DIAGNOSIS & DISRUPTION: UNDERSTANDING GUIDELINE-CONSISTENT DEMENTIA CARE AND PATTERNS OF TRANSITIONS EXPERIENCED BY INDIVIDUALS WITH DEMENTIA

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

in

The Faculty of Graduate & Postdoctoral Studies
(Population & Public Health)

THE UNIVERSITY OF BRITISH COLUMBIA
(Vancouver)

February 2015

ABSTRACT

Introduction

Early detection and management, as outlined in dementia guidelines, can improve outcomes and potentially reduce the number of transitions experienced between care-facilities. The objectives of this thesis were to: conduct a critical assessment of the literature on actual versus guideline-consistent dementia care; use population-level data to examine variations in receipt of guideline-consistent dementia care; understand longitudinal patterns of transitions and the factors that contribute to transitions; and assess if receipt of guideline-consistent dementia care and/or high quality primary care are associated with the number of transitions experienced.

Method

Population-level administrative data in British Columbia were used to identify cohorts of individuals newly diagnosed with dementia in 2001/02 and 2009/10. Dementia guidelines were used to characterize clinical care individuals could receive. The proportion of patients diagnosed with dementia in 2009/10 who received guideline-consistent dementia care and the probability that patient characteristics affected the likelihood of receiving each process was assessed. Those diagnosed with dementia in 2001/02 were followed forward 10-years after the first point of diagnosis and points of care when transitions were highest as well as factors that contribute to those transitions were assessed. The association of receipt of guideline-consistent dementia care and/or high quality primary care with the number of transitions experienced in the year of diagnosis was assessed using negative binomial regression.

Results

Older patients were less likely to receive guideline-consistent dementia care. A quarter of the cohort received an antipsychotic or non-recommended benzodiazepine. Individuals living within rural health-authorities or of low income were more likely to receive antipsychotic treatment. Transitions were highest in the year of diagnosis and at end-of-life, driven by acute hospitalizations. Higher morbidity, living within rural health-authorities, and having behavioural symptoms associated with dementia were strongly associated with the number of transitions experienced. Lastly, receipt of guideline-consistent dementia care and high quality primary care, independently, were associated with fewer transitions across care settings.

Conclusion

Patterns of inequality by age and income may signal barriers to guideline-consistent dementia care. The spike in transitions in the year following diagnosis highlights a distressing period for individuals with dementia, but suggests a useful target for interventions.

PREFACE

This statement is to certify that the work in this thesis was conceived, designed, analyzed and written by Saskia Sivananthan. All research in this dissertation was approved by the University of British Columbia's Behavioural Research Ethics Board: UBC BREB Number H11-02814.

Saskia Sivananthan was entirely responsible for the work in Chapters 1, 2, 4, 6, 7 and 8.

Chapter 3 is based on work conducted by Saskia Sivananthan, Joseph Puyat and Dr. Kimberlyn McGrail. Saskia Sivananthan was responsible for the conception, design, development and management of the study, conducting the analysis and interpretation of the data, writing and revising the manuscript. Joseph Puyat contributed to the collection and analysis, Dr. Kimberlyn McGrail contributed to the analysis, interpretation and edited the manuscript.

Chapter 5 is based on work conducted by Saskia Sivananthan, Ruth Lavergne and Dr. Kimberlyn McGrail. Saskia Sivananthan was responsible for the conception, design, development and management of the study, conducting the analysis and interpretation of the data, writing and revising the manuscript. Ruth Lavergne and Dr. Kimberlyn McGrail contributed to the analysis, interpretation and edited the manuscript.

A version of Chapter 3 has been published:

Sivananthan SN, Puyat JH, McGrail KM. Variations in self-reported practice among physicians providing clinical care to individuals with dementia: a systematic review. Journal of American Geriatric Society 2013; 61(8):1277-85.

A version of Chapter 5 has been accepted:

Sivananthan SN, Lavergne MR, McGrail KM. Caring for dementia: A population-based study examining variations in guideline-consistent medical care. Alzheimer's & Dementia

A version of Chapter 6 is under review:

Sivananthan SN, McGrail KM. Diagnosis & Disruption: Identifying points of care when transitions are highest for individuals with dementia

A version of Chapter 8 has been accepted:

Sivananthan SN. Short End of the Stick? Health Care Inequity in a Vulnerable Population of Individuals with Dementia. Canadian Geriatrics Society Journal of CME 2014.

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LIST OF ABBREVIATIONS

AChI	Acetyl-cholinesterase inhibitor
ACG	Adjusted Clinical Groups
ADG	Aggregated Diagnostic Groups
AD	Alzheimer's Disease
ADLs	Activities of Daily Living
ATC	Anatomical Therapeutic Chemical
BC	British Columbia
CT	Computed Tomography
DAD	Discharge Abstract Database
DINs	Drug Identification Numbers
HA	Health Authority
HCC	Home and Community Care
HSR	Health Service Research
ICD	International Classification of Disease & Related Health Problems
LTC	Long-term care
MRI	Magnetic Resonance Imaging
MSP	Medical Services Plan
NINCDS-ADRDA	The National Institute on Aging and the Alzheimer's Association Workgroup
PCPs	Primary care physicians
RUBs	Resource Utilization Bands
SES	Socioeconomic status
TSH	Thyroid Stimulating Hormone

ACKNOWLEDGEMENTS

I owe a big debt of gratitude first to my supervisor and mentor, Dr. Kimberlyn McGrail. Kim supported, mentored and nurtured me through my uphill battle to induct myself into a new field, make connections across the country and develop a meaningful thesis that I am proud of. This body of work would not be what it is without her sage advice, enthusiasm for results big and small and willingness to be available whenever I needed her. Thank you Kim for bringing me into the CHSPR family and for being such a wonderful supervisor and friend, what more could a graduate student possible ask for?

A big thank you to my secondary supervisor, Dr. Morris Barer, for such thoughtful and meticulous feedback on all of my work. Given everything on your plate, I appreciate the time invested in reviewing my work with a fine toothcomb and for asking the difficult questions. Your running commentary made revisions both valuable and entertaining. As well, I want to thank my committee members, Dr. Margaret McGregor and Dr. Jason Sutherland for their encouragement and for sharing their insights so generously.

To Ruth Lavergne, a special thank you not only for your contributions to this thesis, but also for the pep talks, skype calls, drinks, comfort food and countless other generous ways in which you made this PhD such a great experience. It won't be forgotten. To all my colleagues at CHSPR, particularly Dawn Mooney (I owe you a drink! Your ability to *dawnify* never ceases to amaze me), Sandra Peterson (for your ninja SAS skills and patient responses as I taught myself to code), Rachael McKendry and Lindsay Hedden, your support helped me build this thesis, thank you.

I want to acknowledge my two mentors, Dr. Lynn Beattie and Dr. Larry Chambers, both of whom gave of their time freely, listening to my thesis as it grew and morphed, and always providing sounding boards I could trust. I appreciate your advice and friendship. I also want to thank Responsive Care Management, Bill Dillane and Chris Dalgish who made it possible for me to ground the framework of my thesis by truly experiencing life as a senior at a long-term care facility. A special thank you to Karie Warner (Mill Creek Care Centre), Cathy Fiore (O'Neill Centre), the warm staff and residents at both Mill Creek Care Centre and O'Neill Centre who answered all my questions, treated me as a long-term care resident no-questions-asked while making my stay as comfortable and informative as they could.

Lastly, thank you to mi familia. Amma, Appachchi and Angelo, you have always supported me, my decisions and harebrained adventures. Thank you for being my backbone, strongest champions and defenders. You made the sacrifices to give me the opportunities to be who I am today. I can reach higher in the assurance that you will always be there for me. To Travis, my very own personal cheerleader, thank you for believing in me, nudging me forward when I was hesitant and for never ever allowing me to compromise my dreams. Your unshakable faith in me and dedicated partnership is the foundation of my work.

DEDICATION

This thesis is dedicated to my two favourite people who taught me to value independence and joie de vivre at any stage of life: my grandmother *Sybil Maud Mary Dehideniya* and *Vincent*.

Grandma, you are an inspiration, I am so proud to have a role model like you.

Vince, I still miss you. I know you’re enjoying a beer and a good laugh somewhere.

CHAPTER 1- INTRODUCTION

1.1 Introduction to the Area of Inquiry

Dementia is one of the most significant causes of disability among seniors, affecting 35.6 million people worldwide in 2010 and projected to double every 20 years[1]. In Canada, an estimated 747,000 individuals were living with dementia in 2011 (14.9% of Canadian 65 years or older) [2]. In addition to memory loss, as the disease progresses, impairment manifests itself in other symptoms that include language disorders, difficulty with physically executing learned movement, inability to recognize objects, confusion and behavioral disturbances [3]. The degenerative nature of the disease means that as it progresses, individuals require increased care, social support and assistance with activities of daily living (ADLs) [4,5]. It is a chronic disease with often devastating and long-term financial and social implications for the patient, caregivers and families.

The key contact in establishing a diagnosis, managing the dementia and potentially connecting patients with community resources is the primary care physician. However, many primary care physicians have limited training in geriatric care generally and dementia care specifically. Best practice dementia care guidelines can therefore play an essential role in helping primary care physicians confirm a diagnosis of dementia and then make decisions around managing their patients' care, particularly during the early stages after diagnosis. Guidelines on dementia care have been available, well established and regularly updated for almost three decades [6,7]. Despite evidence that adherence to guidelines on dementia care can improve quality and outcomes for patients, reports of poor detection and inadequate management persist[8,9].

Due to the chronic nature of the disease, physicians need to be able to determine a diagnosis, and develop a management plan as early as possible. Equally important is the development of a longer-term care and life management plan for a condition that will worsen in severity, has no known effective treatment, and significantly affects quality of life and outcomes for patients and those around them. Within that longer term plan, there will be an important series of care-change points, or transitions.

A transition is defined as a situation in which "an individual physically moves from one place to another and stays there for at least one night" [10]. The healthcare system is fractured, often forcing patients to transition between different facilities to receive care when experiencing highly stressful events. A high number of transitions represents a serious challenge to dementia patients and their caregivers because of the importance of stability and familiarity to those suffering from dementia [11,12]. A greater number of transitions between care settings also poses a serious challenge to the continuity of care and the safety of the patient and is associated with medication errors, preventable hospital readmissions and increased mortality risk [13–17]. Some transitions are inevitable, but failure to develop a condition-sensitive care plan can lead to more transitions than are necessary, with effects on the health status and quality of life of the affected patients.

The chronic nature of dementia requires care that provides accessibility, care coordination and continuity in order to meet the ongoing biopsychosocial needs of people with a primary diagnosis of dementia[18,19]. These are all attributes of high performing primary care. High quality primary care has been shown to be associated with fewer of the safety and quality deficiencies identified during transitions [20–22].

However few studies have assessed the experience of primary care in elderly populations and particularly not in vulnerable elderly populations such as those with dementia [23]. As well, primary care physicians are in the best position to provide guideline-consistent dementia which has been shown to be associated with better outcomes for patients [24–26], though no studies have assessed the association between receipt of guideline-consistent dementia care and transitions.

1.2 Research Objectives and Hypotheses

This thesis is designed to add needed research evidence to the area of primary care for people with dementia. The specific objectives and hypotheses of my thesis and the corresponding analytic chapters where they are found are outlined in Table 1.1 and discussed in more detail below.

Table 1.1 – Overview of thesis objectives and corresponding analytical chapters

Objective	Chapter
Conduct a critical assessment examining the existing research literature on actual physician practice patterns associated with the care of people with dementia and to what extent those practice patterns are consistent with published guidelines	3
Examine population-based variations in receipt of guideline-consistent dementia care and patient factors that are associated with that care	5
Examine transitions experienced longitudinally to establish patterns that can help identify points of care when transitions are highest and the factors that contribute to those transitions	6
Assess the association between receipt of guideline-consistent dementia care and/or high quality primary care and the number of transitions experienced	7

Research Objective 1 – A Critical Assessment of Available Research on the extent to which Dementia Care Practice Patterns are Consistent with Guidelines

Primary care physicians are gatekeepers who are often the first point of contact for people with dementia and are therefore in the unique position to make the diagnosis of dementia and to set in motion decisions about clinical care [7,8,27], but limited research is available on physician practice patterns in dementia care. Available studies indicate wide variations in methodologies and responses regarding dementia care provided by physicians [28,29]. Best practice guidelines for dementia care have been established in the medical community for several decades. The use of best practice guidelines has been shown to reduce variation and maintain, or even improve quality of care [30]. Therefore, my first objective is to determine the current state of knowledge on physician practice patterns with regard to dementia care using best practice guidelines and to determine to what extent actual practice, as reported in the literature, is consistent with guideline recommended care. I assess seven dementia care processes recommended by guidelines: formal memory testing; imaging; laboratory-testing; interventions; counselling; community service; and specialist referrals. Results are presented in Chapter 2.

Research Question 1: Based on the current literature, to what extent is actual practice consistent with guideline-recommended care?

Hypothesis:

i) There is wide variation in physician practice patterns with regard to provision of dementia care, particularly discretionary dementia care processes.

Research Objective 2 – Population-based Variation in Receipt of Guideline-Consistent Dementia Care for Individuals with Dementia

The systematic review undertaken to meet research objective 1 showed wide variation in the provision of guideline-recommended care by physicians. Despite this, the available studies had significant limitations in study design, sampling and sample size, limiting interpretation of the extent of variation and its effect on outcomes of care for those with dementia [31]. A recent publication from the Canadian Consensus Conference on the Diagnosis and Treatment of Dementia noted "perhaps more important than any of these knowledge gaps are the large gaps between what we know about diagnosis and what is practiced in many family physicians' offices" [32]. Using administrative data to mitigate many of the limitations identified in past research, I examine the receipt of clinical services by seniors newly diagnosed with dementia in British Columbia (BC), and compare patterns of care to those recommended by dementia care guidelines. By conducting this analysis at a patient level, I am able to examine potentially modifiable patient characteristics associated with any variation and differentiate warranted and unwarranted variation. I assess six dementia care processes measurable in administrative data: imaging; laboratory-testing; physical examination; pharmaceutical interventions; counselling; and specialist referrals, all within the first year of diagnosis. The specific research questions are as follows:

Research Question 2a: What proportion of individuals newly diagnosed with dementia in BC receives each of the guideline-consistent dementia care processes?

Research Question 2b: Is there variation in receipt of guideline-consistent care, and if so, what are the patient characteristics most strongly associated with this variation?

Hypothesis:

i) A high proportion of individuals will receive guideline-consistent laboratory and imaging processes of dementia care as these are more regularly administrated, while a lower proportion of individuals will receive all other, more discretionary processes of care.

ii) There will be warranted variation in receipt of guideline-consistent care that can be explained by geographic location and health status.

iii) There will be unwarranted variation by other patient characteristics, indicating potential inequity and lack of quality of care.

Research Objective 3 – Patterns of Longitudinal Transitions Experienced by Individuals with Dementia

The prevalence of moves between care settings (home, hospital, LTC-facilities), or transitions, is high in the elderly [33,34]. A high number of transitions between care settings poses a serious challenge to continuity of care and the safety of the patient as evidenced by medication errors, quality deficiencies, preventable hospital readmissions and increased risk of mortality [13–17].

For extremely vulnerable individuals with dementia, safety challenges are compounded due to their disorientation [12,35]. Guidelines for good dementia care stress the need for continuity and familiar environments which cannot be consistent with a high number of transitions [10,11,26,36] .

A few studies have begun to examine transitions, describing the dynamic movement of seniors with dementia [12,37]. However, these studies are often over short periods of time with small cohorts and none examine the factors that contribute to these transitions. The objective of this study was to examine transitions experienced longitudinally to establish patterns that can be used to identify points of care when transitions are highest and the factors that contribute to those transitions to help assess the relationship between receipt of care and outcomes.

Research Question 3a: What is the rate of transitions experienced over the study period and what are the points of care during which transitions are highest?

Research Question 3b: Are there individuals who consistently experienced a high number of transitions and if so what are their characteristics?

Research Question 3c: What are the types of transitions experienced and what factors influence these transitions?

Research Question 3d: What factors influence the number of transitions during the peak points of care and overall?

Hypothesis:

i) The number of transitions experienced will be higher at the point of diagnosis and at the end-of-life compared to the time period after diagnosis and before their end-of-life.

ii) The individuals who consistently experience a high number of transitions will have a high number of co-morbidities in addition to dementia and behavioural symptoms of dementia compared to those with a low number of transitions.

iii) Hospitalizations will drive transitions, but a large proportion of the cohort will also move to LTC. Age, morbidity and behavioural symptoms will be the factors associated with hospitalizations or a move to LTC. The lack of a caregiver will be significantly associated with a move to LTC but not hospitalizations.

iv) The factors associated with a higher number of transitions will be age, gender (male), morbidity, behavioural symptoms of dementia and the lack of a caregiver both during the peak points and overall.

Research Objective 4 – Association of Guideline-Consistent Dementia and High Quality Primary Care Received with Transitions Experienced by Individuals with Dementia

The higher the number of transitions experienced, the higher the risk of morbidity and mortality due to medication errors, poor communication, adverse drug interactions and avoidable re-hospitalizations[33]. The clinical trajectories of individuals with dementia have been well-documented and the care needs of these patients should be anticipated by primary care doctors which would minimize the number of transitions experienced. The chronic nature of dementia requires longitudinal care that provides accessibility, care coordination and continuity in order to meet the ongoing biopsychosocial needs of people with a primary diagnosis of dementia, which are also the facets of high performing primary care (Boustani, Sachs, & Callahan, 2007; Boustani, Schubert, et al., 2007; Chodosh et al, 2006).

There is good evidence for the benefits of accessibility, continuity of care and coordination, all of which are key features of high quality primary care. Family physicians are best positioned to ensure effective care coordination which has been shown to be associated with better outcomes [38–40]. However, many of these studies have been conducted in adults and young children but not in elderly populations and particularly not in vulnerable elderly populations such as those with dementia [23]. As well, guideline-consistent dementia care is thought to be associated with better outcomes, though barriers to implementing these guidelines indicate not enough studies demonstrating this association [41].

My final objective therefore is to examine the association between receipt of guideline-consistent dementia care and/or high quality primary care and the number of transitions experienced by individuals with dementia.

Research Question 4a: Is receipt of guideline-consistent dementia care in the year of diagnosis associated with the number of transitions the patient experiences in that year?

Research Question 4b: Is receipt of high quality primary care associated with the number of transitions the patient experiences in the year in which dementia is first diagnosed?

Hypothesis:

i) Holding all else constant, receipt of dementia care that is consistent with guidelines, and appropriate high quality primary care that encompasses continuity of care and coordination will contribute to fewer transitions.

ii) Receipt of guideline-consistent dementia care will be associated with receiving high quality primary care as measured by continuity of care.

1.3 Thesis Roadmap

This thesis includes 8 chapters in total. **Chapter 1** (which you are currently reading) serves as a preamble, providing an executive overview of the thesis and the main objectives examined.

In **Chapter 2**, I provide a literature review relevant to my work. I define dementia and describe its impact on afflicted patients, those immediately surrounding them, and the societies and communities in which they are embedded. I then explore the care that patients with dementia receive within and outside the primary care context, particularly examining the role of guidelines in defining what is considered good dementia care. I provide an overview of variations in dementia care (which is explored in more detail as part of a systematic review in chapter 3) prior to describing the conceptual framework designed to guide and inform the analytic work of this thesis. Following this, I describe the current literature on transitions and their impact on patients.

Chapter 3 is a systematic review of the relevant literature on measures of dementia care processes and physician practice patterns in the context of providing guideline-consistent dementia care. The review highlights significant differences in dementia care practice patterns indicative of inconsistent care received by patients with dementia, but also the limitations in the study methods employed, clarifying the need to examine, at a population-level, the differences in dementia care received by patients and the patient characteristics associated with those differences.

Chapter 4 provides a description of my research design, data sources and methods of analysis. It contains a brief history and description of the use of administrative data in research and outlines in detail the linked administrative datasets utilized, variable definitions and operationalized.

Chapter 5 describes my attempt to fill the gap in knowledge identified through the systematic review in chapter 2. It is a population-level analysis examining the receipt of guideline-consistent dementia care in BC during the first year of diagnosis. I describe the proportions of individuals who receive guideline-consistent dementia care, variations in care experienced and the patient characteristics that influence them.

Chapter 6 descriptively assesses transitions experienced by patients with dementia from the year of diagnosis to a decade later or end-of-life. I explore patterns and types of transitions, identify points of care when transitions are highest as well as the demographic factors that influence these transitions.

Chapter 7, the final empirical chapter of my thesis contains a study that examines if there is an association between the nature of guideline-consistent dementia care patients receive at initial diagnosis, high quality primary care and the number of transitions experienced.

Chapter 8 is the concluding chapter to my thesis which summarizes my results, situates those results as contributions to the field, and makes recommendations for policy, practice and future research.

CHAPTER 2- BACKGROUND & LITERATURE REVIEW

2.1 What is Dementia?

Dementia is an umbrella term that applies to a class of disorders characterized by memory loss and affecting higher brain function as the brain deteriorates [3]. It can be chronic or progressive in older adults, reversible (sometimes as a symptom of an illness which when treated, reverses) or irreversible. The irreversible dementias include vascular dementia, frontotemporal dementia, Lewy body dementia, Creutzfeldt-Jakob disease and the most common, Alzheimer's Disease (AD). Worldwide, 24.3 million people were estimated to be living with dementia in 2001 with that number doubling every twenty years [1]. The highest prevalence of dementia is in China, and the majority (60.1%) of all people with dementia live in developing countries [1].

In 1907 Dr. Alois Alzheimer presented the clinical and neuropathological features of "[a]n unusual illness of the cerebral cortex" seen in a 55-year old woman he had observed for five years in a Frankfurt asylum [42]. The disease that bears his name is now the most common form of dementia (accounting for 50-60% of all cases), with an exponential increase in incidence in those aged 65 and over in developed countries [3]. Alzheimer's Disease can be either sporadic or familial. Familial AD is an autosomal dominant disorder with the age of onset generally before age 65, however this is a rare form with a low prevalence of 0.1% [43]. In the sporadic form, which is the most common, the apolipoprotein E allele 4 has been shown to contribute most of the genetic risk. The key clinical symptom is progressive memory loss, and two distinct neuro-pathological features: extracellular plaque deposits and neurofibrillary tangles. Over one hundred years after its identification, the cause(s) of AD are still debated and a definitive diagnosis of AD can still only be made post-mortem.

Vascular dementia is the second most common form of dementia in the elderly and is usually a result of a series of small, unnoticed strokes, often co-existing with AD. It is characterized by either acute onset (for a large stroke) or a step-wise progression of cognitive impairment [44]. Often, though, patients present as mixed vascular and AD dementia. Other dementias include frontotemporal dementia (including Pick's Disease), Lewy body dementia, Creutzfeldt-Jacob Disease and dementia that occurs with chronic neurodegenerative diseases such as Huntington's disease, Parkinson's disease and Multiple Sclerosis which have the same gradual progression of cognitive decline as AD [2,45].

Early-stage dementia for the two most common forms presents as deteriorating memory and a decline in verbal fluency [46]. Other common symptoms include aphasia (language disorder), apraxia (inability to articulate thoughts or physically execute learned movement), agnosia (inability to recognize objects), deterioration of higher cortical function (confusion, disorientation) and behavioural disturbances (depression, agitation, delusion). Dementia is diagnosed when these symptoms progress to the point where they affect and individual's ability to care for themselves [3].

A definitive physiologic-based diagnosis of dementia can still only be made post-mortem by neuropathology. However, an accurate functional diagnosis can be made through a combination of clinical evaluation, cognitive screening, laboratory testing and structural imaging[5,32]. Canadian consensus guidelines outline three conceptual components to the diagnostic process: 1) the clinical diagnosis, 2) searching for the potential cause and 3) identifying treatable comorbid conditions or factors that may by contributing to the dementia[32].

The clinical diagnosis is based on the patient's history, collateral history from a family member or caregiver (without the patient present), a physical examination and a cognitive assessment. The patient's history would indicate the cadence of the illness and other potential risk factors or causes which can be confirmed by the collateral history from the family member. For example, a gradual onset is often indicative of AD while a step-wise progression is more consistent with vascular dementia. Alcohol abuse may be a cause for dementia and a family history of dementia is considered a risk factor. The physical examination would be conducted to search for specific signs such as a possible stroke. Finally, cognitive function can be tested using any number of validated cognitive tests, all of which provide an indication of the severity of memory and cognitive loss.

Once the presence of dementia is established, the physician would search for a specific cause, first by ruling out other medical and potentially reversible reasons for dementia using further clinical evaluation, laboratory testing and imaging. For example, renal failure, a brain tumor or subdural hemorrhages can present as memory loss but are treatable and easily identified via laboratory testing and imaging. As well, individuals with dementia are at risk for delirium and depression, both of which may be further explored by the physician. A combination of these techniques can allow for an accurate clinical diagnosis of dementia, however the challenges of making this diagnosis should not be underestimated given the range of symptoms and confounding factors present in patients.

A diagnosis of dementia is recorded in the patient's record, but also in diagnostic codes that physicians use to bill for their services. Those diagnostic codes are made up of a United Nations' sponsored standard classification system used by the World Health Organization and adopted internationally to classify diseases as well as more nuanced symptoms, signs, abnormal findings and external causes of injury known as The International Classification of Diseases and Related Health Problems (ICD)[47]. The system provides a means of mapping health conditions under general categories with variations of the condition assigned by codes that can (in its most recent version) be up to six characters long. It enables a comparability in the classification, storage and retrieval of health data and statistics across jurisdictions and over time, and is used for compiling morbidity data, mortality data, as part of reimbursement systems, and as an input to resource allocation decisions [48].

The ICD is periodically revised. Administrative data in BC include both the 9th (ICD-9) and 10th (ICD-10) revisions of the system [49]. The 10th revision of the ICD codes involved a functional change in structure and was not a simple updating. This resulted in more specificity of information conveyed through the codes, an increase in character length to allow the ability to add more codes and fuller code titles to better reflect medical advances in knowledge [50]. There are several codes that capture dementia in both the ICD 9 and 10 revisions (Table 2.1 and 2.2).

Table 2.1 - International classification of disease codes related to dementia, version 9

ICD VERSION	CODE	DESCRIPTOR
ICD-9	290.0	Senile dementia uncomplicated
ICD-9	290.2	Senile dementia with delusions or depressive features
ICD-9	290.3	Senile dementia with delirium
ICD-9	290.4	Arteriosclerotic dementia
ICD-9	294.1	Dementia in conditions classified elsewhere
ICD-9	331.0	Alzheimer disease
ICD-9	331.1, 331.11, 331.19, 331.2, 331.82, 331.89, 331.9	Other cerebral degenerations
ICD-9	797	Senility without mention of psychosis

Table 2.2 - International classification of disease codes related to dementia, version 10

ICD VERSION	CODE	DESCRIPTOR
ICD-10	F00	Dementia in Alzheimer's Disease
ICD-10	F01	Vascular Dementia
ICD-10	F02	Dementia in other diseases
ICD-10	F03	Unspecified dementia
ICD-10	G30	Alzheimer's Disease

2.2 The Social and Financial Impact of Dementia

The first of the largest recent Canadian birth cohort – the baby boomers - turned 65 in 2011, and by the year 2015 Canada will have more individuals aged 65 and older than individuals under 15 years of age [51]. Dementia is one of the most significant causes of disability among Canadians aged 65 and older. It is projected that by 2038 nearly 1.12 million Canadians (2.8% of the Canadian population) will be living with dementia [2]. The nature of dementia means that as it progresses, individuals require increased help with day-to-day ADLs and social support. This additional responsibility usually falls to an informal caregiver who is often a spouse or adult child. Caregivers of patients with dementia dedicate on average 90 hours per week providing care and managing treatment while also bearing financial costs that are both direct (such as home support or therapy) and indirect (such as lost income) in order to spend time assisting patients [52]. The social consequences of dementia therefore affect both the patient and the caregiver(s).

Unlike other chronic diseases, dementia affects cognitive function as opposed to physical function. Because of this, less is known about the inner needs and experiences of individuals with dementia as they become unable to express themselves verbally. The literature reviewed in the next chapter reveals that patients with early stage dementia describe a loss of control and self-identity, as well as a range of emotions including anger, fear, shame, frustration and stigmatization [53]. Many attempt to continue their lives as best they can after the diagnosis, but feel isolated socially and by their healthcare professionals. They expect suitable individual care from health professionals who have the knowledge to meet their needs at the different stages of the disease, but express frustration at their needs being overlooked or misunderstood, and at no longer being treated as accountable adults [53]. Social integration, which is emphasized in the care of younger adults with cognitive impairment, is often replaced with an emphasis on safety and efficiency when it comes to seniors, with the implication of reduced freedom or autonomy [54]. The 2003 World Health Report Global Burden of Disease estimates that dementia accounts for 11% of total years spent with a disability in individuals over the age of 60. This is more than all cancers, stroke or cardiovascular disease combined [1].

Informal caregivers of individuals with dementia describe feelings of isolation, anger, limited social support and feeling overwhelmed in addition to physical and psychological distress [55]. Caregivers of individuals with dementia have 46% more physician visits, 71% more prescribed medications, 63% higher mortality risk, poorer self-rated health and a higher incidence of depression and anxiety compared to matched non-caregivers [55]. Unsurprisingly, the leading reason for institutionalization of seniors with dementia is caregiver distress [56].

The annual cost of healthcare for a person with dementia is estimated to be approximately three times that of a comparable person without dementia (accounting for direct medical and non-medical costs) [57–60]. Costs additionally increase dramatically with increased disease severity [61]. Half of all cost is associated with hospitalizations (including for potentially preventable ambulatory-care sensitive conditions) [59,62]. While there is some variation in cost estimates associated with study design (the costs emerging from the more common cross-sectional designs are higher than those from longitudinal designs [63], the cumulative economic costs of dementia are incontestably substantial -- projections for Canada as high as $872 billion by 2038 have been reported [2]. In short, dementia represents a clear and present danger for all unprepared health care systems.

2.3 Care for Dementia in the Primary Care Setting

The care of patients with dementia in the primary care setting is complex. Dementias often go un- or under-diagnosed in primary care, with some estimating as many as two-thirds of patients with dementia not being identified [8,9,64]. Most studies indicate that patients with dementia have a higher burden of co-morbidity than comparable controls, though there is still some debate around this in the literature [62,65]. Patients with dementia who also have co-morbidities often require a higher level of care because of difficulties with communication and management [4]. This is complicated by multiple prescriptions to manage these co-morbidities in addition to psychotropic drugs for behavioural and psychological symptoms of dementia. Drug interactions can result in higher use of other parts of the healthcare system [66]. The interaction of cognitive, behavioural and functional symptoms of dementia leads to a decreased quality of life for the patient, and often, for (particularly informal) caregivers as well [55].

In BC, as in many other jurisdictions, primary care doctors are the first point of health care system contact for patients or family members who suspect a cognitive problem. Primary care physicians therefore are in the unique position to make the diagnosis of dementia and to set in motion decisions about clinical care, guided by well-established dementia care guidelines (discussed in more detail in section 2.5) [8,27,67]. The primary care physician needs to first provide an accurate, and preferably early, diagnosis. They then, more importantly, need to provide long-term management of dementia in the context of additional co-morbidities [7]. Current dementia care also recognizes the need for counselling and frequent monitoring of the health status of both the patient and the caregiver (regardless of whether the caregiver is a patient of the physician) as informal caregivers play such an essential role in longitudinal dementia care [8]. The initial diagnosis, counselling and management of symptoms fall within what is considered 'dementia care' as outlined by guidelines (see section 2.5) and ideally occur within the first year of diagnosis. However, as previously noted, dementia is a chronic, progressive disease and individuals with dementia often have a high burden of co-morbidity requiring physicians to provide longitudinal primary care to manage the dementia in the context of those co-morbidities.

High quality primary care contributes to better outcomes for patients including better management of chronic conditions, fewer preventable hospitalizations, shorter lengths of stay, reduced use of emergency rooms and reduced risk of mortality [20]. It has been defined as having four main features: first point of access for each new need; longitudinal person-focused (not disease-focused) care; coordination of care provided in other settings or by other practitioners; and comprehensive care that addresses most health needs [22]. While less is known about the association of receipt of high quality primary care with better outcomes of care specifically for people with dementia, it is increasingly clear that in order to meet the ongoing biopsychosocial needs of people with dementia, particularly in the context of co-morbidities, all the facets of high quality primary care as defined by Starfield will need to be addressed [8,18,19].

The complex range of cognitive, social and functional problems involved with dementia often makes it difficult for primary care physicians to manage on their own. The participation of physicians in multidisciplinary professional groups is recommended, often involving a social worker, geriatric psychiatrist and nurse case manager to ensure effective care coordination and to provide support to the patient and caregiver [68]. Physicians are also an important source of referral to home and community services. While, it would be ideal for patients to learn of these support services from physicians during their visit, awareness and outreach have increased so that referrals can now come from nurses, social workers, family members or the dementia patients themselves [69].

All in all, primary care physicians are a pivotal hub. The literature however, also indicates several barriers to practice. Busy primary care physicians have expressed concern about the lack of resources, expertise and time to provide the level of dementia care required resulting in delayed recognition of dementia and adverse outcomes for the patient and their caregivers [70]. The complexity and challenges associated with behavioural symptoms that accompany dementia are particularly difficult challenges for physicians [71]. Finally, despite a high degree of accuracy when dementia diagnostic guidelines are applied, physicians often do not change their practice behaviour to align with widely available guidelines for dementia care [26,28].

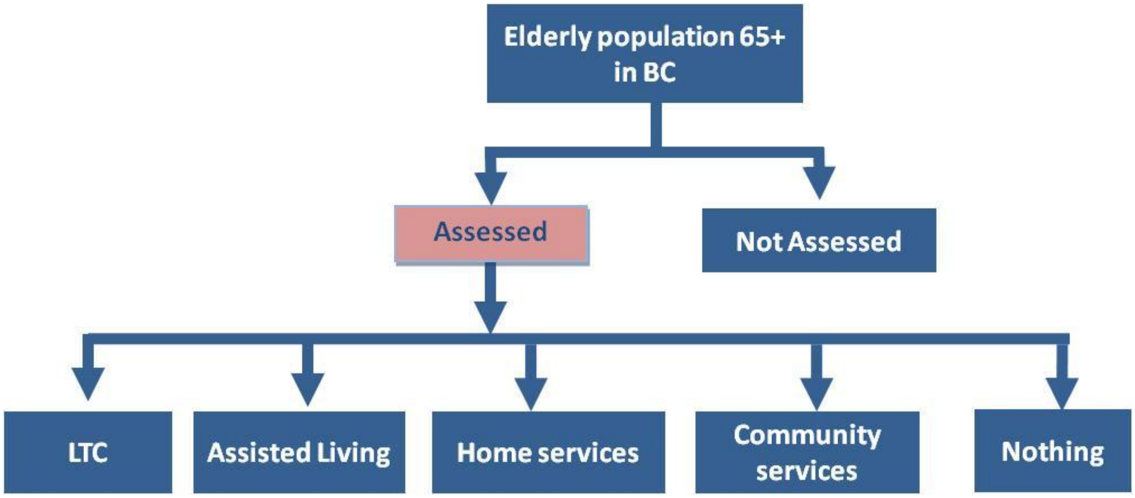
2.4 Overview of Services Outside Primary Care

There are a broad range of health and social services available for all seniors that dementia patients and their families may access beyond the standard set of services offered by physicians and hospitals. Patients with dementia generally need both clinical and social services to support them in their longitudinal care. While the primary care physician is often the first contact at the diagnosis of Alzheimer's disease and other dementias, dementia-specific home and community support services are available and have grown over the years.

In BC, access to other publicly-funded services is mediated through an assessment process [72]. As noted, referrals for assessment can come from a variety of sources. Once a referral is made, there is a formal process by which the individual's physical, mental and functional state is evaluated, along with an assessment of the adequacy of informal supports. All of this information is used to determine the amount, intensity and duration of care individuals are eligible to receive through the public health care system [73–75]. Publicly-funded services may still have a provider pay component, which is based on one's ability to pay. Individuals of course also have the option either of adding to these publicly funded services with additional care, or to forego public services entirely [76]. Patients may have several 'episodes of care' where they move in and out of the system as needed after their initial assessment, but many older adults become long term users as they become more medically frail [72].

The publicly-funded services potentially available in BC fall into three broad categories: home services, community services and long-term care (LTC) services [77] (Figure 2.1).

Figure 2.1 – Assessment and publicly-funded service options in BC



Home services include home nursing, occupational therapy, physical therapy, home support for ADLs and palliative care [72]. Community services range from respite care (provided at home or in the community or on a short-term basis at a facility), to adult day centres, specialized education and peer support programs run by health organizations and local chapters of the Alzheimer's Society. Use and review of these services are still sparse, though several randomized control trials have demonstrated their efficacy in specific settings [78,79]. If adults with dementia are no longer able to live safely in the community or require a higher level of care than is possible with home services, assisted living/supportive housing and LTC/residential care are available.

2.4.1 Home and Community Care in British Columbia

Remaining in the community for as long as is feasible is considered the best possible option both by people with dementia and their caregivers [73,80,81]. The majority of older adults prefer to continue living independently in their own homes, though a diagnosis of dementia can eventually eliminate this possibility due to safety concerns. Home care as well as other community-based services provide a means for older adults with dementia (and their caregivers) to extend their length of stay in the community by managing their health conditions at home and assisting with ADLs such as help with bathing and preparing meals [82].

Like many provinces in Canada, and consistent with the wishes of individuals and their families, having seniors remain in the community for as long as possible has been a priority for BC [83]. Recent analyses, however, have demonstrated that despite this, access to and use of home and community care (HCC) services have decreased over time for a variety of reasons including policy changes and shifts in the demographic of seniors who might need home care [72,84–87].

The literature surrounding the cost of home care has also seen a shift. While home care was previously unequivocally considered more cost-effective for older adults, current studies indicate that this is only the case under specific circumstances, as informal care giving costs are often not adequately accounted for (e.g. loss of caregiver income, caregiver stress and healthcare utilization) [72,88–90]. Regardless, remaining in the community is overwhelmingly what most Canadian seniors (93% of those surveyed) prefer [51,91].

For individuals with dementia, remaining in the community as long as possible has a number of benefits. Transitioning to a new environment such as a LTC facility is stressful for older adults because of the nature of the change and the association of loss [11,80]. Home is associated with continuity, autonomy, competency, privacy and control [92–95]. This is doubly so for individuals with dementia who feel that the home environment provides a sense of personhood and normalcy [93,94,96]. In the face of cognitive and functional disconnection and losses faced through dementia, a familiar environment and routine is useful in the management of dementia care and can be provided with the assistance of home and community care services [97].

For many informal caregivers, being able to provide care to their loved ones at home allows them to ensure that these individuals are receiving individualized care that is appropriate and meets their needs and standards [80]. Given that individuals with dementia often have multiple co-morbidities, primary care physicians who provide early intervention with appropriate monitoring and management of the multiple conditions may be able to help their patients remain in the community longer [26]. Additionally, monitoring of caregiver well-being and assistance in mobilizing social support by primary care physicians can help pre-empt and relieve some of the caregiver stress that is often the trigger for institutionalization [12,55].

2.4.2 Long-Term Care in British Columbia

Home-based services can help people with dementia age in place, but eventually it often becomes very difficult for informal caregivers to manage care for people with dementia at home, particularly during the later stages of the disease or when behavioural symptoms become unmanageable. At that point a move to alternative forms of housing that provide additional supports becomes necessary [98].

In BC the housing menu is somewhat more limited for those with dementia relative to seniors without dementia (Figure 2.1). Assisted living, which is described as a residence that "offers housing, hospitality services and personal assistance to adults who can live independently but require regular help with daily activities" [99] is a form of care between home care and LTC, but is considered unsuitable for people with moderate to more advanced dementia since eligibility criteria in BC (as with most other provinces and states) requires that individuals be able to direct their own care [11,99]. Therefore, individuals in Assisted Living whose dementia makes this impossible, face a second transition to LTC --often the last, and only option [100,101]. But even at this level of care, most LTC facilities as they are currently resourced, are inadequately equipped for dementia patients. Dementia patients are often sequestered in separate or special secured wings with different resourcing within the facility because they require more support than the average LTC resident for any given level of other disabilities or limitations.

While individuals with dementia undeniably require additional support, current literature suggests that more home-like environments are better-suited for individuals with dementia (as well as for all older adults living in LTC facilities). This means not just 'home-like attributes' implemented in the form of decor and the naming of facilities, but social relational care practices as well that are meaningful to the persons with dementia, their families and staff [81]. This idea is being developed in some LTC facilities in BC based on several frameworks [102,103] but has been extended further by others. The Dementia Village in the Netherlands and Beatitudes Campus in Arizona, USA are two such examples. They feature open environments that encourage patients with dementia to be autonomous, focuses on individuality and relationships while maintaining a home-like environment, models that BC is using as templates [104,105]. Residents of LTC facilities surveyed regarding their preferences have indicated support for this sort of social integration as opposed to an over-emphasis on safety and efficiency [54].

Unfortunately, many of the facilities in North America that provide specialized dementia care still have institutionalized settings and care structures. The housing landscape has yet to shift to provide alternate options for dementia patients, though several new models have been developed in North America and are being evaluated [106–108]. For now, the current, traditional, institution-like LTC facility remains the prevailing housing option.

Primary care experiences are also different once a move to a LTC facility is made. Many LTC facilities have in-house physicians or specific family physicians responsible for the care of the majority of the facility's LTC residents. In these cases, the patient-physician relationship developed while a patient lives in the community often ends when the patient becomes a LTC resident; responsibility for primary care is transferred to the physician practicing at the LTC facility to which the patient has been moved [109]. In BC, only 54% of general practitioners provide residential care services with an 18%

increase in the average annual number of residential care visits over the past ten years (2003/04-2012/13)[110]. Indeed, there has been a 13% drop in physicians providing residential care services since 2003/04 despite a 10% increase in the number of residential care patients and a 10% increase in the number of general physicians over the past ten years [110]. This is reflected in the declining comprehensiveness of primary care. Physicians practice in fewer care settings and have a more narrow scope of care [111–113]. A recent study demonstrated that the care of 90% of LTC residents in Ontario was accounted for by only 50% of family physicians with a mean of 42 residents per physician [114]. A similar concentration of residential care services by a small proportion of physicians is seen in BC, though some local health authorities (such as Cowichan and Prince George) do not appear to have this trend [110]. This trend toward more concentrated residential care services plays havoc with continuity of care and may potentially also affect quality of care (as suggested by the high rates of inappropriate prescribing amongst this population) [115,116].

2.5 American and Canadian Guidelines for Dementia Care

Over the past thirty years, there have been several position papers and guidelines published in the US and Canada on evaluating people suspected of having dementia and providing subsequent dementia care. These range from lengthy, detailed recommendations based on consensus expert opinion and/or literature review(s), [5,7,117–120] to short user-friendly flowcharts with brief references [121–123]. Their intent is to provide guidance on the care of individuals with dementia, and they are aimed mainly at primary care physicians who are the initial point of contact for these individuals. The guidelines have undergone significant evolutions since first published in the 1980s. The more recent offerings are based on a better understanding of the long-term social implications of dementia, not just for the patients but also for those who care for them.

Canada first produced national guidelines in 1989 through a national consensus conference bringing together experts in the field [7]. At the time, the focus of the guideline was on accurate diagnosis of dementia with no attention to treatment or management following that diagnosis. This consensus conference was subsequently repeated in 1999, 2006 and more recently in 2012. The resulting guidelines (with those from the 2012 conference still in process) now include treatment and management recommendations. The result of the 3rd consensus conference (in 2006) was the dissemination of a series of six papers: risk factors and prevention [124], investigating and diagnosing dementia [32], defining and diagnosing mild cognitive impairment [125], managing mild and moderate dementia [4], pharmacological and non-pharmacological therapy [126] and finally, managing severe dementia [127]. These contained 146 recommendations that reached strong consensus with the experts.

Three of these papers are of particular interest with regard to dementia care guidelines. The second paper, on the investigation and diagnosis of dementia, provides explicit detail for clinical diagnosis while contextualizing the difficulties in differentiating the dementias and severity levels [32]. Using a vignette, it outlines a detailed clinical evaluation including a history from the patient (focused on the cadence of the illness, vascular risk factors and other risk factors), collateral history from an informant, a physical examination and a formal cognitive test. Recommendations on core laboratory tests remain relatively unchanged from the previous guidelines (complete blood count, thyroid stimulating hormone (TSH), serum calcium, electrolytes, fasting glucose), with the addition of recommendations for B_{12} measures in all older adults. Testing of red blood cell folate and serum folic acid levels is now no longer necessary since the introduction of folic acid into Canadian grain in 1998. Recommendations for neuroimaging (primarily computed tomography and magnetic resonance imaging) are still made; however, the committee determined that there is insufficient evidence to recommend the routine use of functional imaging (magnetic resonance spectroscopy), collection of biomarkers or neuropsychological testing. More importantly, the guidelines make a special recommendation that the results of tests, diagnosis and management be conducted over a series of visits spanning several weeks in order to provide appropriate time to accurately identify dementia and prepare the patient for a diagnosis. The committee concludes with the identification of what members considered the most important current knowledge gap -- what is known about diagnosis and what is actually practiced in a general physician's office. The latter is a specific focus of this thesis.

The fourth paper in the series, on approaches to management of mild to moderate dementia, is of importance because of its guidance in managing a long-term progressive disease like dementia with which most family physicians have had very limited experience [4]. As with previous papers, a vignette is used as an example of how a case can be approached. Fifteen bulleted points highlight important recommendations that touch on disclosure, need for referrals to specialists (because of uncertainty about diagnosis, request for second opinion, need for assistance with pharmacotherapy, expressed interest in research studies, and/or inability to appropriately manage patient), assessment of safety risks (driving, financials, activities of daily living etc), referral to the local Alzheimer's Society chapter and community resources and, finally, managing and responding to therapy, functional problems, behavioural symptoms of dementia and co-morbidities. While the guidelines warn physicians that the needs of the patient and caregiver evolve and will require monitoring for increasing cognitive, functional and behavioural challenges, they do not provide detail on the frequency with which a patient should be monitored or the psychosocial counselling that should be provided. The guidelines also mention the importance of caregivers in the management of patients with dementia; the subject of caregiver support, while mentioned, is rather cursorily covered. The focus is on meeting with the caregiver regularly to assess the status of the patient with dementia, with a particular focus on behaviour, and on finding ways to deal with distressing problems regarding the patient. Multi-component interventions such as providing education, counselling, support and respite for caregivers is stated with no supporting details.

In the fifth paper regarding pharmacological and non-pharmacological interventions, no non-pharmacological interventions are recommended outside of physical exercise. Details on pharmacological interventions are provided, in particular the effectiveness, selection and side effects of acetyl-cholinesterase inhibitors [126].

Unlike Canada, the US has guidelines published by several different national working groups and organizations which appear to work separately as opposed to through a consensus process. For example, 'The National Institute on Aging and the Alzheimer's Association Workgroup' (commonly referred to as NINCDS-ADRDA), first published guidelines in July 1984. These were updated in 2011, and both the original and updated versions place explicit emphasis on clinical criteria [118,128]. They propose different terminology for the classification of what they term probable AD dementia, possible AD dementia and probable or possible AD dementia with evidence of AD pathophysiology. 'The Work Group on Alzheimer's Disease and Other Dementias' published a comprehensive guideline for diagnosis and management of dementia which stressed the evolving complexity and required comprehensiveness of treating dementia [5]. 'The Quality Standards Subcommittee of the American Academy of Neurology' published three evidence-based reviews: Early detection of dementia: Mild cognitive impairment [129], Diagnosis of dementia [130] and Management of dementia [120]. These were abstracted into guidelines by the American Geriatric Society Clinical Practice Committee in 2003. Several other groups have released position papers regarding clinical care for patients with dementia, notably the 'American Association of Geriatric Psychiatry'; however these were not guidelines and therefore were not reviewed [27].

As outlined above, there is a deluge of national guidelines available on dementia care, particularly in the US. Almost all the guidelines focus exclusively on the initial diagnostic process which the literature has identified as a hurdle due to the low diagnosis and treatment rate, particularly in the primary care setting (it is estimated that less than 25% of individuals with Alzheimer's Disease are diagnosed in Canada) [131]. The guidelines across Canada and the US appear relatively complementary at least with regard to the techniques and diagnostic processes, while differing on the classification terminology. Unlike the US guidelines, the Canadian guidelines stress the diagnosis of a more recently identified symptomatic, precursor phase to dementia, mild cognitive impairment [125]. This is perhaps because the development of the cognitive test used to identify mild cognitive impairment was pioneered in Canada [132]. Interestingly, in contrast to Canadian guidelines, none of the US guidelines reviewed make reference to specialist referrals or the conditions under which these referrals should be made. This may be a reflection of the overall differences in the two healthcare systems, and in particular the fact that patients in the U.S. are free to go to a specialist without a primary care referral, so that primary care physicians play less of a quarterbacking role south of the border.

2.5.1 Dementia Care Guidelines in British Columbia

For practitioners in Canada, both the US and Canadian guidelines are well disseminated; however, most are written as lengthy research reports which are perhaps daunting for busy practitioners with limited time. This may have prompted the development of BC-specific dementia care guidelines which are more succinct, easy to peruse and come with a decision support tool [122,133]. Additionally, BC did not cover acetyl-cholinesterase inhibitors (AChI) until the launch of the Alzheimer's Disease Therapy Initiative in 2007; this may have also required the need for guidelines that take this context into consideration [134].

The BC guidelines were developed by a working group independent of the Canadian Consensus Conference working group and reflect province-specific resource availability and medical coverage [122]. The BC guidelines indicate that symptoms of cognitive impairment should be suspected when there is a history that suggests cognitive decline (emerging cognitive problems). This history might be derived either from direct observation or reports from the individual's social network. After a comprehensive medical review and appropriate testing (physical exam, laboratory tests, neuroimaging and administration of the standardized mini-mental examination) a working diagnosis can be arrived at. With disclosure of that initial (or suspected) diagnosis of dementia, physicians should have follow-up visits at least every six months with the patient and their caregiver in which needs, concerns, safety planning, finances and education should be discussed. Physicians should also be periodically reassessing their patients and establishing a relationship with them and their family (and caregiver).

Outside of managing other co-morbidities and counselling, a trial of AChIs is recommended for mild to moderate dementia, but patients using these therapies must be monitored closely and frequently, particularly within the first three to six months. Referral to a specialist (e.g. geriatric psychiatrists) is recommended when diagnosis or management is problematic or uncertain, when patients or family members request a referral, or when management issues are difficult. Finally, physicians are encouraged to be aware of neglect and abuse, and to support patients to function as independently as possible.

Acetyl-cholinesterase inhibitors were not covered under B.C.'s PharmaCare program until the introduction of the Alzheimer's Disease Therapy Initiative in October 2007. [134]. Through this initiative, patients diagnosed with mild to moderate dementia were eligible for coverage of their AChI medication (except for Memantine, a different class of drug more recently introduced to the market for moderate to severe dementia) as long as they enrolled in the program. The Alzheimer's Disease Therapy Initiative was designed primarily as a research study to address what the BC Ministry of Health saw as a lack of clinical evidence for the effects of AChIs [135]. Physicians were required to assess patients' cognitive status every six months for the patients' continued enrollment and therefore coverage of their medication [45]. The study's participant recruitment was completed in October 2011 and the study reports that over 20,000 patients are enrolled and will continue to receive coverage while in the study.

In 2007, the General Practice incentive program was introduced in BC [136]. The program is meant to support and compensate general practice physicians for time spent on providing guideline-consistent care in several areas including chronic care and mental health. The Mental Health Initiative provides several new billing codes to encourage physicians to take more time in their assessment and support of patients with mental health illnesses, including dementia, as well as to participate in broader care teams while accepting responsibility for providing longitudinal, coordinated care for the patient [137]. While the Mental Health Initiative attempts to address many of the facets of good dementia care by incentivizing physicians to take an in-depth record of the patient's history, conduct appropriate memory assessments and provide ongoing counselling, a recent report from the Ministry of health demonstrates very slow uptake of these incentives [138]. Billings for the specific codes (G14043 – GP Mental Health Planning Fee, G14046 to 14048 – Mental Health Management Fee for ages 60 to 69, 70 to 79, 80+) have increased as have the expenditures on these services, however the number of services billed indicates that these codes are not being consistently used by physicians. There is also no reliable way of determining whether the services described by the fee items are actually provided and whether physician practices have changed due to these codes or whether services are being provided but being billed in more traditional ways. For the purposes of this thesis it was not possible to assess more specific physicians' dementia care practice patterns using these Mental Health Initiative billing codes and they will be excluded from any analysis.

2.6 Variations in Dementia Care

Variations in the use of clinical healthcare services have been reported in just about any area examined [139–141] even after controlling for patient characteristics. In dementia care, there is a large and growing literature available on variations in pharmaceutical prescription use by individuals with dementia [115,116,142–145]; however less is known about variations in the use of other dementia-care-related clinical services such as cognitive assessments, counselling, referrals to specialists or community services, frequency of prescriptions, monitoring, etc. These services are recommended for providing appropriate dementia care and are described at length in dementia care guidelines (as detailed in section 2.5 above). The use of guidelines have been shown to reduce variation and maintain, or even improve quality of care [30]. Therefore large variations in the use of these clinical services would be an indication of inconsistent care across the province which could be associated with differences in care outcomes.

Variations in clinical service use by patients with dementia are often examined at the individual-level. Of these, only a handful of studies have examined a fuller scope of clinical dementia care services (though they are self-reported surveys), and comparing across these studies reveals significant variation in the clinical services received by dementia patients [25,26,64,146,147]. For example, Chodosh et al. [146] developed 18 dementia care processes based on available dementia care guidelines. The types of processes were comprehensive, ranging from assessments (cognitive status, activities of daily living, behavioural problems etc.), treatments (care plans, advise to caregivers, implementing non-pharmacological approaches, documenting medication side effects and outcomes etc.), to education/support and safety, all of which are highly recommended for receiving good dementia care. Adherence to the processes ranged from 9 – 79% with 11 of the 18 processes scoring below 40% adherence. In fact, the lowest percentages of patients to receive specific dementia care processes were in the assessment and treatment category. However, almost 79% of patients were referred to a community care support program. This is in contrast to Reuben et al. [25] who found higher adherence to some assessment processes such as assessing cognition (69% of patients) but again, low adherence in assessing functional status (20% of patients), treatment processes (75%) and referrals to community support programs (0% of patients).

Similarly, in one of the earlier studies that examined the use of healthcare services by individuals with dementia, Callahan et al. demonstrated that less than 20% of patients received any neuroimaging a year prior to or after being screened for dementia and less than 50% received any diagnostic blood work to rule out reversible dementias. More interesting is that Callahan et al. collated results from the patients' Short Portable Mental Status Questionnaire and found that 76% of patients with moderate to severe dementia had undocumented impairment as defined by the lack of a dementia diagnosis anywhere in the outpatient file. Callahan's results must be contextualized by the time of publication. In 1995, dementia care guidelines were available, but awareness was still being built and stigmatization was very strong. This may help explain the very high percentage of undocumented impairment. Regardless, the results from all these studies demonstrate widespread variation in dementia care clinical service use and low adherence to guidelines, both of which continue to persist to the present day.

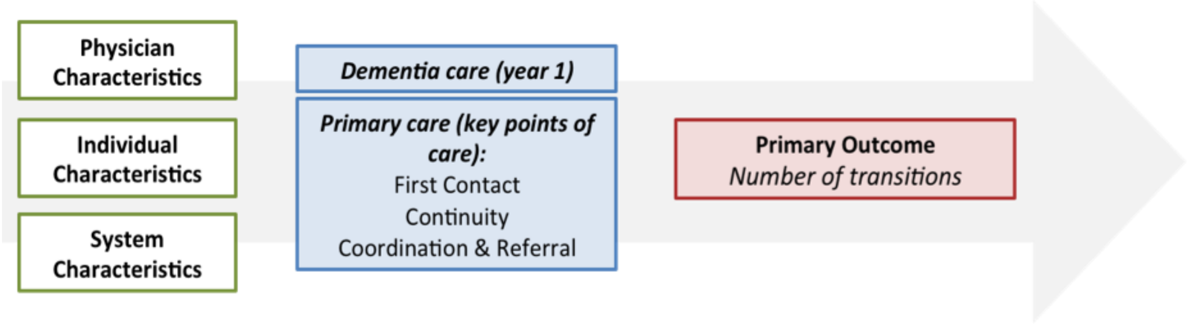
While understanding variations in dementia care and the impact on outcomes is necessary, understanding the factors that contribute to those variations is also important as they may be modifiable by the healthcare system. There are several possible explanations underlying these observed variations including system, provider or patient characteristics. Physician practice patterns have been described previously as contributing to variations in other healthcare areas [141,148–151]. In Canada, there are 63,000 physicians all of whom individually make daily clinical decisions that lead to an average of $1.5 million worth of expenditures on health care services per year [152]. Physicians therefore direct a vast amount of clinical healthcare resources and physician practice style could contribute to variations in clinical healthcare services use by individuals with dementia. Little research is available on physician practice patterns in dementia care despite a recent study in which 95% of seniors reported having a primary care physician [51] and estimates that almost 15% of Canadians 65 years or older suffers from dementia[2]. On this premise, a systematic review of the literature was conducted to better assess the current state of knowledge. This systematic review is presented in Chapter 2.

2.7 Conceptual Framework

There is no single pathway of care that individuals with dementia follow, but nearly all (if not all) journeys will include receipt of some clinical health services. The conceptual framework described here outlines the characteristics and clinical services that may shape care trajectories for patients with dementia.

In my conceptual framework (Figure 2.2), the horizontal arrow represents the aggregation of the factors that ultimately contribute to the primary outcome being measured, transitions. The characteristics on the left (green boxes: physician, individual and system characteristics) are measurable characteristics that contribute both warranted and unwarranted variations to the healthcare activities that are at the core of the framework. Not included in this framework are characteristics not measurable using administrative healthcare utilization data such as cultural beliefs, knowledge and attitude about health and care use which can also affect the type of care received [22]. The central core of the framework contains the two key healthcare activities being measured, dementia care (based on processes of care outlined in best practice guidelines), and primary care (services provided beyond the services measured by dementia care). To the right is the primary outcome of interest, transitions experienced by individuals with dementia. In this framework, transitions can be driven by receipt or lack of dementia care or primary care. Care provisions are driven by physician, individual and system characteristics.

Figure 2.2 – Conceptual framework guiding the thesis



Physician characteristics: Previous studies have indicated that physician age, speciality, practice location (rural/urban), number of years in practice and type of practice population (e.g. number of older patients and number of patients in practice with dementia) are predictors of the type of dementia care provided [153,154]. Similar physician variables were also associated with the provision of full service family practice[112], therefore their inclusion in this framework. As physicians direct a wide range of clinical healthcare resources, their practice style will help shape trajectories of care for people with dementia, and will ultimately shape outcomes of care. These characteristics are depicted at the left hand side of the horizontal framework to indicate their contribution both to the clinical services as well as to the primary outcome.

Individual characteristics: The variables used to measure individual demographic characteristics are key predictors in the receipt/use of dementia and primary care as well as, ultimately, care outcomes. I anticipate that inclusion of these characteristics such as age, sex and neighbourhood socioeconomic status, will allow me to tease apart both warranted and unwarranted variation. Another important characteristic is health status (this measure is described in detail in section 4.4.1.1). Controlling for health status in a regression model assessing variation in clinical services is central to being able to interpret the magnitude and appropriateness of other variations which may be unrelated to patient need; it is critical for being able to differentiate warranted and unwarranted variations. As well, I measure for the presence of an informal caregiver, described in more detail in Section 4.4.1.

System characteristics: The supply of general physicians, specialists and hospitals in a region plays a central role in the type of care provided. For example, areas with fewer specialists per capita will require primary care physicians to take on a larger role in dementia care management for cases that might otherwise have been referred. As well, areas where patients may have difficulty accessing laboratory or imaging facilities may result in fewer laboratory and imaging tests being conducted for diagnostic purposes [155]. BC is divided into five geographic health authorities (Fraser, Vancouver Coastal, Vancouver Island, Northern and Interior). The Fraser, Vancouver Coastal and Vancouver Island health authorities contain major urban centres and a higher per capita supply of specialists, general physicians and hospital beds. The influence of system capacity and other factors such as this constitute the "system" characteristics within the framework. The belief is that these factors will influence both the diagnostic and treatment/care trajectories of patients with dementia.

Dementia care: Dementia-focused care will be defined and explored in detail in Section 3.2.2 of Chapter 3 and Section 5.2.3 of Chapter 5, but briefly, it is care consistent with guidelines for the diagnosis and management of dementia. These clinical services are generally provided within the first two years of diagnosis and consist of services required for diagnosis (laboratory tests, imaging, physical examination), symptom management (pharmaceutical prescriptions), counselling immediately following the diagnosis and referrals to specialists if required. Subsequent care falls within the primary care category with regard to longitudinal management and any other services outside of the ones mentioned.

Dementia care is a pivotal measure in this framework. Receipt of guideline-consistent dementia care is thought to be associated with better outcomes for people with dementia. Good dementia care emphasizes early diagnosis and management which can reduce the number of hospitalizations experienced contributing to a lower overall number of transitions. Measuring any unwarranted variations in receipt of dementia care by individuals newly diagnosed with dementia can indicate inequality or poor quality care, hence its inclusion in the core of the conceptual framework, to be assessed as its own dimension as well as its association with outcomes.

Primary care: High quality primary care has been previously defined [22] and will be measured by three characteristics, first contact with the patient, coordination and referrals as needed, and continuity of care as previously defined [112] and described in further detail in Section 7.2.3. High quality primary care has been shown to contribute to better outcomes for patients, including better management of chronic conditions, fewer preventable hospitalizations, shorter lengths of stay, reduced use of emergency rooms and reduced risk of mortality [20,140]. Dementia is a chronic, progressive disease that patients and their caregivers live with for several years. In order to meet the longitudinal biopsychosocial needs for those patients over that time, particularly in the context of co-morbidities, provision of primary care plays a key role. Primary care's inclusion in the center of the conceptual framework captures the importance of these services with regard to longitudinal care for patients given that dementia care services are primarily provided in the diagnosis year.

Primary Outcome: The final part of the framework suggests that the intensity and scope of primary care, and dementia-focused care will affect a critical aspect of a dementia patient's life: the number and type of transitions experienced. The number of transitions will be examined in more detail in 4.4.2, but briefly, transitions are defined as a physical relocation from one place to another that involves at least one night's stay. Such transitions generally involve moves between home and a variety of care facilities, or between care facilities such as respite care, hospital and LTC. A high number of transitions in seniors diagnosed with dementia is particularly challenging due to the stress of multiple unfamiliar environments. In the conceptual framework, this outcome is shaped by the dementia care and primary care clinical service use as well as by individual, physician and system factors. Good dementia care and primary care is expected to positively influence this outcome, resulting in fewer transitions.

2.8 Primary Outcome Measure: Transitions and Consequences

For the purposes of the research reported here, a transition is defined as a situation in which "an individual physically moves from one place to another and stays there for at least one night" [10]. With an expanding and changing healthcare system, almost everyone will experience at least one transition during his or her lifetime. For many seniors, these transitions occur at various critical points during their trajectory of care, often several times between different care settings. Age, gender and morbidity all affect the number and type of transition (this is particularly true during the last few years of life) [10,12]. Transitions between care settings pose a serious challenge to the continuity of care and safety of the patient.

Care in multiple settings is often provided by physicians who do not have an ongoing relationship with the patient and are therefore unaware of their complete clinical or medication history [156]. Despite advances in technology, adoption of an accessible, universal electronic database that spans across care settings is not yet in sight and physicians continue to reduce their scope of practice, working primarily in siloed, single settings [157,158]. This lack of continuity of care has led to evidence of medication errors and quality deficiencies which pose significant threats to patient safety [159].

A study examining patients discharged from hospitals found that half of adult patients experienced at least one error in medication continuity, diagnostic workup or test follow-up [160]. Other studies find evidence of high adverse event rates after discharge [14,161] with over half to 66% of events due to medication errors [161]. In another study examining 30-day post-hospital care patterns, between 12 and 25% of all care patterns were considered complicated and required re-admittance to higher intensity care settings three weeks after discharge [13]. For patients experiencing a transition from hospital to home, many are also unprepared for the challenges of self-care responsibilities.

2.8.1 Transitions for Seniors

For seniors in particular, changes in health status can mean frequent transitions between care settings. In the US, one in six nursing home residents are hospitalized in any six month period [162] and as many as 80% of elderly people have an acute care hospitalization just prior to their admission to a LTC facility [11,163,164]. Approximately 40% of seniors living in the community are hospitalized every year [165]. These hospitalizations can be precipitated by a variety of events including acute infections, acute episodes of chronic illness and adverse events such as falls [166].

Four system issues have been identified as particularly problematic in hospitalized seniors: poor communication, preventable declines in health status, inadequate discharge planning and major gaps in care during transfers to and from hospitals [167]. One study showed that greater than 60% of chronically ill older adults living in the community had medication errors while transitioning between hospital settings [14]; this is particularly problematic considering the high risk of polypharmacy in seniors [168,169]. Another study demonstrated increased mortality risk associated with transitions [15]. The most significant consequence of these transitions for seniors, however, is preventable hospital readmissions with as high as one fourth of all hospital readmissions of seniors believed to have been preventable [16].

2.8.2 Transitions for Seniors with Dementia

The challenges in medication, quality and continuity of care that affect the safety of patients are compounded in dementia patients if no one is able to provide a verbal history of their care or if they do not have a caregiver who can assist in their transitions

[12,35]. The stress of unfamiliar environments is also particularly disruptive for people with dementia for whom a stable environment is critical [11]. This can lead to additional behavioural disruptions that may not be properly managed, trigger further transitions and can lead to a preventable decline in health status in addition to the adverse outcomes already experienced by seniors in transition [15]. Indeed, individuals with dementia are significantly more likely to be hospitalized for all cause and ambulatory care-sensitive conditions than non-dementia individuals [12,170] and experience a higher number of transitions during the last two years of life [10].

Dementia is a chronic and progressive disease with increasing intensity and need for care over time. The clinical trajectories of these diseases have been well-documented and the care needs of these patients should be anticipated by primary care doctors. Guidelines for good dementia care stress the need for continuity and familiar environments which cannot be consistent with high numbers of transitions [10,22,26]. Family physicians are best positioned to support seniors to ensure effective care coordination. However, seniors often have limited contact with physicians, particularly once in a residential LTC facility [167,171], while physicians have continued to reduce their scope of care to working primarily in one setting which often excludes LTC [112].

There is good evidence for the benefits of continuity of care. Studies have demonstrated that good continuity of care is associated with fewer emergency room visits [172,173], fewer hospitalizations [172,174–176] and avoidable hospitalizations [38], better preventative care [177,178], better medication adherence, better physician recognition of medical problems [179], and greater patient satisfaction [179] and communication [20]. However, many of these studies have been conducted in adults and young children but not in elderly populations and particularly not in vulnerable elderly populations such as those with dementia [23].

In summary, dementia is a common condition with increasing prevalence and significant implications both for the person with dementia and for his / her caregiver(s). Good evidence exists for health care that can help with both the diagnosis and ongoing treatment of individuals with dementia. There is less existing evidence to help understand how well those guidelines and care practices are followed in the actual delivery of health care services, and what the implications might be for outcomes, most specifically transitions. This thesis is aimed at filling in some of these knowledge gaps.

CHAPTER 3 – A SYSTEMATIC REVIEW OF VARIATIONS IN DEMENTIA CARE PHYSICIAN PRACTICE PATTERNS[1, 2]

3.1 Introduction

In Canada, primary care physicians are gatekeepers who are usually the first point of contact for people with dementia [8]. Current guidelines for dementia care recommend that in addition to providing a proper diagnosis, physicians develop a care program for the patient and their caregiver(s), provide accurate information on the progression of the disease, make referrals to local resources, and offer appropriate counseling on the psycho-social impact of the disease [5–7,119]. Physicians therefore direct a wide range of clinical healthcare resources.

Studies on physician practice patterns indicate variation in physician methodologies and responses regarding dementia care processes [28,29]. There is a substantial body of literature on physician prescription patterns with regard to dementia [143,180–183] but in comparison, only a limited number of studies on other physician dementia care practice patterns. While pharmacological management is important, poor detection and general management means people with dementia may not receive appropriate psychosocial interventions, routine monitoring or the recommended multi-dimensional approach to dealing with increasing cognitive and functional challenges [117].

Best practice guidelines for dementia care have been established in the medical community for several decades. The use of best practice guidelines have been shown to

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[1] A version of chapter 2 has been published. Sivananthan SN, Puyat JH, McGrail KM. Variations in self-reported practice among physicians providing clinical care to individuals with dementia: a systematic review. Journal of American Geriatrics, 2013. 61:(8) 1277-1285.

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reduce variation and maintain, or even improve quality of care [30], however there is no existing comprehensive systematic review focused on physician practice patterns associated with the care of people with dementia. It is important therefore to determine to what extent actual practice, as reported in the literature, is consistent with guideline-recommended care. My objective in this systematic review is as follows:

Research Question 1: Based on the current literature, to what extent is actual practice consistent with guideline recommended care?

I hypothesize that there is wide variation in physician practice patterns with regard to provision of dementia care, particularly discretionary dementia care processes.

3.2 Systematic Review Methods

I used the Centre for Reviews and Dissemination's publication on guidance for undertaking reviews in health care to develop the structure of this systematic review, including the protocol and data extraction [184] (see Appendix A for study protocol). The method also meets the criteria outlined by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement for systematic reviews [185].

3.2.1 Search Strategy

A search strategy was developed in consultation with a research librarian. Only English language studies published as of March 1st, 2012 were included with no start date limitation. I was deliberately broad in my search strategy to ensure I captured all relevant studies. Eligible studies met all of the following criteria: 1) were experimental, quasi-experimental (pre-post studies, interrupted time-series) or observational (case control, cohort, cross-sectional) studies; 2) presented original empirical results; 3) presented results at a physician-level; 4) measured physician care provided to seniors 60 years or older diagnosed with dementia; 5) included senile dementia, Alzheimer's Disease or vascular dementia under the term "dementia" as either a primary or secondary diagnoses; 6) measured any clinical service/intervention or combination of clinical services/interventions detailed as appropriate for dementia care management by national and international guidelines; [5–7,119] and, 7) measured actual services provided (vignette-based studies measuring behavioural intentions were excluded). Studies focused exclusively on prescription patterns of AChIs, antipsychotics or psychotropic medications were excluded as this is a vast body of literature and requires a separate, specific review. Studies that assessed dementia care processes in specialist practice settings only were also excluded as the practice patterns and patient demographics in these settings are thought to be very different from that of general practices.

The databases searched were: Web of Knowledge, PubMed, Science Direct, MedLine, PsychINFO, EMBASE and Google Scholar. The search strategy was adapted to each database based on its thesaurus or Medical Subject Headings. An individual search with each of the search terms was also conducted to ensure that no relevant citations were missed. For Google Scholar, only a preliminary search was conducted for the first 500 results to source any key grey literature and determine whether all key citations were captured. References of key studies and all studies that met the inclusion criteria after the abstract review were also scanned. While peer-reviewed and grey literature was included in the original search, the final articles that met the inclusion criteria were all peer-reviewed.

3.2.2 Data Collection and Data Extraction

I conducted the literature search on April 3rd, 2012. Another reviewer (Joseph Puyat) and myself then conducted independent abstract and full-text reviews as outlined in the PRISMA group recommended flowchart (Figure 3.1) [186]. The two lists of eligible studies were compared at each round and disagreements resolved by discussion. Studies were not eliminated on quality due to the limited number of eligible studies that met the inclusion criteria.

For each eligible study, both reviewers independently extracted data. I developed the data extraction tool and it was tested on three studies prior to proceeding with the full data extraction. The following data items were obtained: study year; setting (nursing home or community); study location; associated health networks; study design; study purpose/research question; sample number; sample representativeness; validation of survey; physician specialty; patient population; physician characteristics; approach to screening; reports of diagnosis disclosure; memory test; imaging; blood work; medical prescriptions; non-pharmacological interventions; counselling; specialist referrals; community service referrals; and other. Studies that conducted any form of regression or statistical analysis were noted and their model covariates included.

I defined “dementia care processes” provided by physicians as diagnostic services (memory test, imaging, blood work), management (pharmacological and non-pharmacological interventions, counselling) and referrals (specialist referrals, community service referrals). I developed definitions for each of these in order to standardize the data for the studies that met the inclusion criteria. The definitions were grounded in consensus guidelines[5,6,119] (except for mass screening for which there are no specific recommendations) however, when studies diverged in their measurements of the dementia processes (additional tests, techniques and frequency), the additional test and lowest frequency were included in the definition. These are as follows:

Mass Screening – No guideline recommendations have yet been made regarding mass screening. Study measurement included questioning >21% of patients 65 years and older in the physician's practice about memory problems [153].

Disclosure – Guidelines recommend a physician discloses suspected diagnosis to a patient and also to a family member when possible as soon as it is known[4,5]

Diagnostic Services:

Diagnosis – The physician conducts a formal mental status or memory test to form an initial diagnosis and for staging of dementia. Several tests are recommended by guidelines including the Mini-Mental State Examination, Kokmen Short Test of Mental Status, 7-Minute Screen, Memory Impairment Screen, Montréal Cognitive Assessment, the DemTect, the General Practitioner Assessment of Cognition and the Behavioural Neurology Assessment Short Form [32,121]. Study measurements included other mental status test such as the Blessed information memory concentration test, short portable mental status questionnaire, Washington University SDAT screening battery, Iowa screening battery for mental decline, and Wechsler adult intelligence scale which were not guideline recommended but used as a measure for formal diagnosis by some of the studies [187].

Imaging – A computed tomography (CT) scan or magnetic resonance image (MRI) of the brain is conducted [5,32,121]

Blood work – Guideline laboratory tests routinely ordered to determine the underlying cause of dementia or for rule-out of other causes including a complete blood count, TSH, serum calcium, electrolytes, fasting glucose, vitamin B12 levels and folate levels [5,32]. Other laboratory tests measured by studies include chemical screening, sedimentation rate, test for metabolic disorder, urine analysis and heavy metal screening [188].

Management:

Intervention – All pharmaceutical interventions related to the treatment of dementia (Donepazil, Rivastigmine, Galantamine, Tacerine, and Memantine). Also includes prescriptions for behaviour and mood treatment such as antipsychotics, antidepressants and psychotropics. Non-pharmacological interventions such as changes in ADLs, environmental or communication changes were also included as interventions[5,32,121].

Counselling – Provide counselling to patients with dementia and family members regarding management and future planning. This includes financial planning, advanced directives, end-of-life planning, respite care/caregiver stress, driving risks, management of ADLs, a possible nursing home placement and general family counselling[4,5].

Referrals:

Community Service – Referral to community services who assist patients and caregivers to cope with dementia. Services include the Alzheimer's Association, a support group, an adult day centre, home health agency, respite care, area agency on aging, social workers and recreational therapy[4,5].

Specialist Referral – Referral to a Geriatrician, Neurologist, Psychiatrist, Geriatric Psychiatrist, Neuropsychologist or to a Memory Clinic for further management[4,5].

3.2.3 Data Analysis

The unadjusted proportion of physicians who reported use of each dementia care process was either extracted, when available, or calculated, if possible. In cases where double counting would occur because physicians report use of more than one technique within a process (e.g. the use of more than one memory test), the technique with the highest reported proportion was extracted.

3.3 Results

Through the initial search, 1,264 studies were identified. Of this, 1,222 studies were excluded through a title review. Some of the excluded studies were centered on caregiver practice patterns, others were qualitative studies, but the vast majority of excluded studies were focused on physician prescription patterns in relation to dementia care. For the full-text review, a kappa of 0.71 was reached indicating a formal inter-rater agreement close to complete agreement (kappa=1) [189] (Figure 3.1). After resolving differences in inclusion assessment through discussion and consensus, twelve primary quantitative research studies met the final inclusion criteria [9,69,153–155,187,188,190–

[194]. All the studies assessed actual services provided at a physician-level in patient populations 60 years and older. Fifty percent of the studies focused exclusively on primary care physicians encompassing general, internal and family medicine practitioners [9,69,154,188,190,194] (Table 3.1). The other fifty percent of studies included primary care physicians as well as specialists who were primarily geriatricians, as well as neurologists and psychiatrists [153,155,187,191,193,195]. All twelve studies used cross-sectional surveys, ten of which were either postal or web-based self-administered surveys [9,69,153,154,187,190,191,193–195] while the remaining two were interviewer administered semi-structured surveys [155,188]. Four of the twelve studies used validated survey instruments [9,192–194].

Figure 3.1 – Flowchart describing the approach used to identify all eligible studies

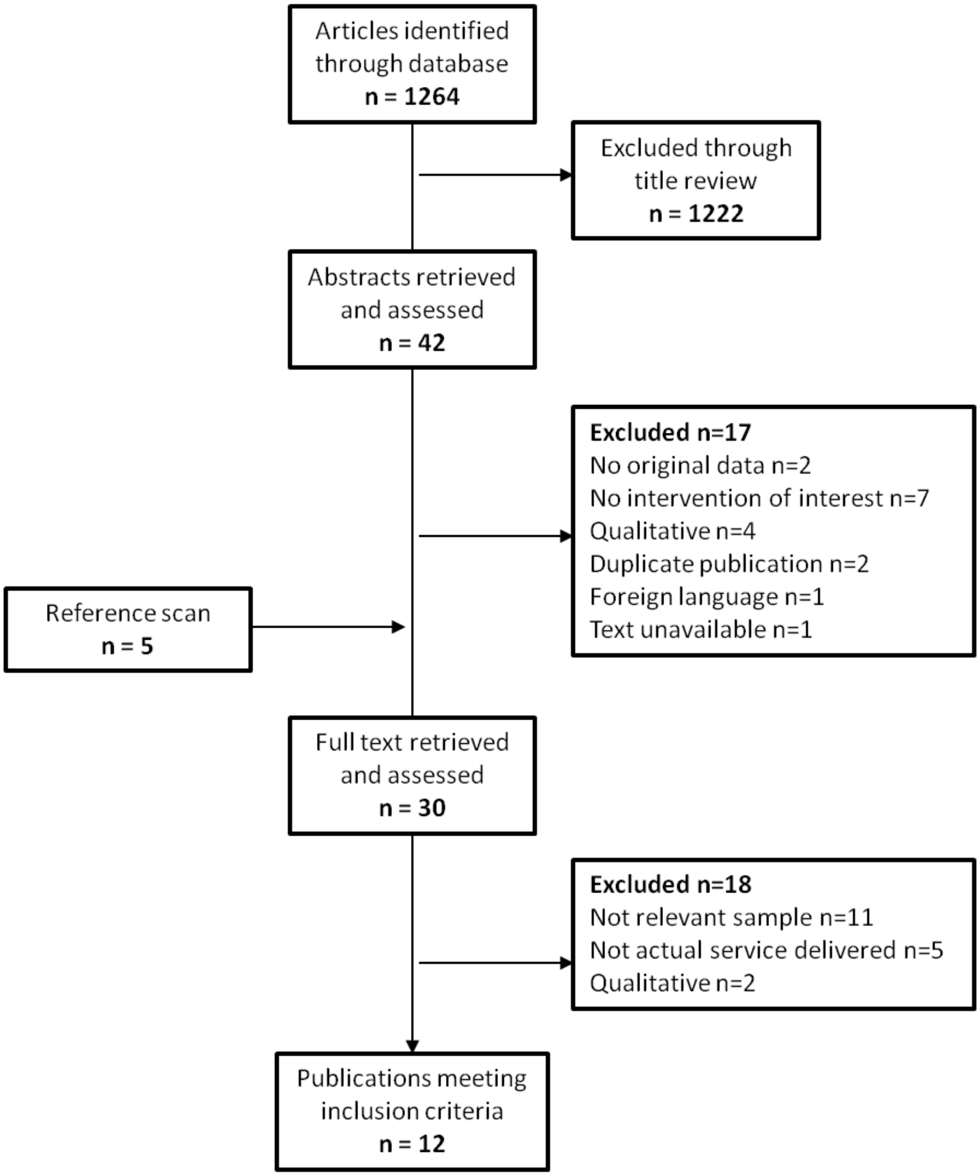


Table 3.1 - Characteristics of studies evaluating physician practice patterns in dementia care

Study	**Research Question**	**Country**	**Year**	**Sample** (response rate)	**Study Design** (validated instrument)	**Sampling Strategy** (representative sampling)	**Physicians speciality assessed**	**Setting**
Rubin	Quantitative data on state of PCPs diagnosis and treatment of dementia	USA	1987	50 (89%)	Interview survey; (N)	Rockford Medical Society; (Y)	Family, Internal	Community, Nursing Home
Somerfield	What are physicians' experience with dementia, services they provide and factors for variation	USA	1991	53 (48%)	Postal survey; (N)	Referrals to John Hopkins, dementia or cognitive neurological clinic; (N)	Family, Internal, Neurology, Psychiatry	Community
Glasser	What are practices of rural physicians in dementia care	USA	1993	102 (72%)	Interview survey; (N)	State directory, medical society records; (Y)	General, Family, Internal, Specialists	Community
Bisset	Can GPs care for dementia patients in community and their view of current resources	USA	1996	143 (41%)	Postal survey; (N)	Grampian state directory; (Y)	General	Community
Fortinsky	How connected are PCPs with community services for dementia care	USA	1998	255 (51%)	Postal survey; (N)	Academy of Medicine of Cleveland; (Y)	Family, Internal	Community, Nursing Home
Brown	How do PCPs engage in AD practice behaviour	USA	1998	403 (27%)	Postal survey; (Y)	American Medical Association; (Y)	General, Family, Internal	Community, Nursing Home

Study	Research Question	Country	Year	Sample (response rate)	Study Design (validated instrument)	Sampling Strategy (representative sampling)	**Physicians speciality assessed**	Setting
Cody	Have educational efforts affected PCPs dementia care	USA	2002	142 (16%)	Postal survey; (Y)	State directory, Annual Family practice board meeting; (N)	General	Community
Cavalieri	Do physicians give advanced care planning advice to patients with AD	USA	2002	63 (23%)	Postal survey; (N)	Kennedy Health System; (N)	General, Family, Internal, Geriatrics	Community
Fortinsky	Comparing dementia care practices of PCPs in two states	USA	2009	422 (27%)	Postal survey; (N)	State directory; (Y)	Family, Internal	Community
Robinson	What are the roles of generalists and specialists in dementia care in Europe	France, UK, Germany, Spain, Italy	2010	500	Postal survey; (Y)	Unknown; (Unknown)	General, Family, Internal, Specialists	Community
Baloch	Does specialty or geriatric training correlate with comfort in dementia care management	USA	2010	134 (25%)	Web-based survey; (N)	Health Texas Provider Network; (N)	Family, Internal, Geriatric	Community
Cohen-Mansfield	Comparing the approach of MDs, PhDs and NPs in dementia related behaviour	USA	2011	108	Web-based survey; (Y)	American Medical Directors' Association; (Y)	All medical practitioners	Nursing Home

There was one multi-jurisdictional study conducted across five countries in Europe [193]. The other eleven studies were conducted in the US, but only two of these used nationally representative samples [9,195](Table 3.1, Figure 3.2).

Figure 3.2 – Geographical locations of eligible studies from the USA

*excludes one study based in Europe

The sample sizes for the studies varied from 50 to 500 practicing physicians. Fifty percent of studies sampled from state directories [69,154,155,188,190,194], 17% used national directories [9,195], 25% sampled from local hospital networks [153,187,191] and one study was unknown [193]. Seven of the studies used representative sampling for the jurisdictions they were surveying [9,69,154,155,188,190,192] and one study did not report on its sampling strategy [193]. Ten of the studies reported response rates ranging from 16% to 89% [9,69,153–155,187,188,190,191,194], though five of those studies reported rates below 27% [9,153,154,191,194].

3.3.1 Variations in Dementia Care Processes

The scope of dementia care processes assessed by each study varied considerably. The nine care processes were categorized based on current North American consensus guidelines [6,7]. While ten of the study research questions identified dementia care practice as the primary interest [9,153–155,187,188,190,193–195], only four assessed the full scope of care processes recommended by guidelines (at least one care process within each of diagnostic, management and referral) [9,153,155,188], three of which were older studies (published prior to 2000) (Table 3.2). Most of these studies had low response rates or fairly small sample sizes. All nine dementia care processes had wide variations in the proportion of physicians who conducted each process (Table 3.2).

Mass screening for dementia is still highly debated so unsurprisingly, only two studies assessed the proportion of physicians who screen regularly [153,190]. However the proportion of physicians who screen for dementia appeared to be high at 68% and 78%. Disclosure to a patient and family member had the least variation with consistently high proportions of physicians (82% and 100%) reporting disclosure to both the patient and family member (versus to only the patient or non-disclosure until diagnosis is certain) in the two studies that assessed this process [153,194].

Wide variation was seen in the formal memory testing process. The studies reported higher proportions of physicians who assess mental status, but these were not formal or written memory tests [9,153,155,187,188,190,194,195]. Of the eight studies that assessed formal memory testing, six reported that the proportions of physicians who conducted formal memory tests were less than 60% [9,155,187,188,190,195](Table 3.2). Indeed, three of these studies reported proportions below 15% [155,188,195]. The lowest proportion of physicians using a formal assessment tool (4%) was reported in 2012 [195]. Similarly, the intervention process, which encompassed a wide range of pharmaceutical medications both for dementia and consequent behavioural problems,

Table 3.2 - Variations in physicians practice patterns measured by proportions for each dementia care process

Study	Guideline Recommended Dementia Care Processes						
	Diagnostic			Management		Referral	
	Memory test	Imaging	Blood work	Intervention	Counselling	Community service	Specialist referral
Rubin (1987); n=50	12%	80%	68%	48%	84%	26%	12%
Somerfield (1991); n=53	57%						58%
Glasser (1993); n=102	<10%	72%*	75%	33%	44%		18%
Bisset (1996); n=143	54%						70%
Fortinsky (1998)†; n=255						83%*	
Brown (1998); n=403	40%	33%		36%*		47%*	21%
Cody (2002); n=142	96%				83%*		
Cavalieri (2002)†; n=63					81%*	53%*	
Fortinsky (2009); n=422				90%*		77%*	
Robinson (2010); n=500				49%	39%	36%*	64%
Baloch (2010); n=134	84%	34%*	94%*		91%*		81%
Cohen-Mansfield (2011); n=108	4%			91%			58%

☐ No text, process not assessed
▨ 0 – 20%
▨ 21 – 40%
▨ 41 – 60%
▨ 61 – 80%
▨ 81 – 90%

*Indicates highest possible value for each process (e.g. Baloch et al., examined two imaging techniques, computer tomography and magnetic resonance imaging. Some physicians use both techniques, so the technique with the highest proportion, computer tomography, was taken) reported proportions ranging from 33% to 91% [9,154,155,188,193,195]. Four of the six studies reported proportions less than 50% [9,155,188,193], which were primarily older studies and may be a reflection of the change in the available pharmacological therapies.

Brain imaging and blood work processes are both recommended by consensus guidelines to aid in diagnosis. The former recommendation applies only in some circumstances and therefore is not a universal guideline. Imaging ranged from 33% to 80% in the proportion of physicians reported using it as a diagnostic tool [9,153,155,188] (Table 3.2). Physicians primarily made use of CT or MRI. All three studies that assessed the blood work process reported consistently high proportions of physician utilization at almost 75% and above [153,155,188] (Table 3.2).

The proportion of physicians who reported providing some form of counselling [153,155,188,191,193,194] was also consistently high with only two of six studies reporting less than 80% [155,193]. Community service referrals on the other hand had a 3-fold variation (26% to 83%) [9,69,154,188,191,193] with four of the studies reporting proportions below ~50% [9,188,191,193], while specialist referral had almost a 7-fold variation (12% to 81%) [9,153,155,187,188,190,193,195] with newer studies (published after 2000) reporting higher proportions.

3.4 Discussion

Existing literature shows wide variation in the proportion of physicians who report conducting the dementia care processes recommended by guidelines. This was of particular note for the formal memory testing process which had a 24-fold difference in the proportion of physicians who reported conducting a formal test. Several factors could have contributed to these care process variations including geography, resource constraints, patient demographics and changes in both recommended practice and approaches to practice over time [148,196]. The high heterogeneity of the included studies prevented any aggregate of results or calculation of adjusted proportions. The study protocol for this review used liberal definitions for each care process. This would tend to push up the proportions reported here, and thus decrease variation. Given the range in proportions reported, the observed variation in physician practice patterns is, if anything, an understatement of ranges in actual patterns of practice.

Only four of the ten studies that identified dementia care as a primary research objective included measures of the full scope of dementia care processes as identified by guidelines. Given the geographic homogeneity of the studies (mainly US based) and the identified research objective for each study, it was expected that the scope of dementia care would be relatively synonymous across studies. The publication date of the studies seems an unlikely explanation as almost all the studies that did measure the full scope of dementia care were older studies (published prior to 2000), indicating that the studies appear to be getting less comprehensive over time.

The range of publication dates should be taken into consideration when examining the variation within each dementia care process, due to the shifting and updating of guidelines and understanding of dementia over the years. Guideline recommended dementia care was first developed in 1984 in the US, prior to the oldest study in this review [128]. However, it contained no specific recommendations regarding the management of dementia with an emphasis placed instead on correctly diagnosing dementia. These guidelines were only recently updated [6], however, other evidence-based best practice guidelines published in the interim provided details on the management of dementia, focusing on long-term counselling and appropriate referrals [120]. The more recently published studies reflect this shift in dementia care understanding with higher proportions of physicians reporting counselling, community service and specialist referrals while the older studies were reporting on practice patterns in the absence of best practice guides.

The widest variation for any care process was noted in the formal memory testing process (4 - 96%) which is the most mature of all the dementia care processes, having guidelines and a large number of formally validated tools available for over three decades [188]. It was surprising then that this was not the primary process used by physicians to identify dementia. It may be that physicians are asking questions about memory during the history-taking process, but formal tests are still necessary for a diagnosis [188].

Similarly, the specialist referral process had relatively wide variations in physician proportions, but with more of a trend toward higher specialist referrals in newer studies. This may be reflecting the shift in physician scope of practice over time [111].

There is some contextual information (Table 3.1) that can aid in the interpretation of the wide variation noted in the dementia care process. For example, Somerfield et al. [187] conducted their survey on physicians who had made at least one referral to a dementia or neurology clinic. These physicians are assumed to be more knowledgeable about dementia and may not be a representative sample, which could have contributed to the higher rate of specialist referral. Glasser et al. [155] conducted interviews on primary care physicians practicing in rural settings which contextualizes the lower specialist referral rate. Finally, Cohen-Mansfield et al. [192] primarily focused on physicians' approach to dementia-associated behavioural issues in nursing homes therefore those physicians who were surveyed are more likely to provide an intervention which may explain the higher intervention rate. Given these differences in the available studies that met the inclusion criteria, the general lower quality of existing studies and the low number of studies, I am limited in my ability to draw firm conclusions about the extent of the variation in the dementia care processes measured.

3.4.1 Limitations

There are some other limitations to this analysis. All the studies that met the inclusion criteria were self-reported cross-sectional surveys with varying sampling strategies, primarily small samples sizes, and low response rates which may be associated with non-response bias and give rise to results that are less likely to represent the target population. None contained data extracted from medical records or administrative data, which would be a better indication of actual services provided. Due to the limited number of studies on physician practice patterns in dementia care, I made no further exclusionary decisions on the quality of the studies, which may have contributed to the variation noted and influenced the quality of the results. Several physician specialties were included in the practice pattern assessment but differences among these specialities were not described as almost all the studies pooled specialists and general physicians in their assessments and of those that conducted regression analysis to determine the effect of speciality on the dementia care processes assessed, only one study [153] noted a difference. Similarly, several studies did not describe what was considered an intervention in their study measure process, therefore I was unable to differentiate whether these were pharmaceutical or non-pharmaceutical interventions and chose to pool the results.

Self-reported results only demonstrate immediate recall and are prone to recall bias. However, since self-reported measures are susceptible to social desirability response bias, participants often over-estimate their answers, yielding higher than actual proportions [197]. The wide variation in each dementia care process that still persists suggests that this bias is not a serious limitation. I was also unable to adjust for the heterogeneity of the studies and only extracted unadjusted proportions. The use of English only studies and primarily databases with peer-reviewed studies introduces the possibility of language and publication bias to this review. Finally, while the MeSH headings used in the search strategy appeared to index studies appropriately, they may not have been consistently used therefore there is some likelihood of missed studies. My search terms were broad precisely to mitigate this possibility.

3.5 Conclusion

There are wide variations, as reported in the literature, in practice among physicians providing clinical care to individuals with dementia despite the availability and dissemination of well-established best practice guidelines. These results are based on a systematic review, but available studies that met the inclusion criteria all have significant limitations as they are cross-sectional, self-reported surveys with often low response rates, sample sizes and of varying research contexts.

As a counter to some of these limitations, I conducted an analysis of the receipt of dementia care at a patient level, utilizing population-based health care services utilization data (administrative data) in BC, described in detail in Chapter 5. Using these comprehensive data at a patient level allows me to a) conduct population level analysis that is not limited by sample size, response rates and is generalizable to the entire BC population b) examine patient characteristics that will allow me to separate out warranted and unwarranted variation and c) potential identify demographic characteristics associated with variation that are modifiable.

Before moving to that study, the next chapter will first outline the analytical methods used in this thesis, followed by the results of my analysis.

CHAPTER 4 – METHODOLOGY

4.1 The Health Services Research Lens

Populations grow and age and prices rise, which means healthcare services will continue to need improvement in quality and efficiency to help control expenditure growth. The magnitude and complexity of any task related to this within healthcare services is daunting. Healthcare delivery encompasses several occupational groups that work with and sometimes compete with each other; standardized processes are difficult because of the uniqueness of each patient and the different types of coordination required for high quality care Unlike other industries, doctors have considerable autonomy in their decision-making and direct most of the resources used; and the complexity of healthcare services is constantly evolving [198]. There are other pressures as well, including several stakeholders' influences such as government attempts at financial control, local opinion, healthcare staff organizations, and the medical product industry with its commercial stake [198]. These are the issues that the field of Health Service Research (HSR) aims to address.

Health services research is a term used to encompass a wide variety of analytical (qualitative and quantitative) methods drawing on several disciplines including epidemiology, economics, geography, political science, statistics and sociology, while also drawing on the clinical and biological sciences. HSR's overarching goal is to "provide unbiased, scientific evidence to influence health services policy at all levels so as to improve the health of the public" [198]. Unlike a clinical lens, HSR often adopts a population perspective to help answer more universal questions that support the healthcare decision-making process. Health services research uses a variety of sources of information, including surveys, interviews, focus groups, randomized trials, and administrative data (collected primarily for other, usually administrative, purposes). Administrative datasets within this sphere were first utilized in the early 1970's [199], but are now a commonly accepted source of research data [200].

4.1.1 Use of Administrative Databases

Administrative databases used for research purposes can be broadly defined as containing pre-existing data that have been collected for different administrative or operational purposes that are usually not research driven. Unlike primary data that are collected specifically for research uses, the use of these data for research purposes is a "secondary use". There are a number of operational purposes underlying the creation of these data sources, including registration or enrolment (e.g. for insurance coverage purposes), payment (for the services of a health care professional, or for a prescription drug or other health care product), or clinical care. The key advantage of using administrative sources of data for research purposes is that they can provide already available population-level information, thereby circumventing the cost and practical barriers to creating purpose-built population-level data resources, and addressing limitations inherently associated with studies using other sources of data such as sampling bias and limited sample sizes [201].

The majority of administrative databases used in health services research are related to the delivery of services, so while covering an entire population, they can also provide a view of people as they move through various components of a healthcare system. This is particularly true in Canada, where universal coverage for some key components of health care services creates population-based data resources as a by-product of system operations.

Administrative data resources are not without challenges when it comes to research applications. Availability, inclusions, frequency and quality can vary, since these will all be affected by the primary purposes for which the data were assembled. Therefore it is necessary to understand the details associated with how the data were collected in order to be able to use them effectively for research purposes. For the purposes of HSR, data from different sources can often be 'linked' in order to more fully explore a research question, while preserving the integrity and privacy of individuals and their information.

4.2 Administrative Data Sources

Individual patient-level, longitudinal data on BC's four million residents is available through Population Data BC (referred to as PopData BC henceforth). Data on individuals and on caregiver-patient transactions are collected by the BC Ministry of Health and used to create comprehensive, population-based health care data sets suitable for research uses. The data provided to researchers contain unique study-specific codes to prevent personal identification of either patients or physicians, while still allowing linkages within and across files, to (approved) external files, and over time [202]. These data files include encounter, enrolment, clinical data and registries.

For this thesis, data were drawn from five internal databases available through PopData BC and two external databases (all described below) which were linked to the internal databases by programmers at PopData BC: 1) the Consolidation File; 2) the

Medical Services Plan (MSP) File 3); the Home and Community Care (HCC) File; 4) the Hospital Separation File; 5) the Vital Statistics Deaths File; 6) the PharmaNet File; and 7) the Practitioner File from the College of Physicians and Surgeons of BC. Data extracted from these linked databases were used to develop the key variables and measures required for my analysis as outlined in Table 4.1.

Table 4.1 - Key variables and data sources for analysis

Key Variables	Data Source
Patient demographics and geography	Consolidation File
Dementia diagnosis, diagnosis of co-morbidities, health status	MSP File, Hospital Separation File
Clinical service use (dementia care services, longitudinal primary care services)	MSP File, Hospital Separation File
Home care and/or community service use patterns	HCC File
Prescription patterns (acetyl-cholinesterase inhibitor and/or antipsychotic)	PharmaNet
Death and cause of death	Vital Statistics Death File
Length of stay in the community prior to moving to LTC	MSP File, HCC File
Hospitalizations	Hospital Separation File
Transitions	Hospital Separation File, HCC File
Physician demographics and geography	Practitioner File

In order to access these databases and publish results using de-identified data extracted from them, Data Access Requests were filed through PopData BC, and the proposed project was reviewed and approved by all relevant Data Stewarts. This data access request process includes providing proof of ethics review, which was provided by the University of British Columbia Office of Research Services Behavioural Research

Ethics Board, and proof of peer review, which was provided by the School of Population and Public Health Thesis Screening Panel and the student's supervisory committee.

4.2.1 The Consolidation File

The Consolidation file [203] is the central demographics file maintained by PopData BC. It is a registry of all residents who meet eligibility criteria for BC health care insurance. It has been augmented by PopData BC to include cases where individuals receive services even in the absence of a valid registration. This file includes demographic information for each individual regardless of whether the individual uses healthcare services. The file is considered as complete a roster of individuals in BC as possible, though there are known limitations including incomplete coverage of First Nations populations and federal employees. For this thesis, demographic variables used included year of birth, sex, and geographic location (health authority and health service delivery area) and neighbourhood income quintiles. Neighbourhood income quintile is a measure of the adjusted income per person equivalent, derived from postal codes of patient's residence and was used to develop a socioeconomic status (SES) indicator variable since SES plays a key role in health service use [204].

The consolidation file also has data on what are termed 'economic families', which provides an indication of household composition and summarized by the 'Shared MSP id variable. In BC, premiums are levied for MSP coverage. The amount of the premium is based on family size and income. The premium may be paid by employers (as a benefit of employment), through public subsidy as in the case of people on income assistance, or by individuals themselves. Lower income families are eligible for either partial or full subsidies, with the level of subsidy determined by the previous year’s family income.

The administrative implication of this premium system is that an economic family is given one MSP contract number while each unique individual receives a Personal Health Number. The combination makes it possible to determine the nature of the economic family to which each person belongs[205]. For the purposes of this thesis, if a person diagnosed with dementia belonged to an economic family of more than one person, this was used as a proxy indicator of the existence of a potential informal caregiver. This process is incomplete, in that it cannot be used to identify individuals living with adult children who would have a separate MSP contract number. That is, while older adults and their adult children may share the same physical location, they do not constitute an economic family for the purposes of defining MSP contract holders. In short, there is no way (using these data) to determine if a person has an informal (family or non-family) caregiver who does not live with them or who lives with them but has a different MSP contract.

4.2.2 The Medical Services Plan File

The MSP file [206] contains payment information for all care provided by physicians to BC residents where the physicians are paid by the province on a fee-for-service basis. The data contained therein describe services used, and each service record includes a patient diagnostic code (using ICD version 9), which has been validated for research uses of this genre)[207]. The service provision descriptors are fee codes -- five-digit codes which indicate the insured service for which the practitioner was paid. These fee codes can be aggregated into service code groupings. Service codes are two-digit codes that indicate the type of service rendered by a practitioner, such as an office visit or a home visit. Fee item codes can be retired, new fee items can be added, and the amount paid associated with a fee item can change over time. Specific fee items used in this thesis were cross-checked for their use and definition over the entire study period. Each record in the MSP fee-for-service payment file also includes the date of each visit, the total amount paid, a unique, study-specific physician identification number and the physician specialty code. Specific fee item codes and the dates of visits were used to create individual-level measures to assess if guideline-consistent dementia care and longitudinal primary care had been provided.

It should be noted that MSP data do not include information on the use of services provided by physicians paid by non-fee-for-service methods, that is, physicians reimbursed through alternative payment arrangements (e.g. paid by salary or for a specified block of time). These alternative payment arrangements have traditionally represented less than 10 percent of total payments to physicians, but their relative importance has been rising in recent years [208], and varies by physician specialty and by region (alternative payment arrangements are more common in rural and remote areas of the province and among specialities such as psychiatry). This information gap means that the analyses reported here are inevitably based on under-counts of incident dementia and use of services for dementia by individuals who receive services from these alternative payment providers.

4.2.3 The Home and Community Care File

Information on eligibility assessments and use of publicly-funded home care, home support, assisted living, LTC services and adult daycare services is contained in the Home and Community Care (HCC) file [72,209]. All residents who receive an assessment, regardless of whether they are approved for care, are included in the file. The data for the HCC file are derived from three other files: 1) the LTC advice file 2) the direct care advice file and 3) the home support claims file. Each of these files contains detailed information on the type of service (for example, LTC service, home nursing, occupational therapy, physical therapy, community rehabilitation therapy, adult day programs, and home support), and amount of service and subsequent transactions which are tracked as service events for the period of time that the client receives care. A client who receives several services throughout the course of care will have multiple records indicating the different services and intensity of care received. Referrals for assessments for HCC do not need to come from a physician, but can also come from hospitals, social workers or the families (or patients) themselves, though the source of the referral is not included in the HCC file. The HCC file also notably only has information on publicly-funded care and therefore does not capture any service information on privately-funded care or care provided by voluntary agencies. Individuals may choose to purchase care privately because their assessment deems them ineligible for public care, as a supplement to publicly funded care, or as a substitute for that care.

4.2.4 The Hospital Separations File

The Hospital Separation file, also sometimes referred to as the Discharge Abstract Database, records all inpatient and day surgery separations (discharges or deaths) from acute care hospitals [210]. The file includes information on BC residents hospitalized in other jurisdictions. The data in the file are extremely detailed and include information on the date of admission and separation, the level of care received (differentiates day surgery, acute, and rehabilitation hospitalization), diagnoses, procedures, interventions and the most responsible physician during each stay. Visits to emergency rooms that result in an inpatient admission are noted; however, other visits to and services received while in the emergency room are not included. Prior to the 2001/2002 fiscal year, hospitals in BC used ICD9 codes. Therefore both ICD9 and ICD10 codes are used in this thesis.

4.2.5 The Vital Statistics Deaths File

The Vital Statistics Deaths file [211] is a record of all deaths in BC, including month, year of death, place of death and underlying cause. It excludes all deaths of BC residents outside of the province (death of non-BC residents that occur in BC are recorded in this file but for the purposes of my thesis can be excluded based on previous healthcare utilization). These records were used to determine if a person in the cohort died prior to the end of the study period, in which case the records of that individual would be right censored in any time-to-event analysis. The cause of death, while provided, was not used for validation of death due to dementia as most people with dementia die due to other causes that are exacerbated by dementia. Dementia is infrequently recorded as a cause of death, though this practice is starting to change [212]. In any case, the cause of death was not needed for the purposes of identifying incident cases of dementia.

4.2.6 PharmaNet

PharmaNet [213] is an online, real-time data system external to PopDataBC which records all prescriptions and medical supplies dispensed in BC [214]. It includes information on prescription drugs dispensed by community pharmacies in BC, through LTC settings, emergency departments and hospital outpatient pharmacies dispensing medications for patients to use at home. Exclusions are over-the-counter medications, cancer medications dispensed by cancer agencies/centers, antiretroviral medications dispensed by HIV centers, and medications dispensed while in hospital. Since it is housed at the BC Ministry of Health, it is considered an external database from PopData BC's repository. The PharmaNet database includes information on all dispensed prescriptions regardless of who pays. PharmaNet records contain detailed information on patient demographics, the prescribing physician (including practitioner type and speciality), the drug information number, its generic name, drug strength, its therapeutic class, the date and quantity of medication dispensed, the number of days of supply and a flag for special authority drugs which is pertinent for AChIs covered under the Alzheimer's Disease Therapy Initiative program mentioned previously. Unfortunately the database does not contain any information on whether drugs dispensed are actually ingested (i.e. there is no way to adjust for non-compliance).

The drugs of interest for this thesis, namely any AChIs, the NMDA-type glutamate receptor inhibitor and antipsychotics, were identified through the Anatomical

Therapeutic Chemical (ATC) classification system which classifies drugs based on the organ they act on [215] and their chemical subgroup (the 5th level of the classification). This allowed identification of broad classes of medications used to treat dementia. Pharmanet identifies drugs via drug identification numbers (DINs) which are 8-digit numbers assigned by a computer system to each drug that has been approved for use in Canada [216]. Therefore, I developed a cross-walk to map DINs into appropriate ATC groups for the medications of interest (Appendix Table B.1).

4.2.7 The College of Physicians & Surgeons of BC File

The College of Physicians & Surgeons of BC file is the second external data file used for this thesis. It contains information collected by the registering and licensing body for physicians in BC; all registered and practicing physicians in the province of BC are included. The records from the Registry file include information on physician age, sex, year of graduation, place of training (Canada, US, Europe, Africa, Asia), specialty and membership status code (indicating whether the physician is currently practicing). Physician characteristics were used to control for practice style and its possible contributions to the trajectories of care experienced by patients.

4.3 Study Design

This thesis was divided into four major research objectives:

1) Conduct a critical assessment examining the existing research literature on actual physician practice patterns associated with the care of people with dementia and to what extent those practice patterns are consistent with published guidelines

2) Examine population-based variations in receipt of guideline-consistent dementia care and patient factors that are associated with that care

3) Examine transitions experienced longitudinally to establish patterns that can help identify points of care when transitions are highest and the factors that contribute to those transitions

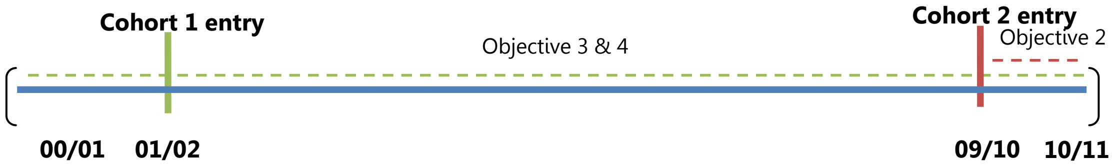
4) Assess the association between receipt of guideline-consistent dementia care and/or high quality primary care and the number of transitions experienced by individuals with dementia

The broad approach uses administrative data with multivariate modelling. The model selection for each objective is described in more detail in Section 4.4.3.

4.3.1 Identification of Study Cohort

For research objective 2, I used a combination of registry and utilization data (described in detail in section 4.2 above). A cohort of seniors 69+ year olds with an incident diagnosis of dementia in 2009/10 (described as cohort 2 in Figure 4.1) was identified. Incidence was identified using a ten-year wash-in period (dating back to 1999/2000) during which no other diagnoses of dementia should have occurred (described in more detail below). Since guidelines for dementia care focus primarily on the measures required for a diagnosis, this study design allowed me to use the incidence of dementia diagnosis to define the cohort and the period during which guideline-consistent care is expected.

Figure 4.1 – Historical cohort study design



For research objectives 3 and 4, a longitudinal historical cohort methodology was developed using registry and administrative data. A cohort of individuals 65+ years old with an incident diagnosis of dementia in 2001/02 was identified and followed forward (to 2010/11) and backward (one year pre-diagnosis, to 2000/01). This is shown as cohort 1 in Figure 4.1. In this case incidence was identified using a two-year wash-in period (dating back to 1998/99) during which no other diagnoses of dementia should have occurred (described in more detail below).

Developing decision rules for defining the cohort was of critical importance to this work. In any given year, there are approximately 500,000 seniors living in BC. Of these, ~15% can be expected to develop dementia [217]. Onset will occur at different times, in different ways, and will be detected at different points in a life trajectory. The inclusion criteria used here for the two (2001/02 and 2009/10 incident) cohorts were as follows:

- All patients over the age of 65 in the year 2001/02 and over the age of 69 in the year 2009/10
- Registered as BC residents for the entire study period
- Newly diagnosed with dementia in 2009/10 (objective 2) or 2001/02 (objectives 3 & 4)

The process of identifying incident cases is always dependent on available information sources. In this case I interpreted "newly diagnosed with dementia" to mean that record including a diagnosis associated with dementia as classified through the International Classification of Diseases (ICD) could be found in the Medical Service Plan data (ICD version 9 code) and the Hospital Separation data (ICD version 9 or 10 code). The specific codes are outlined in Tables 2.1 and 2.2. ICD-9 diagnosis codes for senile dementia, vascular dementia, Alzheimer's Disease and senility (290.xx, 294.9x, 294.1x, 331.xx excluding 331.83 for Mild Cognitive Impairment, 797.xx), and/or ICD-10 diagnosis codes (F00, F01, F02, F03, G30) [10,62,144] were used. Incident diagnosis was defined in a way consistent with prior literature, as patients who had a minimum of two physician diagnoses and/or one hospital diagnosis associated with dementia over a two-year period [218]. This diagnosis requirement was used to increase specificity of identifying confirmed cases of dementia while reducing rule-out diagnoses. [219]. Administrative data have been demonstrated to be quite valid for the purposes of identifying individuals with chronic conditions, including dementia [220].

Often, cases of dementia can remain undetected for years. For the purposes of this thesis, it was important to examine incident cases as identified in the health care system because the focus is on appropriate dementia management, which is most significant during the first year after diagnosis [221] and also because this study aims to describe the longitudinal primary care services experience of dementia patients, which begins at the point of diagnosis. A wash-in period of two years (for cohort 1) or eleven years (for cohort 2) was used in order to capture true incident cases of dementia. In other words, individuals had to meet the case definition as described *and* have no dementia diagnoses in their medical or hospital records in the prior two or eleven years in order to be included in the final cohorts. Cohort 1 was followed for a maximum of ten years from the point of entry (or until death) and cohort 2 was followed for one year from the point of entry.

4.4 Construction of Longitudinal Files

In any given year, each resident of B.C. can generate anywhere from zero to many health care transaction records, which can appear in multiple different data files. The data used here are taken from the seven files described above, covering a twelve year period (from 1998/99 to 2010/11) for the entire population of BC aged 65+ in 2004/05. The first step was to create an analytic record for each patient for each year of the study period. For cohort 1, these records were from 1998/99 until 2010/11 or death (whichever came first) including the two-year wash-in period. For cohort 2, the records were from 1999/2000 to 2010/11, including the eleven-year wash-in period. A unique study-specific patient id was used to link patient information across data files and years. Annual fiscal year data files were produced containing comprehensive analytic[3] and service use variables (described in Section 4.4.1 below) for each person. These annual files were then merged to create two data files. The first data file contained information on cohort 1, individuals who received an incident diagnosis of dementia in 2009/10, and was used to assess receipt of guideline-consistent dementia care in the year after diagnosis, addressing research objective 2. The second file was a longitudinal data file for cohort 2, created to trace individuals who entered the cohort (i.e. received an

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[3] Analytic variables in this case are the independent variables used to describe patient, physician and system characteristics

incident diagnosis of dementia) in 2001/02 and assess their healthcare transitions backward and forward over time to address research objectives 3 and 4.

4.4.1 Analytic and Service Variables

Table 4.2 below lists the annual analytic, service and outcome variables defined for each individual in the cohort, classified by the characteristics identified and contextualized in the conceptual framework used to guide the study in Chapter 2, Section 2.7.

Table 4.2 – Detail of variables measuring characteristics in conceptual framework

Characteristic	Description
Individual characteristics	Age, sex, income category (SES), health status (number of major ADGs or comorbidity), responsive behaviour symptoms, caregiver status proxy (objective 3 & 4)
Physician characteristics	Age, sex, speciality, practice years, # of patients 65+, # of patients with dementia
System characteristics	Health authority of residence or practice
Dementia Care	Imaging, laboratory work, pharmaceutical prescriptions, in-office examination, counselling, specialist referral (all as defined in Chapter 4), home care assessment
Primary Care	First contact (hospital or LTC visits from physician providing plurality of care), continuity (proportion of all visits with physician providing plurality of care), coordination & referral (referrals for imaging & lab tests originating from physician providing plurality of care)

The covariates at the individual-level were divided into five categories: Individual (or patient) descriptor variables, physician descriptor variables, system variables, dementia care service use variables and longitudinal primary care service use variables (Table 4.2). Each of these variables is described in further detail in Table 4.3 including a definition of how they were constructed (if that is the case). Each subsequent Chapter also describes their use in the respective Method sections. All variables were measured annually for the duration of the study period (from 1998/99 to 2010/11) and for both cohorts (except the Primary Care variables which were only measured for Cohort 1).

Individual descriptor variables: These are variables related to care use and outcomes of care. Of these descriptor variables, income category, health status, behavioural symptoms and the informal caregiver status proxy variable require further explanation. Income category is provided in the consolidated file and is derived from the neighbourhood income quintile data. It is used as a proxy indicator of SES, which plays a key role in health service use [204]. Health status is measured in two ways, by the number of multiple chronic conditions each individual has (used for objective 2) or by the number of major aggregated diagnostic groups (ADGs) (used for objective 3 and 4) and described in detail in Section 4.4.1.1 below. The behavioural symptoms variable is derived from two variables indicating receipt of prescriptions of antipsychotics or benzodiazepines. Individuals with dementia who also have behavioural symptoms often have very different use of the healthcare system which needs to be accounted for. Finally, the informal caregiver status proxy variable was used for objective 3 and 4 and was derived from the shared MSP id variable in the Consolidated file. The shared MSP id indicates all family members currently enrolled in the MSP who belong to an 'economic family' and share a household (Described in detail in Section 4.2.1). If a person with dementia belongs to an economic family, my assumption is that any family member(s) living in their household will likely function as a caregiver. Sensitivity analysis measuring this against the caregiver status and marital status variables (more definite measures of having a caregiver) from the HCC data indicated good concordance. The former is used in analyses because the latter are available only for the subset of the population who receive home and community care services.

Physician variables: These were previously described in Chapter 2, Section 2.7, and identified as variables describing physician practice patterns controlled for in Objectives 3 and 4.

System variables: The health authority variable identifies the geographic location in which the patient resides and most likely receives care. Based on the health authority it is possible to determine further descriptive characteristics of that system. There are five geographic health authorities in BC. Three of these, Fraser, Vancouver Coastal and Vancouver Island, contain major urban centres and a higher supply of specialists/family physicians. The Northern and Interior health authorities are considered more rural health authorities because they lack major urban centres and have a lower supply of specialist/family physicians. The Fraser health authority has the largest population of the five, but is geographically the smallest. It is also the most urbanized. The Vancouver coastal health authority includes three major population areas, an urban core (Vancouver, Richmond and the North Shore), a moderately urban area (Howe Sound, Powell River and the Sunshine coast) and a more sparsely populated area (Bella Coola and Central Coast). Its population pyramid has a significant bulge of 20-40 year olds compared to the overall population due primarily to the city of Vancouver. Vancouver Island is less populated and is home to a high number of retirees, reflected in its population pyramid, who reside in the urban areas of Greater Victoria and Nanaimo. The Interior health authority encompasses almost a quarter of BC's land mass with a much lower population density and with a small urban centre. Its population includes a larger proportion of younger children and older adults compared to BC overall. Lastly, the Northern is the largest geographic area but is the smallest health authority by population size. It is the least urbanized and has a smaller proportion of older adults and larger proportion of younger children.

Dementia Care variables: The dementia care service use variables were developed based on best practice guidelines for dementia care published by the BC Ministry of Health and the National Canadian Consensus Conference [7,122] and described in Chapter 4. These were categorized into six categories: recommended laboratory testing (blood work), imaging, physical examination, prescriptions, counselling and referral. I was unable to measure provision of memory tests, non-pharmacological interventions or community service referrals as there was no information on these in the files to which I had access. The imaging category only includes head CT as information on MRI was not available in data files to which I had access. The dementia care service use variables were measured for the year of the first dementia diagnosis and the following year in keeping with guidelines that indicate these services should be provided during the period immediately following initial diagnosis.

Primary Care variables: The primary care service variables were measured annually for the year of diagnosis. Three main characteristics were defined as predictors of high quality primary care, these were: access, long-term person-focused care and coordination of care (described in more detail in Chapter 7 and summarized in Table 7.1). First access was measured in several ways including: the number of settings care was provided, receiving care while in hospital or LTC from the physician providing plurality of care. Long-term person-focused care was measured through continuity of care, while coordinated care was measured by the proportion of all referrals to specialists and for laboratory testing originating from the assigned primary care physician. Patients were assigned to the primary care physician who provided plurality of care, defined as the physician most responsible for each patient and therefore receiving most of the patient's visits (a more detailed description is provided in Section 4.4.1.2 below).

4.4.1.1 Health Status

In addition to basic demographics, heath status needed to be characterized for each patient in order to control for the effects of other chronic conditions on the outcome variables. Health status was proxied using the Johns Hopkins Adjusted Clinical Group Case-Mix system, a risk adjustment methodology [222]. This system uses diagnoses that a patient accumulates from physician and hospital visits over a specific period of time (in this case, a year), to determine a clinical complexity/severity category. Each diagnosis is classified into one of 32 ADGs, which are defined based on clinical similarity (severity, persistence, reoccurrence) and expected health care service utilization (e.g. follow-up visits, specialist referrals). Each individual over the course of the year can then have 1-32 different ADGs assigned. These aggregations are further refined by the system to reflect the concept of major conditions, with eight ADGs identified as "major", including time limited major conditions, chronic unstable conditions, major adverse injuries and malignancy [222].

Combinations of ADGs, along with age and sex, are used to map patients into one of about one-hundred mutually exclusive Adjusted Clinical Groups (ACGs). Each

ACG category is a measure of the patient's expected need for health services over a subsequent period (based on services actually received during the measurement period). ACGs are mutually exclusive and exhaustive. The system has been validated for use with BC administrative data [223]. For simplicity, the mutually exclusive ACGs are combined by the system to measure six levels of overall morbidity (non-users to very high users), termed resource utilization bands (RUBs). For this thesis, only one variable derived from the John Hopkins Adjusted Clinical Group Case-Mix system was used for measurement of health status, the number of major ADGs individuals had upon entry into the cohort.

Within my health status variable cluster, I used a second measure of morbidity -- the number of chronic diseases. A large proportion of individuals with dementia often have several other chronic conditions[224] which can both affect the care they receive at the point of dementia diagnosis and longitudinally, and the outcomes of care. This variable was derived as follows: I identified ten chronic conditions of high prevalence in the older-adult population: diabetes mellitus, stroke, hypertension, chronic kidney disease, liver disease, arthritis/osteoarthritis, congestive heart failure, coronary vascular disease, chronic obstructive pulmonary disease and cancer, [64,65] as well as depression (commonly found in dementia patients)[225]. A variable based on a simple count of co-morbid conditions was then created at entry into the cohort.

4.4.1.2 Physician Attribution Process

In both dementia care and primary care, physician (or practice) characteristics (Described in Table 4.2) have been shown to influence a patient's trajectory of care. Attributing these physician variables depends on identifying a single most responsible primary care physician for each patient. In the absence of rostering in BC, this implies using an attribution process in which individuals are "assigned" to a physician for the purposes of analysis.

For objectives 3 and 4, the assignment of a physician was done annually based on the physician providing plurality of care for each patient in that fiscal year. The physician providing plurality of care was defined as the physician who received the highest proportion of unique visits during the fiscal year. In the event of a tie, the assignment was made to the physician who billed for the most fee items for that patient. Exceptions to these rules were institutional visits as these were measured as service units recording the number of days on which the practitioner saw that person. Limitations to an assignment like this is that for some physicians, the patient 'visit' may actually be only a patient management activity or form fee (such as renewing a prescription over the phone) and did not actually involve a face-to-face contact. No charge referrals, which occur when a patient does not come in to the office for a visit but receives a renewal of a referral to a specialist (referrals to specialists must come from the primary care physician and in BC expire after 6 months), were excluded prior to counting visits.

Sensitivity analysis was conducted to determine what percentage of patients received their dementia diagnosis from the same physician to whom they were assigned through the plurality of care process described. I found that this occurred for 70% of patients who had an incident physician MSP diagnosis code for dementia. Additionally, analysis was conducted to determine the median number of patients with dementia in the cohort treated by the same physician (to determine if clustering needs to be accounted for). Each physician cares for a small number of patients (the median is 2), eliminating concerns of clustering of patients within providers.

Table 4.3 - Key analytic and service variables

Variable	Data Source	Description
Patient Variables		
Age	Consolidated	Age in years
Age Group in 2001/02	Derived	Age variable categorized 65-74, 75-84, 85+ years
Sex	Consolidated	Female or Male
Socioeconomic status	Consolidated	Neighbourhood income measured through Quintile of adjusted income per person equivalent, 1-5 indicating lowest to highest income
Death	Vital Stats	Year and month of death
Behavioural symptoms flag	Derived	Indicator flag for behavioural issues. Composite variable developed from PharmaNet indicating antipsychotic and/or benzodiazepine prescriptions
Adjusted Clinical Group	MSP	Indicator of health status described in Section 4.4.1
Resource Utilization Band	MSP	Uses ACGs to create coarser non-overlapping groups of morbidity levels (0-non user, 1-healthy, 2-low, 3-moderate, 4-high, 5-v high)
# Major Aggregated Diagnostic Groups	MSP	Diagnoses are classified into 1 of 32 Aggregated Diagnostic Groups based on clinical similarity and expected health care service utilization. Eight of these groups are considered 'major'
Has diabetes	MSP	Described in further detail in section 4.4.1.1
Has hypertension	MSP	
Has congestive heart failure	MSP	
Has chronic kidney disease	MSP	
Has liver disease	MSP	
Has arthritis/osteoarthritis	MSP	
Has cancer	MSP	
Has depression	MSP	
Has cardiovascular disease	MSP	
Has stroke	MSP	
Has chronic obstructive pulmonary disease	MSP	
# Multiple Chronic Diseases	Derived	Count of the number of chronic diseases previously defined in section 4.4.1.1
Incidence of dementia flag	Derived	Indicates if incident diagnosis of dementia in that fiscal year
Dementia diagnosis location	MSP	Codes location that patient received dementia diagnosis, hospital or physician office

Variable	Data Source	Description
Caregiver status proxy	Derived	Derived from the shared MSP id variable in the Consolidated file indicating if the individual shares a household described in section 4.4.1
Physician/Practice Variables		
Age	College	Physician age in years
Sex	College	Female or Male
Date of graduation	College	Year of graduation from medical school
Years of practice	Derived	Derived from date of graduation and membership
Place of graduation	College	Indicates if physician is foreign or Canada trained
Speciality	College	Indicates if physician has geriatric, psychiatric or neurological training
# patients 65+	MSP	Indicates if physician has large number of patients 65+
# patients 65+ with dementia	MSP	Indicates the number of patients with dementia physician provides care to
System Variable		
Health Authority	Consolidated	Indicator of region of residence, 1-5 based on health authority delineations
Physician Practice location	College	Health authority physician practices in
Dementia Care Service Variables	Defined in detail in Chapters 3 and 5	
Laboratory testing	MSP	Tests recommended by guidelines to exclude other reasons for dementia-like symptoms
Complete hematology profile		
Serum electrolytes		
Serum calcium		
Serum glucose		
Thyroid stimulating hormone		
B12 vitamin		
Imaging	MSP	Imaging recommended by guidelines to assist with diagnosis
Head computed tomography		
Prescriptions	Pharmanet	Identified using DINs that were converted to ATCs described in section 4.2.6
Acetylcholinesterase inhibitor		
Recommended antipsychotics		
All other antipsychotics		
Trazodone for sleep disorders		
Care Management	MSP	Management processes during diagnosis defined by guidelines
Complete examination in office		

Variable	Data Source	Description
Individual counselling in-office		
Referral		
Referral to specialist re. dementia	MSP	Referral to a Geriatrician, Neurologist, Psychiatrist, Neuropsychologist, Geriatric Psychiatrist
Primary Care Service Variables	Defined in detail in Chapter 7	
Continuity		
# of GP visits	MSP	Number of visits to primary care physician
# of GP visits with attributed physician	Derived	Number of visits with the primary care physician identified as providing plurality of care in the year
Proportion of total visits with attributed physician	Derived	Used as Continuity measure, indicates of all visits, the proportion that occurred with the attributed physician the patient is attributed to in the year
Coordinated & Referral Care		
# lab referrals	MSP	Number of referrals for laboratory tests
# lab referrals with attributed physician	Derived	Number of lab referrals originating from the primary care physician identified as providing plurality of care in the year
# specialist referrals	MSP	Number of referrals to specialists
# specialist referrals with attributed physician	Derived	Number of specialist referrals originating from the primary care physician identified as providing plurality of care in the year
Proportion of total lab referrals from attributed physician	Derived	Used as Coordination measure, indicates of all lab referrals, the proportion that originated from attributed physician in the year
Proportion of total specialist referrals from attributed physician	Derived	Used as Coordination measure, indicates of all specialist referrals, the proportion that originated from attributed physician in the year
Access		
# days care received outside office hours	MSP	Indicates # days care was received outside office hours
# days care in home	MSP	Indicates # days care was received at home
# days care in hospital	MSP, DAD	Indicates # days care was received in hospital
# days care in LTC	MSP, HCC	Indicates # days care was received in LTC
# alternate settings of care	Derived	Indicates the number of settings outside of the office that care was provided by attributed physician (includes home, hospital, LTC, Assisted Living)
Received visit from physician plurality in hospital flag	Derived	Used as Access measure, indicates if patient received visit from attributed physician while in hospital
Received visit from physician plurality in LTC flag	Derived	Used as Access measure, indicates if patient received visit from attributed physician while in LTC
Received service from physician plurality outside office hours flag		Used as Access measure, indicates if patient received service from attributed physician outside of office hours

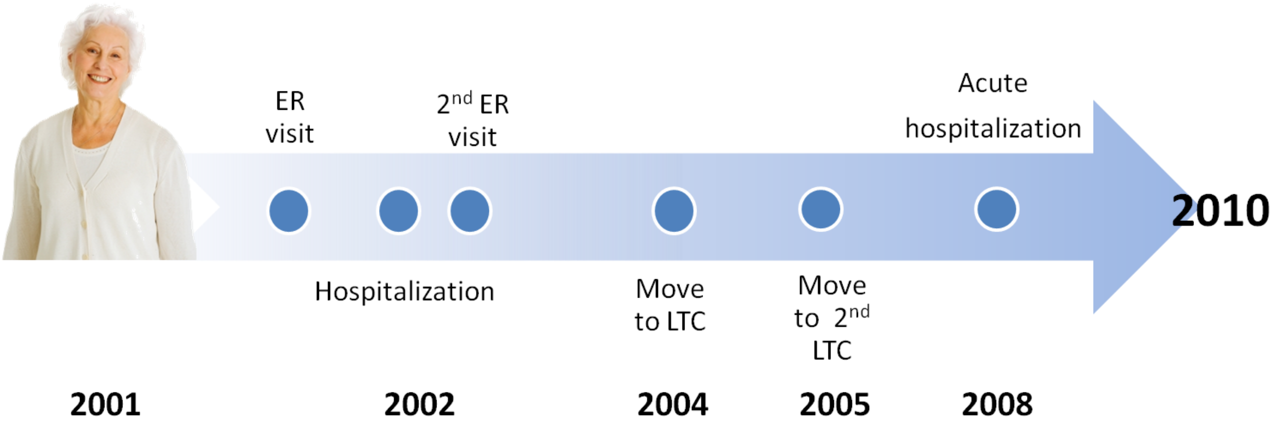
Variable	Data Source	Description
Outcome Variables		
Flag for hospitalization	DAD	Indicates if person had at least 1 hospitalization that year
Number of hospitalizations	DAD	Total number of all hospitalizations (includes acute, rehab, ER etc.)
Total hospital days accrued	DAD	Total number of days accrued in hospital over the year. If admittance and discharge happen on same day, counted as 1 day.
Mean length of stay in hospital	Derived	Mean consecutive number of days spent in hospital that year
LTC Facility flag	HCC	Indicator if person resides in a LTC facility at beginning of year
New LTC Facility flag	HCC	Indicates if person moved into LTC facility during the year
Second move to LTC facility	HCC	Indicates if person moved to a second LTC facility
Length of stay in community	Derived	Tabulates the number of days an individual remains in the community prior to institutionalization. Derived from HCC data
# of transitions annually	Derived	Tabulates the number of transitions between home, hospital, respite care, assisted living and LTC. From MSP and Discharge abstract data
Total number of transitions	Derived	Used as outcome variable. Tabulate the total number of transitions over entire study period
# of months alive annually	Derived	Used as outcome variable. Tabulates the total number of months the person is alive based on Vital Stats records
# of transitions per year alive	Derived	Used as outcome variable. Average of the transitions experienced per year alive

4.4.2 Outcome Variables

For this thesis the primary outcome variable, the number of transitions experienced, was defined as a physical move from one location to another with a stay of at least one night at the destination location, based on the recorded dates of admission and discharge [10,12]. The identification of a "transition" was verified based on a move that accounted for the departure and return locations. Moves that resulted in a return location different from the original departure location would count as two transitions, so long as the "at least one overnight stay" criterion was met for each of the two apparent destination locations. For example, an individual who lives at home, is admitted to the hospital with an overnight stay and returns home will have had one transition; an individual who is admitted to the hospital from home, stays at least one night in the hospital, and then is discharged to a LTC facility will have had two transitions. An exception to this rule is for individuals who experience a move from their home to a LTC facility or Assisted Living and then back home. In these cases, it is rare that an individual who needs the level of assistance that a LTC facility provides would be able to live at home alone again. It is more likely that they have moved back to the community with an adult child or other caregiver, or into a private facility for which no data were available. This type of move was counted as two transitions because daily living circumstances changed twice.

The number of transitions for each patient in the data sets were assessed for each year and summed over the trajectory of the patient's care during the study period as demonstrated in Figure 4.2.

Figure 4.2 – Example of transitions that can be experienced over study period



Hospitalizations of any kind including day surgeries with discharges that occur the following day, respite care and moves to and between LTC facilities or Assisted Living facilities were included. However, in-patient moves within the same ward or institution were excluded [10]. The data cover all public hospitals, residential care facilities and assisted living facilities.

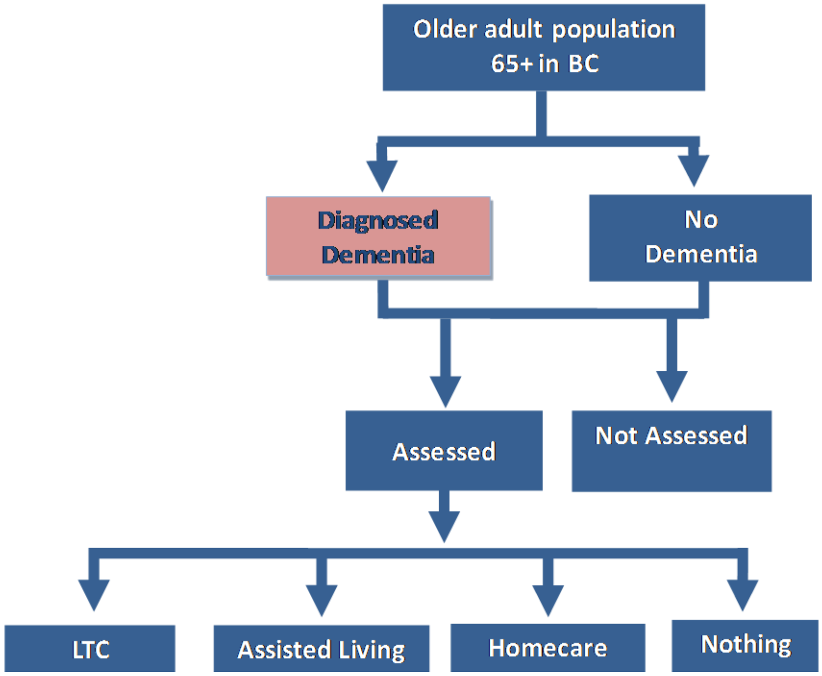
4.4.2.1 Long-Term Care Facility Transition

Approximately 25,000 seniors 65 years and older in BC were referred and initially assessed through the HCC system each year during the study period (Figure 4.3). Home and community care services provide additional support, allowing individuals to remain in the community longer, but also conduct assessments for those who cannot remain in the community to determine a needed level of care including possible moves to an Assisted Living or residential LTC facility. An initial assessment can result in a number of different outcomes. For example, some individuals may be found ineligible for publicly-funded support, in which case they may choose to ‘stay put’, or move into a private facility, data from which are not captured in the data sets available for my analyses.

Those who were considered eligible for public support after an initial assessment could go on to receive home-care services, could be deemed eligible for LTC, and from 2004 onward, could be considered eligible for Assisted Living (2004 was when public funding for Assisted Living began in BC) [226].

While Figure 4.3 offers a snapshot in time of this assessment process, individuals could have been assessed at any time during the study follow-up period; some had multiple assessments and some had already been assessed prior to the start of the study. For the purposes of this thesis, understanding the assessment process for HCC services is necessary in the context of measuring individuals' first transition into a LTC facility. I created two variables, one indicating if a person was already living in a LTC facility at the point of entry into the cohort, and the other indicating the year of a person's first transition into a LTC facility. Measurements regarding transitions into a LTC facility could only be made for the subpopulation that received an assessment from HCC services and moved into a publicly-funded LTC facility of Assisted Living.

Figure 4.3 – Pathways to publicly funded home and community care support



4.4.3 Analytic Models

The analytic methods used for this thesis varied for each objective and are therefore described in detail within the Method section of each chapter though brief descriptions of model selection are provided here. The analytic models described below detail the dependent and independent variables that will be used in the analytic methods to answer each research question.

Research question 2b: *Is there variation in receipt of guideline-consistent care, and if so, what are the patient characteristics most strongly associated with this variation?*

A multivariate logistic (or logit) regression model is utilized when the response variable of interest (y) is dichotomous rather than continuous. This allows me to estimate the probability (p) associated with my response variable (y) for multiple discrete explanatory (independent) variables. In this case, each dementia care process is a dichotomous response variable (received the process of care, yes or no). I estimate the probability that any patient/individual characteristic affects the likelihood that individuals will receive each particular dementia care process. Modelling this probability (p) using a logistic function, $p = \frac{e^{\beta_0 + \beta_1 x}}{1 + e^{\beta_0 + \beta_1 x}}$ means the log odds of the response variable (y) (the logarithm of the odds of success or in this case, receiving the care process) is modeled as a linear combination of all the following discrete patient characteristics:

$$\ln(\text{dementia care process}) = \beta_0 + \beta(\text{age}) + \beta(\text{sex}) + \beta(\text{income}) + \beta(\text{health status}) + \beta(\text{health authority})$$

Research question 3c & 3d: *What are the types of transitions experience and what factors influence these transitions?*

What factors influence the number of transitions during the peak points of care and overall?

To understand what patient characteristics most influence the number of transitions experienced (other than death), over and above physician practice patterns, both system and physician characteristics were controlled for in a negative binomial model, Poisson model or zero-inflated Poisson model. All models are part of the family of Generalized Linear Models and are used for analyzing count data. The choice of particular model and link function was based on the distribution of the particular outcome of interest. While both Poisson and negative binomial regression control for the "rare event" nature of a transition, the negative binomial model's assumptions better fit the transitions data. Negative binomial regression does not assume an equal mean and variance, therefore correcting for over-dispersion (when the variance is greater than the mean) in my data through an extra parameter. Regardless, a preliminary Poisson model was run and the Pearson Chi square Goodness-of-fit test assessed for every outcome (the assumptions being: the probability of an event is proportional to the time of observation, no two events can occur simultaneously, the event rate is constant through time and that the events occur independently). Time was offset to account for the number of months of follow-up in the study.

Of the four outcome variables assessed, two were modelled using negative binomial analysis: 1) transitions in the year of diagnosis; and 2) total transitions experienced over the study period. The count of LTC moves in the year of diagnosis was modelled using

Poisson regression. Lastly, the count of hospitalizations in the year of diagnosis was modelled using a zero-inflated Poisson analysis due to an excess of zero counts. The zero-inflated Poisson model operates in two parts, modelling the count of hospitalizations using Poisson regression and the excess zeros using a logit model. The log of the response variable (y) (the logarithm of the odds of success or in this case, having a transition) is modeled as a linear combination of all the following discrete patient characteristics, controlling for death and physician characteristics:

$$\text{Rate of Transition} = \beta_0 + \beta(\text{age}) + \beta(\text{sex}) + \beta(\text{income}) + \beta(\text{health status}) + \beta(\text{caregiver}) + \beta(\text{responsive behaviour}) + \beta(\text{health authority}) + \beta(\text{end-of-life}) + \beta(\text{GP yrs of practice}) + \beta(\text{\# patients 65+}) + \beta(\text{\# dementia patients})$$

Research question 4a & 4b: *Is receipt of guideline-consistent dementia care in the year of diagnosis associated with the number of transitions the patient experience in that year?*

Is the receipt of high quality primary care associated with the number of transitions the patient experiences in the year in which dementia is first diagnosed?

First, the odds of receiving guideline-consistent dementia care based on the location of diagnosis (community vs. hospital) was assessed to determine whether it should be an explanatory variable that should be included in the larger model examining the rate of transitions. A multivariate logistic (or logit) regression model was used with the response variables (y), which was each dementia care process (as previously described in research question 2b), and an explanatory variable indicating diagnosis location (while controlling for patient characteristics).

$$\ln(\text{dementia care process}) = \beta_0 + \beta(\text{age}) + \beta(\text{sex}) + \beta(\text{income}) + \beta(\text{health status}) + \beta(\text{health authority}) + \beta(\text{dx location})$$

The same model selection process conducted for research question 3 was applied to research question 4a and 4b. The response variable (y) of the number of transitions experienced in the year of diagnosis was modelled using negative binomial regression in two separate models with explanatory variables, dementia care and primary care (after controlling for patient, physician and system characteristics).

$$\textit{Rate of Transition} = \beta_0 + \beta(\textit{age}) + \beta(\textit{sex}) + \beta(\textit{income}) + \beta(\textit{health status}) + \beta(\textit{health authority}) + \beta(\textit{caregiver}) + \beta(\textit{dx location}) + \beta(\textit{GP yrs of practice}) + \beta(\textit{\# patients 65+}) + \beta(\textit{\# dementia patients}) + \boldsymbol{\beta}\ \textbf{\textit{(dementia care)}}$$

$$\textit{Rate of Transition} = \beta_0 + \beta(\textit{age}) + \beta(\textit{sex}) + \beta(\textit{income}) + \beta(\textit{health status}) + \beta(\textit{health authority}) + \beta(\textit{caregiver}) + \beta(\textit{dx location}) + \beta(\textit{GP yrs of practice}) + \beta(\textit{\# patients 65+}) + \beta(\textit{\# dementia patients}) + \boldsymbol{\beta}\ \textbf{\textit{(primary care)}}$$

CHAPTER 5 – CARING FOR DEMENTIA: A POPULATION-BASED STUDY EXAMINING VARIATIONS IN GUIDELINE-CONSISTENT CARE[4]

5.1 Introduction

The systematic review described in Chapter 3 identified wide variation in the application of guideline-recommended practice among physicians providing clinical care to individuals with dementia [31]. This physician practice variation is indicative of inconsistent care received by patients with dementia and may result in differences in care outcomes.

As highlighted in the systematic review, available studies examining this question have significant study limitations. All were chart extractions or self-reported surveys of physicians or patients with low response rates and/or small sample sizes [31,146,153,155,195]. Enlisting administrative data for this question offers one way to avoid the sample, geographic, and response rate limitations of previous studies. By conducting this analysis at a patient level, I will be able to examine potentially modifiable patient characteristics associated with any variation and be able to separate out warranted and unwarranted variation.

The administrative data described in Chapter 4 provide a unique opportunity to compare patterns of care received with those recommended by dementia care guidelines. My research questions therefore are as follows:

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[4] A version of chapter 5 has been accepted. Sivananthan SN, Lavergne KM, McGrail KM. Caring for dementia: A population-based study examining variations in guideline-consistent care. Alzheimer's & Dementia 2015.

Research Question 2a: What proportions of individuals newly diagnosed with dementia in BC receive each of the guideline-consistent dementia care processes?

Research Question 2b: Is there variation in receipt of guideline consistent care, and if so, what are the patient characteristics most strongly associated with this variation?

I hypothesize that a high proportion of individuals will receive guideline-consistent laboratory and imaging processes of dementia care as these are more regularly administrated, however a lower proportion of individuals will receive all other processes of care as these are more discretionary. Secondly, I hypothesize that there will be variation in receipt of guideline-consistent care by location and health status, however variation by other patient characteristics will indicate potential inequity and lack of quality of care.

5.2 Methods

I used the health care administrative data described in Chapter 4 to conduct a population-based study in BC. Detailed analysis was conducted on the study population for fiscal year 2009/10, though data dating back to 2000/01 was utilized for the purpose of identifying incidence of dementia, described in more detail below.

5.2.1 Data Sources

Five of the seven databases described in Chapter 4 were used for this analysis: 1) the central consolidation file 2) the medical services plan (MSP) payment file 3) Hospital abstract data 4) Vital statistics death file and 5) the PharmaNet file.

5.2.2 Study Population

Cohort 2, described in Chapter 4 section 4.3.1 was used for this component of the project. Briefly, these were all community-dwelling seniors in BC, 69 years and older at the time of diagnosis, who were incident cases of dementia in 2009/10 or 2010/11. A case was considered 'incident' if there were no dementia diagnoses during a 10-year wash-in period. Of note, the guidelines themselves, while differentiating the types of dementias in their pathophysiology, do not make distinctions in the diagnostic and subsequent care processes they recommend therefore combining the various types of dementias would not greatly impact my measure of guideline concordance.

Individuals were excluded if they were not registered for MSP coverage for the whole of 2009/10, or if they lived in a LTC facility or died at any point during the one-year follow-up period. The study focused on community-dwelling seniors, as those who live in a LTC facility are known to have different patterns of primary care service use [113,114]. A full year of follow-up was used to provide adequate opportunity to assess receipt of guideline-consistent care. Sensitivity analysis demonstrates that patients who died during the year had very different service use patterns with generally lower rates of receipt of most care processes (Appendix Table C.1, C.2A, B).

5.2.3 Recommended Dementia Care Guidelines

I used the most updated BC Dementia Care Guidelines, released in July 2007, as they reflect province-specific resource availability, were readily available to physicians practicing in BC, and incorporate recommendations from the Canadian Consensus group national guidelines [7,122]. Dementia care processes that were previously developed [31] and described in Chapter 3 section 3.2.2, were used to characterize different types of care received by patients with dementia: laboratory blood work, imaging, pharmacological interventions, counselling and specialist referrals. The care processes can be divided into those that are recommended for all newly diagnosed individuals (laboratory tests, counselling), those that are recommended in some circumstances (imaging, pharmaceuticals, physical exam, specialist referrals) and those that are contra-indicated (benzodiazepines). Therefore, I did not expect 100% adherence as circumstances may vary for patients. My main interest, instead, was in identifying any systematic variation in these care processes by patient characteristics.

The data used for this study did not include information that would have permitted measurement of the provision of memory testing, provision of magnetic resonance imaging, or referral to community services. Service use was measured during the year of diagnosis in order to capture service provided during the lead up to diagnoses captured and in keeping with guidelines that indicate these services should be provided both as part of and after a confirmatory diagnosis of dementia [122]. The definition of each care process is provided below.

Diagnostic Services:

Laboratory tests – These are tests routinely ordered to determine the underlying cause of dementia and/or for rule-out of other causes (e.g. medication-induced dementia-like symptoms). The tests include a complete blood count, serum electrolytes, serum calcium, serum glucose, TSH and vitamin B12 levels.

Imaging – Not routinely indicated but a CT scan of the brain is recommended under certain circumstances such as if the patient is under 60 years of age, has abrupt onset or rapid progression, and has a history of cancer or if there is a history of urinary incontinence or gait disorder.

Physical Examination – A physician exam should be conducted to identify neurological abnormalities and other medical conditions that could be contributing to the cognitive decline

Prescriptions:

Pharmaceutical Intervention – All prescriptions related to the treatment of dementia were examined (Donepazil, Rivastigmine, Galantamine and Memantine). Prescriptions of antipsychotics for behavioural and psychological symptoms are recommended only when alternate therapies are inadequate, symptoms are severe, or there is a risk of harm to the patient and others.

Benzodiazepines are the only class of drugs that the BC guidelines indicate should not be used due to high potential for adverse events. Given this and the fact that I was interested in assessing if changes in antipsychotic drug use might be related to concurrent changes in benzodiazepines, utilization of both was assessed.

Management:

Counselling – Counselling visit for a minimum of 20 minutes provided to patients with dementia and family members during which patient/caregiver guides, support resources, care management, advance and safety planning can be discussed.

Specialist Referral – Referral to a Geriatrician, Neurologist or Psychiatrist is recommended when management or diagnosis is problematic.

5.2.4 Explanatory Variables

I included the following patient demographic variables as possible contributors to variations in provision of dementia care: age, sex, income quintile, number of multiple chronic diseases and location (health authority).

The number of chronic diseases was defined in two different ways. One counted the occurrence of the twelve most prevalent chronic conditions in seniors [65] measured by the presence of at least two physician diagnoses over a two-year period, consistent with prior literature on chronic condition ascertainment [218]. The chronic conditions included hypertension, depression, arthritis or osteoarthritis, cancer, congestive heart failure, diabetes, cardiovascular disease, stroke, chronic obstructive pulmonary disease, chronic kidney disease, liver disease. I used a 10-year assessment period counting back from the date of dementia diagnosis to ensure complete capture of prevalent disease. A second measure validated in the literature, the count of major adjusted diagnostic groups (mADGs), was characterized for each patient using the John Hopkins Adjusted Clinical Group Case-Mix system as previously described in Chapter 4, section 4.4.1.1. This measure of mADGs was used to test the sensitivity of my measure of co-morbidity and no difference was found between the count of prevalent chronic conditions versus number of mADGs therefore the count of prevalent chronic conditions was used as a better adjustment for rule out diagnostic testing.

5.2.5 Statistical Analysis

Characteristics of the patient cohort and dementia care processes are described using counts and percentages. Each dementia care process was a dichotomous response variable (received the process of care, yes or no), therefore I estimated the probability that patient characteristics (i.e. age, gender, income, co-morbidity and geography) affected the likelihood that individuals will receive each particular dementia care process using multivariate logistic regression analysis. All variables were retained in the model regardless of significance and coefficients displayed as odds ratios. All variables were tested for collinearity. Model fit was assessed using Hosmer-Lemeshow goodness-of-fit test. Analyses were performed using STATA, version 10 [227].

5.3 Results

The study population was limited to community dwelling seniors because those who live in a LTC facility are known to have attenuated service use once admitted. Separate analyses of seniors living in a LTC facility revealed that they receive a significantly lower proportion of guideline-consistent dementia care processes compared to non-residents (Table 5.1). This is particularly apparent for the imaging, counselling and specialist referral dementia care processes where residents are unlikely to leave the LTC facility for a CT scan (18% received a CT scan) or referral to a specialist (1% received a referral). An extremely low proportion of residents receive in-office examinations (4%) and in-office individual counseling (5%); this is not un-expected given that the majority of residents of LTC facilities are seen by facility physicians. Given these differences in primary care utilization patterns, seniors living in a LTC facility or newly admitted to a facility in 2009/10 were excluded from the analysis reported here.

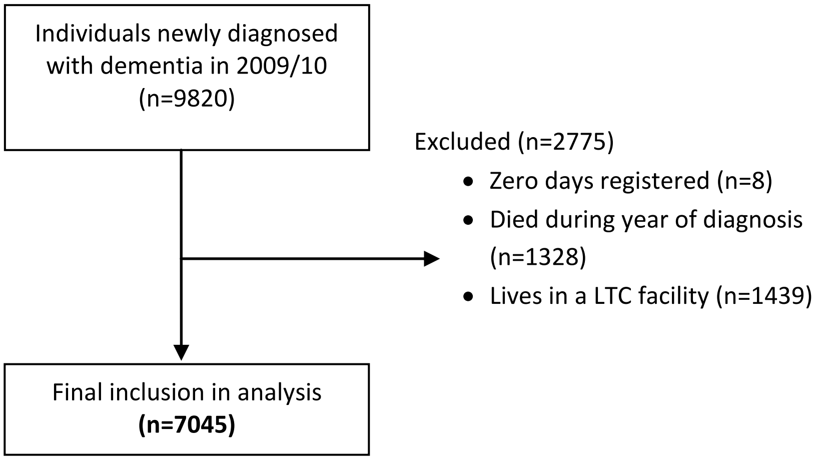
Table 5.1 – Proportion of seniors 69+ years of age residing in a LTC facility receiving guideline-consistent care

Dementia Care Process	Service Measured	Lives in LTC facility (n=1107)*
Laboratory	Complete hematology profile	73%
	Serum electrolytes	70%
	Serum calcium	13%
	Serum glucose	39%
	Thyroid stimulating hormone	54%
	B12 vitamin	34%
Imaging	Head computed tomography	18%
Counselling & Specialist Referral	Complete examination in-office	4%
	Individual counselling in-office	5%
	Referral to specialist re. Dementia	1%

*Excludes individuals who died

In 2009/10, 9820 individuals were newly diagnosed with dementia in BC. Of these, 8 were not registered in BC for the full year, 1328 were excluded due to death during the one-year follow up period and 1439 were residents in a LTC facility or newly entered a LTC facility and were excluded. This left a study population of 7045 individuals (Figure 5.1).

Figure 5.1 – Flow of study participants



5.3.1 Final Study Participants

Patients in the community dwelling dementia cohort had a mean age of 83±6.41, were primarily female (59%) and had a mean income quintile of 2.91±1.60 (where 1 indicates low and 5 indicates high, Table 5.2). Over 50% had three or more chronic diseases other than dementia. The five most prevalent chronic conditions were hypertension (72%), arthritis/osteoarthritis (39%), cancer (32%), depression (28%) and diabetes (26%) (Table 5.2). The study population had a mean number of 2.51±1.29 major ADGs, which indicates this is a high-needs population (1 indicates low and 5 indicates high, Table 5.2). The dementia cohort was fairly evenly distributed across the four larger health authorities, with the fifth contributing 3.3% of the cohort, consistent with the small population in this health authority.

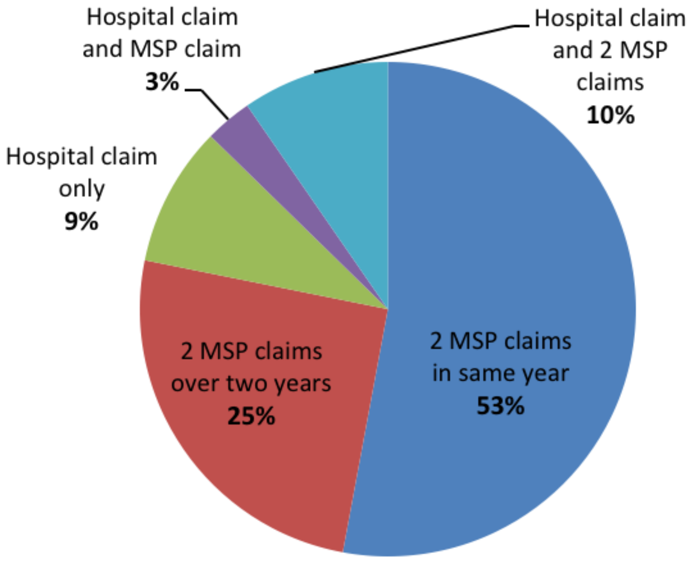
Table 5.2 – Baseline characteristics of community-dwelling individuals newly diagnosed with dementia in 2009/10

Characteristics	**Patients with Dementia** (n=7,045)
Age in years (mean± SD)	82.71 ± 6.41
69-80	37.5%
81-90	51.3%
91+	11.2%
Sex*	
Male	41.2%
Female	58.7%
Income Quintile (mean± SD)*	2.91 ± 1.60
1- Lowest income	24.3%
2- Lower income	21.0%
3- Medium income	18.8%
4- Higher income	17.2%
5- Highest income	17.5%
Multiple other chronic diseases (not including dementia)	
0 chronic diseases	5.6%
1 chronic disease	18.2%
2 chronic diseases	25.8%
3+ chronic diseases	50.4%
Number of major ADGs (mean± SD)	2.51 ± 1.29
Treatment Prevalence of major chronic diseases	
Hypertension	72.0%
Depression	27.6%
Arthritis or Osteoarthritis	38.7%
Cancer	31.6%
Congestive heart failure	19.6%
Diabetes	25.7%
Cardiovascular disease	18.3%
Stroke	8.4%
Chronic obstructive pulmonary disease	8.0%
Delirium	7.7%
Chronic kidney disease	6.2%
Liver disease	0.7%
Health Authority*	
Interior	22.5%
Fraser	27.3%
Vancouver Coastal	25.0%
Vancouver Island	21.7%
Northern	3.3%

*Missing data: Sex Unknown=13, Income Unknown=98, Quintile HA Unknown=17

The majority (75%) of patients were determined to be newly diagnosed incident dementia cases using family physician payment records showing a minimum of two MSP claims associated with ICD-9 dementia codes (Figure 5.2). Nine percent of patients received the designation as a result only of a hospital diagnosis; the remaining 16% received both a hospital diagnosis and a diagnosis on at least one MSP claim. For 71% of those who received their diagnoses through the family physician payment claim route, both initial MSP claims originated with the same family physician. Of those who received a hospital diagnosis and a minimum of two MSP claims, 59% of incident cases were based on MSP claims from the same physician. Receiving a diagnosis of dementia in hospital may be indicative of patients whose dementia went unrecognized in the community and therefore may have more severe dementia.

Figure 5.2 – Location of diagnosis of dementia (Cohort 2)



5.3.2 Variations in Dementia Care Processes

Overall, a high percentage of the cohort received most of the guideline-consistent laboratory tests (between 74 to 89%, except calcium and B12) and imaging (58% received a head CT) (Figure 5.3A) within a year of diagnosis. Under half of the cohort received a prescription for an AChI (40%) or antidepressant (43%) (Figure 5.3B). However, over a quarter of the cohort received an antipsychotic (28%), suggested for use only when other non-prescription therapies have been exhausted. A further 26% receive a benzodiazepine, which is specifically not recommended for seniors with dementia. A low percentage received referrals to a specialist (9%), or complete in-office examinations (32%).

Figure 5.3A – Percentage of seniors receiving guideline-consistent lab testing and imaging

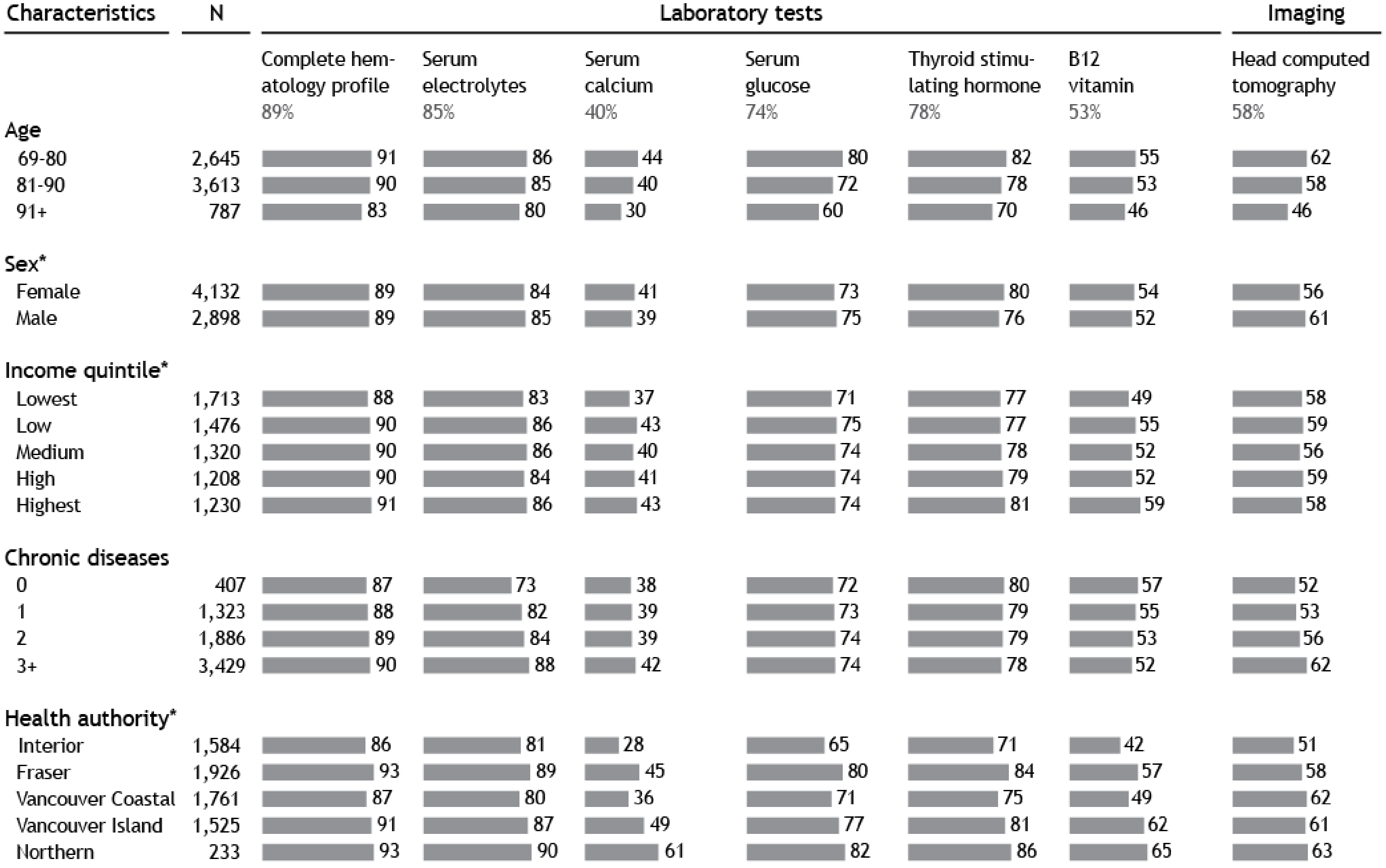


Figure 5.3B – Percentage of seniors receiving guideline-consistent prescription and dementia care management processes

Characteristics	N	Prescriptions					Management		
		Acetylcholinesterase inhibitor 40%	Anti-psychotics 28%	Trazodone 9%	Anti-depressants 43%	Benzo-diazepines† 26%	Complete exam in-office 32%	Individual counselling in-office 44%	Spec. referral re. dementia 9%
Age									
69-80	2,645	44	27	9	46	26	38	49	13
81-90	3,613	40	29	8	41	25	31	43	8
91+	787	22	32	8	37	28	20	31	3
Sex*									
Female	4,132	40	28	9	46	28	30	45	8
Male	2,898	39	29	9	38	23	35	43	11
Income quintile*									
Lowest	1,713	35	31	10	45	27	32	41	8
Low	1,476	39	29	8	43	25	31	43	9
Medium	1,320	42	27	9	43	26	32	45	10
High	1,208	41	28	8	42	26	34	46	9
Highest	1,230	43	26	8	40	25	33	48	12
Chronic diseases									
0	407	47	25	6	23	19	37	44	11
1	1,323	45	26	7	32	22	30	44	8
2	1,886	44	29	8	39	24	33	44	9
3+	3,429	34	29	10	51	29	32	45	10
Health authority*									
Interior	1,584	36	32	10	45	29	27	44	7
Fraser	1,926	48	27	8	43	25	33	44	13
Vancouver Coastal	1,761	34	28	10	41	22	30	40	12
Vancouver Island	1,525	40	28	8	42	27	38	50	6
Northern	233	35	31	6	40	26	27	45	3

In multivariate analysis, after adjusting for patient demographic characteristics, there is a consistent decreasing gradient in receipt of guideline-consistent dementia care with age (Figure 5.4A-C; Appendix C.3A, B). Seniors 91 years and older had significantly lower odds of receiving a specialist referral (0.24 CI 0.14-0.40), an AChI (0.33 CI 0.26-0.42), the serum glucose test (0.35 CI 0.28-0.44), a complete examination in-office (0.38 CI 0.30-0.49), individual counselling in-office (0.41 CI 0.33-0.50), a head CT (0.51 CI 0.42-0.63) and all other laboratory tests compared to seniors 69-80 years old. A comparable pattern was noted for seniors 81 to 90 years old compared to the reference.

Figure 5.4A – Adjusted odds ratio of receiving calcium, B12, laboratory tests and computed tomography scans

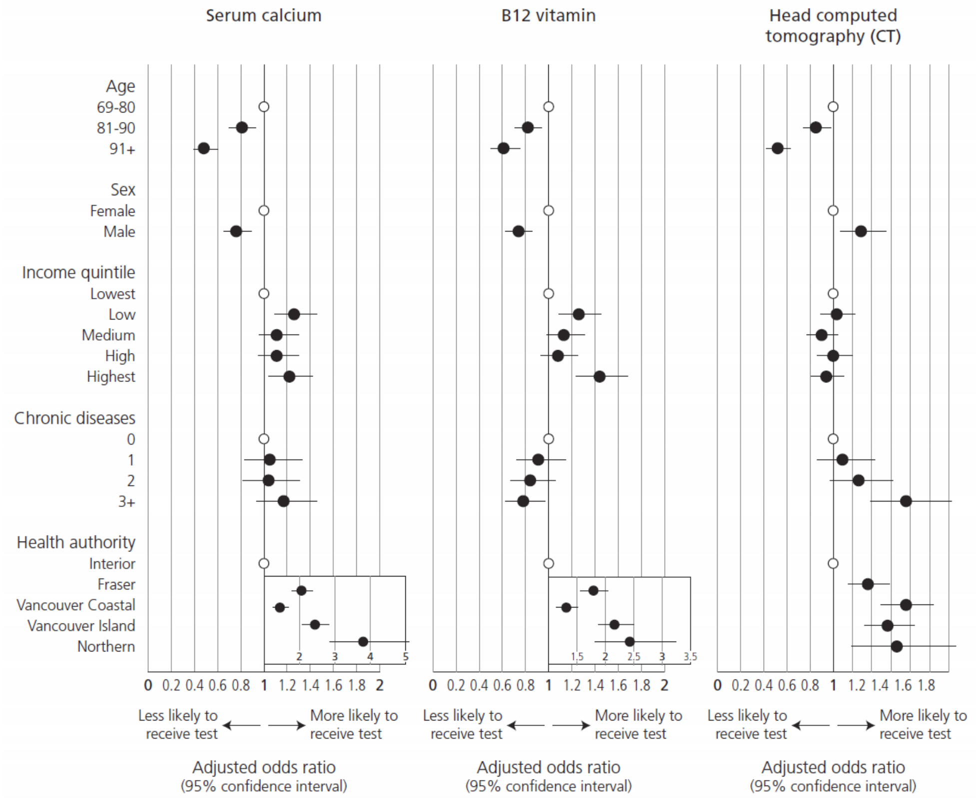


Figure 5.4B – Adjusted odds ratio of receiving acetyl-cholinesterase inhibitors, antipsychotics and non-recommended benzodiazepines

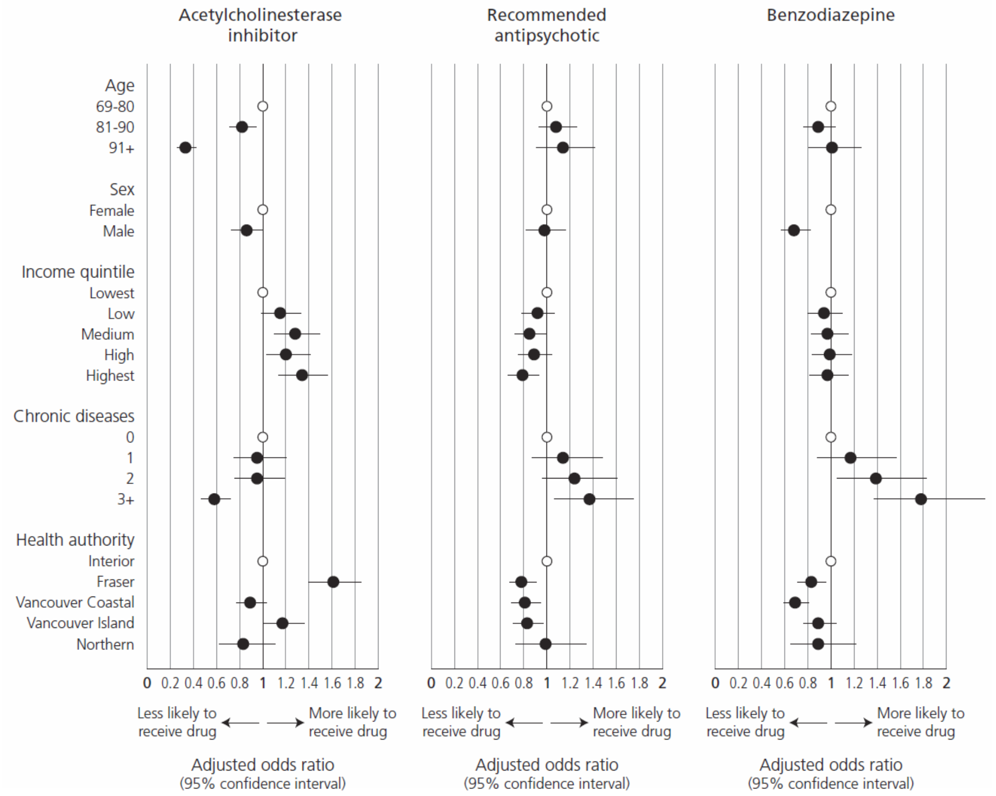
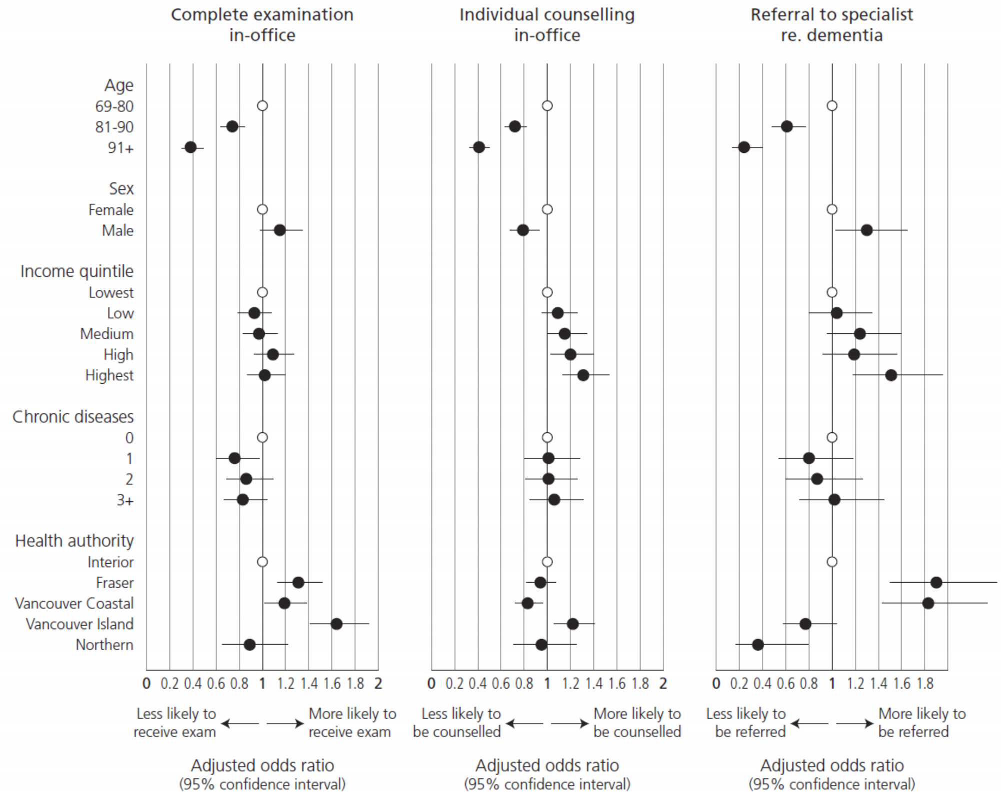


Figure 5.4C – Adjusted odds ratio of receiving a physical exam, counselling or specialist referral



Similar to age, there is a gradient by income. After adjusting for other characteristics, those in the medium, higher and highest income categories had higher odds of receiving individual counselling in-office (1.15, 1.20 and 1.31 respectively) compared to those in the lowest income category (Figure 5.4C). Individuals in the highest income category had higher odds of receiving a specialist referral (1.51 CI 1.18-1.95) with a 4% difference in proportion compared to those in the lowest income category. They also had higher odds of receiving an AChI (1.34 CI 1.14-1.56), but lower odds for all other prescriptions of antipsychotics (0.79 CI 0.67-0.93), trazodone (0.71 CI 0.54-0.92) and antidepressants (0.85 CI 0.73-1.00) (Figure 5.4B). Of note, individuals with dementia and other co-morbidities had significantly higher odds of receiving antidepressants, particularly those with three or more co-morbidities (4.10 CI 3.18-5.28) compared to individuals with dementia and no co-morbidities.

Despite having the smallest population, the Northern health authority had the highest proportion of individuals receiving laboratory tests and head CTs compared to the other health authorities (Figure 5.3A) with higher odds for both processes compared to the Interior health authority (Figure 5.4A). The Fraser health authority, which contains a major urban centre, had a significantly higher proportion of seniors receive an AChI (43%) with a 12% difference and an odds ratio of 1.61 (CI 1.40-1.85) compared to the reference (Figure 5.3B, Figure 5.4B). Conversely, individuals in the Fraser (0.78 CI 0.68-0.91), Vancouver Coastal (0.81 CI 0.70-0.94) and Vancouver Island (0.84 CI 0.71-0.97) health authorities (all with major urban centres) had lower odds of receiving an antipsychotic compared to the Interior health authority reference. The Fraser (0.83 CI

0.71-0.96) and Vancouver Coastal (0.69 CI 0.59-0.81) health authorities also had a lower odds for receiving a benzodiazepine.

5.4 Discussion

There is significant variation in the proportion of individuals newly diagnosed with dementia who receive guideline-consistent dementia care. In a universal healthcare system like Canada's where there are no explicit financial barriers to care, this variation is still associated with income and geography, as well as age and sex. These results are consistent with those reported elsewhere [31,155,192]. However, to the best of my knowledge, this is the first study to use administrative data to capture provision of clinical services at a population-level to all seniors newly diagnosed with dementia and to assess the full scope of dementia care processes.

I find that the magnitude of variation for what may be considered essential dementia care processes, such as regularly administered laboratory exclusionary tests (except calcium and vitamin B12) and head CTs, is comparatively small. As expected, at least 60% of patients received these care processes. This is also not surprising as over 75% of the individuals had two or more chronic diseases and would have received many of the laboratory tests or a CT scan as part of standard diagnostic protocol in cases involving multiple concurrent chronic conditions. However, this is not the case for more discretionary but equally important processes, such as a complete examinations in-office, in-office counselling and specialist referrals. It is expected that dementia care management processes such as these, particularly counselling, should have a smaller magnitude of variation. Counselling is essential for lowering anxiety and preparing the patient and family for what to expect in light of such a devastating diagnosis. Given that physician-reported barriers to provision of dementia care highlight insufficient time, difficulty in accessing specialists, and lack of expertise as key constraints, the magnitude of variation is unsurprising [70,71].

Age significantly influences many of the dementia care processes assessed in this study. Given the increased probability of concurrent multiple chronic disease with advanced age, physicians may be less inclined to do extensive laboratory test or CTs on patients as they get older due to complications and unnecessary hardship. However this rationale does not hold for the absence of counselling or specialist referrals for those of advanced age. Indeed, these processes should be provided, particularly in the case of multiple co-morbidities, to better explore and alleviate potential medication interactions, complex symptoms and develop strategies to cope [4]. One possibility is that of age discrimination in practitioners' attitude toward providing early diagnosis and broader interventions to older individuals. This has been described previously as a barrier to provision of good dementia care with physicians' negative perceptions in diagnosing dementia being associated with therapeutic nihilism, stigma and ageism[41,228]. Second is the lack of time to appropriately support older individuals with more complex symptoms and difficulty accessing specialists with limited availability[41,71]. An alternate possibility is that the severity of dementia at diagnosis, which I was unable to measure, may play a role in mediating the relationship between age and the management care processes.

I also find a pattern of inequality, in which seniors newly diagnosed with dementia in higher income categories had significantly higher odds of receiving individual counselling and referrals compared to those of lower income. However it is impossible to know if this pattern arises because of patient health seeking behaviour where those with higher education are associated with asking for services [204] or because of a bias in physician behaviour. Insofar as income is unrelated to patient need for services, these observations deserve further attention.

Variations in use of medications recommended for dementia are more nuanced. Consistent with earlier work, a lower percentage of seniors newly diagnosed with dementia receive recommended AChIs [143]. This discretionary prescription practice may be related to cautions both in the guidelines and literature around the small to modest benefits of AChI over short durations, the side effects and potential polypharmacy associated with their use in individuals with higher co-morbidity [229–231]. Receipt of AChIs is influenced by income with individuals in higher income categories having higher odds of receiving AChIs. Coverage of AChI in BC is only available under a program designed to provide coverage of AChIs to patients with mild to moderate Alzheimer's Disease who also agree to participate in a research study to assess the clinical effectiveness of AChIs [134]. Therefore, for all other individuals with dementia, use of AChIs would be an out-of-pocket expense, explaining the income related variation.

In contrast, I find a higher than expected percentage of seniors with dementia receiving antidepressants, antipsychotics and non-recommended benzodiazepines. The off-label use of antipsychotics and benzodiazepines to treat behavioural and psychological symptoms of dementia has been shown to have low efficacy at best and to introduce significantly increased risk of adverse effects at worst [232,233]. Use of atypical antipsychotics in seniors with dementia comes with a black box warning, but there is also no evidence that typical antipsychotics and benzodiazepines mitigate the risk of death in dementia any better than atypical antipsychotics [231]. The guidelines recommend extreme caution when prescribing antipsychotics and only when alternate options to control these behavioural symptoms such as environmental (identifying potential triggers during meal or bath times) or psychosocial interventions (music, pet therapy, light exercises) are inadequate [122]. I measure use of these drugs among patients in the early stages of a diagnosis of dementia, during which neuropsychiatric symptoms have generally not fully manifested, who should not require the use of these therapeutics, that is, unless diagnosis has been delayed and the dementia has progressed in severity or these drugs prescribed for a different condition. Yet I find that over one quarter of seniors newly diagnosed with dementia receive an antipsychotic (28%) and/or benzodiazepine (26%). Additionally, individuals in low-income categories and living within health authorities with smaller urban centres (and less access to specialists/family physicians) were more likely to receive antipsychotic treatment. I noted a similar geographic trend with the variation in benzodiazepine use. Use of these drugs should be sporadic, short-term and infrequent in this population. These trends are an indication of larger issues within a healthcare system with drugs substituting for other forms of more appropriate non-pharmacological care.

5.4.1 Limitations

There are some limitations to this analysis. I am not able to account completely for patient need, including assessing dementia severity; nor can I completely account for psychiatric illness, co-morbidities, or patient preferences for care, health seeking behaviours or health goals. To the extent that variation is the result of clinical assessment of need (which may be the case considering age, sex and co-morbidities) variations may be appropriate. However the full magnitude of variation by age, as well as those observed by income and geography, are unlikely to be explained by patient need or preference and merit further investigation. I was also unable to measure cognitive testing which is a key component of the diagnostic process and has been shown previously to have significant variation [31]. Administrative data cannot shed light on the important behavioural management aspects of dementia care. Lastly, I was unable to measure referrals to community care, mental health or speciality services which are invaluable resources for both patients and their caregivers to meet the long-term psychosocial management needs of dementia. These services are able to provide specialized education and support to patient and physicians, though I do not anticipate that this should affect receipt of other guideline-recommended services.

Programs for pharmaceutical coverage in BC also complicate interpretation of findings with respect to income and pharmaceutical use. For example, Fair Pharmacare is an income-related program which could contribute to the income-related variation in the use of other drugs assessed in this study. While the BC guidelines and national Canadian guidelines have almost identical recommendations, unlike the BC guidelines, the national guidelines do recommend the short-term use of benzodiazepines for behavioural-related symptoms. In both cases, recommendations are based on management of dementia alone, despite the fact that co-morbidity is high in this patient population.

5.5 Conclusion

The systematic review from Chapter 2 demonstrated that self-reported dementia care practices amongst physicians have wide variability, particularly for use of a formal memory test, therapeutics and making referrals to specialists or community services. The findings here, based on analysis of administrative data, are consistent with those earlier conclusions. I found wide variation in use of pharmacological interventions, particularly those not recommended for dementia patients, and in specialist referrals along with in-office examinations and counselling. In particular, I observe patterns of antipsychotic and benzodiazepine prescription that are indicative of their use as substitutions for other types of non-pharmaceutical care. Encouragingly, several other dementia care processes such as exclusionary blood work and imaging had relatively high proportions of use with less variation.

There is no expectation that everyone will receive all guideline-recommended care because of differences in needs based on personal circumstances and the severity of dementia when it is diagnosed. Of more interest are the variations I find in use of services across patient characteristics. These differences unrelated to patient need say more about equity in health care services use. Patterns of inequality by age, income and geography may signal barriers to care, particularly for the management of dementia care processes such as counselling and referral to specialists.

These results add to our understanding of actual physician dementia practice patterns and highlight the gap between actual practice and guideline-recommended care. This has important implications as it corroborates the qualitative literature around barriers to providing good dementia care including time constraints during appointments, problematic attitudes resulting in age discrimination, lack of interdisciplinary teams and difficulty accessing community resources [41,71] resulting in patterns of inequity. Physician education that goes beyond the pathophysiology and pharmacological treatment of dementia as a disease and instead emphasizes dementia as a chronic, complex condition which can benefit from timely diagnosis, comprehensive biopsychosocial treatment and management would play an essential role in reframing physicians' approach. At a policy level, these results indicate the need to recognize that primary care physicians alone may not be able to provide adequate care and the need for integration across care systems to adequately support patients. The next step in this analysis will be to examine the association between receipt of dementia care processes and health outcomes. Chapter 6 will provide more detailed descriptives on the health outcome of interest, transitions, before I model associations in Chapter 7.

CHAPTER 6 – IDENTIFYING POINTS OF CARE WHEN TRANSITIONS ARE HIGHEST AND THE FACTORS THAT CONTRIBUTE TO THEM

6.1 Introduction

A transition is defined as a physical move to a formal acute or community-based healthcare institution other than the home with a stay of at least one night[10]. A greater number of transitions between care settings poses a serious challenge to continuity of care and the safety of the patient and is associated with medication errors, preventable hospital readmissions and increased mortality risk [13–17]. Safety challenges are compounded by symptoms of dementia such as disorientation and behavioural outbursts, and these are potentially exacerbated and if a caregiver is not present to assist in the patient's transitions [12,35]. Particularly important is the fact that the overall number of transitions experienced is higher for people with dementia compared to those without dementia [37]. Guidelines for good dementia care stress the need for continuity and familiar environments which cannot be consistent with a higher number of transitions [10,11,22,26].

Given the adverse outcomes associated with transitions, particularly for dementia patients, surprisingly few studies have examined the longitudinal dynamic of transitions between home, hospital, respite care and LTC facilities experienced by individuals with dementia [10,12,37] and only one has done so beginning in the year in which a diagnosis of dementia was first established[37]. Individuals newly diagnosed with Multiple Sclerosis and Parkinson's disease have been shown to experience peaks in healthcare utilization and transitions in the year of diagnosis[234–236]. Individuals with dementia also shows peaks in use, but this has not been examined specifically in the year of diagnosis[37]. Research literature on end-of-life has demonstrated that individuals living in the community with dementia experience 32% more care transitions than those without dementia in the two years before death [10]. As outlined in my conceptual framework in Chapter 2, Section 2.7, age, gender, morbidity[10,15,237], behavioural symptoms associated with dementia[238] and the presence of a caregiver[35,100] are thought to affect the number and type of transitions, Yet none of the studies that have longitudinally described transitions have examined these factors.

Examining transitions experienced longitudinally has the potential to identify points of care when transitions are highest and the factors that contribute to those transitions. Understanding these patterns can help assess the relationship between receipt of care and outcomes and can identify possible points of intervention to reduce transitions. My research questions are:

Research Question 3a: What is the rate of transitions experienced over the study period and what are the points of care during which transitions are highest?

Research Question 3b: Are there individuals who consistently experienced a high number of transitions and if so what are their characteristics?

Research Question 3c: What are the types of transitions experienced and what factors influence these transitions?

Research Question 3d: What factors influence the number of transitions during the peak points of care and overall?

I hypothesize that:

i) The number of transitions experienced will be higher at the point of diagnosis and at the end-of-life compared to the time period after diagnosis and before their end-of-life;

ii) The individuals who consistently experience a high number of transitions will have a high number of co-morbidities in addition to dementia and behavioural symptoms of dementia compared to those with a low number of transitions;

iii) Hospitalizations will drive transitions, but a large proportion of the cohort will also move to LTC. Age, morbidity and behavioural symptoms will be the factors associated with hospitalizations or a move to LTC. The lack of a caregiver will be significantly associated with a move to LTC but not hospitalizations;

iv) The factors associated with a higher number of transitions will be age, gender (male), morbidity, behavioural symptoms of dementia and the lack of a caregiver both during the peak points and overall.

6.2 Methods

I analyzed eleven years of retrospective health care administrative data (April 2000/01 to March 2011) for a cohort of individuals newly diagnosed with dementia in 2001/02.

6.2.1 Data Sources

All seven databases described in Chapter 4 were used for this analysis. That includes: 1) the central consolidation file 2) the medical services plan (MSP) payment file

3) Hospital abstract data 4) Vital statistics death file 5) Home and Community Care data 6) PharmaNet file 7) the College of physicians and surgeons of BC file.

6.2.2 Study Population

Cohort 1, described in Chapter 4 section 4.3.1 was used for this component of the project. Briefly, these were all seniors in BC, 65 years and older, with a new diagnosis of dementia in fiscal year 2001/02, followed backward one year (April 2000) and forward until death or the end of the study period (March 2011). A wash-in period of two years was used to ensure no other dementia diagnoses occurred and that new incident cases were being captured[5]. Individuals were excluded if they were not registered for health care coverage for the whole study period (prior to death) or if they were not an incident case in 2001/02, i.e. if they had dementia diagnoses during a 2-year wash-in period (April 1999 – April 2001).

6.2.3 Primary Outcome – Transitions

Care transitions are defined as a physical move from one location to another with a stay of at least one night. Only transitions between among, publicly-funded respite care, Assisted Living, LTC and hospitals were included. Outpatient care or moves between in-patient wards of the same facility were excluded, consistent with prior literature[10,37]. These variables were calculated on an annual fiscal year basis for each year of the study period (2000/01 – 2010/11) during which the participants were alive.

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[5] While the cohort was only followed backward one year for analysis, incidence was determined based on a two year wash-in period, accessing data from 1999/2000

6.2.4 Explanatory Variables

I examined the association between the number of transitions experienced and the following patient variables: age; sex; neighbourhood income quintile; health status (measured by number of major ADGs, described in detail below); caregiver proxy status (identified using a shared MSP id variable in the consolidation file, described in detail in Chapter 4, Section 4.2.1); health authority of residence (described in detail in Chapter 4, Section 4.4.1); and the presence of treated behavioural symptoms (measured by a prescription of an antipsychotic or benzodiazepine, described in Section 4.4.1). Further analysis demonstrated that 45% of those in the cohort prescribed a benzodiazepine in the year of diagnosis had not received a prescription for a benzodiazepine at any point in the three previous years. This suggests the prescription in the year of diagnosis was likely related to the dementia diagnosis (data not shown). Fifty-five percent had at least one prior prescription and 28% a prescription in all three years preceding diagnosis, indicating long-term use for reasons unrelated to dementia (such as anxiety or insomnia).

In addition to patient-level variables, I adjusted for physician practice variables including the number of years the physician had been practicing, the number of patients over the age of 65 in the practice, and the number of dementia patients in the practice. These were attributed to the patient-level data based on the physician providing plurality of care, described in detail in Section 4.4.1.2.

Patient health status was defined in two different ways. As previously described, these were to 1) count the occurrence of the ten most prevalent chronic conditions in seniors [65] measured by the presence of at least two physician diagnoses for that condition over a two-year period; and 2) count the number of major conditions (adjusted for in regression analysis), using the Johns Hopkins Adjusted Clinical Group Case-Mix system, described in Chapter 4, Section 4.4.1.1.

6.2.5 Statistical Analysis

Characteristics of the patient cohort are described using counts and percentages. The mean annual number of transitions experienced during the entire study period, total number of care transitions, average rate of transitions per year alive, percentage of participants who experienced transitions, hospitalizations, LTC moves, second LTC moves and the length of stay in hospital are reported.

The data were analyzed using negative binomial regression to account for over-dispersion for two outcomes: a) the number of transitions experienced in the year of diagnosis and b) the number of transitions experienced over the entire study period. Zero-inflated Poisson analysis and standard Poisson analysis were used for the remaining two outcomes respectively: c) the number of hospitalizations experienced in the year of diagnosis; and d) the number of moves between LTC facilities experienced in the year of diagnosis.

The choice of models in each case was determined empirically. The mean and variance for each outcome variable was first assessed to determine if they fit Poisson assumptions of the mean being equal to the variance. A histogram of each outcome variable was graphed to determine its distribution. An exploratory Poisson regression model was run for all four outcomes and the Pearson Chi-Square goodness-of-fit test used to measure the distribution of the outcome variable. When the Pearson goodness-of-fit test results were significant (indicating that the distribution of the outcome variable differs significantly from a Poisson distribution), other models were considered. Larger standard errors and wider confidence intervals were also assessed as those indicate the Poisson model did not fit the data.

If the distribution of the outcome variable showed an excess of zero counts, a zero-inflated Poisson regression model was employed with the option of robust standard errors. The Vuong test was used to measure if a zero-inflated model was better than an ordinary Poisson regression model. In other cases, a negative binomial model was used and the Likelihood Ratio test was used to measure if this distribution was a more appropriate fit than Poisson (a large test statistic and an alpha significantly different from zero would suggest the outcome is over-dispersed and a simpler Poisson distribution is not sufficient). Finally, in all cases, model fit was determined by the adjusted coefficient of determination (R^2), indicating how much of the variance in the data is accounted for by the model. The data was formatted with time, counted as months from the diagnosis to death. All models adjusted for individual characteristics, death and physician practice variables except for when modelling the total number of transitions experienced over the study period as it was not possible to accurately attribute a single physician who provides plurality of care over the entire study period. Analyses were performed using STATA, version 10 [227].

6.3 Results

6.3.1 Baseline Characteristics

In BC, 6876 individuals were newly diagnosed with dementia in 2001/02. The cohort had a mean age of 82.3 ± 6.96 years upon entry, was primarily female (62%) and had a median average income quintile of 2.8 ± 1.5 (where 1 indicates low and 5 indicates high, Table 6.1). Over one-third of the cohort received their diagnosis of dementia in hospital, either through a dementia hospital code alone or a combination of hospital and one MSP code (37%) (Figure 6.1). Just under a quarter (23%) of the cohort had no evident chronic disease other than dementia, while 44% had two or more chronic diseases with an average of 2.6 ± 1.3 major ADGs (including dementia), indicating a somewhat high needs population. At the time of entry, 75% of the cohort were living in the community and were fairly evenly dispersed across the health authorities, except for the Northern health authority which contained 3.8% of the cohort, consistent with its small population size. Within the first year 18% of the cohort died and more than 50% died by year 4 (Figure 6.2).

Table 6.1 – Baseline characteristics of individuals newly diagnosed with dementia in 2001/02

Characteristics	**Patients with Dementia** (n=6,876)
Age in years (mean± SD)	82.3 ± 6.9
65-75	17.4%
76-85	47.9%
86+	34.7%
Sex*	
Male	37.7%
Female	62.0%
Income Quintile (mean± SD)*	2.8 ± 1.5
1- Lowest income	24.8%
2- Lower income	19.4%
3- Medium income	16.8%
4- Higher income	15.6%
5- Highest income	17.1%
Multiple chronic disease (not including dementia)	
0 chronic diseases	23.1%
1 chronic disease	32.9%
2 chronic diseases	25.3%
3+ chronic diseases	18.7%
Number of major ADGs (mean± SD)	1.5 ± 0.7
Treatment Prevalence of major chronic diseases (other than dementia)	
Hypertension	36.4%
Depression	21.3%
Arthritis or Osteoarthritis	18.1%
Cancer	16.8%
Congestive heart failure	14.8%
Diabetes	13.9%
Cardiovascular disease	12.3%
Stroke	5.3%
Chronic obstructive pulmonary disease	4.2%
Chronic kidney disease	1.3%
Liver disease	0.3%
Living in a LTC Facility	
Yes	11.2%
No	88.8%

Characteristics	Patients with Dementia
Health Authority*	
Interior	18.9%
Fraser	26.1%
Vancouver Coastal	26.7%
Vancouver Island	24.4%
Northern	3.8%

*Missing data: Sex unknown=26, Income unknown=430, Health Authority unknown=45

Figure 6.1 – Location of diagnosis of dementia (Cohort 1)

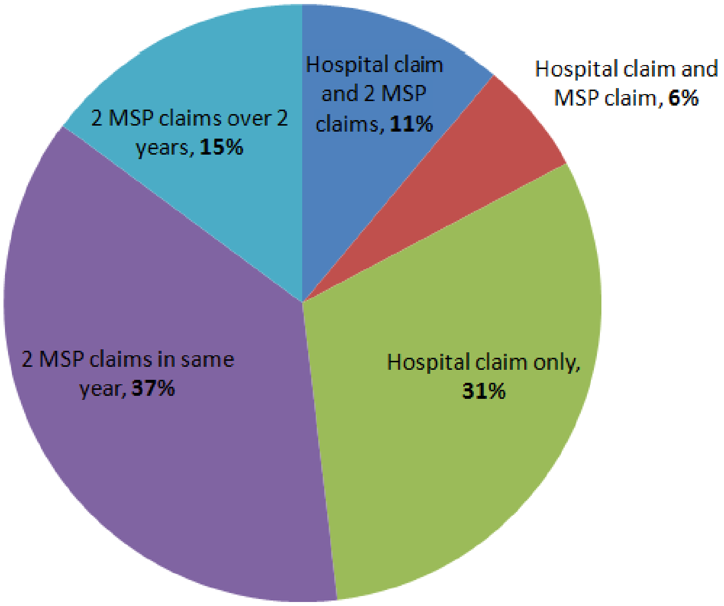
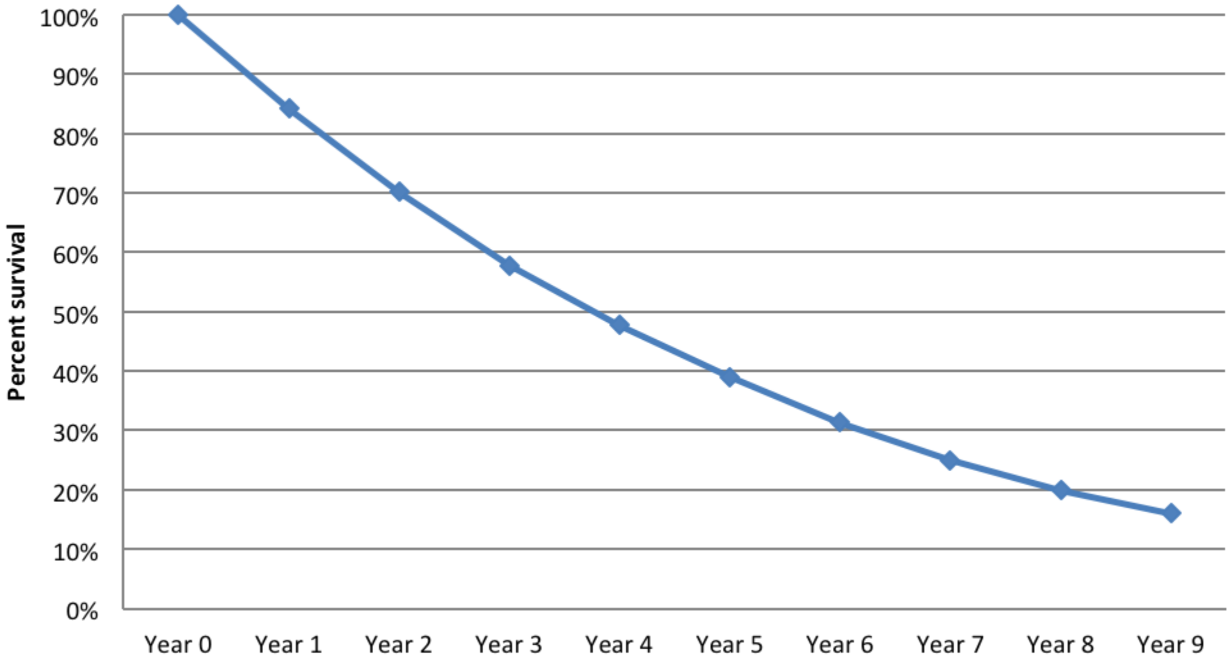


Figure 6.2 – Survival curve of cohort



6.3.2 Aggregate Healthcare Use and Transitions

Table 6.2 shows aggregate healthcare use during the entire period. On average, participants survived a relatively short period after diagnosis (median 4.6 years), experiencing a mean of 3.7 (± 2.9) transitions, or a rate of about one transition per year alive (0.9 ± 0.8 transitions) (Table 6.2). Almost 90% of the cohort experienced a hospitalization at some point during their trajectory, with a median of 32 accrued hospital days.

Table 6.2 – Transitions and healthcare use during the entire study period

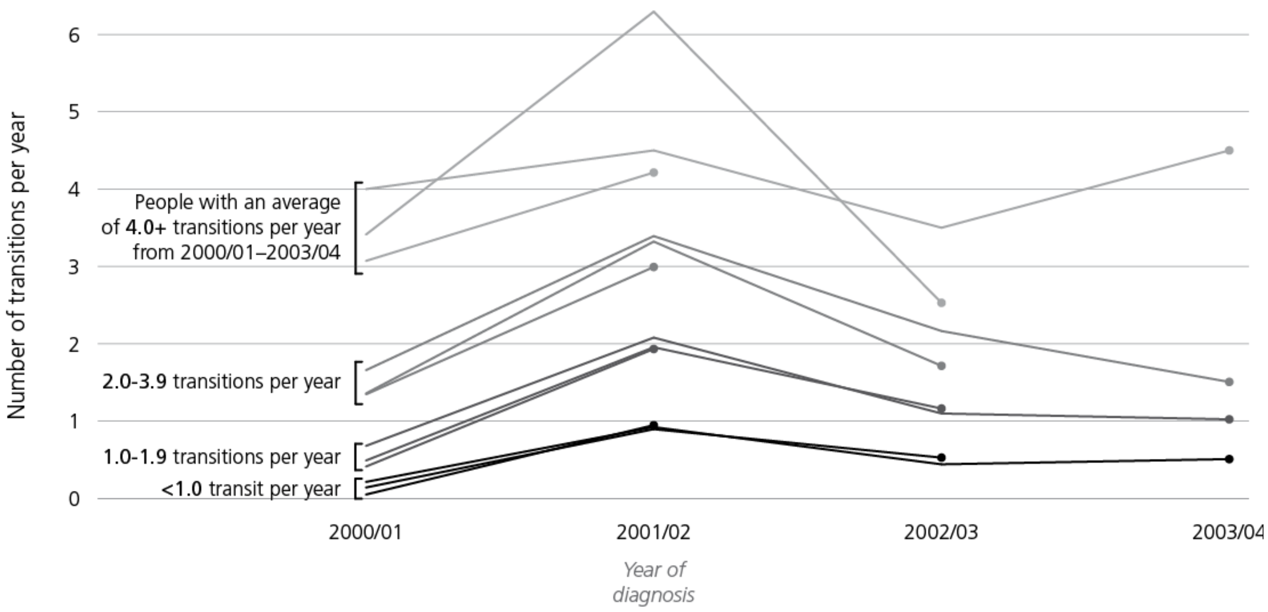
Use	Total Sample (n=6,876)
Total transitions (mean ± SD; median)	3.7 ± 2.9; 3.0
Total years alive (mean ± SD; median)	5.2 ± 3.2; 4.6
Transitions per year alive (mean ± SD)	0.9 ± 0.8
Participants who experienced a transition	94.6%
Participants who died (%)	83.9%
Participants with any hospital stay (%)	87.5%
Total hospital days accrued (mean ± SD; median)	50.1 ± 58.0; 32.2
Patients with LTC use (%)	57.6%

When the cohort was stratified by the rate of transitions experienced per year alive, 5% experienced no transitions while 1% experienced 4 or more transitions per year alive (Table 6.3). Participants who experienced 4 or more transitions per year alive had shorter survival post-diagnosis than those with fewer transitions (2.0 ± 1.2 years), had higher needs (3.6 ± 1.2 major ADGs), a majority had behavioural symptoms of dementia (70% received a prescription for an antipsychotic or benzodiazepine), 42% had a caregiver and only 29% remained in the community over the study period. Conversely, participants who experienced no transitions during their life time survived on average for 5.3 ± 3.6 years, had fewer major ADGs (1.7 ± 1.0), only 34% received a prescription for an antipsychotic or benzodiazepine, 31% had a caregiver and 62% remained in the community over the study period. Examined further, participants categorized by the *average* rate of transitions experienced over their time alive consistently remained in that category even when examining total transitions they experienced in each year (Figure 6.3). For example, individuals categorized into the high average transition category (4+ transitions) had a high number of total transitions (between 3 to 6 transitions) in each year that they survived, not just an overall high average (Figure 6.3).

Table 6.3 – Cohort characteristics stratified by rate of transitions

	No transits (n=375)	**≤1 transit/yr** (n=4279)	**>1-≤2 transits/yr** (n=1586)	**>2-≤4 transits/yr** (n=572)	**4+ transits/yr** (n=64)
% of cohort	5%	62%	23%	8%	1%
Age (mean ± SD)	82.9 ± 8.0	83.0 ± 7.0	82.7 ± 6.7	82.8 ± 6.6	82.5 ± 7.8
Gender (% female)	69%	65%	56%	53%	53%
Years alive (mean ± SD)	5.3 ± 3.6	6.2 ± 3.1	3.6 ± 2.2	2.6 ± 1.3	2.0 ± 1.2
No. major ADGs	1.7 ± 1.0	2.3 ± 1.2	3.1 ± 1.3	3.6 ± 1.3	3.6 ± 1.2
Prescription of antipsychotic or benzo (%)	34%	43%	56%	62%	70%
Has a caregiver (%)	31%	38%	35%	38%	42%
Remained in community (%)	62%	52%	26%	20%	29%

Figure 6.3 Transitions rate in each year for those with <1.0, 1.0-1.9, 2.0-3.9 and 4.0+ average transitions per year for 2001/02-2003/04, by year of death (up to 2003/04)



6.3.3 Transitions during Year of Diagnosis

Over the study period, individuals experienced a high number of transitions during the year of diagnosis, regardless of survival time (Figure 6.4A). Sixty-six percent of the cohort experienced at least one transition, while 17% of the cohort experienced 3 or more transitions that year (Appendix Table D.1). The transitions were primarily driven by hospitalizations (Figures 6.4B, 6.4C).

Figure 6.4A – Transition rates over time for those diagnosed in 2001/02, by year of death

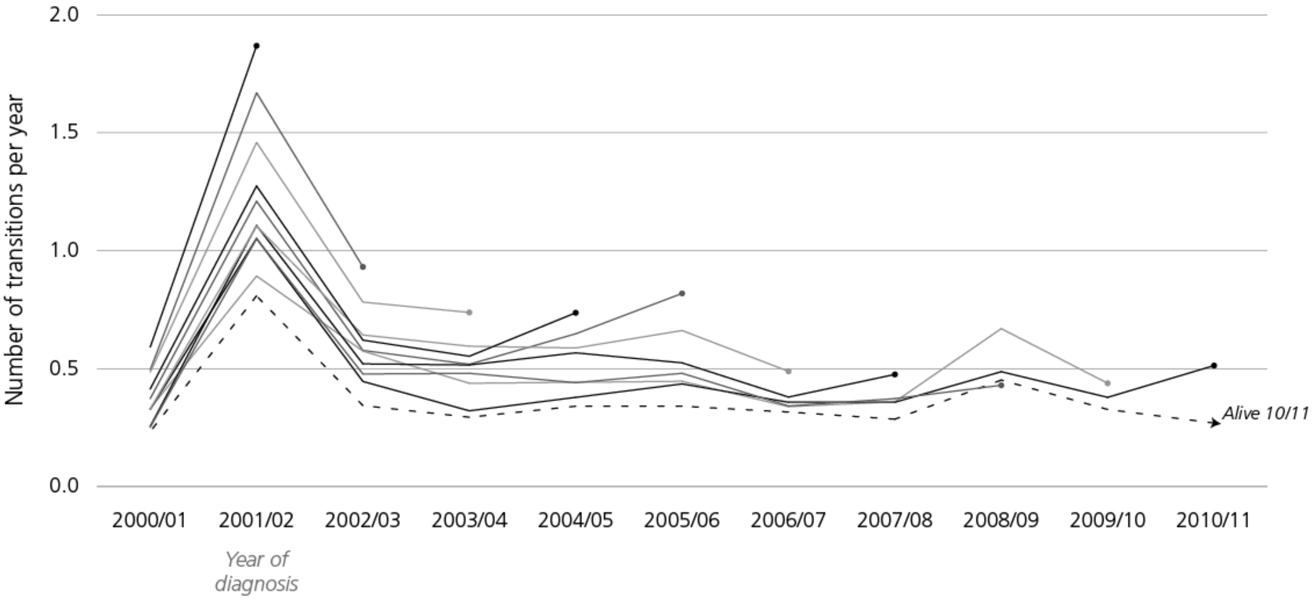


Figure 6.4B – Hospitalization rates over time for those diagnosed in 2001/02, by year of death

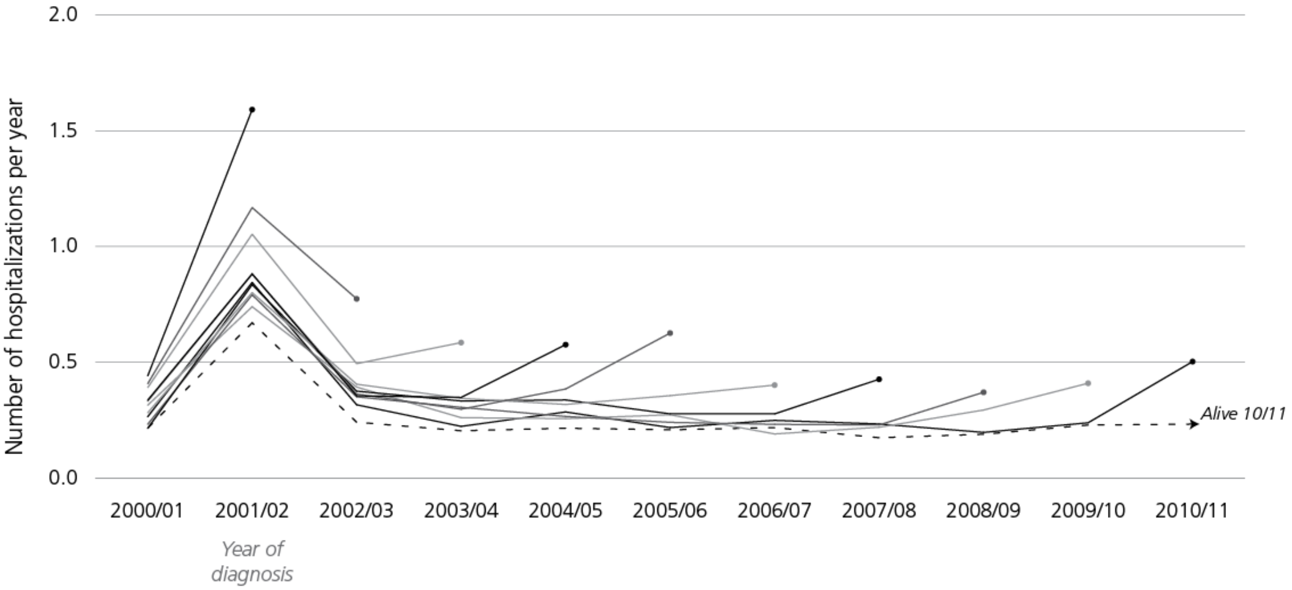
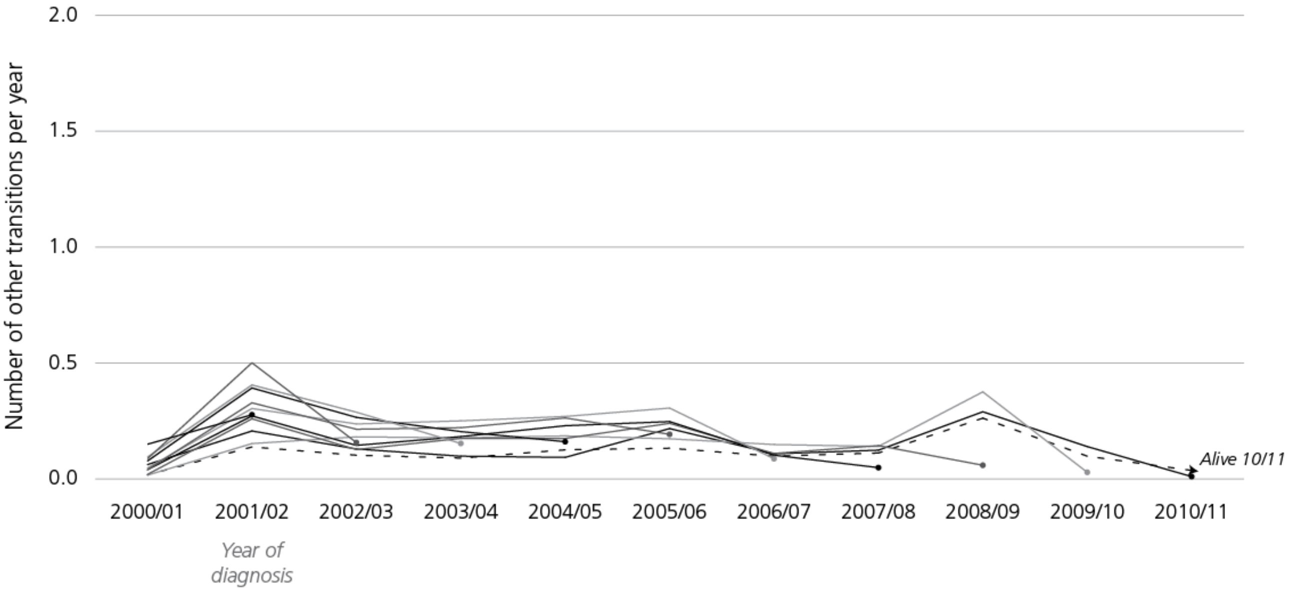


Figure 6.4C – Other transitions over time for those diagnosed in 2001/02, by year of death

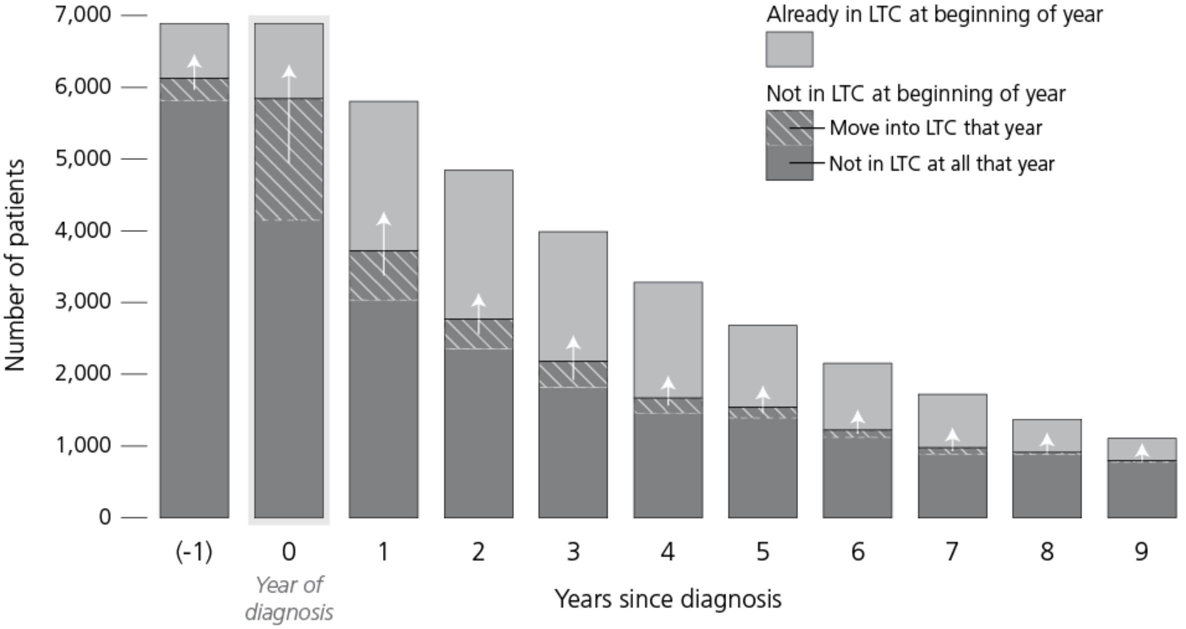


Over 60% of the cohort experienced a hospitalization in the year of diagnosis with a length of hospital stay of 41.7 ± 49.5 days (median 25 days). Over one third of the cohort was identified based on dementia hospital codes only, or a hospital and one MSP code (Figure 6.1). Of this group, only 15% received dementia as a principal diagnosis when hospitalized (Appendix Table D.2). The remainder received a secondary diagnosis of dementia but were hospitalized for other reasons with the most frequent three being a fractured femur (9%), pneumonia (5%) and heart failure (4%) (Appendix Table D.2). Excluding this group, the average number of transitions in the year of diagnosis was 1 where 49% of the cohort diagnosed in the community experienced at least 1 transition and 12% experienced 3 or more transitions (data not shown).

Looking a little more closely at those who did not receive their initial diagnosis of dementia in hospital, a quarter made their first move to LTC in the year they received their diagnosis. Of these movers, those who experienced a hospitalization had a mean length of stay in hospital of 51.4 days while those who did not move to LTC that year had a mean length of stay in hospital of 29.7 days (data not shown). In comparison, for those who received their initial dementia diagnosis in hospital, 36% made their first move to LTC in the year they received their diagnosis and had a mean hospital length of stay of 58.6 days (data not shown). Those in this group that did not move to LTC had a mean hospital length of stay of 29.3 days (data not shown).

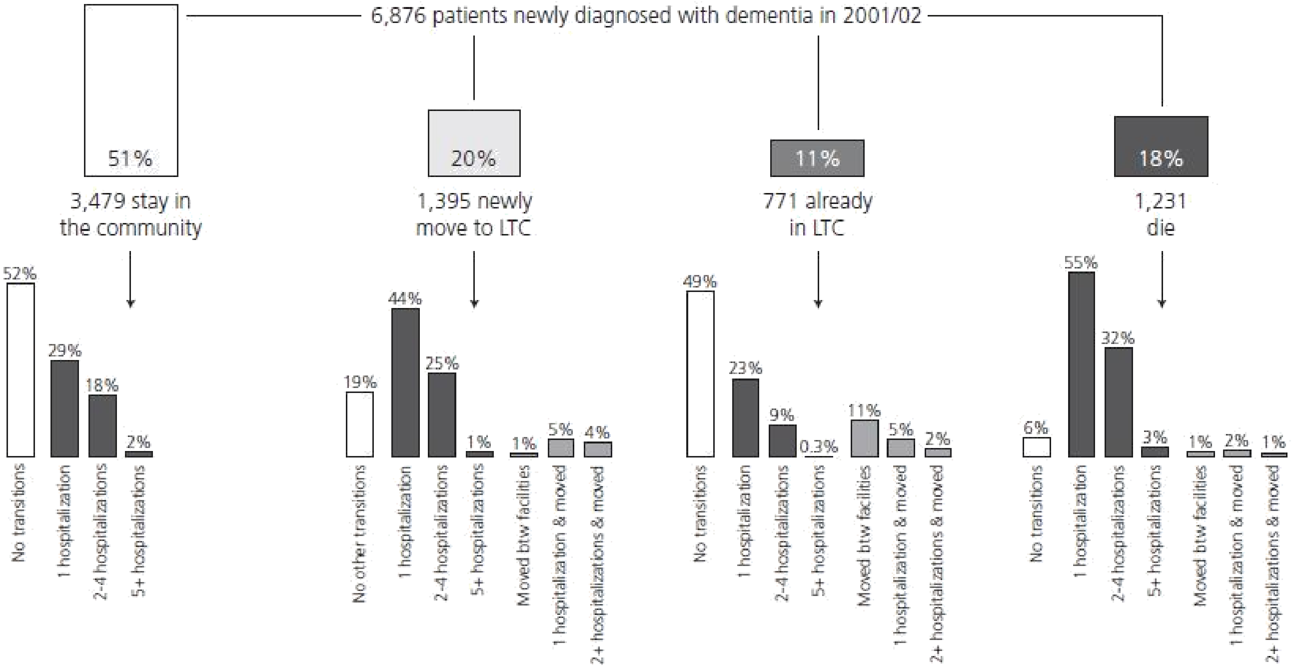
The risk of moving to a LTC facility was highest early in the care trajectory, specifically during the year of diagnosis, and diminished markedly over time (Figure 6.5). Indeed, the longer individuals survived post diagnosis, the less likely they were to end up in LTC, though survivorship bias needs to be considered as individuals with a better health status may be more likely to survive longer and remain in the community.

Figure 6.5 – Number and proportion of those eligible moving from community to LTC, by years since diagnosis



About half of those who remained in the community experienced a hospitalization, while 1 in 5 of those in the community experienced at least one re-hospitalisation (Figure 6.6). Among those who newly moved to LTC in the year of diagnosis, only 19% experienced no other transition while most patients had two (45%), three to five transitions (30%), or more (5%) transitions including re-hospitalizations and moves between LTC facilities (Figure 6.6). Of the 11% who were already in LTC when they received their diagnosis, just under half had no transitions, while almost 1 in 4 individuals were hospitalized. Over 10% experienced re-hospitalizations and 11% were transitioned to a different care facility, despite being in LTC when they received their diagnosis. Of the 18% of the cohort that died in the year of diagnosis, the majority experienced a transition (55%) and a further 36% experienced re-hospitalizations (Figure 6.6). Stratified by location, half of the cohort remained in the community during the year of diagnosis.

Figure 6.6 – Frequency of different transition types experienced by newly diagnosed dementia patients



6.3.4 Transitions at End-Of-Life

Participants who survived longer over the ten-year study period had fewer transitions and hospitalizations over time (Figures 6.4A, B). However, regardless of survival time, participants not in LTC facilities experienced a marked increase in hospitalizations in the year prior to and the year of death, often exceeding hospitalizations in the year of diagnosis (Figure 6.7A). Further, those with a high number of major ADGs experienced a significant increase in hospitalizations regardless of whether they lived in a LTC facility or in the community, whereas those who had no major ADGs other than dementia did not experience this increase at end-of-life. This suggests that it is not dementia alone, or even primarily, that drives hospitalizations at end-of-life (Figure 6.7B).

Figure 6.7A – Hospitalization rate over time for those diagnosed in 2001/02, by LTC status and year of death

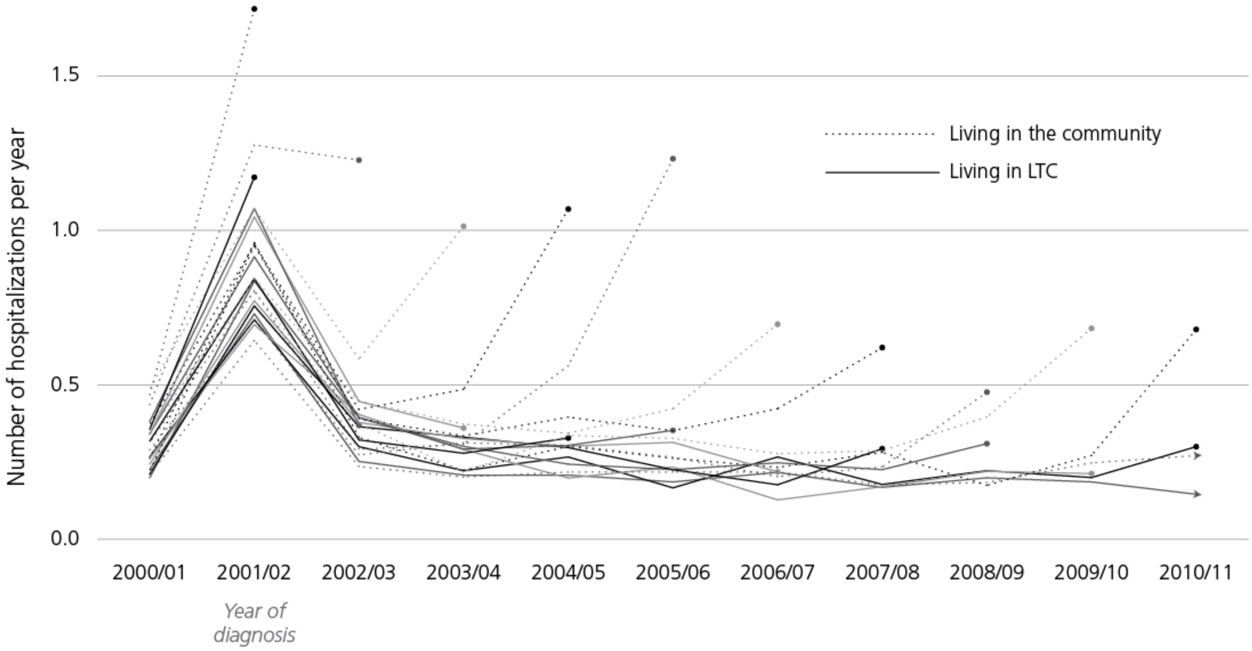
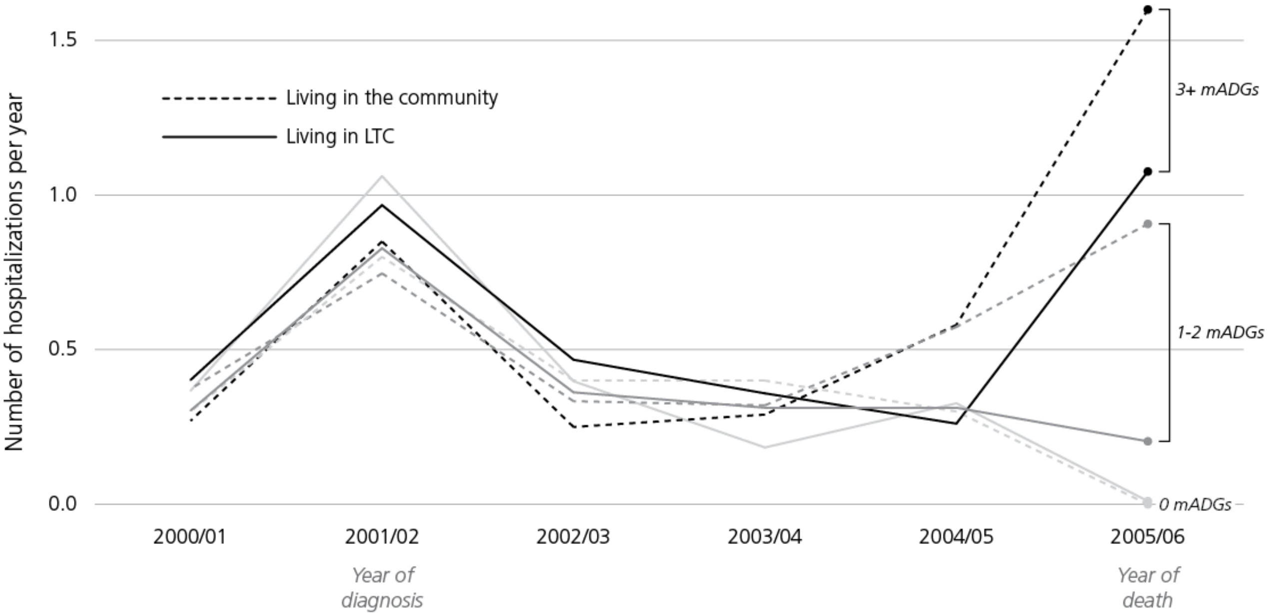


Figure 6.7B – Hospitalization rate over time for those diagnosed in 2001/02, by LTC status and number of major ADGs



6.3.5 Factors Associated with Transitions

Multivariate analyses showed that the patient factors associated with a higher rate of transitions in the year of diagnosis (after adjusting for physician practice patterns and death) were: poor health status, age (older experienced more transitions, except the oldest old), residing in health authorities with small urban centres, and at least one prescription for a benzodiazepine or antipsychotic prescription drug (Table 6.4). Multivariate analysis for the overall rate of transitions experienced over the entire study period demonstrated that age was no longer significant, but all previously identified factors associated with transitions in the year of diagnosis still were, with the addition of gender (being male).

Looking at hospital transitions more specifically, poor health status, residing in health authorities with small urban centres and receipt of a prescription for a benzodiazepine were all associated with a higher rate of hospitalizations in the year of diagnosis (Table 6.4). Neither age nor gender was significant. For transitions between LTC facilities, poorer health status and living in rural health authorities continued to be associated with a higher number of transitions between LTC facilities. However, age (being older) and receipt of a prescription of benzodiazepine or antipsychotic drug were also associated with transitions between LTC facilities. The presence of a caregiver was associated with fewer transitions between LTC facilities (Table 6.4).

Table 6.4 – Multivariate regression analysis examining patient and practice factors associated with transitions experienced

	Transitions in Year of Diagnosis	Transitions over Years Alive ^{NB1}	Hospitalizations in Year of Diagnosis	Moves between LTC in Year of Diagnosis
PATIENT VARIABLES				
Number Major ADGs				
None	Reference	Reference	1.4 (1.3-1.4)‡ ^{NB2}	Reference
1-2	2.6 (2.0-3.4)‡	1.4 (1.2-1.5)‡		1.2 (0.9-1.6)
3-4	5.8 (4.5-7.5)‡	2.3 (2.0-2.5)‡		1.6 (1.2-2.2)‡
5+	8.1 (6.2-10.5)‡	3.1 (2.7-3.5)‡		1.8 (1.3-2.5)‡
Age				
65-75	Reference	reference	Reference	Reference
76-85	1.1 (1.0-1.2)‡	1.0 (0.9-1.1)	1.0 (0.9-1.1)	1.3 (1.2-1.6)‡
86-95	1.2 (1.1-1.2)‡	1.0 (0.9-1.1)	1.0 (0.9-.1.1)	1.7 (1.5-2.0)‡
96+	1.0 (0.9-1.2)	0.9 (0.8-1.1)	0.9 (0.7-1.1)	1.7 (1.3-2.3)‡
Sex				
Female	Reference	Reference	Reference	Reference
Male	1.0 (0.9-1.0)	1.1 (1.1-1.2)‡	1.0 (0.9-1.0)	1.0 (0.9-1.1)
Health Authority				
Interior	Reference	Reference	Reference	Reference
Fraser	1.0 (0.9-1.1)	0.9 (0.9-1.0)	1.0 (0.9-1.1)	1.1 (1.0-1.2)
Vancouver Coastal	1.3 (1.2-1.4)‡	1.2 (1.1-1.3)‡	1.2 (1.1-1.3)‡	1.2 (1.0-1.4)†
Vancouver Island	1.0 (0.9-1.1)	0.9 (0.9-1.0)	1.0 (0.9-1.1)	0.9 (0.8-1.1)
Northern	1.3 (1.2-1.5)‡	1.3 (1.2-1.4)‡	1.2 (1.1-1.4)‡	1.0 (0.7-1.3)
Income Quintile				
1- Lowest	Reference	Reference	Reference	Reference
2- Low	1.0 (0.9-1.1)	1.0 (0.9-1.0)	1.0 (0.9-1.1)	1.0 (0.9-1.2)
3- Medium	1.0 (0.9-1.1)	1.0 (0.9-1.0)	1.0 (0.9-1.1)	0.9 (0.8-1.1)
4- High	1.0 (0.9-1.1)	1.0 (0.8-1.0)	0.9 (0.9-1.0)	1.0 (0.9-1.1)
5- Highest	0.9 (0.9-1.1)	0.9 (0.8-0.9)‡	0.9 (0.9-1.0)	0.8 (0.7-0.9)‡
Prescription for benzodiazepine	1.2 (1.1-1.3)‡	1.2 (1.1-1.3)‡	1.2 (1.1-1.3)‡	1.3 (1.2-1.4)‡
Prescription for antipsychotic	1.1 (1.1-1.2)‡	1.1 (1.0-1.1)‡	1.1 (1.0-1.1)	1.6 (1.5-1.8)‡
Presence of a caregiver	0.9 (0.9-1.0)	0.9 (0.9-1.0)	0.9 (0.8-1.0)	0.8 (0.7-0.9)‡

‡ - P value <0.001, † - P value <0.01,* - P value <0.05
NB1: Practice variables were not included in this model
NB2: Was modelled using a zero-inflated Poisson analysis with the number of major ADG variable as continuous
All models controlled for death and physician practice patterns except as noted in NB1

6.4 Discussion

To the best of my knowledge, this is the first time administrative data have been used to assess longitudinal patterns of transitions experienced by individuals newly diagnosed with dementia. My data demonstrate that while individuals newly diagnosed with dementia in B.C. in this particular year did not experience as high a number of transitions overall as individuals in the US[37] (11.2±10.2), they did still experience on average a transition per year alive, primarily to an acute care hospital. Over the ten-year trajectory, I was able to identify two points of time during which a high number of transitions were experienced: 1) the year of diagnosis and 2) the year of death. My results corroborate others who have demonstrated that end-of-life is associated with higher healthcare utilization and transitions [10,239]; however, this is the first time that the year of diagnosis has been identified as a period of high transitions and disruption for those with dementia.

The spike in transitions during the year of diagnosis occurs even after accounting for end-of-life or newly moving to a LTC facility, and occurs regardless of survival time or care location (i.e. living in the community or LTC). Transitions in this year are primarily hospitalizations, followed by multiple moves between LTC facilities for those who reside in one. Some of the moves between multiple LTC facilities may have been influenced by a policy implemented in BC in April 2002 which created a shift to needs-focused residential care access, a dimension of which included the expectation that individuals accept the first available LTC bed in any health authority, within 48 hours of notification [240]. Individuals could subsequently move to their preferred location following processes each health authority had in place. It is also likely that once an individual received a diagnosis of dementia, they were moved to a different LTC facility better equipped to meet their needs.

Similar increases in hospitalizations, healthcare service use and costs have been identified within the year of diagnosis for individuals with other chronic, degenerative diseases [234–236]. Dementia is not an acute condition nor is it effectively managed in acute hospital settings, so why the increase in hospitalizations and extended length of stay? Examining those who received their incident diagnosis of dementia in hospital indicated that for the majority, dementia was not the primary reason they were hospitalized, yet a large percentage of the cohort received an initial diagnosis of dementia in hospital (37%). It is possible that the symptoms of dementia went unrecognized by the primary care physician for a while, were not communicated to the patient and caregiver or was simply not coded by the primary care physician so that it was only eventually recorded in the hospital record. Regardless, it appears other adverse events are what prompt the initial acute hospitalization[62,165]. Certain underlying conditions such as stroke can increase the risk of dementia, or other conditions that develop with the onset of dementia (difficulty swallowing, increasing the risk of pneumonia, increased risk of a fall) can trigger a hospitalization[170,241]. This was paralleled in the cohort I examined where a fall, pneumonia and stroke were the top three reasons for the initial hospitalization in which dementia was subsequently diagnosed. Lastly, the vast majority of individuals newly diagnosed with dementia are multimorbid. The literature indicates that dementia is generally not diagnosed early so that when diagnosis does occur, the primary symptoms of deteriorating global cognition and verbal fluency would already be pronounced. This can significantly inhibit the individual's ability to self manage their chronic conditions, locate or even communicate symptoms which could trigger acute hospitalizations and rehospitalizations[170,242]. The long stays in hospital may be because individuals with dementia take longer to recover and require more rehabilitation, particularly after the effect of a changed environment which can be particularly distressing for individuals with dementia[236]. But it is more likely that the long stays are also because the hospital determines that they can no longer go home so they remain in hospital until they are discharge to a LTC facility[240].

Another unanswered question is why the peak in hospitalizations in the year of diagnosis but not other years (other than end-of-life)? First, other studies have demonstrated an association of incident dementia with increased hospitalizations[170]. One explanation is that a large proportion of the cohort moved to a LTC facility during the year of, and the year after diagnosis. The LTC facilities have a primary care team that can provide appropriate care and are trained to recognize symptoms that patients with dementia cannot communicate, decreasing the need for hospitalizations in subsequent years. As well, receiving the diagnosis and becoming more familiar with the disease, what to anticipate and perhaps being connected with HCC services can assist patients, their caregivers and physicians to better manage the dementia and the effects of dementia on co-morbidities after the year of diagnosis. For those with dementia and their caregivers, the year of diagnosis is an overwhelming period of stress during which major decisions about care need to be made in addition to grappling with the long-term implications of a diagnosis. Each new transition experienced increases the risk of medication errors, miscommunication, preventable readmissions and mortality [15,156,160,167]. This is therefore, an opportunity for a point of intervention during which patients can be referred to appropriate services and provided support to ensure continuity while minimizing the number of transitions (and in particular acute hospitalizations) experienced. Studies that reported on the introduction of a care transition intervention for dementia patients newly discharged from hospital or residing in LTC facilities found sharply reduced rehospitalisation rates, correlated with lower hospital costs[243,244]. Similar interventions need to be considered during the year of diagnosis. In addition, providing better education to caregivers of dementia about the trajectories of dementia, its effect on co-morbidities and how to anticipate and react to events prior to a crisis are essential.

A second spike in transitions is noted at end-of-life. I find that regardless of survival period post-diagnosis, people in the community with dementia start experiencing an increase in hospitalizations the year prior to death and then a sharp spike in the number of hospitalizations in the year of death. This is in marked contrast to those in LTC. These results mirror findings from Finland[10]. The literature indicates poor prognosis and limited life expectancy for people with end-stage dementia following acute illness and aggressive medical treatment[245]. The majority of people with dementia have expressed a wish to die at home without major medical interventions[246] and yet for those in the community with dementia, hospitalization in the year of death continues to occur, a venue in which decision-making is more rushed, care is fragmented and aggressive interventions to prolong life are more readily performed[247,248]. These results indicate that the care at end-of-life for those with dementia follows the same general patterns as those in the general population despite recognizing that they require different care[239].

The reasons for the spike in acute hospitalizations at end-of-life were not examined but are likely multifaceted and may not be specific to individuals with dementia. Two-thirds of all deaths in Canada occur in hospital despite most people's wish to die at home[91]. The proportions of individuals with dementia who die and access palliative care is low even though such care is associated with better quality of care at end-of-life[249,250]. Once hospitalized, individuals with dementia are more likely to be given active, acute care treatment at end-of-life instead of palliative care and they receive inadequate pain control[251]. This could be because, as previously highlighted, it can be difficult for physicians to appropriately assess and treat symptoms in individuals with dementia so that when a decline in health occurs, it triggers a crisis and hospitalization. Individuals with dementia living in the community nearing end-of-life may have caregivers receiving inadequate home support who are ill equipped to handle the last stages of a person dying with dementia, particularly if they are multimorbid[252]. Many caregivers of individuals with dementia report high levels of stress, poor health and burnout[55,82,91]. Caregivers have also reported needing adequate, realistic information about issues such as pain management, navigating the system, accessing respite care and palliative care[252]. Lastly, individuals with dementia living in the community are less likely to have advanced care orders, including do-not-resuscitate and do-not-hospitalize[253]. Given this, it is even more important to provide patients and caregivers better education and user-friendly information about advanced care planning and palliative care options. Physicians need to be provided tools to begin discussions around end-of-life early as part of comprehensive dementia care management, similar to discussions that occur during cancer care.

Of note is the overall survival time post-diagnosis for patients with dementia. I find a median of nearly 5 years survival post-diagnosis (note, this is not post-onset of dementia as there is no accurate way to measure this). This finding corroborates existing evidence [37,254–256]. While this may seem to be a long period with enough time for physicians to discuss end-of-life options, given the progressive degenerative nature of dementia, discussing end-of-life options early, even within the year of diagnosis, would provide individuals with dementia better opportunity to make decisions about their care before they are no longer capable of making such decisions[36,257].

I find that higher morbidity, living in more rural health authorities, and having behavioural symptoms associated with dementia are strongly associated with the number of transitions experienced both in the year of diagnosis and transitions overall in the study period, after adjusting for physician practice style. This parallels observations from other studies about the importance of these factors[15,238]. Morbidity plays the biggest role. Indeed, patients with dementia and a high burden of other sources of morbidity experienced the highest number of hospitalizations overall and at end-of-life regardless of whether they lived in a LTC facility or the community. LTC is considered a better/more appropriate care setting for this complex population than the community. These patients receive better medical support to manage their conditions and such facilities should be better equipped to provide good end-of-life care [33]. Yet, I find that the hospitalizations for people with a high burden of morbidity in LTC are similar in frequency and pattern to those in the community. Both of these are significantly higher than for those who only have dementia. This suggests that the spike in hospitalizations at end-of-life is being driven by co-morbidities combined with the dementia, not by the dementia alone. More needs to be done to understand what supports need to be in place to manage and minimize the transitions experienced by this complex population and particularly why these patients are being hospitalized while in LTC.

Interestingly, the presence of a caregiver has a weak association with fewer moves between LTC facilities in the year of diagnosis. This is in the direction hypothesized, and the fact that it is not more strongly significant may reflect that the proxy variable used as a measure of caregiver status is imperfect and likely underestimates the effect of having access to an informal caregiver. It is likely that the lower transitions and LTC moves associated with individuals in the highest income categories are an indication of the use of private facilities which I lack information on.

6.4.1 Limitations

This study faced several limitations. The reasons for institutionalization are varied, and include availability of a caregiver, difficult to manage behavioural symptoms, and progression and severity of the dementia[246]. I was unable to separate out and measure these factors using the administrative data available for this study. I was unable to measure the location of death and whether patients receive palliative care while in hospital or in LTC, though previous studies have indicated that older residents with dementia who die in LTC or hospital generally do not receive palliative care[247,258,259]. Despite the availability of universal, publicly funded healthcare services and LTC, there are several private LTC facilities in the province for which there is no publicly available information. In order to have a longer follow-up period, I identify patterns of diagnosis beginning in 2001/02, however, these patterns may be different in more current years. Finally, there is the potential for omitted variable bias given the type of data I had available. However, the variables identified as being significantly associated with transitions in the models have been validated through other quantitative and qualitative studies, and as long as any omitted variables are uncorrelated with the independent variables included, my regression analysis should still produce unbiased estimates.

6.5 Conclusion

For people with dementia for whom familiar environments and routines are important, frequent transitions (particularly to a hospital environment) are especially distressing and can cause further disorientation, and decline[11,12]. As well, each new transition increases a multitude of risks. The spike in transitions during the year of diagnosis highlights an unsettling situation affecting a frequently distressing period for individuals with dementia and their caregivers, but also suggests a useful target for interventions that might be effective in reducing such transitions. In my next chapter I explore in further detail whether receiving what is considered guideline-consistent dementia care and/or high quality primary care is associated with fewer transitions experienced.

CHAPTER 7 – GUIDELINE-CONSISTENT DEMENTIA CARE AND HIGH QUALITY PRIMARY CARE – IS THERE AN ASSOCIATION WITH TRANSITIONS?

7.1 Introduction

The chronic nature of dementia requires care that provides accessibility, care coordination and continuity in order to meet the ongoing biopsychosocial needs of people with a primary diagnosis of dementia[18,19]. These are also the attributes of high performing primary care -- there is good evidence that these result in better management of chronic conditions, fewer preventable hospitalizations, shorter lengths of stay, reduced use of emergency rooms and reduced risk of mortality[20–22], However, many of the studies that have examined primary care have focused on adults and young children but not on elderly populations and particularly not on vulnerable elderly populations such as those with dementia[23].

In the previous chapter I identified the year of initial diagnosis and the year of death as crucial time points during which individuals with dementia experience a peak in the number of transitions. Guidelines for dementia care outline diagnostic and treatment services that are (or should be) heavily concentrated in the first year after diagnosis. The hypothesis is that adherence to guidelines will lead to better outcomes, but studies that have assessed physician barriers to implementing these guidelines indicate skepticism among healthcare providers regarding the strength of this association[41]. Therefore, my research questions are as follows:

Research Question 4a: Is receipt of guideline-consistent dementia care in the year of diagnosis associated with the number of transitions the patient experiences in that year?

Research Question 4b: Is receipt of high quality primary care associated with the number of transitions the patient experienced in the year in which dementia was first diagnosed?

I hypothesize that holding all else constant, receipt of guideline-consistent dementia care, and appropriate primary care that encompasses continuity of care and coordination will contribute to fewer transitions. I also hypothesize that receipt of guideline-consistent dementia care will be associated with receiving high quality primary care as measured by continuity of care.

7.2 Methods

The same cohort described in chapter 6 was used in this section of the analysis. Here, I focused on the year of diagnosis as this was the year in which I measured receipt of guideline-consistent care. As well, this was when the cohort experienced a high number of transitions and when the largest proportion of the cohort moved to LTC or died.

7.2.1 Data Sources and Study Population

The same data sources and study population as described in Chapter 6 were utilized in this analysis. For consistency and comparison with Cohort 2 from Chapter 5, the main cohort in this analysis excluded individuals who died during the year of diagnosis and/or lived in LTC at the time of diagnosis. However, separate focused sensitivity analyses were conducted on two groups, 1) individuals who newly moved to LTC in the year of diagnosis (referred to as sub cohort 1 as these individuals were included in the main cohort) and 2) individuals who died during the year of diagnosis.

7.2.2 Primary Outcome - Transitions

The same primary outcome as described in Chapter 6, Section 6.2.3 was used. Briefly, care transitions are defined as a physical move from one location to another with a stay of at least one night. Only transitions between the community, respite care, Assisted Living, LTC and hospitals were included. Outpatient care or moves between in-patient wards of the same facility were excluded; this approach was consistent with prior literature [10,37].

7.2.3 Measures of Guideline-Recommended Dementia Care & High Quality Primary Care

I examined the association between receipt of 1) guideline-consistent dementia care and 2) high quality primary care, with the number of transitions experienced. Guideline-consistent dementia care was described in Chapter 5 (see also Sivananthan, Lavergne, & Mcgrail, 2013) but briefly, the guidelines were derived from the most updated BC Dementia Care Guidelines, released in July 2007, as they reflect province-specific resource availability, were readily available to physicians practicing in BC, and incorporate recommendations from the Canadian Consensus group national guidelines [7,122]. The care processes I expected to find in guideline-consistent care, in the first year of diagnosis (2001/02), were: laboratory exclusion tests (any one of blood count, serum electrolytes, serum calcium, serum glucose, TSH and vitamin B12); a CT scan of the brain; prescription of an AChI, antipsychotic or benzodiazepine, trazodone or antidepressant; a physical examination; counselling; referral to a specialist (Geriatrician, Neurologist or Psychiatrist); and receipt of a HCC assessment.

Receipt of high quality primary care was based on a definition developed by Starfield et al. [22]**.** Three dimensions of primary care were measured: 1) access 2) long-term person focused care and 3) coordinated care from an assigned primary care physician. Patients were assigned to the primary care physician who provided the highest proportion of unique visits during the fiscal year of initial diagnosis. In the event of a tie, the physician who billed the largest number of fee items (essentially visits) was assigned as the most responsible source of primary care.

The following attributes were measurable within the context of those dimensions (they are also summarized in Table 7.1):

Access - Defined as care from the assigned primary care physician in alternate settings (e.g. hospital) or outside regular office hours. Access was measured as three binary variables indicating receipt (or not) of a visit from the assigned primary care physician outside office hours or while the patient was in hospital or, for the sub cohort, while in LTC. Receipt of house calls from the assigned physician was extremely low and therefore excluded as a measure.

Long-term person-focused care –Defined as providing longitudinal care to patients across the spectrum of their needs. I was unable to operationalize 'person-focused' care with administrative data, however, continuity is an essential requisite to person-focused care since it is impossible to understand the values and context of a patient without following them over time. Therefore provision of continuity of care serves as a reasonable marker for 'person-focused'. This was measured as the number of visits with assigned primary care physician, divided by total number of visits patient had that year[261]. This measure of continuity of care was chosen because it was easier to interpret and operationalize.

Coordinated care – Defined as the coordination of care across care settings, including referrals to specialists and for laboratory testing. This was measured by the proportion of all referrals to specialists and for laboratory testing originating from the assigned primary care physician.

Table 7.1 – Description of primary care dimensions measured

PRIMARY CARE DIMENSIONS		
ACCESS		
Received hospital visit from assigned physician	Flag of billings in hospital by assigned physician while patient was in hospital	patient level
Received LTC visit from assigned physician	Flag for billings in LTC by assigned physician while patient was in LTC	patient level
Received visit from assigned physician outside office hours	Flag for billings indicating services were provided outside of office hours by assigned physician	patient level
LONG-TERM PERSON FOCUSED CARE		
Continuity of care	# visit with assigned physician divided by total number of visits patient had in the year	patient level
COORDINATED CARE		
Proportion of specialist referrals originating from assigned physician	# outpatient specialist referrals originating from assigned physician divided by total number of specialist referrals in the year	patient level
Proportion of laboratory referrals originating from assigned physician	# outpatient laboratory referrals originating from assigned physician divided by total number of laboratory referrals in the year	patient level

7.2.4 Controlled Explanatory Variables

All explanatory variables described in Chapter 6, Section 6.2.4 were used for adjusted for. Briefly, baseline patient characteristics included age, sex, income quintile (measured at the neighbourhood level), health status (measured by number of major ADGs as previously described), caregiver proxy status (identified using a shared MSP id as previously described in Section 4.2.1), health authority, and receiving a dementia diagnosis in hospital (versus the community). These are described further in section 7.2.5. Physician practice characteristics adjusted for included the number of years the physician had been practicing, the number of patients over the age of 65 in the practice and the number of dementia patients in the practice. These were based on the physician providing plurality of care, described in detail in Section 4.4.1.2.

7.2.5 Statistical Analysis

The proportion of the cohort to receive guideline-consistent dementia care and high quality primary care were described using counts and percentages for the main cohort and sub-cohort. The association between location of the incident dementia diagnosis (hospital versus community) and receipt of dementia care was examined via logistic regression to determine whether the location was a variable of importance to be included in the final model.

The data were analyzed using negative binomial regression for three models: the association between 1) receipt of guideline-consistent dementia care and transitions 2) receipt of high quality primary care and transitions 3) receipt of both guideline-consistent dementia care and high quality primary care and transitions. Model selection and fit followed the same process as described in Chapter 6, Section 6.2.5. When both guideline-consistent care and high quality primary care were examined in a model, I tested for collinearity in the measures related to laboratory and specialist referrals.

Chapter 6 showed that the highest number of deaths and moves to LTC was in the year of diagnosis, a period during which transitions may be modifiable by primary care. Therefore sensitivity analyses were conducted to examine the relationship between receipt of high quality primary care and transitions for individuals who newly moved to a LTC facility (sub-analysis 1, conducted on a sub cohort) in the year of diagnosis or those who died and were excluded from the main cohort (sub-analysis 2) (summarized in Table 7.2). For sensitivity, these analyses were also conducted in the year following diagnosis (2002/03) to see if the same trends were observed. Analyses were performed using STATA, version 10 [227].

Table 7.2 – Summary of sub-analyses and sub-cohorts

	Analytic Model	Cohort description
Model A	Rate of Transition= β_0 + β(age) +β(sex) +β(income) +β(health status) + β(health authority) + β(caregiver) + β(dx location) + β(GP yrs of practice) + β(# patients 65+) + β(# dementia patients) + **β (dementia care)**	Main cohort
Model B	Rate of Transition= β_0 + β(age) +β(sex) +β(income) +β(health status) + β(health authority) + β(caregiver) + β(dx location) + β(GP yrs of practice) + β(# patients 65+) + β(# dementia patients) + **β (primary care)**	Main cohort
Model C	Rate of Transition= β_0 + β(age) +β(sex) +β(income) +β(health status) + β(health authority) + β(caregiver) + β(dx location) + β(GP yrs of practice) + β(# patients 65+) + β(# dementia patients) + **β (dementia care) + β (primary care)**	Main cohort
Model D (sub-analysis 1)	Rate of Transition= β_0 + β(age) +β(sex) +β(income) +β(health status) + β(health authority) + β(caregiver) + β(dx location) + β(GP yrs of practice) + β(# patients 65+) + β(# dementia patients) + **β (primary care)**	Sub-cohort of individuals who newly move to LTC
Model E (sub-analysis 2)	Rate of Transition= β_0 + β(age) +β(sex) +β(income) +β(health status) + β(health authority) + β(caregiver) + β(dx location) + β(GP yrs of practice) + β(# patients 65+) + β(# dementia patients) + **β (primary care)**	Individuals who died (excluded from main cohort)

7.3 Results

7.3.1 Descriptive Analyses

After exclusion for death in the year of diagnosis (n=1,231) and living in a LTC facility at the beginning of the year (n=771), 4,711 individuals newly diagnosed with dementia remained in the main cohort. The main cohort experienced a median of 1 transition in the year of diagnosis, while 27% of those who experienced a transition had 3 or more transitions. Almost 60% of individuals in the main cohort experienced at least 1 hospitalization, half of whom (53%) were diagnosed with dementia in hospital (Table 7.3). In comparison, the sub-cohort (those who newly moved to LTC) had a median of 2 transitions (including their move to LTC), almost 50% had 3 or more transitions, and 80% experienced at least 1 hospitalization (Table 7.2). Individuals who died in the year of diagnosis also had a median of 2 transitions in the year of diagnosis, 30% experienced 3 or more transitions and 97%of that cohort experienced at least 1 hospitalization.

7.3.2 Receipt of Guideline-Consistent Dementia Care and High Quality Primary Care Process

For the main cohort, in the year of diagnosis, a high percentage of the cohort received laboratory tests (90%) and half received imaging (50%) consistent with guideline dementia care processes (Table 7.2). One-third of the cohort was prescribed an AChI, while between one-third and one half of the cohort received an antidepressant (46%), antipsychotic (39%) or benzodiazepine (37%), used for behavioural symptoms of dementia. However, an extremely low percentage of the main cohort received any discretionary dementia care processes such as counselling (5%), physical examination (4%) or a referral to a specialist (15%). Just over 60% received a HCC assessment, which would determine eligibility for home care or LTC services; referral for this assessment does not necessarily get initiated by a physician, so the proportion referred by physicians would undoubtedly be lower than 60%.

Primary care was measured through three processes (Table 7.3). Access to a physician in alternate settings demonstrates that individuals in the main cohort received care, on average, in 2 settings. A high proportion of the main cohort that experienced a hospitalization in the year of diagnosis received a visit from their physician (72%) and 58% of the cohort that newly moved to a LTC facility received a visit from their physician (Table 7.3). Long-term person-focused, or continuity of care, was high in the cohort in the year of diagnosis, with on average 75% of visits being with the assigned physician. Broken down further, 16% of the cohort had all visits with the same physician while 21% of the cohort had 50% or less of their visits with the assigned physician. With respect to coordinated care, 59% and 63% of patients respectively, received all their specialist and all their laboratory referrals from the same physician.

With regard to the three dimensions of high quality primary care for individuals who newly moved to LTC during the year of diagnosis, individuals in that sub-cohort received care in a median of 3 settings, had lower continuity of care (median 67% of physician visits with the 'assigned' primary care physician) but otherwise did not appear to differ significantly from the main cohort. A higher proportion of these individuals (73%) received all their specialist referrals from the assigned physician (Table 7.3). Individuals who died in the year of diagnosis (and were excluded from the main cohort) also received care in a median of 3 alternate settings and a very high percentage received a visit from the assigned physician when in hospital or LTC (84% and 80% respectively) (Table 7.3).

Table 7.3 –Dementia care and primary care use in year of diagnosis

Receipt of Services	Main cohort (n=4711)	% of cohort	Sub cohort (newly moved to LTC) (n=1326)	People who died† (n=865)
Number of transitions experienced *(median)*		1 transition	2 transitions	2 transitions
Experienced at least 1 transition	2940	62.4%	79.3%*	96.3%
Experienced 3+ transitions	791	26.9%	48.7%	30.0%
Experienced at least one hospitalization	2699	57.3%	79.3%	96.3%
Experienced 2+ hospitalizations	1076	39.9%	38.1%	43.5%
DEMENTIA CARE				
Laboratory testing	4217	89.5%		
CT scan	2386	50.6%		
Prescription for AChI	1529	32.5%		
Prescription for antipsychotics	1828	38.8%		
Prescription for benzodiazepines	1736	36.8%		
Prescription for trazodone	326	6.9%		
Prescription for antidepressants	2146	45.6%		
Counselling	250	5.3%		
Physical examination	182	3.9%		
Referrals for dementia	714	15.2%		
Home & community care assessment	2907	61.7%		
PRIMARY CARE				
Access				
# alternate care settings *(median)*		2.0	3.0	3.0
Received hospital visit from assigned physician (for those hospitalized)	1943	72.0%	72.5%	84.1%
Received LTC visit from physician assigned physician (for those newly in LTC)	769	58.0%	58.0%	80.3%
Long Term Person-Focused Care				
Proportion of all visits from assigned physician *(median)*		75.1%	66.8%	67.3%
Received 100% of care from assigned physician	767	16.3%	9.4%	23.9%
Received 50% or less of care from assigned physician	245	21.2%	31.5%	26.9%
Coordinated Care				
Received 100% of specialist referrals from assigned physician	1226	59.0%	72.6%	75.6%
Received 100% of laboratory referrals originating from assigned physician	2406	62.7%	61.7%	75.3%

*NOTE: All individuals moved to LTC which was counted as a transition, therefore this is a measure of an additional transition
†NOTE: These are all individuals who died and were excluded from the main cohort

Individuals who received a diagnosis of dementia in the community had a much higher likelihood of receiving laboratory testing, acetyl-cholinesterase inhibitors, counselling, a physical examination and referral to a specialist for dementia, all processes associated with guideline-consistent dementia care (Table 7.4). They were also less likely to receive a prescription for an antipsychotic or benzodiazepine.

Table 7.4 – Odds of receiving guideline-consistent care based on receiving a diagnosis in the community (relative to receiving an initial diagnosis in hospital)

Dementia Care	Odds	CI
Laboratory testing	2.4	1.9-2.9
CT scan	0.9	0.8-1.1
Acetyl cholinesterase	1.9	1.7-2.2‡
Antipsychotics	0.7	0.4-0.9‡
Benzodiazepines	0.8	0.7-0.9‡
Trazodone	0.9	0.7-1.2
Antidepressants	1.1	1.0-1.3
Counselling	3.0	2.1-4.2‡
Physical examination	2.4	1.6-3.4‡
Referrals for dementia	1.5	1.3-1.9‡
HCC assessment	0.3	0.3-0.4‡

‡ - P value <0.001, † - P value <0.01,* - P value <0.05
Controlling for age, sex, income, health authority, health status

7.3.3 Regression Analysis

Preliminary analysis indicated that variables used to measure the primary care dimension of access appeared to have occurred mainly in emergency situations. Receipt of care outside of office hours, while in hospital and while in LTC were all significantly associated with a higher number of transitions. If at all, it would have been anticipated that receipt of these services would be associated with fewer transitions unless they were provided in emergency situations during which patients are already experiencing multiple transitions. The use of a physician-level variable indicating provision of care outside office hours was tested for sensitivity (as it was hypothesized a physician-level variable that measures access would be a better indication of a physician's willingness to provide care outside office hours, without necessarily being a proxy for care in emergency situations) and was not significant. The measure of access as a dimension of high quality primary care was therefore excluded from subsequent regression analysis.

In multivariate analysis, after controlling for patient and practice characteristics and for receiving a diagnosis of dementia in hospital; receiving guideline-consistent laboratory testing, an acetyl-cholinesterase inhibitor, counselling, a physical examination and a referral to a specialist for dementia were associated with fewer transitions (Table 7.5, model A). However, receiving a prescription for an antipsychotic or benzodiazepine, and a HCC referral were associated with a higher number of transitions.

Similarly, controlling for patient and practice characteristics, higher continuity of care was highly associated with fewer transitions in the year of diagnosis. Receiving a higher proportion of specialist referrals from the assigned physician was also associated with fewer transitions (Table 7.5, Model B). When receipt of high quality primary care and guideline-consistent dementia care were both assessed in one model, the same processes of care that were independently associated with transitions remained significant, with only the continuity of care measure dropping slightly in the strength of its association (Table 7.5, Model C). Due to collinearity between receipt of laboratory tests/ specialist referrals in guideline-consistent dementia care and coordination of referrals for laboratory tests/specialists in high quality primary care, the coordination variables used to measure high quality primary care were dropped in this model as they were more indirect measures.

The sensitivity analysis that focused on individuals who newly moved to LTC in the year of diagnosis demonstrated that higher continuity of care is associated with a fewer number of transitions, but receiving a higher proportion of laboratory referrals from the assigned physician was associated with a higher number of transitions (Table 7.5, Model D). This same association was seen in the sub-analysis on individuals who died in the year of diagnosis (Table 7.5, Model E).

Table 7.5 – Multivariate regression analysis examining association of dementia care and primary care with transitions experienced in the year of diagnosis

	Transitions (Model A)	Transitions (Model B)	Transitions (Model C)	Transitions - sub analysis 1 (Model D)	Transitions - sub analysis 2 (Model E)
PRIMARY CARE VARIABLES					
Continuity of care		0.4 (0.4-0.5)‡	0.5 (0.4-0.6)‡	0.6 (0.5-0.8)‡	0.6 (0.4-0.7)‡
Coordination of specialist referrals		0.9 (0.8-0.9)‡	-	1.1 (1.0-1.2)	1.0 (0.9-1.2)
Coordination of lab referrals		1.0 (0.9-1.1)	-	1.1 (1.0-1.2)*	1.1 (1.0-1.3)*
DEMENTIA CARE VARIABLES					
Lab	0.9 (0.8-1.0)†		0.9 (0.8-1.0)*		
CT scan	1.1 (1.0-1.1)*		1.1 (1.0-1.1)		
AChI	0.7 (0.6-0.7)‡		0.7 (0.6-0.7)‡		
Antipsychotics	1.2 (1.1-1.3)‡		1.2 (1.1-1.2)‡		
Benzodiazepines	1.2 (1.2-1.3)‡		1.2 (1.2-1.3)‡		
Trazodone	1.1 (1.0-1.2)		1.1 (1.0-1.2)		
Antidepressants	1.1 (1.0-1.1)*		1.1 (1.0-1.1)		
Counselling	0.8 (0.7-0.9)‡		0.8 (0.7-0.9)†		
Physical examination	0.7 (0.6-0.9)‡		0.7 (0.6-0.7)‡		
Referrals for dementia	0.9 (0.8-1.0)†		0.9 (0.8-1.0)†		
HCC assessment	2.2 (2.0-2.4)‡		2.1 (2.0-2.3)‡		

Sub analysis 1: sub-cohort of individuals who newly moved to LTC; Sub analysis 2: individuals who died

‡ - P value <0.001, † - P value <0.01, - P value <0.05*

Controlling for age, sex, income, health authority, health status, behavioural symptoms, receipt of diagnosis in hospital, physician practice characteristics

7.4 Discussion

Receipt of guideline-consistent dementia care and high quality primary care, are independently associated with fewer transitions across care settings for patients newly diagnosed with dementia in the year of diagnosis. While, in general, guidelines introduced and followed lead to more uniformity [30] and concordance with best practice guidelines has been shown to be associated with better outcomes [24–26], previous studies have consistently demonstrated a lack of concordance between best-practice recommendations for dementia care and actual practice, leading to under-diagnosis and poor management [8,28,29,119,262,263]. Barriers to physician adoption of dementia guidelines include a myriad of issues such as a perceived lack of evidence for better outcomes [41]. These data demonstrate, for the first time, that receipt of some guideline-consistent dementia care, independent of continuity of primary care, are associated with fewer care transitions. This is important in this population because transitions are associated with poorer outcomes.

Fewer transitions are the result of fewer hospitalizations and fewer physical moves between LTC facilities or Assisted Living facilities during the year of diagnosis. Given the peak in transitions, and particularly the high number of hospitalizations during the year of diagnosis (as demonstrated in Chapter 6), the finding here demonstrates that guideline-consistent dementia care is associated with fewer transitions during this chaotic period. This is not only consistent with my hypothesis, but reinforces the importance of finding ways to improve the uptake of care guidelines for this population. This is particularly true for receipt of discretionary dementia care management processes such as counselling and a referral to a specialist for dementia.

It is important to acknowledge that I am not able to show a causal relationship with this analysis; however my hypothesis was based on literature which has demonstrated that, for example, counselling better prepares patients and their caregivers in terms of what to expect given a diagnosis and communicates techniques to handle symptoms, potentially reducing the need for hospitalization [53,127,264]

Notably, receiving a prescription for an antipsychotic or benzodiazepine is associated with a higher number of transitions. I was unable to determine whether individuals who were prescribed these medications had a clinical indication for their receipt, though the literature indicates low lifetime prevalence of most psychiatric illnesses that would have required a prescription of this type [265,266]. My results are consistent with the literature which indicates that 1) individuals with behavioural symptoms of dementia experience a higher number of transitions across care facilities [238,246] and 2) receipt of prescriptions for antipsychotics or benzodiazepines is associated with a higher risk of adverse events [232]. Of note, accelerated cognitive and memory decline are predictors of hallucinations and psychosis [267]. Given that I was unable to measure functional status or severity of dementia, it is possible that the acuity of dementia at the point of diagnosis was higher in individuals receiving these prescriptions for behavioural symptoms, and that it is this, rather than the prescriptions, that was contributing to a higher number of transitions. As well, cognitive, functional and behavioural changes are considered primary stressors leading to institutionalization [246], and I was unable to capture these within the data available to me.

Receiving a HCC referral was also associated with a higher number of transitions. This may be because receiving the referral means individuals are more likely to be assessed, which would allow them access to LTC and contribute to a transition. Interestingly, individuals diagnosed with dementia in the community were less likely to receive a HCC referral than those newly diagnosed in hospital. While these referrals do not need to originate from a physician, it is possible that 1) primary care physicians practicing in the community are unaware of the referral process and not referring their patients, 2) patients who are diagnosed in hospital have a poorer health status/severe dementia and are referred, or 3) the hospitalization itself brings patients to the attention of the system and they are therefore more likely to be referred.

Similar to guideline-consistent dementia care, I found receipt of high quality primary care, measured through higher continuity and coordination of care, to be associated with fewer transitions. Given that these are attributes of a high performing primary care system, with good evidence for better outcomes of care, the results are not surprising. However this is a contribution to the continuity of care literature, because that literature lacks studies on elderly vulnerable populations such as those with dementia. Further, this strong association with higher continuity exists at the end-of-life and for individuals newly moving to a LTC facility even after controlling for morbidity and other relevant factors. However, higher coordination of laboratory referrals was associated with more transitions. This may be because at both those care points (moving to LTC and end-of-life) receiving higher coordination of laboratory referrals, similar to the measure of access, is provided under emergency circumstances.

Newly moving to a LTC facility is a major life event for an elderly person with dementia; having high continuity of care would ensure that the individual's care needs are recognized and met and multiple medications are reconciled early in the transition.

Similarly, as demonstrated in Chapter 6, end-of-life is a period during which individuals with dementia experience a second peak in transitions. This can be due to a variety of factors. Often, individuals with dementia are multi-morbid and these other conditions are exacerbated (and masked) by the dementia. As well, pain management is difficult to ascertain and control in individuals with dementia [268,269] which can trigger hospitalizations during which more extreme, life-prolonging interventions are taken. These generally result in poor outcomes for elderly patients with dementia, particularly at end-of-life [245]. Having high continuity of care at end-of-life would allow the physician who is aware of the patient's history, medications and perhaps end-of-life wishes to: assess and manage symptoms to ensure early interventions are provided before symptoms worsen; communicate with the caregiver and provide support as to what to expect; and ensure the wishes of the patient are followed at end-of-life (if they had been previously documented). They would therefore be providing informational, management and relational continuity during essential periods of care [40].

I hypothesized that higher continuity of care is the pathway through which better guideline-consistent dementia care is provided. Yet my analysis demonstrates that the two appear to be independent effects. The strength of the association between guideline-consistent dementia care and transitions remained the same even after the continuity of care measure was introduced; it was in fact the strength of the continuity of care measure that dropped (though only slightly). This indicates that 1) receiving guideline-consistent dementia care alone is important and 2) providing better continuity is not the mechanism by which guideline-consistent care appears to occur; the effects are separable. This goes counter to my hypothesis, but is not unrealistic for actual practice. Many reasons have been identified for why physicians do not provide guideline-consistent dementia care, but this does not mean that the physician is not providing good continuity of care. Continuity would allow the physician to still monitor the patient, notice any decline or worsening of symptoms and potentially also monitor the health of the caregiver, which are predictors of institutionalization and hospitalizations.

Finally, receiving a diagnosis of dementia in hospital is not optimal. People who received their diagnosis in hospital had a higher number of transitions, and were less likely to receive guideline-consistent dementia care. Those who received their diagnosis of dementia in hospital also had higher odds of receiving a prescription for an antipsychotic or benzodiazepine, both of which are used to control the behavioural symptoms of dementia. It was, however, not possible to determine the mechanism through which this occurs, for example which came first, being more likely to receive these prescriptions because these individuals were hospitalized, or being hospitalized because of symptoms. As previously discussed, it is possible that individuals who received prescriptions for antipsychotics or benzodiazepines had a higher acuity of dementia and are therefore more likely to be hospitalized. Regardless, trends over time (comparing between Cohort 1 and Cohort 2, Figure 5.2 and Figure 6.1 respectively) indicate a shift toward diagnosis in the community.

7.4.1 Limitations

There are several limitations to the analysis reported in this Chapter. First, these results demonstrate association, not causality. My model cannot establish, unequivocally, an order of cause and effect. For example, high transitions and disruptions may make it difficult for physicians to provide guideline-consistent dementia care. Indeed, the transitions themselves may prompt investigation of cause that leads to a dementia diagnosis. This would be consistent with the high proportion of patients receiving a diagnosis of dementia in hospital. Other studies will need to study causality more directly, but if implementing better guideline-consistent dementia care results in fewer transitions, it could be a significant cost saving and life-improving, strategy. A potential method to estimate causality could be the use of an instrumental variable to control for unobserved confounding and measurement error, thereby allowing for the possibility of causal inferences from observational data. The key would be determining a good instrument for this purpose. Given this, there is the potential for omitted variable bias due to the type of data I had available. However, the variables identified as being significant in the models have been validated through other quantitative and qualitative studies and as long as any omitted variables are uncorrelated with the independent variables included, my regression analysis should still produce unbiased estimates

I was unable to determine if individuals who were prescribed antipsychotics or benzodiazepines had a clinical indication for their prescriptions; however the prevalence of schizophrenia (0.87% lifetime prevalence), bipolar I disorder (0.35% lifetime prevalence), major depressive disorder with psychotic features (0.35%), general psychosis (1.7%) and neurotic disorders (2.4%) is low [265,266]. While there may be clinical indications for prescriptions of antipsychotics other than the behavioural/psychosis symptoms of dementia, I would not expect those indications to explain all of the prescriptions. I was unable to measure the severity of dementia at diagnosis given the nature of the administrative data to which I had access. This, obviously, could influence the number and types of transitions experienced by individuals.

7.5 Conclusion

The results of Chapter 6 showed that the year of diagnosis is critical. The analyses here are consistent with, and suggestive of, the importance of increasing uptake of guideline-consistent dementia care. Previous studies have indicated that physicians perceive a lack of evidence demonstrating the value of implementing guideline-consistent dementia care[41]. This study now contributes to that body of literature, demonstrating a clear association between guideline-consistent dementia care and outcomes. As well, these results provide evidence for the continued value of high quality primary care in a complex population during key points in time of a patient's care trajectory when gaps in continuity usually occur.

CHAPTER 8[6,7] - CONCLUSION

8.1 Summary and Key Contributions

This thesis had four main objectives:

1) Conduct a critical assessment examining the existing research literature on physician practice patterns associated with the care of people with dementia and to what extent those practice patterns are consistent with published guidelines

2) Examine population-based variations in receipt of guideline-consistent dementia care and patient factors that are associated with that care

3) Examine transitions experienced longitudinally to establish patterns that can help identify points of care when transitions are highest and the factors that contribute to those transitions

4) Assess the association between receipt of guideline-consistent dementia care and/or high quality primary care and the number of transitions experienced by individuals with dementia

A systematic review of the literature demonstrated that there is wide variation in self-reported physician practice patterns with regard to provision of guideline-consistent dementia care. The review also highlighted significant limitations of existing research in that all the studies that met the inclusion criteria were self-reported survey

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[6] A version of chapter 8 has been accepted. Sivananthan SN. Short End of the Stick? Health Care Inequity in a Vulnerable Population of Individuals with Dementia. Canadian Geriatrics Society Journal of CME 2014

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designs with varying sample strategies and small sample sizes. This led to my second objective which was to use population-based administrative data, organized at a patient-level, to address the study limitations seen in the systematic review, but also to examine potentially modifiable patient-related factors associated with any variation as a way to differentiate warranted and unwarranted variation. My results corroborated what was seen in the systematic review, with wide variation in receipt of guideline-consistent dementia care processes. My research also showed that this variation was associated with income, geography, age and sex of dementia patients, indicating potential inequities in care. The next step in my analysis was to examine if there is an association between receiving these dementia care processes and my primary health outcome, transitions between living/care locations. Transitions were chosen as an outcome variable of particular interest for this population because the literature demonstrates that dementia patients fare better with minimal physical disruption and changes to routine. A greater number of transitions between care settings poses a serious challenge to the continuity of care and the safety of the patient and is associated with medication errors, preventable hospital readmissions and increased mortality risk [13–17]. Existing literature lacks in-depth descriptions of longitudinal patterns of transitions experienced by individuals newly diagnosed with dementia. My research illustrated that over a ten-year follow-up of a cohort newly diagnosed with dementia, transitions are highest during the year of diagnosis and at end-of-life. In both cases, the primary driver is hospitalizations. Finally, I found that, holding all else constant, receipt of guideline-consistent dementia care is associated with fewer transitions in the year of diagnosis, independent of receipt of high quality primary care.

These findings are significant in that they demonstrate the lack of concordance between guideline-recommended care and actual practice using data and a method adapted to address the biases that limited the generalizability of previous studies. From a policy-guidance perspective, these findings also highlight patterns of inequity in receipt of dementia care unrelated to need, while demonstrating the value of providing guideline-consistent dementia care in the year of diagnosis during which patients experience the highest number of transitions and flux in care. This is particularly timely as Canada, a member of the G8 Summit on Dementia in 2013 [270], recently increased its research investment in the prevention, diagnosis and care of dementia [271] and co-hosted a Global Dementia Legacy event to explore the value of academia-industry collaborations in September 2014 [272]. BC specifically, was one of the first provinces to recognize the need for a provincial dementia strategy which the government released in the form the Dementia Action Plan in November 2012 [273]. Advances based on the three priorities identified 1) support prevention and early intervention, 2) ensure quality person-centred dementia care and 3) strengthen system capacity and accountability is still ongoing. The Action Plan outlines high-level strategic goals to address gaps in care which are supported by the evidence in this thesis.

This concluding chapter is organized into three sections. First I provide a brief summary of the primary findings of the research chapters (Chapters 3, 5-7), their contribution to knowledge in the field contextualized by our current understanding of dementia care, and potential policy implications that flow from them. Second I comment on the strengths and limitations of the overall thesis, extending beyond the specific limitations already addressed in each research chapter. Finally, I discuss future strategies that can build on the evidence presented here.

8.2 Research Findings

8.2.1 Variations in Guideline-Consistent Dementia Care – Lesson Learned from a Systematic Review

Guidelines are created based on existing evidence and are meant to indicate approaches to practice that are likely to produce the best results for individual patients. They are published to encourage specific processes of care and to create more uniformity in practice with the expectation that this will improve patient care and outcomes [30]. Guidelines are particularly important in care for dementia patients because of the evolving nature of our understanding of optimal dementia care and because assessment and subsequent treatment is provided by primary care physicians who often have limited knowledge of changes to guidelines and sometimes limited experience with dementia patients [6,7,41] .

In Chapter 3, I systematically review the existing literature on physician practice patterns associated with the care of people with dementia, through a lens of consistency with published guidelines. My results demonstrate wide variations in the proportion of physicians who report providing guideline-consistent dementia care. For example, I saw a large difference in the percentage of physicians who report providing a formal memory test, fundamental for an accurate diagnosis of dementia. Similar variations were seen in the use of guideline-recommended therapeutics, referrals to specialists and referrals to community services, the first two of which assist in managing the more difficult symptoms of dementia. There was less variation in other services assessed, and encouragingly, exclusionary blood work and provision of counselling are generally widely used.

The large variations in the dementia care processes surfaced by this systematic review are eye-opening as they are an indication that patients are not receiving appropriate, equitable or in some cases adequate care despite widely available guidelines. This in turn can have significant consequences for the accuracy of their diagnosis, access to resources, management and their future outcomes of care. This is the first systematic review to summarize and examine the variations reported in the literature. These results also have important implications as they corroborate the qualitative literature around barriers to providing good dementia care which include inadequate time to fully explore issues during appointments, challenging behavioural symptoms, problematic physician attitudes toward providing care to individuals with dementia resulting in age discrimination, lack of interdisciplinary teams to appropriately address the multifaceted psychosocial issues and difficulty accessing community resources resulting in patterns of inequity [41,70,71,165,269].

While these results add to our understanding of actual physician dementia practice patterns, and highlight the gap between actual practice and guideline-recommended care, there are some reasons for caution. There are several factors unrelated to physician practice decisions or styles that could contribute to the variations reported in this literature. These might include, for example, geography, patient demographic characteristics and changes in guideline recommendations over time. The heterogeneity of study populations and settings made it impossible to assess these factors in the review.

8.2.2 Persistent Variation – Getting Past Self-Report using Administrative Data

As a counter to some of the limitations previously highlighted in the systematic review, in Chapter 4, I conducted an analysis of the provision of dementia care utilizing population-based health service administrative data from BC.

My population-based study of community-dwelling seniors demonstrated that a high percentage of B.C. dementia patients had been receiving guideline-consistent diagnostic care processes. This finding corroborated trends surfaced in my systematic review. However, on the treatment side, use of pharmacological interventions such as anti-psychotics (typical and atypical) and benzodiazepines, which are generally not recommended in this population (in which such prescribing is often contra-indicated), was frequent. The overall rates for discretionary dementia care management processes (specialist referrals, counselling and in-office examination) were found to be generally low. More importantly, I found that variations in dementia care management processes were influenced by income, age and geography.

Limiting the analyses to community-dwelling seniors makes the conclusions particularly compelling from a policy perspective, as many seniors have expressed a wish to remain in the community longer. Physician practice patterns are very different in LTC, where rates of pharmacological intervention tend to be higher since many of the patients have complex neuropsychiatric symptoms that prevent them from living in the community safely and there is a larger team providing primary care services [114]. The frequent use of antipsychotics and benzodiazepines was not anticipated for community-dwelling seniors; this has serious policy and health consequences due to an association with falls, increased risk of cerebrovascular adverse events and, worse, increased risk of mortality [232,233,274,275].

Variations in the guideline-consistent dementia care management processes were influenced by income and age. Canada functions under a universal, first-dollar coverage of hospital and physician services which means there are no explicit financial barriers to access those components of care. The variation related to age may be due to the possibility of age discrimination in practitioners' attitudes toward providing early diagnosis and broader interventions to older individuals. This has been described previously as a barrier to provision of good dementia care, with physicians' negative perceptions in diagnosing dementia being associated with therapeutic nihilism, stigma and ageism [41]. Other possible reasons for age-associated differences in care processes is the lack of time that physicians have to appropriately support older individuals with more complex symptoms, and age-related difficulty accessing specialists with limited availability [71]. However, insofar as income and age are unrelated to patient need for service, my results indicate potential inequity and require further attention.

8.2.3 Transitions – The Year of Diagnosis and Disruption

The prevalence of multiple moves, or transitions, is high in the elderly [33,34] and poses a serious challenge to the continuum of care and the safety of the patient as demonstrated by medication errors, quality deficiencies, preventable hospital readmissions and increased mortality risk [13–17]. Three previous studies have assessed transitions longitudinally, ranging from eighteen months [12] to seven years [37]. However, no previous literature has tracked patients from the year of diagnosis and followed them over such an extensive period (ten years), nor have any of the longitudinal studies examined the factors that contribute to transitions.

My contributions to the literature are three. First, I demonstrate that the year of diagnosis and the year of death are the points in care when transitions are highest. This is important information for clinical and policy decision-makers. End-of-life literature long ago identified the year of death (and often the year prior to death) as a period of high transitions with fragmented care and rushed decision-making often leading to overly aggressive interventions to prolong life [10,239,248,269]. Understanding the end-of-life care trajectory and attempting to put in place better quality indicators and measures to ensure individuals' wishes are respected is still a work in progress. What is new here is that my study also identifies the year of diagnosis as an important point in the care trajectory, with the high number of transitions representing a second (and of course earlier) potential point of intervention for decision-makers.

Second, the transitions occurring during the year of diagnosis were dominated by hospitalizations, though moves from community to LTC are also highest in this year. Primary care physicians control many of the services provided in the year of diagnosis and, given the right resources, can connect patients with appropriate support services early to reduce the number of transitions. Increased home support, better integration of primary and community care and expanding community-based palliative care are potential strategies described in more detail later. Particularly in the year of diagnosis, higher morbidity, living in health authorities with smaller urban centres and having behavioural symptoms of dementia are strongly associated with the number of transitions experienced. These are factors that allow the identification and targeting of patients at high risk of multiple transitions, for early intervention.

Finally, the focus of most guideline-consistent dementia care processes is during the year of diagnosis. As the results from chapter 7 demonstrate, receiving guideline-consistent dementia care is associated with fewer transitions. This highlights the importance of finding ways to support physicians in providing better guideline-consistent care that can mitigate transitions during the year of initial diagnosis.

8.2.4 The Effectiveness of Guideline-Consistent Dementia Care

Given the importance of the year of diagnosis in a dementia patient's life, guidelines play a key role as their emphasis is on accurate diagnosis and management. The diagnostic processes obviously cluster in the year of initial diagnosis. But to a significant extent, decisions and patterns related to management are also set in motion in that year. While guidelines have been shown to be associated with better outcomes for patients [24–26], studies have also demonstrated hesitancy on the part of physicians in implementing these guides [41] and a consistent lack of concordance with best practice recommendations leading to under-diagnosis and poor management [8,28,29,119,262,263]. My work in the previous chapter adds further evidence of the value of following guideline-consistent care. My results also confirm that continuity of care is highly associated with fewer transitions, regardless of whether it is the year of diagnosis, death, or move to LTC.

While these results demonstrate association not causality, there is a hypothesized causal pathway. Guideline-consistent dementia care encourages early diagnosis (with the use of diagnostic tools such as lab tests and imaging), which would allow for early management of dementia. Early and appropriate management both through guidelines and high quality primary care would allow physicians to educate patients and their caregivers on what to expect before the dementia has progressed too far in severity. They can then monitor that progress, adjusting management of dementia and any co-morbidities before patients reach crisis, which is what triggers multiple hospitalizations. For example, some recommended management process from dementia guidelines include: reconciliation of prescriptions which can prevent medication-error induced hospitalizations; appropriate counselling which helps patients and caregivers understand the prognosis of dementia, anticipate further decline, the effects of dementia on self-management of other chronic diseases and develop strategies to deal with these issues before they become acute; referrals to specialists who can provide additional monitoring and specialized care in difficult cases so that patients do not seek that care in emergency rooms; and referrals to community services that can assist patients and caregivers to manage care before caregivers reach a point of crisis. Continuity of care becomes particularly important in being able to monitor the patient, knowing their medical history and therefore being able to address issues before it reaches the point where a patient is hospitalized.

A number of policy implications emerge. Recent data indicate that patients with a diagnosis of dementia account for a large proportion of alternate level of care (ALC) hospitalizations and ALC hospital days [276,277]. ALC hospitalizations describe patients in acute care beds waiting to be moved to a different, more appropriate, care setting, most frequently residential care [51]. Prolonged stays in ALC are associated with serious adverse outcomes, including functional decline and infections; they are particularly traumatic for individuals with dementia [277]. As previously discussed, early diagnosis and management of dementia based on guidelines could conceivably address some of these patients' (and caregivers') needs prior to a crisis that triggers an acute hospitalization. Therefore, guideline-consistent dementia care could not only ensure better outcomes for patients but could also reduce the burden of dementia patients on ALC beds. Interventions to reduce transition are likely to have the most effect if aimed at this diagnosis period.

8.3 Strengths and Limitations

Each research chapter discusses the limitations associated with the methodological approach, data and interpretation of results. Therefore, here I will limit my discussion to the strengths and limitations of the overall thesis.

A key strength of the analyses described here is the use of health care administrative data for the entire population of BC newly diagnosed with dementia, and the ability to follow a cohort over a period of eleven years. This allowed me to circumvent the biases inherent in other studies examining guideline-consistent dementia care because of their predominant use of self-reported survey data with limited sample sizes, limited geographic coverage and varying sampling strategies. The population-based nature of my research helps with external validity, meaning my results are more generalizable, at least to other provinces, and to other countries with similar public health care benefit structures that might affect access to care for patients with dementia. As well, the ability to follow a cohort over eleven years allowed me to assess trends over the entire arc of a patient's care trajectory. The median survival time of individuals with dementia in my cohort, from point of diagnosis, was nearly 5 years, and a ten-year follow up period enabled complete capture of all points between diagnosis and death for 84% of the cohort (i.e. only 16% of the original 2001-diagnosed cohort was alive at the end of the study period).

Another important strength in this study design was the ability to identify individuals newly diagnosed with dementia. By being able to focus on this crucial point in the trajectory, I was able to measure receipt of guideline-consistent dementia care during the year of diagnosis and highlight the peak in transitions that occurred during this period at a population level. The use of administrative data allowed me to trace the healthcare utilization patterns of this cohort from diagnosis and up to nine years post diagnosis, while giving me a wealth of patient, physician and system characteristics to explore and control for in my analysis to tease out specific associations.

Despite the advantages of using administrative data, they also bring with them some important limitations. Administrative data are subject to transcription and other quality errors, and missing information, in addition to problems with loss of subjects which occur regardless of the source of data. Nevertheless, the linked data sources I used have been shown to have good validity [278]. I was not able to measure all of the dementia care processes included in the dementia care guidelines, particularly the use of formal memory tests and the specific role of physicians in referrals to HCC services which play such a key supportive role in the lives of individuals with dementia and their caregivers. I also did not have access to data that would have given me in-depth demographic and functional data which would have been valuable in determining living arrangements, caregiver status and dementia severity. These variables have been shown to play mediating roles in dementia care. However, previous work has also shown that the presence of a caregiver has a larger role to play with regard to receipt of home care, remaining in the community and institutionalization[100,279,280], but not with regard to transitions that are primarily driven by hospitalizations or receipt of guideline-consistent care[281]. These would be expected to be more heavily influenced by physician decisions. I was able to develop a proxy variable for caregiver status which was used for a sensitivity analysis described in Chapter 4, Section 4.4.1. The results of that analysis allowed me to proceed with subsequent analyses, confident that caregiver status was not going to create any significant omitted variable biases.

All the healthcare utilization data I used are for services provided by physicians paid through the fee-for-service system. This excludes services provided by physicians paid through alternative payment arrangements. While in general less than 10 percent of physicians are paid exclusively through non-fee-for-service methods, this does mean that my analyses likely under-count the incidence of dementia and are missing the care utilization data for those patients.

8.4 Future Directions

Specific policy recommendations based on the result of each research objective have been described in Section 8.2, however there are some overarching observations and recommendations that are important to highlight at this juncture.

My findings indicate differences in actual care provided and wide variations in receipt of guideline-consistent dementia care that are influenced by age, income and geography. The lack of concordance despite evidence of better outcomes for patients has continued to be a major issue and several factors have been previously identified[41]. I also provide evidence that transitions peak in the year of diagnosis and that receiving guideline-consistent dementia care in particular is associated with better outcomes, i.e. fewer transitions.

There would appear to be four recommendations that fall rather naturally out of the findings reported here. The first relates to physician training. If we are to see more physicians adopt guideline-consistent care for dementia patients, a reframing and refreshing of physician education may be necessary. Exposure needs to go beyond the pathophysiology and pharmacological treatment of dementia as a disease. Instead education should emphasize dementia as a chronic, complex condition which can benefit from timely diagnosis, comprehensive biopsychosocial treatment and management in the context of the patient's other conditions. Second, a shift in focus for guidelines needs to occur. Guidelines would be more effective if they provided more detail around long-term management. For example, physicians should be provided with evidence-based, relevant environmental interventions for behavioural symptoms which are often the most difficult management aspect of dementia [117,282]. Studies have demonstrated that verbal redirection, reassurance, reduced stimulus, and determining triggers and eliminating them are valuable interventions. But these often require more frequent monitoring and interdisciplinary team resources for effectiveness [282,283]. Another example is the management of dementia when patients have multiple major co-morbidities (more often the rule rather than the exception); this tends to be a barrier to implementing guideline-consistent care. The field has not yet fully recognized the complexity of providing care in this context, but examples from other fields such as cancer care could be useful where for example reliable and valid instruments that assess outcomes and care for older cancer patients with pre-existing co-morbidities are being developed [284–286].

Third, these results indicate the need to recognize that primary care physicians alone may not be able to provide adequate dementia care and that more resources are needed to support them [8]. Patients living at home require a cooperative and coordinated response from physicians, HCC and social services [287]. Fortunately, several promising models of care have been piloted and may provide a useful foundation. Case management programs that provide individualized, flexible responses to people's needs by integrating care across clinical and social services with high intensity support have been shown to be particularly effective when appropriately implemented [78]. These case management programs often include collaborative, interdisciplinary teams with the primary care physician at the core and including other service providers such as social workers, psychiatrists and advanced practice nurses who assist with assessing and monitoring care. Collaborative, interdisciplinary teams have been piloted in multiple clinical trials and have yielded better outcomes relating to incidence of adverse behavioural symptoms, quality of patient care, caregiver health scores and adherence to guidelines [18,26,288–290].

Another example is the increased role of skilled staff such as physician assistants, care coordinators and nurse practitioners in situations of workforce or financial limitations. After some training, these skilled staff work in a dyad with the physician to provide better case management and referral services [165,291,292]. This is thought to be particularly effective in more rural settings in the absence of access to specialists or community resources [293]. Last are programs like First Link, used by the Alzheimer's

Society of Canada [21,294]. These programs work with physicians to connect people newly diagnosed with dementia with services offered through the Alzheimer's Society. In this case, community service providers actively work with the physician to refer patients to the program, making them aware of services they can refer patients to. Since many patients do not contact community resources (despite a referral from the physician) until in crisis, the First Link program removes the onus of responsibility from the patient by reaching out first and linking patients with programs as soon as possible. Preliminary analysis has demonstrated that primary care physicians had improved knowledge on community support services available, better relationships/partnerships between physicians and community resource staff, and more effective coping by caregivers of individuals with dementia [295].

The fourth recommendation is to further explore interventions that are effective at reducing transitions, particularly during the year of diagnosis. To be clear, not all transitions are bad and some transitions are certainly necessary. However, not developing care sensitive long-term plans for individuals can result in more transitions than are necessary. Several interventions have been implemented that have been shown to be promising at reducing unnecessary transitions. For example, improving early, advanced care planning that ensures appropriate care consistent with individuals' wishes (e.g. medical orders for life sustaining treatment or hospitalizations) has been shown to be effective both at reducing transitions and deaths in hospital [176,293,296,297]. This could prove to be particularly important for individuals with dementia (most of who are also multi-morbid) at end-of-life, but also perhaps earlier on. Given the predictable cognitive decline associated with dementia, discussing scope of care, care settings and appointing a substitute decision maker while the person with dementia is still able to contribute to these decisions could mean better quality of care and a lower burden on the caregiver who is often forced to make decisions that leave feelings of guilt and depression [80].

A second example of an intervention that may decrease transitions is the use of patient navigators. Patient navigators are skilled staff such as registered nurses or trained educators who act as the patient's advocate and personal guide while the patient is in hospital. They coordinate patient care, communicate with the patient, their family and physician and help oversee care transitions both within the hospital and post-discharge. The program was initially implemented in cancer care to improve access to care for underserved patients but has now been adopted by several other units in chronic and complex care[298]. One hospital that implemented the program for their complex inpatient care unit (the majority of whom are elderly patients with dementia) reported shorter lengths of stay in hospital and lower hospital 30-day readmission rates [299]. Using patient navigators during the year of diagnosis of dementia has the potential to significantly influence the number of transitions experienced in that year (i.e. reduce rates of re-hospitalization) as well as the quality of care and should be more carefully explored. The value of integrating care across settings cannot be emphasized enough. My results and those of the other studies cited in this thesis highlight how essential it is to provide continuity of care across care settings.

8.5 Areas for Further Inquiry

While I highlight some policy implications from my research in section 8.4 above, there are still many further areas of inquiry that would help add to our understanding of patterns and trajectories of care for people with dementia. I highlight a few of these here.

First, the outcome of interest for this thesis was the number of transitions for individuals, examining a 10-year follow-up period from initial diagnosis of dementia, or until death. This is not the only potential outcome of interest. Future research could examine effects on the quality of life of patients, as well as the quality of life and health outcomes for caregivers. Another important outcome is length of time spent at home (i.e. not in LTC) after diagnosis. I was not able to pursue that outcome because of a lack of comprehensive information on functional and cognitive status, living arrangements and presences of informal caregivers, all of which are known to affect an individual's ability to remain in the home[82,300,301]. Indeed, future research that is able to incorporate details on the ongoing functional and cognitive status of individuals with dementia and indicators of social support would greatly enhance the conclusions that can be drawn. One possible source of this information is the interRAI suite of minimum data sets, which are standardized assessment tools designed to gather information for both assessment and care planning[302]. InterRAI data collection has been mandated since the mid to late 2000s in BC's Home and Community Care Offices for assessment for both home care and LTC.

Second, there may be interest in understanding more than just the number of transitions, but also the time between transitions and factors that influence that timing. Alternatively, understanding the timing and kinds of transitions that are associated with increased risk of functional decline and medical complications may have useful policy planning implications. Again, this line of inquiry would be aided with a fuller understanding of patients' living arrangements, functional and cognitive status.

Finally, there is more research that could be done on the best approaches and supports to increasing provider awareness of appropriate dementia care, and in particular the effects of community supports that are available such as the First Link program[295]. These programs are thought to be particularly important for providing caregivers with additional support and information that physicians may be unable to provide due to limited time, knowledge or training.

8.6 Conclusion

The results of my research demonstrate that the need to better understand the patterns of care experienced by individuals with dementia is paramount to providing more appropriate, strategic support to the physicians who manage their care as well as the patients and caregivers themselves. The BC Ministry of Health and the Federal Ministry of Health have both identified dementia as a growing concern for Canadians who are looking for a responsive healthcare system that provides sustainable, quality care [270,272,273]. My research illustrates patterns of inequity in receipt of dementia care unrelated to need, while demonstrating the value of providing guideline-consistent dementia care (as well as continuity of care) in the year of diagnosis during which patients experience the highest number of transitions and flux in care. This is evidence that the current system of care for individuals with dementia is not adequately addressing their needs. If the BC Ministry of Health is truly committed to improving the health system for all individuals with dementia and their caregivers while incorporating new approaches to service delivery [273], an evidence-based approach that provides targeted resources to physicians that encourages guideline-consistent dementia care and focusing on the year of diagnosis may prove to be a potentially valuable starting points of intervention.

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APPENDIX A, CHAPTER 3

A.1 Objective of Study Protocol

The objective of this review is to assess the evidence for variations in physician practice patterns in caring for people with dementia in a systematic way.

Objective 1: Are there variations in clinical services provided to seniors?
Objective 2: Are there variations in referral services for additional care (e.g. home care, adult day care, respite care etc.) provided to community dwelling seniors?

A.2 Method

A.2.1 Study Design

This systematic review will include all quantitative study designs including experimental, quasi experimental (pre-post studies, interrupted time-series) and observational (case control, cohort, cross-sectional) studies. While randomized control trials are the optimal design, it is not anticipated that there will be many conducted in this field, therefore quasi-experimental and observational studies will also be included. Editorials, commentaries and letters that do not report information on original empirical results will not be included. Qualitative studies will also be indexed, but separated.

A.2.2 Population/Comparators

General physicians providing care to seniors 60 years or older diagnosed with dementia, both primary and secondary diagnoses. Specialist providing dementia care will also be evaluated separately if possible. If it is possible to investigate sub-populations of patients, I will do so (i.e. Alzheimer's disease, Parkinson's disease, Frontal Temporal Dementia, Vascular Dementia) as well as differentiate between home care and residential care patient population when possible.

A.2.3 Interventions

Any clinical service or combination of clinical services detailed as appropriate for dementia care management (hereafter referred to as ‘dementia care processes’). These are all services outlined by national and international guidelines such as physical checkup, history taking, formal memory testing, neuropsychological testing, disclosure of diagnosis, imaging, blood workups, prescriptions for dementia, depression, behavioural challenges, non-pharmaceutical therapeutics, environmental interventions, counseling and referrals to specialists. Referral to services for additional care or support will also be included such as home and community services, respite care, support groups, Alzheimer's association, adult day centres etc.

A.2.4 Outcomes

Any quantitative clinical outcome measures (e.g. rates, prevalence, odds ratios, rate ratios etc.), both unadjusted and adjusted.

A.2.5 Inclusion and Exclusion Criteria

Inclusion criteria:

- All English language studies
- Peer reviewed and grey literature
- Published prior to March 1st, 2012
- Quantitative experimental, quasi-experimental and observational studies

Exclusion criteria:

- Published studies not reporting on original empirical results
- Conference abstracts, book chapters
- Studies focused exclusively on prescription patterns of acetyl-cholinesterase inhibitors, antipsychotic or psychotropic medications
- Studies focused on caregiver patterns of care
- Physician practice patterns assessed for variability analyzed at a patient-level
- Presenile dementia or age 60 and below
- Non-primary care setting
- Only specialist practice patterns
- Vignettes (i.e. Only assess actual services provided)

A.3 Review Process

A.3.1 Search Method

I will employ a two-stage search strategy for this review. In consultation with a research librarian, I will develop a search strategy for the following electronic subscription databases for primary studies: Web of Knowledge database (ISI/Thompson), PubMed, Science Direct, MEDLINE (Ovid), PsychINFO and EMBASE (Ovid). To expand my search for grey literature, I will do a preliminary search in Google Scholar for the first 500 results. The search strategy will be adapted to each database based on its thesaurus or Medical Subject Headings. An individual search with each of the search terms will also be conducted to ensure that no relevant citations are missed. The concept of practice patterns and dementia will be combined with filters for language (English only) and publication dates where possible.

To increase the probability of capturing all potentially relevant studies, I will perform a secondary search by looking at the reference list of key studies that met my inclusion criteria.

A.3.2 Data Collection and Extraction Procedure

After consultation with a librarian, the literature search will be conducted by reviewer 1 (SS). The search results will be screened by title for potential inclusion in the review (SS). All studies that meet inclusion criteria by title will be included for abstract review. Abstracts will be extracted by reviewer 1 (SS) and the abstract review will be conducted independently by both reviewers (SS and JP). Results will be compared and disagreements resolved by discussion until consensus is reached.

Reviewer 1 (SS) will then obtain full-texts of all articles that met inclusion criteria after abstract review and store them in the reference manager Mendeley's shared online folder, accessible only by both reviewers. Full-texts will then be reviewed to determine if studies continue to meet inclusion criteria. Particular attention will be paid to the participants (type of physicians assessed), level of analysis (patient or physician-level), methodology, dementia care processes assessed and the outcome reported. Only studies indentified by both reviewers will be included for data extraction. If consensus cannot be reached, a third reviewer can be requested for independent assessment.

A data extraction tool will be developed by reviewer 1 (SS) to extract all relevant data. This tool will be tested by both reviewers independently on three studies drawn at random from the final list of included studies. Once the tool's effectiveness has been agreed upon by both reviewers, it will be used on the remaining studies. Independent data extractions will be conducted by each reviewer who will then meet to compare and discuss the extracted data until consensus is reached.

A.3.3 Critical Appraisal

Reviewer 1 (SS) will conduct a critical appraisal of the results of each study. The quality of the studies may not be assessed if there are a limited number of studies. The following criteria will be considered:

- The magnitude of difference in the outcome measurement across studies
- The potential for bias (classification, selection, measurement bias)
- Publication year and the availability of best practice guidelines

APPENDIX B, CHAPTER 4

Table B.1 - Cross-walk mapping a sample of drug identification numbers to corresponding anatomical therapeutic chemical groups for medications of interest

Drug Type	Drug Identification Number	Anatomical Therapeutic Chemical Group
Acetyl-cholinesterase Inhibitor (excluding Memantine)	02232043, 02232044	N06DA02
	02269457, 02269465	
	02242115, 02242116	N06DA03
	02242117, 02242118	
	02266733, 02316943	N06DA04
	02316951, 02316978	
	02344807,02348950	N06DX01
	02349116, 02366487	
Memantine	02260638, 02320908	N06DX01
	02321130, 02324067	
	02344807, 02348950	
	02349116, 02366487	
Antipsychotics	00346780, 00346799	N05AH01
	00346802, 00346810	
	02229250, 02229269	N05AH03
	02229277, 02229285	
	02299038, 02299046	N05AH04
	02299054, 02299062	
	02025280, 02025299	N05AX08
	02025302, 02025310	
Trazodone	00579351, 00579378	N06AX05
	00702277, 00824135	
	01937227, 01937235	
	02053187, 02053195	
Benzodiazepines	00012874, 00013285	N05BA01
	00013293, 00013757	
	00020915, 00020923	N05BA02
	00020931, 00134325	
	00231363, 00295698	N05BA04
	00402680, 00402737	
Antidepressants	00010448, 00353868	N06AA01
	00353876, 00425265	
	00010464, 00010472	N06AA02
	00010480, 00021504	

(Full table available upon request)

APPENDIX C, CHAPTER 5

Table C.1 – Baseline characteristics of individuals newly diagnosed with dementia in 2009/10 who died during study period

Characteristics	Patients with Dementia (n=1,328)
Age in years (mean± SD)	85.90 ± 6.61
69-80	21.8%
81-90	53.5%
91+	24.7%
Sex*	
Male	51.0%
Female	48.9%
Income Quintile (mean± SD)*	2.78 ± 1.52
1- Lowest income	24.5%
2- Lower income	24.4%
3- Medium income	19.9%
4- Higher income	15.0%
5- Highest income	15.2%
Multiple chronic disease (not including dementia)	
0 chronic diseases	3.6%
1 chronic disease	12.3%
2 chronic diseases	21.6%
3+ chronic diseases	62.4%
Number of major ADGs (mean± SD)	3.72 ± 1.27
Treatment Prevalence of major chronic diseases	
Hypertension	71.0%
Depression	25.0%
Arthritis or Osteoarthritis	35.6%
Cancer	42.0%
Congestive heart failure	38.2%
Diabetes	28.1%
Cardiovascular disease	25.1%
Stroke	12.2%
Chronic obstructive pulmonary disease	11.9%
Chronic kidney disease	10.8%
Liver disease	0.2%
Health Authority*	
Interior	28.8%
Fraser	24.3%
Vancouver Coastal	26.7%

Characteristics	Patients with Dementia (n=1,328)
Vancouver Island	3.76%
Northern	3.3%

*Missing data: Sex Unknown=1, Income Unknown=11, Quintile HA Unknown=1

Table C.2A – Percentage of individuals who died during study period who received laboratory testing and imaging processes outlined in guidelines stratified by patient characteristics

	Laboratory Testing						Imaging
Patient Characteristics	Complete hematology profile	Serum electrolytes	Serum calcium	Serum glucose	Thyroid stimulating hormone	B12 vitamin	Head computed tomography
Age							
69-80	63	60	26	39	36	19	66
81-90	58	55	19	38	38	20	57
91+	50	50	14	26	30	15	46
Sex*							
Female	53	52	19	32	35	17	53
Male	60	57	20	39	36	19	60
Income Quintile*							
Lowest	52	50	15	33	34	17	57
Low	58	55	19	37	37	20	57
Medium	57	55	22	30	35	13	53
High	59	57	22	43	38	21	63
Highest	62	58	21	37	34	22	50
Multiple Diseases							
0 diseases	37	21	5	11	24	16	50
1 disease	43	34	14	22	24	15	46
2 diseases	57	57	19	39	43	23	51
3+ diseases	61	60	22	38	36	18	61
Health Authority*							
Interior	54	52	14	27	31	15	44
Fraser	60	59	22	41	41	20	60
Vancouver Coastal	54	50	17	37	35	17	65
Vancouver Island	62	61	27	37	36	24	62
Northern	56	51	28	39	31	13	44

Table C.2B – Percentage of individuals who died during study period who received prescriptions and dementia care management processes outlined in guidelines stratified by patient characteristics

	Prescriptions					Counselling and Specialist Referral		
Patient Characteristics	AChI	Antipsychotics	Trazodone	Antidepressants	Benzodiazepines	examination in-office	counselling in-office	Referral to specialist
Age								
69-80	9	24	6	35	26	10	25	4
81-90	14	24	6	29	24	9	20	5
91+	7	28	5	25	23	9	11	2
Sex*								
Female	11	24	6	30	26	9	18	2
Male	12	26	6	28	22	10	19	5
Income Quintile*								
Lowest	13	28	6	25	22	10	18	2
Low	9	21	6	32	26	10	17	3
Medium	9	23	7	34	25	10	20	2
High	12	21	2	27	23	10	20	6
Highest	13	33	8	28	26	3	20	6
Multiple Diseases								
0 diseases	8	26	3	21	18	3	11	5
1 disease	11	23	4	18	18	9	11	6
2 diseases	14	28	6	24	25	13	20	3
3+ diseases	11	25	6	26	34	8	20	3
Health Authority*								
Interior	11	31	8	35	33	8	19	2
Fraser	12	15	3	27	17	8	16	5
Vancouver Coastal	13	30	6	28	22	8	17	4
Vancouver Island	9	22	5	28	27	14	27	3
Northern	13	26	8	23	16	13	8	3

Table C.3A - Proportional odds ratio for factors associated with receiving guideline-consistent care from multivariate modelling

	Adjusted Odds Ratio (95% Confidence Interval)						
	Laboratory Tests						Imaging
Independent Variables	Complete hematology profile	Serum electrolytes	Serum calcium	Serum glucose	Thyroid stimulating hormone	B12 vitamin	Head computed tomography
Age							
69-80	1.00	1.00	1.00	1.00	1.00	1.00	1.00
81-90	0.85 (0.67 - 1.08)	0.89 (0.73 - 1.08)	0.81 (0.70 - 0.93)†	0.63 (0.53 - 0.74)‡	0.75 (0.63 - 0.90)†	0.82 (0.71 - 0.94)†	0.85 (0.74 - 0.98)*
91+	0.48 (0.36 - 0.65)‡	0.68 (0.52 - 0.89)*	0.48 (0.39 - 0.60)‡	0.35 (0.28 - 0.44)‡	0.48 (0.38 - 0.61)‡	0.61 (0.50 - 0.75)‡	0.52 (0.42 - 0.63)‡
Sex							
Female	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Male	0.91 (0.7 - 1.19)	0.93 (0.75 - 1.16)	0.76 (0.65 - 0.89)‡	0.99 (0.82 - 1.21)	0.67 (0.54 - 0.82)‡	0.74 (0.63 - 0.86)‡	1.24 (1.06 - 1.46)†
Income Quintile							
1- Lowest	1.00	1.00	1.00	1.00	1.00	1.00	1.00
2- Low	1.14 (0.92 - 1.43)	1.17 (0.96 - 1.43)	1.26 (1.09 - 1.46)†	1.16 (0.99 - 1.37)	0.95 (0.80 - 1.12)	1.26 (1.09 - 1.45)†	1.03 (0.89 - 1.19)
3- Medium	1.18 (0.94 - 1.49)	1.19 (0.97 - 1.46)	1.11 (0.96 - 1.30)	1.13 (0.95 - 1.33)	1.01 (0.85 - 1.21)	1.13 (0.98 - 1.31)	0.90 (0.77 - 1.04)
4- High	1.12 (0.88 - 1.42)	1.01 (0.82 - 1.23)	1.11 (0.95 - 1.30)	1.07 (0.90 - 1.27)	1.07 (0.89 - 1.28)	1.08 (0.93- 1.25)	1.00 (0.86 - 1.17)
5- Highest	1.33 (1.04 - 1.71)*	1.23 (1.00 - 1.51)*	1.22 (1.04 - 1.42)†	1.10 (0.92 - 1.30)	1.18 (0.98 - 1.42)	1.44 (1.24 - 1.68)‡	0.94 (0.81 - 1.09)
Multiple Chronic Diseases							
0 diseases	1.00	1.00	1.00	1.00	1.00	1.00	1.00
1 disease	1.17 (0.83 - 1.64)	1.72 (1.32 - 2.24)‡	1.05 (0.83 - 1.33)	1.07 (0.83 - 1.38)	0.95 (0.71 - 1.25)	0.91 (0.72 - 1.15)	1.07 (0.86 - 1.34)
2 diseases	1.28 (0.92 - 1.78)	1.98 (1.54 - 2.56)‡	1.03 (0.82 - 1.29)	1.14 (0.89 - 1.46)	0.95 (0.72 - 1.24)	0.84 (0.67 - 1.05)	1.20 (0.97 - 1.50)
3+ diseases	1.44 (1.05 - 1.98)*	2.83 (2.21 - 3.63)‡	1.21 (0.98 - 1.51)	1.19 (0.95 - 1.51)	0.92 (0.70 - 1.20)	0.80 (0.64 - 0.98)*	1.51 (1.23 – 1.87)‡
Health Authority							
Interior	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Fraser	1.92 (1.54 - 2.41)‡	1.79 (1.48 - 2.17)‡	2.06 (1.79 - 2.38)‡	2.07 (1.77 - 2.41)‡	2.17 (1.84 - 2.56)‡	1.79 (1.56 - 2.05)‡	1.30 (1.13 - 1.49)‡
Vancouver Coastal	1.04 (0.85 - 1.27)	0.91 (0.76 - 1.09)	1.45 (1.25 - 1.69)‡	1.32 (1.14 - 1.53)‡	1.23 (1.05 - 1.43)†	1.31 (1.14 - 1.51)‡	1.63 (1.41 - 1.87)‡
Vancouver Island	1.64 (1.30 - 2.07)‡	1.55 (1.27 - 1.89)‡	2.44 (2.09 - 2.83)‡	1.76 (1.50 - 2.07)‡	1.75 (1.47 - 2.08)‡	2.16 (1.87 - 2.50)‡	1.47 (1.27 - 1.70)‡
Northern	2.01 (1.18 - 3.41)†	2.05 (1.31 - 3.23)†	3.80 (2.85 - 5.07)‡	2.24 (1.57 - 3.21)‡	2.37 (1.60 - 3.51)‡	2.43 (1.82 - 3.25)‡	1.55 (1.16 - 2.06)†

‡ - P value <0.001 † - P value <0.01 * - P value <0.05

Table C.3B – Proportional odds ratio for factors associated with receiving guideline-consistent prescriptions and dementia care management processes, from multivariate modelling

	Adjusted Odds Ratio (95% Confidence Interval)							
	Prescriptions					**Management**		
Independent Variables	AChI	Antipsychotics	Trazodone	Antidepressant	Benzodiazepine†	Complete examination in-office	Individual counselling in-office	Referral to specialist re. Dementia
Age								
69-80	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
81-90	0.82 (0.71 - 0.94)†	1.08 (0.93 - 1.26)	0.81 (0.64 - 1.03)	0.75 (0.65 - 0.86)‡	0.89 (0.76 - 1.04)	0.74 (0.64 - 0.85)‡	0.72 (0.63 - 0.82)‡	0.61 (0.48 - 0.77)‡
91+	0.33 (0.26 - 0.42)‡	1.14 (0.91 - 1.42)	0.76 (0.53 - 1.08)	0.53 (0.43 - 0.66)‡	1.01 (0.81 - 1.26)	0.41 (0.30 - 0.49)‡	0.41 (0.33 - 0.50)‡	0.24 (0.14 - 0.40)‡
Sex								
Female	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Male	1.15 (0.73 - 1.00)*	0.92 (0.82 - 1.16)	0.93 (0.71 - 1.21)	0.66 (0.56 - 0.77)‡	0.69 (0.57 - 0.82)‡	1.15 (0.98 - 1.35)	0.79 (0.68 - 0.93)†	1.30 (1.03 - 1.65)*
Income Quintile								
1- Lowest	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
2- Low	1.15 (0.99 - 1.33)	0.92 (0.79 - 1.07)	0.77 (0.60 - 0.98)*	0.93 (0.80 - 1.07)	0.94 (0.80 - 1.10)	0.93 (0.79 - 1.08)	1.09 (0.95 - 1.26)	1.04 (0.80 - 1.34)
3- Medium	1.28 (1.10 - 1.49)‡	0.85 (0.72 - 0.99)*	0.83 (0.65 - 1.06)	0.92 (0.79 - 1.07)	0.97 (0.83 - 1.15)	0.97 (0.83 - 1.13)	1.15 (1.00 - 1.34)*	1.24 (0.96 - 1.60)
4- High	1.20 (1.03 - 1.41)*	0.89 (0.75 - 1.04)	0.77 (0.59 - 1.00)*	0.90 (0.77 - 1.04)	0.99 (0.84 - 1.18)	1.09 (0.93 - 1.27)	1.20 (1.03 - 1.40)*	1.19 (0.92 - 1.56)
5- Highest	1.34 (1.14 - 1.56)‡	0.79 (0.67 - 0.93)†	0.71 (0.54 - 0.92)†	0.85 (0.73 - 1.00)*	0.97 (0.82 - 1.15)	1.02 (0.87 - 1.20)	1.31 (1.13 - 1.53)‡	1.51 (1.18 - 1.95)‡
Multiple Chronic Diseases								
0 diseases	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
1 disease	0.96 (0.76 - 1.21)	1.06 (0.82 - 1.37)	1.24 (0.78 – 1.98)	1.64 (1.26 - 2.13)‡	1.21 (0.91 - 1.60)	0.76 (0.60 - 0.97)*	1.04 (0.83 - 1.30)	0.80 (0.54 - 1.16)
2 diseases	0.94 (0.76 - 1.17)	1.20 (0.93 - 1.53)	1.37 (0.88 - 2.15)	2.29 (1.78 – 2.96)‡	1.41 (1.07 - 1.85)*	0.88 (0.70 - 1.11)	1.06 (0.85 - 1.33)	0.85 (0.60 - 1.22)
3+ diseases	0.60 (0.49 - 0.74)‡	1.21 (0.95 - 1.53)	1.79 (1.17 - 2.75)†	3.87 (3.03 – 4.95)‡	1.81 (1.39 - 2.36)‡	0.85 (0.67 - 1.05)	1.11 (0.89 - 1.37)	1.021(0.72 - 1.43)
Health Authority								
Interior	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Fraser	1.61 (1.40 - 1.85)‡	0.78 (0.68 - 0.91)‡	0.78 (0.61 - 0.99)*	0.89 (0.77 - 1.02)	0.83 (0.71 - 0.96)†	1.31 (1.13 - 1.52)‡	0.94 (0.82 - 1.07)	1.90 (1.50 - 2.42)‡
Vancouver Coastal	0.89 (0.77 - 1.03)	0.81 (0.70 - 0.94)†	1.10 (0.87 - 1.39)	0.81 (0.70 - 0.93)†	0.69 (0.59 - 0.81)‡	1.19 (1.02 - 1.38)*	0.83 (0.72 - 0.96)†	1.83 (1.43 - 2.34)‡

	Adjusted Odds Ratio (95% Confidence Interval)							
	Prescriptions					Management		
Independent Variables	AChI	Antipsychotics	Trazodone	Antidepressant	Benzodiazepine†	Complete examination in-office	Individual counselling in-office	Referral to specialist re. Dementia
Vancouver Island	1.17 (1.01 - 1.36)*	0.83 (0.71 - 0.97)*	0.80 (0.62 - 1.03)	0.85 (0.73 - 0.98)*	0.89 (0.76 - 1.05)	1.64 (1.41 - 1.92)‡	1.22 (1.06 - 1.41)†	0.77 (0.58 - 1.04)
Northern	0.83 (0.62 - 1.11)	0.99 (0.73 - 1.34)	0.61 (0.35 - 1.08)	0.81 (0.60 - 1.08)	0.89 (0.65 - 1.22)	0.89 (0.65 - 1.22)	0.95 (0.71 - 1.25)	0.36 (0.17 - 0.79)‡

‡ - P value <0.001 ‡ - P value <0.01 * - P value <0.05

APPENDIX D, CHAPTER 6

Table D.1 - Longitudinal health care use

	Year (-1)	Year 0	Year 1	Year 2	Year 3	Year 4	Year 5	Year 6	Year 7	Year 8	Year 9
	2000/01	**2001/02**	**2002/03**	**2003/04**	**2004/05**	**2005/06**	**2006/07**	**2007/08**	**2008/09**	**2009/10**	**2010/11**
Total cohort at beginning of year (n)	6,876	6,876	5,788	4,828	3,970	3,281	2,683	2,153	1,719	1,372	1,105
Cohort survival (%)	*100%*	*100%*	*84%*	*70%*	*58%*	*48%*	*39%*	*31%*	*25%*	*20%*	*16%*
HOSPITAL USE											
No hospital stay (n)	5,356	2,619	4,098	3,675	3,032	2,591	2,192	1,780	1,435	1,151	919
Had hospital stay (n)	1,520	4,257	1,690	1,153	938	690	491	373	284	221	186
Cohort with hospital stay (%)	*22%*	*62%*	*29%*	*24%*	*24%*	*21%*	*18%*	*17%*	*17%*	*16%*	*17%*
Mean number hospital admissions for those hospitalized (mean ± SD)	1.56	5.1	2.2	2.38	2.18	2.26	1.73	1.71	2.02	1.79	1.82
Mean LOS at hospital for those hospitalized (mean ± SD)	23.10 ± 40.42	41.71 ± 49.52	28.52 ± 41.23	23.08 ± 33.93	20.74 ± 29.67	22.81 ± 34.03	20.28 ± 30.88	18.44 ± 25.66	18.20 ± 23.25	17.80 ± 27.80	18.79± 28.61
TRANSITIONS											
Experienced a transition (n)	1,750	4,570	2,096	1,493	1,231	1,090	598	464	487	283	196
Cohort who experienced atleast one transition (%)	*25%*	*66%*	*36%*	*31%*	*31%*	*33%*	*22%*	*22%*	*28%*	*21%*	*18%*
Cohort who experienced 3+ transitions (%)	*4%*	*17%*	*6%*	*4%*	*5%*	*4%*	*2%*	*3%*	*3%*	*2%*	*2%*
Total transitions (mean ± SD)	0.41 ± 0.88	1.34 ± 1.40	0.62 ± 1.05	0.51 ± 0.98	0.52 ± 1.00	0.52 ± 0.98	0.34 ± 0.80	0.34 ± 0.82	0.43 ± 0.81	0.30 ± 0.69	0.27 ± 0.69

Table D.2 – Principal diagnoses for patients newly diagnosed with dementia in hospital only

Principal Diagnosis	Proportion of Patients (n=2499)
Dementia	14.95%
Fracture of femur	8.96%
Pneumonia	4.80%
Heart Failure	3.68%
Stroke	2.92%
Rehabilitation care	2.76%