasing service use. Indeed, the estimated 95% prediction intervals indicated that an important increase in service use may be associated with these interventions. I highlighted that this increase in service use could be associated either to beneficial or adverse outcomes. For example, the literature shows that self-management interventions for caregivers, have led to non-intended beneficial outcomes: increased service use due to increased caregiver awareness of symptoms, diagnosis procedures and treatment options [38,60]. On the contrary, the literature shows that self-management in patients with chronic obstructive pulmonary disease (COPD), have led to non-intended adverse outcomes. A decreased service use due to patient overconfidence in self-management leading to higher mortality [67]. I argued that it was crucial to 1) measure the effect and potential unintended effects and adverse outcomes of any policy or interventions, 2) better characterize hospital use and avoidable hospital use, so that beneficial and adverse non-intended outcomes could be sorted out to ultimately improve the policy. This is why, in the two studies I conducted on hospital use in community-dwelling persons with dementia in Quebec, I characterized hospital use using measures of potentially avoidable hospital use related to a conceptual framework and linked to primary care gaps and potential primary care interventions.

Third, I generated evidence on the impact of two different strategies to reduce potentially avoidable hospital use in community-dwelling persons with dementia: 1) health service intervention, and 2) primary care continuity.

On the one hand, I showed that, to date, no health service intervention beyond usual care was found to reduce hospital use in community-dwelling persons with dementia. I argued that the interventions may not have effectively addressed the causes of acute hospital use [16,85,86]. I proposed three avenues that could be followed to decrease acute hospital use in community-dwelling persons with dementia: 1) to improve access to primary care and train home-care staff on early detection and appropriate management of the common causes of acute hospital use such as infections, falls and their consequences, and acute exacerbations of chronic conditions [41,61]; 2) to offer timely support to caregivers through respite care or temporary home care [16]; 3) to offer a palliative care approach with discussion of advanced directives and preferences for end-of-life care [10,87,88].

On the other hand, I showed a negative, large, and statistically significant association between primary care continuity and hospital use, especially potentially avoidable hospital use. I proposed several potential explanations to this impact. I argued that a long-standing primary care relationship might be necessary to detect and treat acute exacerbations of chronic diseases in persons with dementia. Indeed, persons with dementia might be less able to identify and communicate about acute symptoms, and symptoms of common acute diseases are less typical, and often mixed with delirium and behavioral and psychological symptoms of dementia [4,41]. Second, I argued that a long-standing primary care relationship might be necessary to assess and address caregiver burden and stress [16]. Third, I argued that a long-standing primary care relationship may ease a palliative care approach with discussion of advanced directives and preferences for end-of-life care, allowing preventing undesired hospital use in patients and caregivers, preferring to obtain end-of-life care at home [10,87,88].

Fourth, I proposed several avenues to increasing primary care continuity in the care of persons with dementia. By sharing these results with policy-makers, primary care physicians, specialists, patients and their caregivers, and the Alzheimer's society, we could stress the importance of aiming for quality, continuous relationship with one trusted primary care physician. Through policies and care organization, we could enable primary care physicians to be available to their patients during acute episodes and for a proactive follow-up to provide high-quality primary care and in turn reduce avoidable hospital use.

8.5 Future Directions

In my research program, I will explore the avenue, that I have identified as promising, during my PhD, to reduce potentially avoidable hospital use in community-dwelling persons with dementia: continuity of care with the primary care physician. In the following paragraphs, I provide a draft outline of my research program for the next five years.

Most of the persons with dementia live in the community, and this proportion is growing [89]. However, there is a dearth of evidence on patterns of primary care use and primary care continuity impact in community-dwelling persons with dementia worldwide, but especially in Canada. In Quebec, to our knowledge, there is no study of patterns of primary care use in community-dwelling persons with dementia. In addition, since 2000, a major reform of primary care delivery occurred in Quebec, including the implementation of multidisciplinary primary care teams, the Family Medicine Groups (FMGs)[90–92]. The impact of this reform on patterns of primary care use in community-dwelling persons with dementia in Quebec is unknown. In order to inform decision-makers and especially the Qc Alzheimer's Plan design and implementation team, and the "*Direction des orientations* *des services aux aînés en perte d'autonomie*", there is a need to describe and better understand primary care patterns of use and impact in community-dwelling persons with dementia.

I plan to describe patterns of primary care use, and continuity over the last 15 years in Quebec, with repeated yearly cohorts in the provincial administrative database. As patterns of primary care use might differ by rurality, socio-economic status, sex, and type of primary care delivery site (interdisciplinary primary care team like: Family Medicine Groups or solo-practice), I plan to stratify my analysis by these variables.

I will further explore the impact of primary care continuity. I will explore the impact of primary care continuity on other key outcomes like potentially inappropriate medications, long-term care admissions, mortality and place of death. I will explore whether this impact is modified by rurality, socio-economic status, sex or site of primary care delivery. I will conduct propensity score analyses and explore effect measure modification of the impact of primary care continuity on hospital use and avoidable hospital use.

In parallel, I will further my understanding of the impact of primary care continuity on potentially avoidable hospital use, in conducting similar analyses in another context: community-dwelling frail older persons in France. Indeed, I have developed an international collaboration with Dr Beuscart, Lille University, expert in health service research in older persons. We plan to study the impact of primary care continuity, with similar methods I used in my PhD thesis, in the French health administrative database. Comparison of the Quebec and French results will help further understand the impact of primary care continuity but also the potential underlying causal mechanisms explaining these impacts.

For this research, I have already obtained two fundings: one as a co-investigator to describe patterns of health care use stratified by rurality, and sex (*Réseau Québécois de Recherche sur le Vieillissement,* 20,000 CAD, 2019), and some seed grant to develop a pilot study on the French administrative database (Lille University, France, 2,000 euros, 2019).

8.6 Conclusion

In this PhD thesis, I generated evidence in support for a call for action to develop evidence-based policies to reduce avoidable hospital use in community-dwelling persons with dementia. I exemplified the importance to attaching a sound evaluation to any policy or intervention. I showed that, to date, no health service intervention beyond usual care was found to reduce hospital use in community-dwelling persons with dementia. I showed a negative, large, and statistically significant association between primary care continuity and hospital use, especially potentially avoidable hospital use. I proposed several avenues to increasing primary care continuity in the care of persons with dementia. Throughout this thesis, robust evidence was generated by using advanced statistical methods and rigorous approaches in health service research.

Increasing primary care continuity might be an avenue to reduce avoidable hospital use in community-dwelling persons with dementia. As the dementia population is mostly cared for in primary care, improving primary care continuity might be a powerful avenue to decrease avoidable hospital use. As Canada is implementing its federal dementia strategy, as several provinces are conducting dementia initiatives and Quebec reconducting its Alzheimer's Plan, these findings are particularly relevant and timely [93]. One of the three national objectives of the 2019 Canadian national dementia strategy is to improve the quality of life of those living with dementia and their caregivers, especially through an improvement of the quality of care they receive [93]. Reducing avoidable hospital use in persons with dementia is one of the avenues to improve the quality of life of persons with dementia and their caregivers, as well as to prevent rising health care costs and adverse outcomes for persons with dementia.

9 Chapter 9: Thesis references

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10 Chapter 10 : Appendices

10.1 Appendix 1: Presentation of the database and selected variables of interest

I conducted study 2.1 and 2.3 with data extracted from the Quebec linked population-based health administrative database referred to as the Quebec Integrated Chronic Disease Surveillance System (QICDSS) [74]. The QICDSS database records all services provided via the public universal health insurance system. It is the linkage of 5 health administrative databases covering the Quebec health services offerings: individual level demographics, health care services utilization (medical consultation, hospitalization, prescription drug use) and deaths [100,101]. The QISDSS was developed to allow chronic diseases surveillance [100,101]. Every person "potentially having a chronic disease" is included in the database [100,101]. This dataset covers 99% of the 65+ population of Quebec [100,101].

When the analysis of study 2.1 was performed data were available from April 1st 1996, to March 31st 2016. When the analysis of study 2.3 was performed data were available from April 1st 1996, to March 31st 2017.

The following variables and algorithms were available in the database:

- For each person: date of birth and death, sex, small-area level socioeconomic status (Pampalon index of material deprivation [102–104]), small-area level measure of rurality;
- For each medical service billing: the date of the service, the service provider (identification number and specialty) and the location of service delivery;
- For each hospital stay, the date of admission, and discharge, the diagnoses, provenance and discharge destination, ALC status;
- For each dispensed drug: date of dispensation and name;
- A validated algorithm identifying persons living with dementia [75] (See Appendix 2: Algorithm identifying persons living with dementia)

- A validated comorbidity index [105];
- A validated algorithm identifying distinct ED visits [106] (See Appendix 3: Precisions on indicators of service use);
- An algorithm identifying distinct hospital stays (See Appendix 3: Precisions on indicators of service use.

I chose after a comprehensive literature review to use the following additional measures. They were coded by Louis Rochette in the database:

- Two measures of ACSC hospitalization (general and older population definitions) [10,49,107] (See operationalized definitions of these measures in Appendix 5.9.2 in Chapter 5);
- Operationalized definitions of 16 comorbid conditions chosen by Mondor et al, to be described in the dementia population in Ontario "based on their large economic impact and high prevalence in the general population"[14].

The following definitions and measures were unavailable in the database. For each of them, I developed an algorithm for their identification. They were coded by Louis Rochette in the database:

- Identification of community-dwelling older persons [108] (See Appendix 5: Algorithms identifying community-dwelling populations and long-term care admissions),
- Identification of long-term care admission [108] (See Appendix 5),
- Identification of ambulatory care visits (See Appendix 6: Algorithm identifying ambulatory care visits and primary care visits).

10.2 Appendix 2: Algorithm identifying persons living with dementia

Dementia diagnosis was identified through a validated algorithm, developed in Ontario at the Institute for clinical evaluative Sciences (ICES) and adopted by the Canadian Public Health Agency [75].

The definition of dementia used to develop the algorithm includes Alzheimer's disease, vascular dementia, dementia in other diseases classified elsewhere (frontotemporal dementia, idiopathic normal pressure hydrocephalus), and unspecified dementia (senile dementia, presenile dementia). The International Classification of Diseases (ICD)-9 and 10 codes used are: ICD-9 (46.1, 290.0, 290.1, 290.2, 290.3, 290.4, 294.x, 331.0, 331.1, 331.5, 331.82); ICD-10 (F00.x, F01.x, F02.x, F03.x, G30.x).

The following characteristics were found in a validation study using as reference diagnoses recorded in electronic medical records : sensitivity 79.3% (confidence interval (CI) 72.9–85.8%), specificity 99.1% (CI 98.8–99.4%), positive predictive value 80.4% (CI 74.0–86.8%), and negative predictive value 99.0% (CI 98.7–99.4%) [75]

Persons were considered as diagnosed for dementia if they had at least 1 of the following conditions:

- One dementia diagnosis (primary or secondary) in the hospitalization dataset ("*MedEcho*"), since the age of 40;
- OR: At least 3 dementia diagnoses at least 30 days apart in a two-year period in the medical consultation dataset ("*Services Médicaux*"), since the age of 40;
- OR: One prescription of a dementia related drug in the prescription drug use dataset ("*Base medicaments*"), since the age of 40 (drugs are recorded in the database as of 65 for every Quebecer, and for around on third of 40-64) ;

The date of diagnosis was the date on which the first of the three criteria became positive. For persons whose algorithm becomes positive through medical claims, the first medical claim was considered as the date of diagnosis. These criteria were the same for study 2.1 and 2.3.

10.3 Appendix 3: Precisions on indicators of hospital use

10.3.1 Validated algorithm identifying distinct ED visits.

I measured ED visits as routinely performed in the QICDSS, using a validated algorithm [106]. Indeed, the QICDSS is not linked to the Qc database that records every Emergency Department visit.

This algorithm considers as one ED visit, physicians' claims billed in the Emergency room during a maximum period of two days. Two visits are counted, when physicians' claims are billed in the ED for more than two days, three visits are counted, for more than 4 days, … etc.

10.3.2 Algorithm identifying distinct hospital stay

I measured hospitalizations as routinely performed in the QICDSS. In the event of hospital transfer during a hospitalization, only one hospitalisation was counted, rather than several separate hospitalizations.

Day surgeries were excluded from the computation of hospitalizations ("Code type de séjour: 27") for study 2.1 and 2.3.

10.4 Appendix 4: Eligibility and computation of events for indicators of hospital use

Different criteria were used to determine the eligibility of hospitalizations in study 2.1 and study 2.3. In study 2.1, rate of hospitalization was measured yearly. Hospitalizations which date of admission was within the yearly follow-up period were counted. In study 2.3, two eligibility criteria were followed. Before March 31st, 2015; for the predictors of the propensity score, hospitalizations which date of discharge occurred during the year were counted. After March 31st, 2015, in the follow-up period, one hospitalization was counted, every time there was at least one day of hospitalization during the follow-up period.

These different eligibility criteria allowed for cross-provincial comparison of the result of study 2.1, which is part of a larger pan Canadian research project (ROSA team). In addition, they allowed in the repeated yearly estimates (study 2.1 and 2.3 predictors of the propensity score) not to artificially increase the number of hospitalizations while counting twice hospitalizations that date of admission and date of discharge occurred in two different years. Finally, they allowed for an accurate picture of the hospitalizations occurring during the one-year follow-up period in study 2.3, where every hospitalization was counted.

10.5 Appendix 5: Algorithms identifying community-dwelling populations and long-term care admissions

No straightforward identification of community-dwelling persons aged 65+ was feasible in the QICDSS. No algorithm for their identification had previously been developed in the QICDSS. No previously published study identified this population in the QICDSS. I developed algorithms to identify community-dwelling populations and admissions to long term care, in collaboration with a Qc researcher knowledgeable of the Qc long-term care offering and support services organisation (Machelle Wilchesky), my supervisors who have expertise in the Qc administrative database and Qc health service organization, and researchers and data analysts, knowledgeable of the Qc administrative database (José Perez, Julie Fiset-Laniel, Mamadou Diop, Geneviève Noury) [108] (See table 10.1).

In Quebec, several types of collective dwelling are available for older persons:

- "*Centre d'hébergement et de soins de longue durée*" ("*CHSLD*"), or residential and long-term care centre, where persons require at least 3 hours of nursing care a day and 24/7 nursing care is offered;
- "*Ressources non institutionnelles*" (including: "*Ressources de type familiale*" and "*Ressource de type intermédiaire*") where less than 3 hours of nursing care a day are offered;
- "*Résidences privées pour aînés*", similar to private apartment, where persons might access home care services and support from the local community service centre *("Centre local de services communautaires" "CLSC")*.

We used different algorithms for study 2.1 and 2.3. Study 2.1 was simultaneously conducted in Ontario. Thus, we aimed at identifying comparable populations in Ontario and in Quebec. In Ontario the long-term care facility definition was restricted to facilities offering 24/7 nursing care. In Quebec, these facilities are the "*Centre d'hébergement et de soins de longue durée*" ("*CHSLD*"). For study 2.1, we excluded from the community-dwelling population the persons living in *CHSLD*, and considered a person admitted to LTC when admitted to *CHSLD*.

In study 2.3, we aimed at identifying a community-dwelling population, that would not live in a collective dwelling, and for which the decision to transfer to an acute care hospital would be made most of the time by a non-healthcare professional. We aimed at excluding, from the community-dwelling population, in addition to the population excluded in study 2.1, the persons waiting for a LTC bed in an acute care hospital (Alternate Level of Care status), and persons likely to be living in collective dwelling with less than 24/7 nursing care available like "*Ressources non institutionnelles*", or "*Résidences privées pour aînés*". However, it is to be noted that no code exists in the administrative database to identify "*Résidences privées pour aînés"*. Thus, we used a different algorithm as in study 2.1 to identify the community-dwelling population. We used the same algorithm as in study 2.1 for admission to long-term care.

Table 10.1: Algorithms identifying long-term care admission and community-dwelling populations

Identification of long-term care admission, i.e. admission to CHSLD. **Study 2.1 and 2.3**	**Identification of the community-dwelling population** **Study 2.1**	**Identification of the community-dwelling population** **Study 2.3**
Having at least one the following codes. The date of admission was the date of the first of the following criteria that became positive. For the: "Tab 14 MedEcho Séjour hospitalier criteria, the date of hospital discharge was considered".	Never having any of the following code on the date of interest, i.e. 1st of April of each year.	Meeting all of the following criteria
• At least one : Tab 6 Admissibilité Assurance Médicament : Code Plan 64 ans et + : 97 "Personne hébergée", since the age of 65 (this code does not exist in the 65- population) • At least one of the following : Tab 14 MedEcho Séjour hospitalier, since the year 2000-2001 o TYP_LIEU_SEJ_HOSP_PROVN 03 Centre d'hébergement et de soins de longue durée	• Tab 6 Admissibilité Assurance Médicament : Code Plan 64 ans et + : 97 "Personne hébergée", since the age of 65 (this code does not exist in the 65- population) • Tab 14 MedEcho Séjour hospitalier, since the year 2000-2001 o TYP_LIEU_SEJ_HOSP_PROVN 03 Centre d'hébergement et de soins de longue durée o TYP_LIEU_SEJ_HOSP_PROVN 10 Centre d'hébergement et de	Never having had any of the following code on the date of interest, i.e. 31st of March 2015 • Tab 6 Admissibilité Assurance Médicament : Code Plan 64 ans et + : 97 "Personne hébergée", since the age of 65 (this code does not exist in the 65- population) • Tab 14 MedEcho Séjour hospitalier, since the year 2000-2001 o TYP_LIEU_SEJ_HOSP_PROVN 03 Centre d'hébergement et de soins de longue durée

o TYP_LIEU_SEJ_HOSP_PROVN 10 Centre d'hébergement et de soins de longue durée, hors province o TYP_LIEU_SEJ_HOSP_DEST 03 Centre d'hébergement et de soins de longue durée o TYP_LIEU_SEJ_HOSP_DEST 10 Centre d'hébergement et de soins de longue durée, hors province • At least one of the following : Tab 7 Service_Medical NO_ETAB_USUEL, since the year 2000-2001 o NO_ETAB_USUEL 1X5 Centre d’accueil public : Hébergement public o NO_ETAB_USUEL 2X5 Centre d’accueil privé : Hébergement privé pour personnes âgées	soins de longue durée, hors province o TYP_LIEU_SEJ_HOSP_DEST 03 Centre d'hébergement et de soins de longue durée o TYP_LIEU_SEJ_HOSP_DEST 10 Centre d'hébergement et de soins de longue durée, hors province • Tab 7 Service_Medical NO_ETAB_USUEL, since the year 2000-2001 o NO_ETAB_USUEL 1X5 Centre d’accueil public : Hébergement public o NO_ETAB_USUEL 2X5 Centre d’accueil privé : Hébergement privé pour personnes âgées	o TYP_LIEU_SEJ_HOSP_PROVN 10 Centre d'hébergement et de soins de longue durée, hors province o TYP_LIEU_SEJ_HOSP_DEST 03 Centre d'hébergement et de soins de longue durée o TYP_LIEU_SEJ_HOSP_DEST 10 Centre d'hébergement et de soins de longue durée, hors province • Tab 7 Service_Medical NO_ETAB_USUEL, since the year 2000-2001 o NO_ETAB_USUEL 1X5 Centre d’accueil public : Hébergement public o NO_ETAB_USUEL 2X5 Centre d’accueil privé : Hébergement privé pour personnes âgées
		Never having had any of the following code on the date of interest, i.e. 31st of March 2015 • Tab 7 Service_Medical NO_ETAB_USUEL, since the year 2000-2001

		○ NO_ETAB_USUEL 0X4 Longue durée: soins prolongés ○ NO_ETAB_USUEL 0X5 Longue durée: hébergement
		Not having this code on the 31st of March 2015 • MedEcho database Séjour hospitalier base services: "Type de séjour" TYP_SEJ: 03 = Occupe un lit de soins de courte durée dans l'attente de soins de longue durée.
		Not having an invalid address on the 31 of March 2015
		Not living in a RLS where 20% or more of the population is living in a collective dwelling on the 1st of April 2013 or on the 1st of April 2014

10.6 Appendix 6: Algorithm identifying ambulatory care visits and primary care visits

10.6.1 Identification of ambulatory care visits

In the QICDSS, the “*Services médicaux”* database records all physicians’ billings. For each billing, the date and the setting of the service are recorded. No algorithm existed to identify ambulatory care visits performed either in a community-based clinic or in a hospital-based outpatient clinic. I developed an algorithm identifying ambulatory care visits, in collaboration with my supervisors who have expertise in the Qc administrative database and Qc health service organization, and researchers and data analysts, knowledgeable of the Qc administrative database (Louis Rochette, Eric Pelletier, José Perez, Julie Fiset-Laniel, Mamadou Diop).

It is to be noted that only services payed through fee-for-service are recorded in the database. Thus, visits performed by salaried physicians or paid through hourly rates are not recorded in the database. Most physicians working in CLSC and in LTC are salaried, and most home visits are billed with hourly rates. These physician’ visits are not recorded in the database. However, in Quebec, most clinical payments are made through fee-for-service (79%) [109]. And 98% of physicians received at least one payment through fee-for service [109].

Table 10.2 : Algorithm identifying ambulatory care visits in study 2.3.

Identification of ambulatory care visits
One ambulatory care visit is identified when a person has a billing or several billings performed in one of the following setting by one physician on one day. Two visits are counted when these billings are performed either by two physicians on the same day, or by the same physicians on different days.
Identification of ambulatory care visits performed in community-based clinic

Any billing with any of the following “*numéro d’établissement usuel”*

- 0 : Cabinets privés Sans numéro de municipalité
- 6XX: Cabinets privés Avec le numéro de municipalité
- 54X: Clinique privée - Clinique médicale codifiée pour les GMF (groupe de médecine de famille) Clinique privée - Clinique médicale codifiée pour la gestion d’autres ententes (ex : clinique réseau)
- 55X: Clinique privée Clinique médicale codifiée pour la gestion des groupes de pratique: Clinique privée - entente particulière de prise en charge et suivi de la clientèle et autres ententes
- 57X: Clinique médicale codifiée pour la gestion des groupes de pratique: - entente particulière de prise en charge et suivi de la clientèle et autres ententes

Identification of ambulatory care visits performed in a hospital-based outpatient clinic

Billing with any of the following “*numéro d’établissement usuel”* ; that occurred outside of an inpatient stay

- 0X0: Unité clinique des CENTRES HOSPITALIERS, unité de réadaptation, unité d’alcoologie, unité de toxicomanie, unité "moyen séjour" unité "hôpital de jour" unité de cytologie unité de soins palliatifs unité de pneumologie
- 0X1: Clinique externe
- 0X2: Département de gériatrie moyen séjour
- 0X3: Section générale courte durée spécialisée
- 0X8: Section Psychiatrique

It is to be noted that some billing codes may be billed outside of an actual physician visit: the “*codes liés à des forfaits*” and “*codes liés à des regroupements d’actes*”. No exhaustive and updated list of these codes exists. Thus, it was not possible to simply exclude them from our count of visits.

We performed a sensitivity analysis to check whether not excluding these billing codes potentially not associated with an actual visit would change the total number of visits. Erin Strumpf’s team had compiled an exhaustive and updated list of these codes up to 2010. We explored the total number of visits during the year 2009-2010, while excluding and not excluding these codes. We found that not excluding these codes, added only 1% to the total number of visits for this year. For feasibility reasons we did not exclude these codes.

10.6.2 Identification of primary care visits

Ambulatory care visits were considered primary care visits if they were billed by a primary care physician. We identified primary care physicians if they had any of the following “*Code d'entente du dispensateur traitant*” or “*Code de spécialité du dispensateur*”

Table 10.3: Identification of primary care physicians

Code d'entente du dispensateur traitant	
1	Omnipraticiens (FMOQ)
00	Omnipratique
38	Santé communautaire
39	Médecine familiale
83	Première ligne

10.7 Appendix 7: Association between high primary care continuity and ALC hospitalizations

10.7.1 Method

Outcome:

We measured ALC hospitalizations. These hospitalizations are considered potentially avoidable in the context of better outpatient care. ALC hospitalizations may be avoidable through pro-active primary care and especially timely supportive care access [68]. (See rationale in Chapter 3). High continuity with a primary care physician may ease timely supportive care access. ALC hospitalizations is coded in the administrative database as "a person who has completed the acute care phase of his or her treatment but remained in an acute care bed." [50]

10.7.2 Result

Association between high primary care continuity and ALC hospitalizations

High primary care continuity was non significantly associated with potentially avoidable hospitalization in the following year (Bonferroni correction) (Table 2). The relative risk reduction for ALC hospitalizations was 0.84 (CI [0.74;0.97]; P=0.025). The number of persons needed to treat with high primary care continuity to prevent one ALC hospitalizations was 130 (CI [71;880]).

Table 10.4: Estimated association of high primary care continuity and hospital use in the weighted sample (N= 22033).

	Persons exposed to high primary care continuity N = 14498 (weight = 14498)	**Persons unexposed to high primary care continuity** N= 7535 (weight = 14503)	**p value**	**Absolute Risk Reduction**	**Risk Ratio**	**Number Needed to Treat to prevent one event**
Hospital use	**No. (%)[b]**	**No. [a] (%)[c]**		**Point estimate [95%CI]**	**Point estimate [95%CI]**	**Point estimate [95%CI]**
At least one ACSC hospitalization (general population)	567 (3.91)	690 (4.76)	**0.004**	0.85 [0.28;1.45]	0.82 [0.72;0.94]	118 [69;356]
At least one ACSC hospitalization (older population)	1069 (7.37)	1236 (8.52)	**0.002**	1.15 [0.40;1.91]	0.87 [0.79;0.95]	87 [52;252]
At least one 30-day readmission	648 (4.47)	797 (5.50)	**<.001**	1.03 [0.41;1.66]	0.81 [0.72;0.92]	97 [60;247]
At least one ALC hospitalization	601 (4.15)	713 (4.91)	0.025	0.77 [0.11;1.41]	0.84 [0.74;0.97]	130 [71;880]
At least one ED visit	7362 (50.78)	8000 (55.16)	**<.001**	4.38 [2.96;5.80]	0.92 [0.90;0.95]	23 [17;34]
At least one hospitalization	4437 (30.60)	4937 (34.04)	**<.001**	3.44 [2.11;4.78]	0.90 [0.86;0.94]	29 [21;47]

CI: Confidence interval; ACSC: Ambulatory Care Sensitive Conditions; ALC: Alternate Level of Care; ED: Emergency Department.

a = numbers from the weighted analytical sample rounded to the integer;

b = percentage of persons exposed to high primary care continuity with at least one event.

c = percentage of persons unexposed to high primary care continuity with at least one event.

10.7.3 Discussion

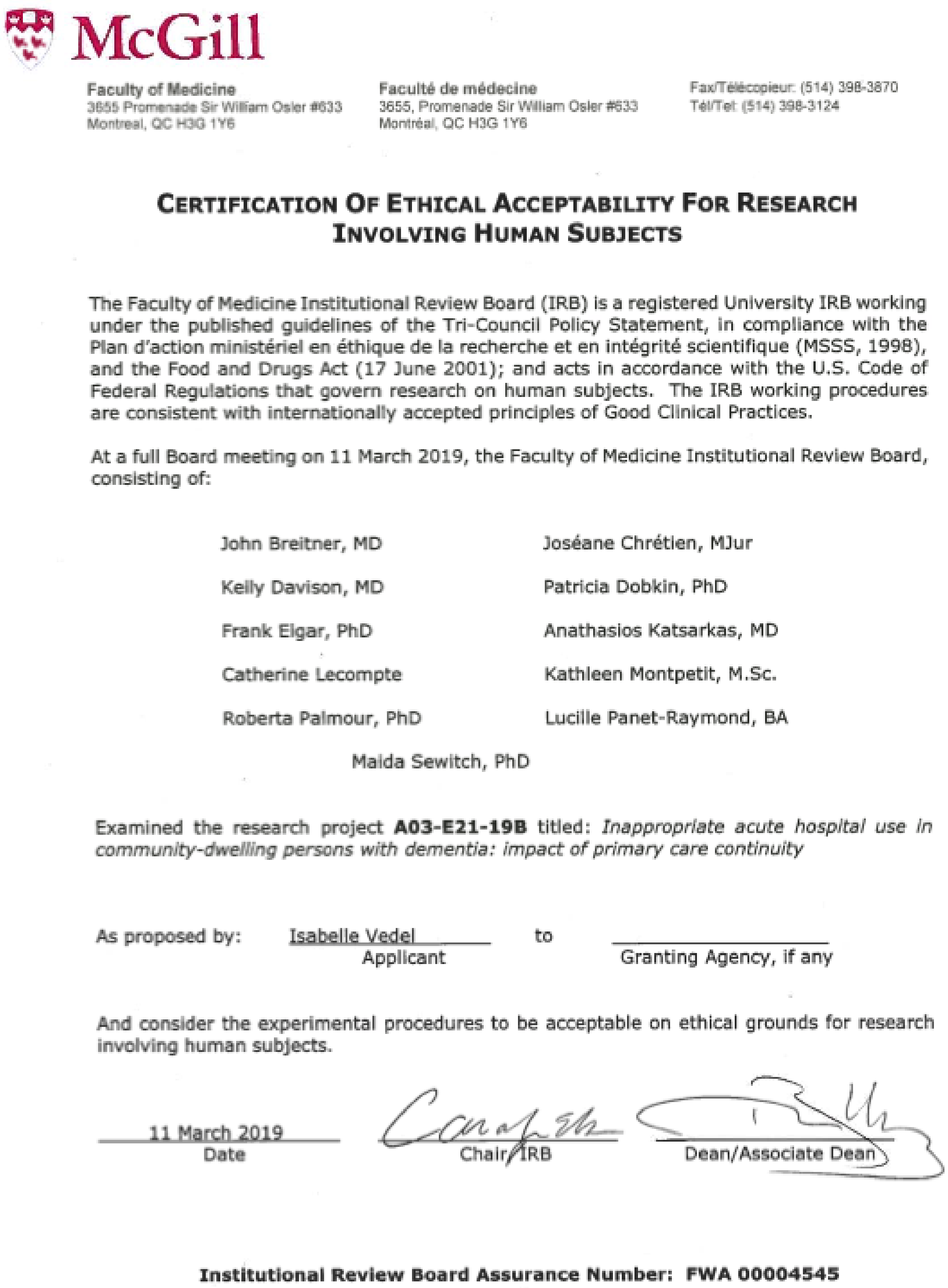
In the first study on the association between high primary care continuity and ALC hospitalizations in community-dwelling persons with dementia, we show a negative, large, but non statistically significant association. High continuity with a primary care physician was non significantly associated with fewer ALC hospitalization.

Our results are consistent with the broader literature on older persons, where primary care continuity is associated with a reduction in hospitalization and potentially avoidable hospitalization [25,53–55]. No previous study measured the association between primary care continuity or timely access to support services and ALC hospitalization in community-dwelling persons with dementia [70]. Two reasons could explain the absence of statistically significant association with ALC hospitalization. First, a lack of statistical power. ALC hospitalizations are rare events. We might not have had the power to show a statically significant association. Second, the strength of association with high primary care continuity might be lower than with the other outcomes. Our hypothesis, grounded in the Gruneir's framework was that ALC hospitalizations may be avoidable through pro-active primary care and especially timely supportive care access [68]. We also hypothesised that high continuity with a primary care physician may ease timely supportive care access. However, these associations might be less strong than with the other outcomes. Further studies with data on support services could explore the association between timely supportive care access and ALC hospitalizations.

10.8 Appendix 8: Ethic approval

Studies 2.1 and 2.3 are part of the continuous chronic disease surveillance mandate granted to the National Public Health Institute of Quebec (*Institut national de santé publique du Québec;* INSPQ) by the provincial minister of health and social services. They were approved by the provincial Ethics Committee of Public Health.

In addition, these studies were approved by the McGIll Institutional Review Board: under the research project number: A03-E21-19B.



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CERTIFICATION OF ETHICAL ACCEPTABILITY FOR RESEARCH INVOLVING HUMAN SUBJECTS

The Faculty of Medicine Institutional Review Board (IRB) is a registered University IRB working under the published guidelines of the Tri-Council Policy Statement, in compliance with the Plan d'action ministériel en éthique de la recherche et en intégrité scientifique (MSSS, 1998), and the Food and Drugs Act (17 June 2001); and acts in accordance with the U.S. Code of Federal Regulations that govern research on human subjects. The IRB working procedures are consistent with internationally accepted principles of Good Clinical Practices.

At a full Board meeting on 11 March 2019, the Faculty of Medicine Institutional Review Board, consisting of:

John Breitner, MD
Kelly Davison, MD
Frank Elgar, PhD
Catherine Lecompte
Roberta Palmour, PhD
Joséane Chrétien, MJur
Patricia Dobkin, PhD
Anathasios Katsarkas, MD
Kathleen Montpetit, M.Sc.
Lucille Panet-Raymond, BA
Maida Sewitch, PhD

Examined the research project **A03-E21-19B** titled: *Inappropriate acute hospital use in community-dwelling persons with dementia: impact of primary care continuity*

As proposed by: Isabelle Vedel (Applicant) to ____________________ (Granting Agency, if any)

And consider the experimental procedures to be acceptable on ethical grounds for research involving human subjects.

11 March 2019
Date

Chair/IRB

Dean/Associate Dean

Institutional Review Board Assurance Number: FWA 00004545