Long-term Healthcare Transition Pathways Among Community Dwelling Adults with Dementia in Alberta, Canada; A retrospective cohort analysis

by

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ABSTRACT

In Canada, one in five adults over the age of 80 have dementia. Dementia negatively impacts other chronic conditions and is associated with a higher risk of death, frailty and higher health-care costs. Health care transitions are major events; the abrupt nature of transitions, are confusing and frustrating events for both patients and caregivers and there is increasing evidence that patient safety is jeopardized during transitions. Patient transition pathways through the health care system are complex and are inadequately captured by standard single outcome and transition models, so I developed a multi-state model to better reflect complex transition pathways. I did this by constructing a retrospective cohort of 10,287 older community-dwelling adults living with dementia, and the transitions they experienced over a two-year period, from administrative databases and electronic medical records. This data was summarized and then analyzed. I found that frequent transitions and complex pathways characterize long-term transition pathways for older adults living with dementia. Additionally, older age, being male, increased comorbidity and number of previous transitions increase the complexity of long-term transition pathways through the healthcare system.

PREFACE

This thesis is an original work by Joshua D. Hathaway. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Office, Project Name “Older Adults with Dementia and Their Use of Acute Care Services in Alberta”, Study ID Pro00055126, December 22, 2015.

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TABLE OF CONTENTS

CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1: LITERATURE REVIEW

THESIS OVERVIEW

This paper-based thesis is composed of four chapters. The first chapter will serve to contextualize the problem of interest by reviewing the current state of the literature; in addition to clearly stating the research objectives and research questions. Chapter two consists of the self-contained manuscript to be submitted to PLOS Medicine: "Long-term Healthcare Transition Pathways Among Community Dwelling Adults with Dementia in Alberta, Canada; A retrospective cohort analysis". This chapter will focus on the methods for building the cohort that was analyzed as well as present the findings on patient demographics and transition frequencies and types. It will continue with an in-depth analytical look at transition probabilities experienced by the cohort using a multi-state model which also will provide information on how transitions are affected by age, sex, comorbid severity, and transition history. Chapter three will be the conclusion which provides a detailed overview and interpretation of the main findings as well as next steps. Chapter four is a reflection on lessons learned during my time working on my thesis.

DEMENTIA

Dementia refers to a class of neurodegenerative disorders characterized by progressive deterioration of cognitive functioning.[4] Memory loss, impaired judgment, and reasoning, as well as changes in mood, behavior, and ability to communicate are common symptoms.[4] Age is the largest risk factor; dementia prevalence doubles every 5 years from 2-3% of adults aged 65-74, to over 30% of adults over the age of 80.[5] In 2011, 747,000 Canadians were living with dementia and this number is projected to double to 1.4 million by 2031.[6] The total cost of dementia is $33 billion a year currently, and projected to swell to over $293 billion by 2040, this accounts for both direct medical expenses as well as indirect costs such as lost earnings of informal caregivers.[6]

MULTIMORBIDITY

Multimorbidity, defined as having two or more chronic conditions is highly prevalent, and significantly increases with age.[7–9] Fortin et al. (2005) in Quebec looked at adults seen in family practice, 74% of men and 77% of women over the age of 65 had 5 or more chronic conditions.[10] Kone Pefoyo et al. looked at Ontario's population in a retrospective cohort study and found between 2003 and 2009 there was a 40% increase in the prevalence of multimorbidity; this trend was seen across all subcategories and surprisingly had no dominant patterns of co-occurring conditions.[7] The authors found the prevalence of three or more chronic conditions almost doubled between 2003 and 2009, all the while the prevalence of having only one condition remained stable at roughly 26%.[7] More concerning, in 2009 over 80% of older adults over 75 had two or more chronic conditions and over 20% had five or more.[7] Kone Pefoyo et al. suggested that since they were unable to find any combinations of conditions that were dominant that the single disease-oriented approach to chronic conditions management would be less effective than a person-centered approach.[7,8]

Multimorbidity has been shown to be significantly related to decreased quality of life and functional status, and increased health care use and mortality.[11] Clinical practice guidelines tend to focus on almost exclusively a single condition and have been found to be ill-suited at providing an evidence-based approach to providing quality care in older adults with multiple chronic conditions.[12,13] Individuals who have multiple chronic conditions have been shown to use primary care disproportionately, one study finding that 16% of patients in the study who had more than one chronic condition accounted for 32% of all consultations.[14]

Multimorbidity also leads to increased health care costs, a cross-sectional analysis found that Medicare expenditures for beneficiaries over the age of 80 without a chronic condition had an annual average cost of $222 compared to beneficiaries with four or more chronic conditions having an annual average cost of $13,973.[15] In the United States health care expenditures exceed $1.7 trillion and individuals with multiple chronic conditions are estimated to account for 95% of all Medicare spending.[9] Total health expenditures in Canada are expected to reach $228.1 billion in 2016, and it has been shown that people with chronic conditions are higher users of health care services than those without long-term health problems, and the use of care increase with the number of comorbid conditions.[16] CIHI reported that older adults with 3 or more chronic conditions accounted for 40% of reported health care use, even though they only account for 25% of all seniors.[17]

CHRONIC CARE AND SELF-MANAGEMENT

There is an emphasis on the importance of self-care in the management of chronic conditions. For example, some self-management interventions suggested for individuals with diabetes include exercise, nutritional education, and relaxation training.[18] Wagner et al. suggest four components of self-management of chronic conditions:

> "1) Engaging in activities that promote physical and psychological health, 2) interaction with health care providers and adherence to suggested interventions, 3) monitoring health status and making associated care decisions, and 4) managing the impact of an illness on physical, psychological, and social functioning."[19]

They have also identified many barriers to self-management of chronic conditions such as

> "physical limitations, lack of knowledge, financial constraints, logistics of obtaining care, a need for social and emotional support, aggravation of one condition by symptoms of or treatment of another, multiple problems with medications, and overwhelming effects of dominant individual conditions."[19]

Many of these barriers are directly linked to risk factors for and the consequences of having multiple chronic conditions.

MULTIMORBIDITY VS. COMORBIDITY

It should be noted that multimorbidity and comorbidity are used somewhat interchangeably in the literature. The technical difference between the two is multimorbidity is defined as simply having two or more chronic conditions whereas comorbidity looks at chronic conditions in addition to a particular index chronic condition. For example, an individual that has dementia, diabetes, and hypertension has multimorbidity because they have three chronic diseases. If we are explicitly interested in dementia, it would be considered the index condition, and we would say that diabetes and hypertension are comorbidities. It is a subtle difference but is an important distinction to make for this work.

DEMENTIA AND MULTIMORBIDITY

Multimorbidity is common in people that have dementia, 61% of whom have three or more comorbid chronic conditions. The average number of chronic conditions among people with dementia is 4.6.[20] A 2006 study by Schubert et al. found on average patients with dementia were prescribed more than five medications and had moderate to severe comorbidity.[21] In a recent analysis by Callahan et al. they found patients with dementia had significantly higher occurrences of arthritis, cancer, coronary artery disease, congestive heart failure, chronic obstructive pulmonary disease, diabetes mellitus, hypertension, liver disease, renal disease, and stroke; showing relative increases between 2.5% and over 300%, for cancer and stroke respectively, when compared to those without dementia.[1]

The presence of dementia in an individual with other chronic conditions can lead to a decreased capacity for self-management of other conditions leaving daily self-care tasks to family members or health professionals.[20] Self-management of a chronic condition would require an individual to understand their condition and follow through on instructions from a health provider. This lack of understanding can present a significant challenge to someone with dementia. For example, people with dementia and diabetes have trouble understanding their conditions, managing medication and monitoring their blood glucose.[22]

People with dementia are also more likely to be untreated for other comorbid conditions when compared to individuals with similar health conditions but without dementia.[20] A scoping review by Bunn et al. found that the presence of dementia reduced the likelihood of being monitored for diabetes-related problems.[22] People with dementia also experience less accessible treatments for stroke, cataracts, age-related macular degenerations (AMD), and diabetes.[22] The same Canadian study even found "evidence that pain is underrated in people with dementia and arthritis".[22]

Many factors influence the lack of appropriate and timely care. Including a potential difficulty attending regular visits to the physicians (potentially due to lacking a regular caregiver), the decreased capacity to self-report changes, the reluctance of clinicians to investigate and treat (due to difficulties of gaining consent, or inappropriateness of treatment) and dementia potentially masking other conditions. This results in the misattributions of symptoms to dementia.[20] Bunn et al. suggested that dementia could overshadow other conditions that have behavioral and psychological symptoms of diabetes, such as confusion as a result of elevated blood sugar or incontinence. Both of which are falsely attributed to dementia.[20] This also happens with other conditions such as visual or auditory impairments.[20]

HEALTH CARE USE

Older adults with dementia use both acute and primary care more frequently than those without dementia, an Ontario report has shown that within one year, older adults with dementia visit emergency departments twice as often (43% vs. 24.6%), experience more acute care hospital admissions (22.3% vs. 10.7%), are four times more likely to have home care services (34.4% vs. 9.0%) and are 16 times more likely to apply for long-term care home admission (8.0% vs. 0.5%) than older adults without dementia.[23] The increased prevalence of comorbidities in individuals with dementia can also lead to complexities in their care.[24]

Care for individuals with dementia in the hospital can be complicated due to the higher risk of delirium, falls, and other adverse events.[25] Dementia accounts for a small proportion of all hospital admissions, yet it is among the 10 most costly reasons for hospitalization in Canada.[26] Dementia is the most common diagnosis associated with alternate level of care (ALC) stays; one of the most significant factors in acute care bed shortages, accounting for more than one third of all ALC days.[27]

In an observational cohort study, Lamantia et al. looked at the differences in emergency department (ED) usage among older adults with and without dementia. They found that ED usage among individuals with a dementia diagnosis was almost double that of those without a dementia diagnosis in a given year. Patients with dementia were admitted more frequently and had a higher frequency of rehospitalization within 30 days of the index ED visit than those without dementia. Those with dementia also had significantly lower 6-month, 12-month and 60-month survival rates when compared to those without dementia.[28]

TRANSITIONS

Healthcare transitions, defined as a change in the healthcare setting, are significant events. Transitions include, but are not limited to, admission to a long-term care home, an emergency department visit, an inpatient visit at a hospital and a discharge from the hospital or emergency department back home. The abrupt nature of transitions are confusing and frustrating events for both patients and caregivers, and there is increasing evidence of jeopardized patient safety during transitions.[29] Patients with dementia experience frequent transitions over relatively short periods of time, in one study people with dementia, experienced 32% more transitions in their last two years of life (starting from home) than people without dementia.[30,31]

Callahan et al. conducted a prospective cohort study using electronic medical records and administrative health data from 2001 to 2008 to describe the types and frequency of transitions in care experienced by older adults with dementia with a mean follow-up of 5.2 years.[1] The study found that older adults with prevalent cases of dementia had 4 times the nursing facility use, 1.5 times the hospital use, and 2 times the home health use. They experienced on average almost 2 times more transitions per person-year of follow-up than those never diagnosed with dementia while controlling for demographic variables and comorbid conditions.[1] Older adults diagnosed with dementia were also more likely to die and had earlier times to death than those without a dementia diagnosis.[1]

The researchers also determined the probabilities of inbound and outbound transitions between two sites of care for older adults with dementia. Inbound being the probability of transitioning into a site and outbound being the probability of transitioning out of the site. The study explored transitions between four sites of care (1) the individual's home without formal services, (2) home with formal services, (3) nursing facilities, and (4) hospitals. The specific inbound and outbound probabilities are summarized in the table below. [1] Possible transitions are visualized in figure 1.1 below.

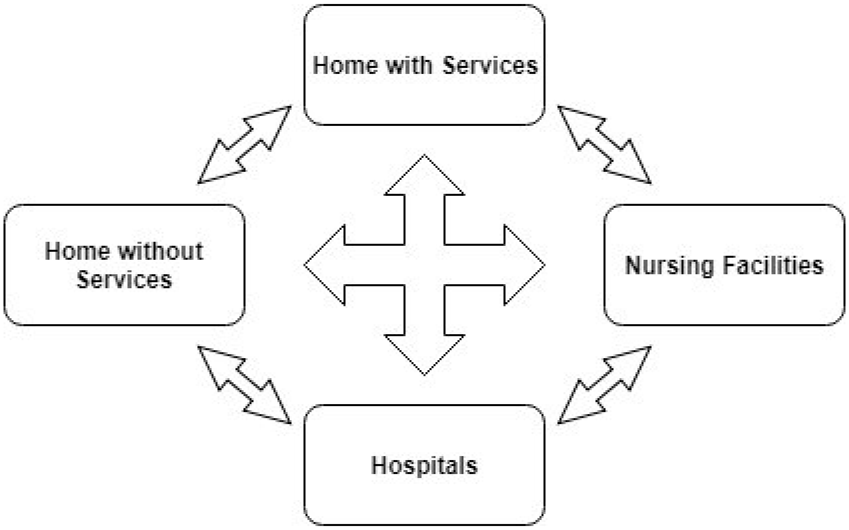

Figure 1.1 Site of care transition matrix for Callahan et al. (2012)

Outbound Transition Probabilities Summarized from Callahan et al. (2012, page 816)

From:	To: Hospital	Nursing Facility	Home with Services	Home without Services
Hospital	x	38.1%	16.4%	40.1%
Nursing Facility	43.9%	x	9.4%	39.2%
Home with Services	38.1%	3.5%	x	64.4
Home without Services	53.9%	11.2%	29.7%	x

Inbound Transition Probabilities Summarized from Callahan et al. (2012, page 816)

To:	From: Hospital	Nursing Facility	Home with Services	Home without Services
Hospital	x	23.4%	17.1%	59.5%
Nursing Facility	73.7%	x	3.6%	22.7%
Home with Services	31.4%	9.1%	x	59.5%
Home without Services	42.7%	21.1%	36.2%	x

Table1.1 [Taken from Callahan et al. 2012] Summarizes the outbound and inbound probabilities between 2 sites of care for older adults with dementia from Callahan et al. 2012. Sums <1 in the outbound table due to death.[1]

Callahan highlighted the burden of the sheer number of transitions of care experienced by older adults with dementia, including the dynamic nature of movement into and out of nursing facilities.[1] The data also demonstrated the complexity of long-term patterns of healthcare transitions between nursing facilities, hospitals, and homes.[1]

COMPOUND TRANSITIONS

Of interest, Callahan characterized “compound transitions” which they defined as a “ping-pong” effect between sites of care these could occur on a timeframe of days to years.[1] Three dominant patterns arose when looking at compound transitions from nursing facilities, the most prevalent (experienced by 20% of participants) being nursing facility → hospital → nursing facility. The second most common (experienced by 14% of participants) being nursing facility → home (with or without care) → hospital. The third compound transition (experienced by 10% of the participants) being nursing facility → home (with or without care) → nursing facility.[1]

Compound transitions starting at the hospital looked different than those starting at a nursing facility. For instance, 29% of all participants discharged from hospital to a nursing facility had a subsequent hospitalization; 28% of participants released from the hospital were rehospitalized within 30 days, and the rehospitalization rate for older adults with dementia was 23%. Of this 23% of individuals with dementia rehospitalized within 30 days 17% were discharged from the index hospitalization to home with home services, 38% were released from the index hospitalization to home without home health services, and 45% were discharged from the index hospitalization to a nursing facility.[1]

There is little literature when it comes to compound transitions. Compound transitions start to look at the long-term trajectories of care that older adults with dementia take through the healthcare system. Even they are limited to looking at three transition events over time. There is a knowledge gap when it comes to what the typical healthcare journey looks like for an older adult with dementia, beyond single or even compound transitions.

OBJECTIVES

The objectives of this project are to:

1. Describe the types and frequencies of healthcare transitions experienced by adults aged 80+ with dementia over a two-year period.
2. Identify the long-term patterns of healthcare transitions between sites of care for older adults with dementia, beyond single transitions.
3. Estimate the effect of age, sex, comorbid severity and previous transition history on the number, type, and patterns of transitions experienced by older adults with dementia over a two-year period.

RESEARCH QUESTION

- What impacts long-term healthcare transition trajectories for community dwelling older adults with dementia?

- To what extent does age, sex, comorbid severity and previous transitions influence healthcare trajectories for older adults with dementia?

IMPORTANCE OF THE PROJECT

This project aims to meet three gaps in the current literature. Looking at the interplay between dementia and comorbid severity, accounting for multiple transitions and transition types, and identifying trajectories that move beyond a single transition.

The focus in the literature when it comes to healthcare transitions for older adults with dementia and other chronic conditions is limited to mostly single transitions.[1,30,31] There is a lack of information characterizing multiple and complex healthcare transitions for these individuals. To improve care across the continuum for older adults with dementia a better understanding of how these individuals utilize the healthcare system and where they may be vulnerable is needed. Understanding the journey these individuals take may improve both clinical outcomes and care across the continuum for older adults.

This study is important because it will address the lack of information about complex healthcare transitions older adults with dementia experience through the community, acute care, inpatient, and long-term care settings. The identification of these pathways has the potential to provide unique insights into how to improve clinical outcomes and care across the continuum.

CHAPTER 2:
LONG-TERM HEALTHCARE TRANSITION PATHWAYS AMONG COMMUNITY DWELLING ADULTS WITH DEMENTIA IN ALBERTA, CANADA; A RETROSPECTIVE COHORT ANALYSIS

FORWARD

This chapter is intended to be a manuscript; therefore, themes from the first chapter will be echoed in this manuscript. We are looking to publish in PLOS Medicine.

INTRODUCTION

Dementia refers to a class of neurodegenerative disorders characterized by progressive deterioration of cognitive functioning.[4] Memory loss, impaired judgment, and reasoning, as well as changes in mood, behavior, and ability to communicate are common symptoms. Age is the largest risk factor; dementia prevalence doubles every 5 years from 2-3% of adults aged 65-74, to over 30% of adults over the age of 80.[5] In 2011, 747,000 Canadians were living with dementia and this number is projected to double to 1.4 million by 2031.[6] The current total cost of dementia is estimated at $33 billion per year and projected to swell to over $293 billion by 2040, this accounts for both direct medical expenses as well as indirect costs such as lost earnings of informal caregivers.[6]

Multimorbidity, defined as having two or more chronic conditions, is seen in most people that have dementia, 61% of who have three or more comorbid chronic conditions. The average number of chronic conditions among people with dementia is 4.6.[20] Patients with dementia experience moderate to severe comorbidity and higher prevalence of comorbid conditions such as: arthritis, cancer, coronary artery disease, congestive heart failure, chronic obstructive pulmonary disease, diabetes mellitus, hypertension, liver disease, renal disease, and stroke; than those without dementia.[1,21] Older adults with dementia use both acute and primary care more frequently than those without dementia.[23] An Ontario report has shown that within one year, older adults with dementia visit emergency departments twice as frequently, experience more acute care hospital admissions, are four times more likely to have home care services and are 16 times more likely to apply for long-term care home admission than older adults without dementia.[23]

Healthcare transitions, defined as a change in the healthcare setting, are significant events. Transitions, in this study, include 1) admission to a long-term care home, 2) an emergency department visit, 3) an inpatient visit at a hospital, 4) a discharge from the hospital or emergency department back home, and 5) death. Many transitions ultimately end with the patient no longer being community dwelling due to admission to long-term care or through death. The abrupt nature of transitions are confusing and frustrating events for both patients, and caregivers and there is increasing evidence that patient safety is jeopardized during transitions.[29] Patients with dementia experience frequent transitions over relatively short periods of time, in one study people with dementia, experienced 32% more transitions in their last two years of life (starting from home) than people without dementia.[30,31] Chronic comorbidity has been shown to be associated with longer lengths of stay, in-hospital mortality and increased readmission at 30 and 365 days.[32] While there is a wealth of information on older adults with dementia and single healthcare transitions all of these studies tend to focus on single transitions or simple compound transitions.[1,30,31]

Pathways are complex for many reasons first emergency department visits may or may not result in admissions into the hospital, one can transition directly from home to a scheduled inpatient setting, and from these settings, they can transition back home. These three settings (home, emergency, and hospital) alone can be repeated many times further complicating the pathway. There can also be transitions from either hospital or the emergency department to long-term care or even death.

Unfortunately, these studies do not inform what types of long-term pathways individuals take through the healthcare system. This study is important because it will address the lack of information about complex healthcare transitions older adults with dementia experience through the community, acute care, inpatient, and long-term care settings. The identification of these pathways has the potential to provide unique insights into how to improve clinical outcomes and care across the continuum for older adults living with dementia and other comorbid conditions. The objectives of this study are to (1) describe the types and frequencies of healthcare transitions experienced by older adults with dementia over a two-year period, (2) identify the long-term patterns of healthcare transition between sites of care for older adults with dementia, beyond single transitions and (3) estimate the effect age, sex, comorbid severity, and previous transition history have on transition probabilities from one site of care to the next.

METHODS

The University of Alberta's Research Ethics Office (REO) approved this study. The cohort was built by linking Alberta Health and Alberta Health Services administrative databases and was accessed via the AHS analytics unit's research request portal. With approval from Alberta Health for the use of Practitioner Claims (CLAIMS), Pharmaceutical Information Network (PIN) and the Alberta Continuing Care Information System (ACCIS) and approval from Alberta Health Services for the use of Discharge Abstract Database (DAD), National Ambulatory Care Reporting System (NACRS), Alberta Ambulatory Care Reporting System (AACRS), and Alberta Health Care Insurance Premium Registry (AHCIP).

STUDY DESIGN AND SETTING

The Canadian province of Alberta has a single health authority and a vertically integrated government-funded healthcare delivery system that provides universal coverage for medically necessary care (primarily including hospital-based and physician services, but does not generally include medications or elective services) to the province's population of 4.06 million people.[33] Many administrative databases are maintained within the province, and even though their primary function is not for research, they are of high quality and often used for research purposes and is leveraged by initiatives like Strategy for Patient Oriented Research (SPOR).[34] Each database contains a unique patient identifier that facilitates linkage to derive information as required. My cohort was created by linking seven provincial administrative databases with data that were relevant to my study; I describe each database as follows:

a) Discharge Abstract Database (DAD) which captures admissions to acute care facilities including dates, a primary diagnosis, and up to 24 secondary diagnoses coded using the Canadian Enhancement of the International Statistical Classification of Diseases, 10th Revision (ICD-10). Trained nosologists code diagnosis codes, and record data elements according to national guidelines set forth by the Canadian Institute for Health Information (https://www.cihi.ca/en/discharge-abstract-database-metadata).

b) Practitioner Claims Database, which records physician billing claims and up to 3 diagnosis codes, coded using the International Statistical Classification of Diseases, 9th Revision (ICD-9).

This data is collected primarily to facilitate payment to physicians by the provincial government but is commonly used for health research studies.

c) National Ambulatory Care Reporting System (NACRS, since 2010) and Alberta Ambulatory Care Reporting System (AACRS, before 2010), which include visits to emergency departments including relevant dates, a primary diagnosis, and up to 9 secondary diagnoses coded using ICD-10. Diagnosis codes are coded by trained nosologists using national guidelines, and data elements are recorded according to national guidelines set forth by the Canadian Institute for Health Information (https://www.cihi.ca/en/discharge-abstract-database-metadata);

d) The Alberta Continuing Care Information System (ACCIS), which houses long-term care & community care service data from 2010 onwards;

e) Alberta Health Care Insurance Premium Registry (AHCIP), which is a provincial registry which records death dates;

f) Pharmaceutical Information Network (PIN) which captures over 95% of all prescriptions filled by community pharmacies in the province (data available since 2008) and can be identified using the Anatomical Therapeutic Chemical (ATC) Classification System)

f) Census derived Alberta population estimates, which include annual population estimates, including a breakdown by age and sex.

I captured a transition to ED by an appearance in the National Ambulatory Care Reporting System (NACRS) with the appropriate emergency code. A transition to a hospital was caught by an appearance in the Discharge Abstract Database (DAD). I captured a transition to LTC or death by an appearance in the Alberta Continuing Care Information System (ACCIS) or the Provincial Registry, respectively. I captured a transition to home when a discharge date from NACRS or DAD did not coincide with a subsequent admission, within a 24-hour window, in the NACRS, DAD, ACCIS, or provincial registry.

STUDY POPULATION

The cohort itself consists of all community dwelling adults aged 80 years and older on January 1, 2014, who have interacted with any health service provider in Alberta and had a diagnosis of dementia. I treated January 1, 2014, as the index date for all patients and they were observed for two years. I defined dementia as having at least one hospital record, or 3 physician claims for dementia (defined by ICD9/10 codes in Appendix A) or use of any cholinesterase inhibitor (see DIN codes in Appendix A) within a two year look back period from January 1, 2014, my study start date. This coding algorithm has been shown to have high sensitivity and specificity as well as high positive and negative predictive values in Canadian administrative health databases.[35]

COVARIATES

I specifically investigated the effects of four covariates age, sex, comorbidity burden, and the number of previous transitions. In addition to primary demographic variables (age, sex, geographic region), I identified comorbid medical conditions. I focused on the 17 defined comorbid conditions used in the calculation of the Charlson Comorbidity Index[2]. These were identified through the use of Quan et al.'s ICD9 and ICD10 coding algorithms, which was adapted for use with administrative databases, specific codes are in the appendix.[2] A patient was considered to have a comorbid condition if they had any hospital record within 5-years before their index date or had two physician claims with the proper ICD codes in a 2-year before their index date. This methodology was chosen due to the high prevalence of comorbid conditions among individuals with dementia.[20] Comorbid severity was calculated using the Charlson Comorbidity index which has been previously used in studies with mortality and resource use as outcome variables.[11] I categorized comorbidity burden as mild, moderate, and severe with a Charlson Index of 1-2 being mild, 3-4 being moderate and 5+ as severe, mild was the reference group. This was chosen because all individuals in our cohort would have a Charlson index of 1 due to dementia, one additional comorbid condition was deemed mild. More than one additional condition, or one that was weighted heavier, would constitute moderate. More than four additional comorbid conditions, or some combination of various weighted conditions, would constitute severe comorbidity.

To investigate the effect of multiple transitions has on the probability of transitioning from one state to another, I recorded the number of previous transitions, to any state, as a covariate. The number of previous transitions will account for transition history in our multi-state model. At study start every patient started with a count of zero at home and once any transition was experienced the covariate would increase by one. Each record in the data set was a transition experienced by a member of the cohort and was analyzed according to its time stamp. With this proxy variable, I was able to determine the effect the number of previous transitions had on future transition probabilities between states, with an accurate time-varying variable representing transition history.

ANALYSIS

Descriptive analysis of the cohort at baseline was conducted then again repeated once all transitions were captured and summarized.

I followed patients for up to 2 years until a transition to long-term care (LTC) or death, indicating they were no longer community dwelling. I summarized the creation of the base cohort in figure 2.1. I captured healthcare transitions by patients' appearance in different databases in chronological order. I identified four unique states 1) home, 2) emergency department (ED), 3) hospital admission, and 4) non-community dwelling. The cohort consisted only of individuals who were dwelling at home on the study start date; I know this because there was no record of them in any ED, hospital, or LTC site. Once a patient transitioned to LTC or died, they were censored thereby creating an 'absorbing state,' having no outgoing transitions. This led to the consolidation of LTC and death into the single non-community dwelling absorbing state, which simplified the multi-state model analysis. This was justified since the analysis of a five-state model where LTC and death were separate absorbing states would increase data demands, increase the complexity of the problem space for the model, potentially add noise that could mask trends and finally add no further analytical insight into the transition patterns of community-dwelling adults with dementia. I note that the consolidation of LTC and death into a single absorbing state is because this study is concerned with community dwelling adults with dementia, it is in no way a value judgment that LTC and death are equivalent outcomes.

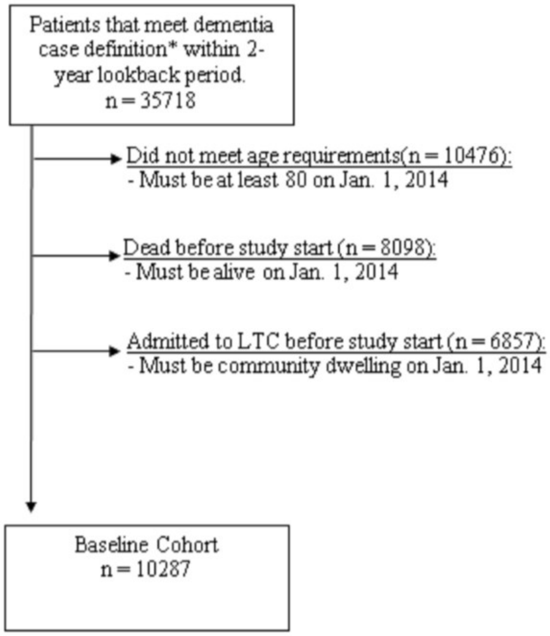

Figure 2.1 Cohort creation.

To analyze these complex transition pathways, I used a multi-state model. Once we captured the cohort and all transitions the final data set was then exported for use in R using the msm package.[36] Figure 2 outlines all four states and possible transitions between them. All members of the cohort started at home (state 1) and from home could transition to the ED (state 2), the hospital (state 3) or non-community dwelling (state 4).

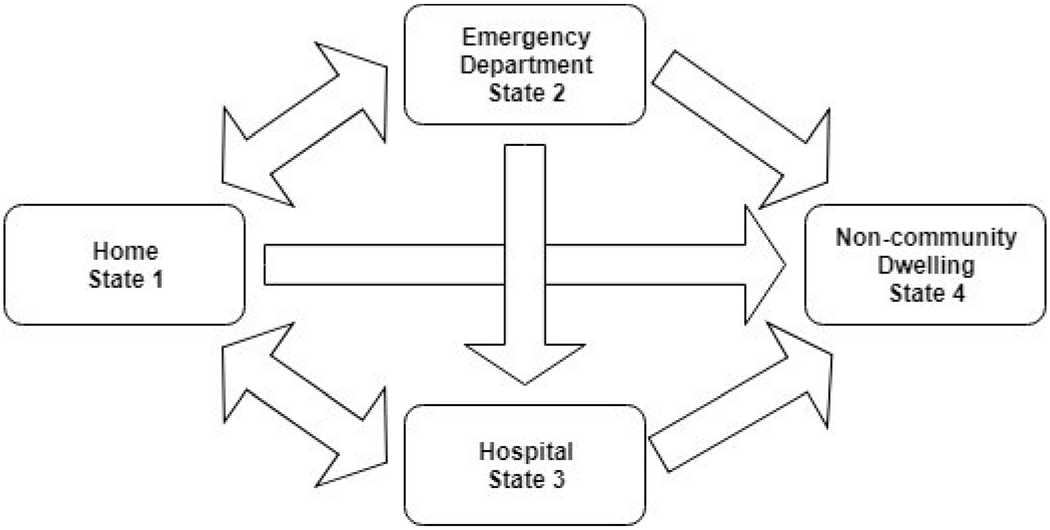

Figure 2.2 State transition matrix

Cohort construction and demographic analysis were conducted using SAS software, version 9.3 of the SAS System for Windows using a .05 level of significance. The multi-state model was performed using RStudio (version 1.0.143) and the msm package for Windows.

RESULTS

BASELINE CHARACTERISTICS

I created a final cohort of 10,287 individuals with dementia, living at home, and at least 80 years of age on January 1, 2014, (figure 1). I show patient demographics at baseline in table 2.1. The average age was 86.5 (4.5) years old, with 66.7% of the cohort being female. Geographical zones were broken down into Edmonton (36%), Calgary (29.7%), central (14.4%), south (12.7%), and north (7.2%) with 13.9% of the cohort residing in a rural location. The average Charlson Index score was 2.9 (2.3), and the average number of comorbid conditions was 1.4. The most prevalent comorbid conditions in the cohort were chronic pulmonary disease (22.9%), congestive heart failure (19.4%), cerebrovascular disease (19.3%), diabetes both with and without complications (17.8% and 12.8%, respectively), renal disease (11.4%), myocardial infarction (11.1%), and cancer (11.1%).

Characteristic	**Cohort N = 10287**
Characteristic	Cohort N = 10287
Age, mean (SD)	86.5 (4.5)
Age Categories, n(%)	
80-85	4741 (46.1)
85-90	3527 (34.3)
91-95	1657 (16.1)
95+	362 (3.5)
Male, n(%)	3426 (33.3)
Rural residence, n(%)	1426 (13.9)
Zone, n(%)	
Edmonton	3706 (36.0)
Calgary	3058 (29.7)
South	1304 (12.7)
Central	1477 (14.4)
North	742 (7.2)
Visit, n(%)	9924 (96.5)
Diagnosis, n(%)	
Dementia	10287 (100.0)
Chronic Pulmonary Disease	2353 (22.9)
Congestive Heart Failure	1997 (19.4)
Cerebrovascular Disease	1987 (19.3)
Diabetes without complications	1830 (17.8)
Diabetes with complications	1316 (12.8)
Renal Disease	1177 (11.4)
Cancer	1142 (11.1)
Myocardial Infarction	1140 (11.1)
Peripheral Vascular Disease	728 (7.1)
Peptic Ulcer Disease	342 (3.3)
Connective Tissue Disease-Rheumatic Disease	290 (2.8)
Metastatic Carcinoma	198 (1.9)
Paraplegia and Hemiplegia	198 (1.9)
Mild Liver Disease	104 (1.0)
Moderate or Severe Liver Disease	27 (0.3)
AIDS/HIV	0 (0.0)
Charlson Index, mean (SD)	2.9 (2.3)
Comorbid Count, mean (SD)	1.4 (1.6)
Comorbid Conditions, n(%)	
0	3653 (35.5)

Table 2.1 Baseline demographics for the cohort at study start (Jan. 1, 2014).

TRANSITIONS

Over the two years, the cohort had 45,465 individual healthcare transitions. I depicted these transitions in table 2.2. There were 8 possible transitions; Home to Emergency Department (42.5%), Home to Hospital (0.9%) without going through the ED, Home to Non-community Dwelling (2.1%), Emergency to Home (18.6%), Emergency to Hospital (16.9%), Emergency to Non-community Dwelling (1.4%), Hospital to Home (11.7%), Hospital to Non-community Dwelling (6%). Just over twenty percent of the cohort experienced no transitions (20.7%), over seventeen percent experienced only a single transition (17.7%) and over three percent of the cohort experienced two transitions (3.5%). The cohort underwent a minimum of 0 transitions, a median of 3 transitions, an average of 4.4 transitions, and a maximum number of 89 transitions. Just over a tenth (10.2%) of the cohort had 4 or more emergency department visits during the two-year follow-up.

Summary of 45,465 transitions experienced by the cohort (n = 10,287) over 2 years

From:	To: Home	Emergency	Hospital	Non-Community Dwelling
Home	-	19275 (93.4%)	390 (1.9%)	975 (4.7%)
Emergency	8450 (50.4%)	-	7676 (45.8%)	632 (3.8%)
Hospital	5328 (66.1%)	-	-	2738 (33.9%)
Non-community Dwelling	-	-	-	-

Table 2.2 This table contains all the transitions experienced during follow-up for the cohort with the percentages in brackets showing the proportions of individuals who transitioned to a given state (columns) from a starting state (rows).

To better understand the differences between patients with a higher than average number of transitions over the follow-up period, I defined patients that experienced the most transitions (the 90th percentile) as high-frequency transitioners. High-frequency transitioners had more comorbid conditions and experienced on average 5.6 times (16.8 vs. 3, $p < 0.0001$) more transitions than the rest of the cohort, as shown in table 2.3.

Characteristic	Bottom 90% of transitioners (n = 9196)	Top 10% of transitioners (n = 1091)	Total cohort (n = 10287)
Age, mean (SD)*	86.6 (4.5)	86.0 (4.3)	86.5 (4.5)
Age Categories, n (%)			
80 – 85*	4183 (45.5)	558 (51.1)	4741 (46.1)
86 – 90	3158 (34.3)	369 (33.8)	3527 (34.3)
91 – 95	1515 (16.5)	142 (13.0)	1657 (16.1)
95+	340 (3.7)	22 (2.0)	362 (3.5)
Male, n (%)*	2983 (32.4)	443 (40.6)	3426 (33.3)
Rural, n (%)*	1150 (12.5)	276 (25.3)	1426 (13.9)
Charlson Index, mean (SD)*	2.8 (2.3)	4.0 (2.7)	2.9 (2.3)
Comorbid Count, mean (SD)*	1.3 (1.5)	2.3 (1.8)	1.4 (1.6)
Total Transitions, mean (SD)*	3.0 (2.8)	16.8 (7.7)	4.4 (5.6)
Transitions to ED, mean (SD)*	1.2 (1.2)	7.2 (3.6)	1.9 (2.5)
Transitions to hospital, mean (SD)*	0.6 (0.7)	2.6 (1.8)	0.8 (1.1)
Transitions home, mean (SD)*	0.7 (1.0)	6.5 (3.6)	1.3 (2.3)

* Statistically significant differences between groups $p < 0.0001$

Table 2.3. Number of transitions experienced by the top 10% of transitioners in the cohort compared to the bottom 90% of transitioners.

COMORBIDITY

Those with a more substantial comorbidity burden experienced more transitions; an ad hoc analysis showed the average number of transitions for those with 0, 1, 2-3 and 4+ comorbid conditions were 3.2 (3.9), 4.0 (4.8), 5.3 (6.4) and 7.0 (8.0) respectively. A one-way ANOVA was used to show that there was a statistically significant increase in the average number of transitions as comorbid conditions increased (F=183.84, p<0.0001). The types of transitions also differed between the four comorbid condition groups. As the number of comorbid conditions increased, there was a statistically significant ($x^2 = 103.54$, $p < 0.0001$) decrease in both transitions to the emergency department and the absorbing non-community dwelling state while transitions to the hospital and home increased.

Further exploratory analysis showed that as comorbid conditions increased, the proportion of males also increased from 25.6% among those with no comorbidities to over 64% among those with 7 or more comorbid conditions (p<0.001). See Table 2.4.

Characteristic	0 Comorbid Conditions (n = 3653)	1 - 3 Comorbid Conditions (n = 5439)	4 - 6 Comorbid Conditions (n=1114)	7+ Comorbid Conditions (n = 81)
Age, mean (SD)*	86.6 (4.4)	86.6 (4.5)	86.0 (4.3)	85.5 (4.0)
Age Categories, n (%)				
80 – 85	1635 (44.8)	2504 (46.0)	557 (50.0)	45 (55.6)
86 – 90	1267 (34.7)	1856 (34.1)	380 (34.1)	24 (29.6)
91 – 95	625 (17.1)	877 (16.1)	144 (12.9)	11 (13.6)
95+	126 (3.4)	202 (3.7)	33 (3.0)	1 (1.2)
Male, n (%)*	936 (25.6)	1912 (35.2)	526 (47.2)	52 (64.2)
Charlson Index, mean (SD)*	1.0 (0.0)	3.2 (1.4)	7.3 (1.9)	11.3 (2.1)
Total Transitions, mean (SD)*	3.2 (3.9)	4.7 (5.7)	6.9 (7.7)	9.1 (11.2)
Transitions to ED, mean (SD)*	1.4 (1.8)	2.0 (2.5)	2.8 (3.4)	3.7 (5.1)
Transitions to Hospital, mean (SD)*	0.6 (0.8)	0.8 (1.1)	1.3 (1.6)	1.7 (1.9)
Transitions Home, mean (SD)*	0.9 (1.6)	1.4 (2.4)	2.2 (3.3)	3.0 (5.1)

* Indicates statistically significant result $p < 0.0001$.

Table 2.4. Patient characteristics and transitions by comorbidity.

MULTI-STATE MODEL

The multi-state model calculates, using the inputted data, the likelihood of a transition from one state to another using four covariates age, sex, comorbidity burden, and the number of previous transitions. Table 2.5 displays the hazard ratios for each possible transition. Age increased the probability of transition to the ED, and to non-community dwelling. Males were more likely to transition from home to the emergency department but less likely to transition from the emergency department to either home or hospital when compared to females. Males also had a decreased probability of transitioning from the hospital back home and an increased chance to transition from hospital to long-term care or death. Those that had moderate or severe comorbidity were more likely to experience a transition from the emergency department or hospital back home than those who with mild comorbidity. While severe comorbidity was associated with an increased probability to transition from hospital to non-community dwelling this was not seen with moderate comorbidity was not statistically associated with that transition, when compared to mild comorbidity. For each previous transition, while controlling for the other covariates, the likelihood of several transitions increased; from home to emergency (5%), home to hospital (2%), emergency to home (6%), emergency to hospital (4%), emergency to non-community dwelling (3%), and hospital to home (3%).

Transition	Age HR (95% CI)	Moderate Comorbidity ¥ HR (95% CI)	Severe Comorbidity ¥ HR (95% CI)	Male vs. Female HR (95% CI)	Number of Transitions HR (95% CI)
Home to Emergency	1.01* (1.01,1.02)	1.10* (1.06, 1.2)	1.19* (1.14, 1.24)	1.10* (1.06, 1.14)	1.05* (1.04, 1.05)
Home to Hospital	0.95* (0.91, 0.99)	1.36 (0.91,2.03)	1.24 (0.82,1.88)	1.32 (0.94,1.14)	1.02 (0.99, 1.05)
Home to Non-Community Dwelling	1.00 (3.34e-6,3.11e+5)	6.98 (1.66e-61, 2.93e+62)	0.20 (2.83e-136,1.44e+134)	21.58 (1.24e-82,3.73e+84)	1.06 (0.06,18.07)
Emergency to Home	0.97* (0.97, 0.98)	1.21* (1.15, 1.28)	1.54* (1.46, 1.63)	0.86* (0.82, 0.90)	1.05* (1.05, 1.06)
Emergency to Hospital	0.99 (0.99, 1.00)	1.27* (1.20, 1.34)	1.61* (1.52, 1.70)	0.85* (0.81, 0.89)	1.04* (1.01, 1.04)
Emergency Non-Community Dwelling	1.03* (1.02, 1.05)	1.18 (0.98, 1.43)	1.13 (0.92,1.39)	0.89 (0.75, 1.05)	1.03* (1.01, 1.04)
Hospital to Home	0.99* (0.98, 0.99)	1.19* (1.11, 1.27)	1.44* (1.35, 1.54)	0.92* (0.87, 0.98)	1.03* (1.02 1.03)
Hospital Non-Community Dwelling	1.04* (1.04, 1.05)	0.97 (0.88,1.06)	1.14* (1.04, 1.26)	1.12* (1.03, 1.21)	1.00 (0.99,1.01)

Table 2.5. Hazard ratios, to 2 decimal places, from the multi-state model using age, comorbid severity, sex and number of previous transitions as covariates. The covariates are the columns, and all possible transitions are the rows. It is best to look across rows to see the effects that each of the covariates has on each transition.

* Indicates a significant HR $p < 0.05$

¥ Comorbidity levels were split into mild (Charlson Index of 1-2), moderate (Charlson Index of 3-4) and severe (Charlson Index 5+) with the reference category being mild

DISCUSSION

In this cohort of community dwelling adults, aged 80+ with dementia, I found that transitions were frequent and that the frequency of transitions increased with the number of chronic conditions. Overall, I identified 45,465 unique transitions to four unique states being the home, emergency department, hospital, and non-community dwelling. Age increased the probability of transition to the ED from home, and to non-community dwelling from emergency and hospital. Males were more likely to transition to the ED from home, and to non-community dwelling from the hospital. Comorbid severity leads to an increased probability of complex transition pathways. The number of previous transitions only increased the likelihood of several transitions and had no protective effect for any of them.

I defined individuals in the top 90th percentile, regarding number transitions experienced, as high-frequency transitioners. This was defined to explore the potentially different patient demographic profiles between high-frequency transitioners and the rest of the cohort. On average high-frequency transitioners experienced 16.8 transitions over the two-year follow-up period, which was 5.6 times greater than the rest of the cohort. When thinking about this vulnerable population and how stressful transitions can be to the individual and their care partners, it is very disconcerting that some patients could experience a transition every two months. Further investigation is needed to understand why these individuals are undergoing so many transitions. High-frequency transitioners had more comorbid conditions than the rest of the cohort on average (2.3 vs. 1.3 respectively). CIHR and CIHI used a similar method with their dynamic cohort of complex, high system users. The dynamic cohort is comprised of patients in the top 10% of 4 subsets 1) highest acute care cost, 2) highest length of stay, 3) most frequent hospitalizations, and 4) most frequent emergency room visits. Each of these four subsets is further divided into adult and children cohorts leading to 8 subgroups.[37]

Higher comorbidity was associated with higher total transitions and was shown to change the type of transitions experienced by patients. As comorbidity increased transitions to the emergency department and non-community dwelling decreased, and transitions to a hospital and home increased. Increased comorbidity leading to an increased number of transitions is consistent with our previous findings. The reason transitions to the emergency department decrease are due to the increased frequency of transitioning to a hospital and then home. Although it seems counterintuitive that transitions to the non-community dwelling state decreased as comorbidity increased, that is consistent with experiencing more transitions. This is because once transitioned to this absorbing state no more transitions are recorded, leading to lower average transitions. Individuals with a higher number of transitions spent more time interacting with the system by living at home before transitioning out of the community, where follow-up ceased. Individuals with a higher comorbidity burden are more likely to have frequent and more complex transitional journeys as they venture between home, emergency, and hospital. This is supported by a recent study of a similar population-based cohort of older adults with dementia in Ontario which found that the risk of hospitalization and ED visits increased with higher levels of multimorbidity.[38]

Another interesting finding in my cohort was that as comorbidity increased the proportion of males also significantly increased. Suggesting that men, in our cohort, on average tended to have a heavier comorbidity burden, as they represented 64% of those who had 7 or more comorbid conditions and only 25.6% of those who had 0 comorbid conditions, which puts them at higher risk of multiple transitions. It is important to note that comorbid conditions were defined using the 17 Charlson Comorbidity Index comorbidities, outlined in table I in appendix A, not included in those comorbidities are conditions like arthritis and osteoporosis which are usually more common among women. In addition to the conditions to be considered affecting the comorbid disparity between sexes, a comprehensive systematic review found that the prevalence of multimorbidity is higher amongst women.[39]

To look at this single event, I could have used a competing risk regression model, but since I was looking at these complex transition pathways, I needed to use a multi-state model which is an analytical tool that runs all the competing risk regressions at the same time with the same data.[40,41] This is more efficient and reduces the possibility of losing data by stitching together the results from multiple competing risk regressions. That way I could investigate the effects that specific covariates have on transition probabilities from a given state.

There were three noteworthy results found from the multi-state model, seen in table 5, being the effects of sex, comorbidity severity, and the number of previous transitions had on various transition types. The impact of sex on the different transitions also highlighted that men were 9% more likely to visit the emergency department but less likely to transition from emergency to home or hospital (15% and 16% respectively), and the effect that sex had on the transition from the emergency department to non-community dwelling was not significant. I also found that males were 8% less likely to transition from the hospital back home and 11% more likely to transition from hospital to non-community dwelling. Showing that men were more likely to start a transition pathway and that their paths often were more serious, fewer discharges from ED and hospital back home and more discharges to non-community dwelling, due to men having highly morbid disease patterns when comparing patterns of multimorbidity between men and women, as found in an observational retrospective multicenter study that used electronic medical records in 2014.[42] These findings also align with previous studies where they found that men were more likely to be admitted to long-term care than women.[43] A surprising result since LTC is typically such a female dominated environment.

Moderate and severe comorbidity was associated with an increased probability to transition from the emergency department back home (21% and 54% respectively), from the emergency department to the hospital (26% and 61% for moderate and severe comorbidity, respectively), from hospital back to home (19% and 44% for moderate and severe comorbidity, respectively), and for severe comorbidity from hospital to non-community dwelling (14%) when compared to mild comorbidity. This result seems to indicate that as comorbidity increases so too does the severity and complexity of the transition trajectory experienced by those individuals. One potential factor might be that community dwelling adults with dementia have more demanding care needs as comorbidity increases and that there is a lack of available care, within their community, which leads to more unexpected trips to the emergency department. This is congruent with research that shows subpar community-based services result in greater acute care use.[44,45] Once at the emergency they are more likely to transition to the hospital where they are more likely to transition back to home than a long-term care facility which may be due to long-term care bed availability, or patient choice. Only severe comorbidity was associated with an increased likelihood for a transition from the hospital to non-community dwelling (14%), but even then, it was over four times more likely for a patient with severe comorbidity to transition back home from a hospital stay (61% vs. 14%).

I used the number of previous transitions as an estimation of transition trajectory complexity, the premise being that more previous transitions one had the more complicated their journey is. The number of prior transitions increased the probability of the most common transitions experienced by the cohort (being home to the emergency, emergency to home, emergency to the hospital, emergency to non-community dwelling, and hospital to home) but did not increase the probability of transitioning from the hospital to long-term care or death. This, in addition to the fact that just over twenty percent of the cohort experienced no transitions, seems to indicate a snowball effect where once transitions start occurring there is an increased risk of having increasingly adverse and complex transition trajectories.

The final result in table 2.5 that we need to address is the wildly large confidence intervals for the home to non-community dwelling transition. These large confidence intervals are most likely an artifact in the model due to the rarity of transitioning to non-community dwelling from home. These transitions were rare comprising only 2% of all transitions experienced by the cohort.

There are some limitations to this study. The first is that administrative data while a valuable tool cannot give the full picture. For example, in this study, the number of additional comorbid conditions was lower than those found in other studies in Canadian populations.[10,38] The most parsimonious explanation of this is that this study focused on Charlson comorbidities which focus on those conditions considered to be predictive of higher mortality and resource use. This limited the number of comorbid conditions, such as arthritis and osteoporosis, which are included in other studies. This study used the Charlson comorbidities due to well defined and verified coding algorithms for use with Albertan administrative data and its predictive properties for mortality and resource use. This study also has no way to account for home-based health services being either formal or informal care partners or other community-based programs. This limitation is partially mitigated by the fact that other studies have found that community based health services are inadequate for individuals living with dementia.[44–46] Since I focused on all-cause hospitalizations and ED visits I am unable to inform interventions to prevent these transitions by stratifying by reason of the visit.[38] Finally, it should be noted that while in my study we focused on community dwelling older adults with dementia this meant that older adults with dementia living in long-term care facilities are not represented in this study. Future work should keep this in mind and investigate transition pathways unique to long-term care dwelling older adults with dementia. Strengths of this work include a large and representative population-based sample of community-dwelling older adults with dementia in Alberta. Results would be expected to be generalizable to other provinces due to comparable healthcare systems that provide similar community-based services.[38]

CONCLUSION

I have shown that older adults living with dementia in Alberta are a diverse group of people who have a high burden of comorbidity which reinforces calls for person-centered care approaches for this population. That there is an association between comorbid severity and a higher number of transitions and more complex transitional pathways for older community-dwelling adults living with dementia. Finally, some high-risk individuals are experiencing a large number of transitions, which represents an opportunity to be more efficient and effective in meeting the needs of older adults with dementia within community settings.

CHAPTER 3: IMPLICATIONS

I conducted a large retrospective cohort study that followed over ten thousand Albertans—community dwelling older adults, living with dementia—over two years tracking their transitions through their healthcare journeys. In this chapter, I will review the objectives of this study, touch on why this project is relevant, examine the results in the context of our goals, offer some insights and lessons learned from the process and finally discuss next steps.

OBJECTIVES

This study set out to answer two research questions:

RESEARCH QUESTION

- What do long-term healthcare transition trajectories look like for older adults with dementia?
- To what extent do age, sex, comorbid severity and previous transitions influence healthcare trajectories for older adults with dementia?

PROJECT RELEVANCE

This project aims to meet three gaps in the current literature. Looking at the interplay between dementia and comorbid severity, accounting for multiple transitions and transition types, and identifying trajectories that move beyond a single transition.

The focus in the literature when it comes to healthcare transitions for older adults with dementia and other chronic conditions has been limited to mostly single transitions.[1,30,31]. There is a lack of information characterizing multiple and complex healthcare transitions for these individuals. To inform care across the continuum for older adults with dementia a better understanding of how these individuals utilize the healthcare system and where they may be vulnerable is needed. Understanding the journey these individuals take may improve both clinical outcomes and care across the continuum for older adults.

This study is important because it addresses the lack of information about complex healthcare transitions older adults with dementia experience through the community, acute care, inpatient, and long-term care settings. The identification of these pathways has the potential to provide unique insights into how to improve clinical outcomes and care across the continuum.

COHORT TRANSITIONS

Over the two-year follow-up period, the cohort of over ten thousand individuals experienced 45,465 transitions. Transitions occurred between four states: 1) home, 2) the emergency department, 3) the hospital, and 4) non-community dwelling. It is worth reiterating that since I focused on community-dwelling older adults living with dementia that once an individual transitioned to long-term care, they were removed from the model; this is called an absorbing state. Since I was looking exclusively at community-dwelling older adults with dementia, I collapsed long-term care and death into the single non-community dwelling category since they were both absorbing states. This merging of states is in no way a value judgment or comparison between long-term care and death; it is strictly a technical distinction used to focus on the particular question at hand. The reason that I did not merely continue to follow patients once they transition to long-term care is that I was interested in defining transition pathways for community-dwelling older adults with dementia. Once they transitioned to long-term care, by my definition, they were no longer community dwelling.

The first thing that I noticed after compiling all the transitions between the states was the overwhelming heterogeneity when it came to individual transition trajectories. Even in a model as simplified as ours which only looked at four potential states the nearly innumerable combinations of transition type and time necessitated the use of a more robust statistical technique, a multi-state model, to divine meaning from the unintelligible mess that we saw.

Overall the most frequent transition experienced by the cohort was from home to emergency which accounted for over forty percent (42.4%) of all transitions experienced. Followed by emergency to home (18.6%), emergency to hospital (16.9%), hospital to home (11.7%), hospital to non-community dwelling (6.0%), home to non-community dwelling (2.1%), emergency to non-community dwelling (1.4%), and finally home to hospital (0.8%).

These results paint a picture of what one might expect a normal transition trajectory to look like. An older adult living at home with dementia experiences an event which leads them to the emergency department where they are assessed and either treated and sent home or admitted to the hospital. Once in the hospital, they are more likely to be released back home than to long-term care. Once at home the cycle starts again until they eventually transition out of the community. This interpretation, however, fails as it is at the wrong level of granularity. It cannot see that there are indeed many types of complex transition trajectories experienced within the cohort; in other words, the transition patterns in this study are more complicated than what I expect to see. For instance, those in the top ten percent when it came to the number of transitions on average experienced 560% (3.0 vs. 16.8) more transitions than the rest of the cohort. This stark comparison between groups should raise a red flag when it comes to evaluating our continuum of care in Alberta. Specifically, we show that 1) there is a small group of high system users whose healthcare costs is disproportionately more substantial than the rest of the population and 2) these high-frequency transitioners are experiencing an undue and onerous amount of uncertainty when it comes to their long-term healthcare journeys.

COVARIATES AND COMPLEX TRANSITION TRAJECTORIES

The level of analysis up to this point in the study failed to capture the nuance of these complex transition trajectories. To rectify this a multi-state model (msm) was used to determine the effects age, sex, comorbid severity, and the number of previous transitions had on transition probabilities.

Let us continue with the example of our hypothetical transition trajectory above. An individual is transitioning from home to emergency then the hospital and then to long-term care or death. I can look at the hazard ratios provided by the msm model, presented in table 2.5, to see if they support or conflict with this hypothetical trajectory.

I assert that both anomalous and intuitive results are the product of an association between a covariate and an increase in transition trajectory complexity.

The model found that age while controlling for sex, comorbid severity and the number of previous transitions was associated with statistically significant ($p < 0.05$) increased probabilities of transitioning from home to emergency, and emergency to non-community dwelling while simultaneously decreasing the likelihood of transitioning from the emergency back home. Age was also statistically significant ($p<0.05$) with an increased probability of transitioning from the hospital to non-community dwelling and a decreased likelihood in transitioning from the hospital back home. So far, these results reinforce our intuitive transition trajectory. As people age, they are more likely to experience transitions to the emergency, hospital and non-community dwelling and less likely to experience transitions back home.

Males had a higher probability of transitioning from home to emergency, and from hospital to long-term care when compared to females. Men also had a lower likelihood of transitioning from emergency to home, emergency to the hospital, and hospital to home when compared to women. This is the next counterintuitive result we must be integrated into our understanding of transition trajectories. It is not apparent why males would be less likely to transition from emergency to either home or hospital than females.

Comorbid severity is where things start to get interesting. Comorbid severity was categorized into mild (the reference category), moderate or severe based on a Charlson Index score of 1-2, 3-4, and 5+ respectively. The model associated moderate comorbidity with a statistically significant ($p<0.05$) increased probability of transitioning from home to emergency and emergency to hospital, which I expected. It also increased the likelihood of transitioning back home from both hospital and emergency. This is the first result that goes against our hypothetical transition trajectory. Severe comorbidity had stronger effects on the transition probabilities than did moderate comorbidity and had the same counterintuitive results as moderate comorbidity did. I should note that only severe comorbidity was associated with a statistically significant ($p<0.05$) increase in the probability of transitioning from the hospital to non-community dwelling when mild severity was the reference category. Before trying to interpret these counterintuitive results, let us look at the last covariate for the insights they offer.

The last covariate examined was the number of previous transitions. I used this covariate as an estimate of transition complexity, the assumption being the more previous transitions you experienced, the more complicated your trajectory has been. I saw that number of prior transitions increased the probability of transitioning home to the emergency, emergency to home, emergency to the hospital, emergency to non-community dwelling, and hospital to home but most importantly not significantly associate with hospital to non-community dwelling. This once again is another counter-intuitive result: previous transitions make you more likely to experience all other transitions; while at the same time not associated with a transition out of the community, the intuitive result expected.

The pattern that emerges from the model suggests that transition trajectories are more complicated for older men, who have moderate or severe comorbidity and that complexity increases with each subsequent transition. This pattern can simultaneously explain both the anomalous and intuitive results. The model comes to counterintuitive results when a covariate is associated with an increase in transition trajectory complexity. The line of reasoning developed above contends that both anomalous and intuitive results are the product of an association between a covariate and an increase in transition trajectory complexity.

IMPROVING CARE ACROSS THE CONTINUUM

These results suggest that to improve care across the continuum for older adults with dementia two steps can be taken. The first is to monitor the comorbid severity experienced by each patient closely.

Knowing that increases in comorbidity increase the likelihood of a complicated health care trajectory can help formal and informal care partners to plan and prepare accordingly to prevent unnecessary transitions. The second step would be to prevent unnecessary transitions as early as possible. It was seen in the model that there was a snowballing effect that the number of previous transitions had on experiencing more transitions. Preventing unnecessary transitions, through careful monitoring of comorbid conditions, will reduce the stress experienced by patients and their care partners and improve the continuum of care for older community-dwelling adults with dementia.

NEXT STEPS

The next steps to build on what was presented in this study would be first to identify the similarities and differences in transition pathways for older adults living with dementia who are community dwelling compared to non-community dwellers. This would give a more comprehensive picture of what older adults living with dementia experience.

The second would be to create a mixed methods study that would allow for the generation and integration of qualitative patient and caregiver knowledge. One of the main downsides of this study is that I do not have any patient perspectives or data informing us as to their lived experiences going through the healthcare system. A comprehensive study that looked at older adults with dementia in a prospective cohort while collecting both quantitative and qualitative data would go a long way to understanding what gaps are being experienced by this population when it comes to the continuum of care. Due to the nature of this study community offered services, not captured in administrative data, could also be accounted for, something that cannot be done with administrative data alone. A study of this kind would be of great use in informing policymakers, knowledge translation experts, and other stakeholders as to where they can improve the overall healthcare experience for this vulnerable population.

In order to inform specific interventions to improve the continuum of care for this population additional resources need to be allocated to investigate the experience of caregivers for those with dementia. The influence of sex and gender on these complex health care pathways needs to be addressed more robustly. Acute care is also just one of the ways that older adults with dementia are interacting with the continuum of care in Alberta and further research must flesh out the whole picture the effects of home care measures implemented by Alberta Health Services and the ramifications that this has on this vulnerable population needs to be addressed. When a transition is deemed a failure, as it is in clinical practice, the reasons why older community dwelling adults are experiencing these complicated transition trajectories warrants deeper investigation in order to inform specific interventions to do better for these people.

CHAPTER 4: REFLECTIONS

THE ROAD SO FAR…

Several years of formal training and work boiled down into a 15-page manuscript fail to capture all that was learned, the obstacles overcame, and the decisions that had to be made along the way.

The original vision of this work was to identify the transition pathways of older community-dwelling adults with dementia over time. This was to address the lack of information regarding transitions beyond single events.

Originally, I set out to create a time series graph that would have states on the Y-axis and time on the X-axis. I thought that I would be able to pull out dominant patterns in the data and discuss frequent transition pathways. There were a couple of things wrong with this idea when I set out. First, that would require graphing individual-level data, and that goes against data privacy laws and ethics both at AHS and at the University. The second was that with a cohort so large any hope of graphically visualizing these complicated trajectories was lost. This led to the use of the multi-state model.

INTENTION VS PRACTICALITY

This was proposed to be a thesis with three results chapters. The first chapter would break down the demographics that characterized our cohort. The second chapter was going to be an unsupervised learning model, such as an artificial neural network, where we would give the model the data, and it would generate results. While this would have been interesting to do there was no way that it was practical both due to the potential ambiguous nature of the results or the amount of time dedicated to it. Additionally, this is a method that is not usually done in this field of research. The third chapter was intended to be the multi-state model which is a form of supervised learning. This would have allowed for an interesting comparison between the results of the unsupervised and supervised models but was deemed to be outside the scope of this project, rightly so.

LESSONS LEARNED

There were several lessons learned during this process. The first and foremost is that everything takes much longer than anticipated.

When it came to the data processing, I took for granted how quickly we can analyze what I think are large data sets. Working with vast amounts of administrative health data is much more complicated and time-consuming. Some of the more ambitious data queries to start the cohort would take almost a full day to pull. Part of what I learned through this project was how to efficiently pull the data to reduce the resources needed. For example, when querying the physician claims database which is very large, I can cut down on resources needed by pulling out only the variables that are of interest. By pairing specific selection criteria such as a date range and diagnosis code, I can reduce the run time of my program from hours to minutes.

When it came to data processing and storage, I learned the importance of having a step by step syntax to have reproducible results as well as how crucial it is to have multiple backups of your data. Between December 2017 and January 2018 AHS upgraded its SAS server from Citrix to SAS studio. During this migration, my data for my cohort was lost. There were no backups, and I was back to square one. Luckily, I had all my syntax saved locally, and over the course of a week, I was able to rebuild the cohort and verify that I had the exact 10,287 individuals as before. This would have taken multiple weeks, if not months, to do if the code was also lost.

Once I had chosen the multi-state model, there was still the issue of getting the cohort data I had into a format that could be analyzed by the R package. This was an issue because the first R-package I tried to use required data in a wide format, that is each row would be a unique patient and a record of every transition they had and at which time. This was simply unmanageable as we had 10,287 individuals and a maximum number of transitions being 89 that meant there had to be an onerous number of variables, which for most individuals would not be used. To rectify this issue, I found the msm package that was eventually used which ran the same model but was formatted to use data in long format. That is each row was a transition event. If there were no transitions for a patient, there would only be one row, but for the patient with 89 transitions, they would have 89 additional rows. This led us to a reasonably sized data set and the interpretable results that were attained.

WHAT WOULD I DO DIFFERENTLY?

If I were to start this project today, it would look different. Specifically, I would have investigated transitions after admission to long-term care facilities. Not in the same model, since we were looking at community dwelling adults and they are no longer community-dwelling adults. I would create a subcohort for all those who experienced a transition to a long-term care facility. That sub-cohort and their transitions would then be analyzed in a second multi-state model. The hypothesis is that the transitions experienced by non-community dwelling adults would be different than community-dwelling adults. This would also allow us to investigate the effects comorbid severity has on the transition pathways of non-community dwelling older adults with dementia which would be a valuable piece of information which is currently not addressed in this work.

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APPENDIX A

Conditions	ICD-9-CM Codes	ICD-10 Codes
Dementia	290.x, 294.1, 331.2	F00.x-F03.x, F05.1, G30.x, G31.1
Myocardial infarction	410.x, 412.x	121.x, 122.x, 125.2
Congestive heart failure	398.91, 402.01, 402.11, 402.91, 404.01, 404.03, 404.11, 404.13, 404.91, 404.93, 425.4-425.9, 428.x	109.9, 111.0, 113.0, 113.2, 125.5, 142.0, 142.5-142.9, 143.x, 150.x, P29.0
Peripheral vascular disease	093.0, 437.3, 440.x, 441.x, 443.1-443.9, 47.1, 557.1, 557.9, V43.4	170.x, 171.x, 173.1, 173.8, 173.9, 177.1, 179.0, 179.2, K55.1, K55.8, K55.9, Z95.8, Z95.9
Cerebrovascular disease	362.34, 430.x-438.x	G45.x, G46.x, H34.0, 160.x-169.x
Chronic pulmonary disease	416.8, 416.9, 490.x-505.x, 506.4, 508.1, 508.8	127.8, 127.9, J40.x-J47.x, J60.x-J67.x, J68.4, J70.1, J70.3
Rheumatic disease	446.5, 710.0-710.4, 714.0-714.2, 714.8, 725.x	M05.x, M06.x, M31.5, M32.x-M34.x, M35.1, M35.3, M36.0
Peptic ulcer disease	531.x-534.x	K25.x-K28.x
Mild liver disease	070.22, 070.23, 070.32, 070.33, 070.44, 070.54, 070.6, 070.9, 570.x, 571.x, 573.3, 573.4, 573.8, 573.9, V42.7	B18.x, K70.0-K70.3, K70.9, K71.3-K71.5, K71.7, K73.x, K74.x, K76.0, K76.2-K76.4, K76.8, K76.9, Z94.4
Diabetes without chronic complication	250.0–250.3, 250.8, 250.9	E10.0, E10.1, E10.6, E10.8, E10.9, E11.0, E11.1, E11.6, E11.8, E11.9, E12.0, E12.1, E12.6, E12.8, E12.9, E13.0, E13.1, E13.6, E13.8, E13.9, E14.0, E14.1, E14.6, E14.8, E14.9
Diabetes with chronic complication	250.4–250.7	E10.2–E10.5, E10.7, E11.2–E11.5, E11.7, E12.2–E12.5, E12.7, E13.2– E13.5, E13.7, E14.2–E14.5, E14.7
Hemiplegia or paraplegia	334.1, 342.x, 343.x, 344.0–344.6, 344.9	G04.1, G11.4, G80.1, G80.2, G81.x, G82.x, G83.0–G83.4, G83.9
Renal disease	403.01, 403.11, 403.91, 404.02, 404.03, 404.12, 404.13, 404.92, 404.93, 582.x, 583.0–583.7, 585.x, 586.x, 588.0, V42.0, V45.1, V56.x	I12.0, I13.1, N03.2–N03.7, N05.2– N05.7, N18.x, N19.x, N25.0, Z49.0– Z49.2, Z94.0, Z99.2
	140.x–172.x,	

Conditions	ICD-9-CM Codes	ICD-10 Codes
Any malignancy, including lymphoma and leukemia, except malignant neoplasm of skin	140.x–172.x, 174.x–195.8, 200.x–208.x, 238.6	C00.x–C26.x, C30.x–C34.x, C37.x– C41.x, C43.x, C45.x–C58.x, C60.x– C76.x, C81.x–C85.x, C88.x, C90.x–C97.x
Moderate or severe liver disease	456.0–456.2, 572.2–572.8	I85.0, I85.9, I86.4, I98.2, K70.4, K71.1, K72.1, K72.9, K76.5, K76.6, K76.7
Metastatic solid tumor	196.x-199.x	C77.x-C80.x
AIDS/HIV	042.x-044.x	B20.x-B22.x, B24.x

Table I. ICD-9-CM and ICD-10 codes for Charlson comorbidities from Quan et al.[2]

WHO ATC/DDD Index Classification	Drug ATC Code
Anti-dementia drugs	N06D
Anticholinesterases	N06DA
Other anti-dementia drugs	N06DX

Table II. Anti-dementia ATC codes courtesy of the World Health Organization (WHO) ATC/DDD index.[3]