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DEGREE SOUGHT: MSc Family Medicine (Thesis)

TITLE OF THESIS: How many fit? Latent class analysis of administrative data on healthcare utilization by older adults with dementia in Quebec, Canada

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How many fit? Latent class analysis of administrative data on healthcare utilization by older adults with dementia in Quebec, Canada

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August 2021

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree
of Master of Science in Family Medicine

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Abstract

BACKGROUND: Persons with dementia have complex and heterogeneous needs in the year following diagnosis, which leads to extensive use of healthcare services. A focus on addressing their differential needs would better enable effective interventions and care planning to prevent unnecessary use of services.

OBJECTIVES: The aim of the present study was first to identify differential healthcare use groups using latent class analysis and secondly, to complete a descriptive analysis to highlight the sociodemographic factors, comorbidities and medication use associated with membership in the identified healthcare user groups.

METHODS: This retrospective cohort study used provincial administrative data to identify an incident cohort of older adults with dementia. Persons were included if aged 65 and older, community-dwelling and diagnosed with dementia based on one of three criteria (prescription profile consistent with dementia, one hospitalization with dementia code or 3 physician visits with a dementia code) between April 1 2015 and March 31 2016. A latent class analysis was conducted to identify subgroups of differential healthcare users based on family physician, cognition specialist, other specialist, emergency department visits, hospital, and alternate level of care (ALC) use, as well as long-term care (LTC) admissions and mortality. A descriptive analysis was conducted to better understand the sociodemographic, comorbidities, psychotropic medication use and polypharmacy that characterized each group of healthcare users.

RESULTS: The study cohort was of 15, 584 persons newly diagnosed with dementia. Four groups of healthcare users were identified: Low Users (36.4% of the persons), Ambulatory-Centric Users (27.5%), High Acute Hospital Users (23.6%) and LTC-Destined Users (12.5%). The Low Users were likely a heterogeneous group of persons with met and unmet needs, Ambulatory-Centric Users were notably disproportionately male and the youngest group, High Acute Hospital Users had the highest comorbidities, and the LTC-Destined Users were the eldest and had the highest use of ALC.

CONCLUSION: The identification of defined subgroups of healthcare users with dementia among a heterogeneous cohort of persons with dementia provides context for further research and interventions targeted to the differential needs of persons with dementia.

Résumé

CONTEXTE : Les personnes atteintes de troubles neurocognitifs majeurs (Maladie d'Alzheimer et maladies apparentées) ont des besoins complexes et hétérogènes dans l'année suivant le diagnostic, ce qui mène à une utilisation intensive des services de santé. Il est important de répondre à leurs besoins différentiels pour intervenir efficacement et pouvoir planifier les soins afin d'éviter l'utilisation non-efficiente des services de santé.

OBJECTIFS : L'objectif de la présente étude était premièrement d'identifier des groupes d'utilisateurs de soins de santé différentiels en utilisant une analyse de classe latente. Ensuite, une analyse descriptive a été faite afin d'identifier les différentes caractéristiques sociodémographiques, de comorbidité et de consommation de médicaments des groupes d'utilisateurs de soins de santé.

MÉTHODES : Cette étude de cohorte rétrospective a utilisé les données administratives provinciales pour identifier une cohorte incidente de personnes âgées atteintes de troubles neurocognitifs majeurs. Les personnes incluses étaient âgées de 65 ans et plus, vivaient dans la communauté et avaient reçu un diagnostic de trouble neurocognitif majeur selon l'un de trois critères (profil de prescription compatible avec un trouble neurocognitif majeur, hospitalisation avec un code de trouble neurocognitif majeur ou trois visites chez le médecin avec un code de trouble neurocognitif majeur) entre le 1er avril 2015 et le 31 mars 2016. Une analyse de classe latente a identifié des sous-groupes d'utilisateurs de soins de santé en fonction des niveaux de recours aux médecins de famille, spécialistes de la cognition, autres spécialistes, services d'urgence, hospitalisation et soins de niveau alternatif (SNA), ainsi que les admissions en centre d'hébergement et de soins de longue durée (CHSLD) et la mortalité. Une analyse descriptive a été menée pour décrire les caractéristiques sociodémographiques, les comorbidités, l’utilisation de médicaments psychotropes et la polypharmacie de chaque groupe d'utilisateurs de soins de santé.

RÉSULTATS : La cohorte comprenait 15 584 personnes nouvellement diagnostiquées pour un trouble neurocognitif majeur. Quatre groupes d'utilisateurs de soins de santé ont été identifiés : les faibles utilisateurs (36,4 % des personnes), les utilisateurs ambulatoires (27,5 %), les grands utilisateurs de l’hôpital (23,6 %) et les utilisateurs admis en CHSLD (12,5 %). Les faibles utilisateurs constituaient possiblement un groupe hétérogène de personnes ayant des besoins comblés et non comblés, les utilisateurs ambulatoires avaient une large proportion d’hommes et étaient les plus jeunes des groupes, les grands utilisateurs hospitaliers avaient une plus grande comorbidité et les utilisateurs admis en CHSLD étaient le groupe le plus ainé et avec la plus grande utilisation des SNA.

CONCLUSION : L'identification de sous-groupes définis d'utilisateurs de soins de santé atteints d’un trouble neurocognitif majeur au sein d'une cohorte hétérogène permet de développer des interventions ciblées pour répondre aux besoins différentiels des personnes atteintes d’un trouble neurocognitif majeur.

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List of Tables and Figures

Acronyms

AChEI	Acetylcholinesterase Inhibitor
AIC	Akaike Information Criterion
ALC	Alternate Level of Care
BIC	Bayesian Information Criterion
BPSD	Behavioural and psychological symptoms of dementia
CP	Conditional probability
ED	Emergency department
H criterion	Hospitalization cohort inclusion criterion
HCU	Healthcare use
INSPQ	Institut National de Santé Publique du Québec
LCA	Latent class analysis
LTC	Long-term care
M criterion	Multiple physician visits cohort inclusion criterion
MCI	Mild cognitive impairment
R criterion	Prescription profile cohort inclusion criterion

Acknowledgements

This master's thesis was completed with the help of a substantial network of support including funding agencies, professors, research teams, statisticians, family, friends and most importantly, my supervisors. Funding for this master's was provided from the following sources: Fonds de Recherche du Quebec en Santé and the Canadian Institute of Health Research via both the Frederick Banting and Charles Best Canada Graduate Scholarship Canadian Institute of Health and the Canadian Consortium on Neurodegeneration and Aging. Tuition assistance and travel awards were provided by the Department of Family Medicine Graduate Studies. Thank you to all these institutions for providing opportunities for growth and for their support in the completion of this thesis and degree.

If there is one thing that researchers know – young and seasoned ones alike – it is that research is not a linear process; my belief is that the support, mentorship and collaborative spirit I was lucky to witness, participate in and receive were among the most important aspects of my time as a master's student.

First and foremost, thank you to my co-supervisors, Dr Isabelle Vedel and Dr Catherine Hudon. Your unwavering support these past three years has been comforting, humbling and inspiring to me. You both commit to your roles as supervisors far beyond requirement or expectation; thank you for challenging me and for having compassion in the times I was not up for a challenge. The encouragement, mentorship and support I have received from you both have been driving forces in the completion of this thesis. From the bottom of my heart, thank you.

My thesis committee were also vital in the completion of this study and the interpretation of the latent class analysis. Dr Claire Godard-Sebillotte, you approached your role on my committee, as my INSPQ preparation person and the conception of this project with enthusiasm

and passion. Thank you for your insights on how to navigate Sainte-Foy, orienting me to INSPQ data, help with relevant literature, insightful interpretations, and reliable presence. To Dr Caroline Sirois, thank you for your calm, encouraging and present approach to your role on my thesis committee. Your insights on both theoretical and logistical aspects of this thesis were invaluable and getting to meet you in-person at the INSPQ was truly a pleasure during my time in Sainte-Foy.

None of the analyses in this thesis could even have begun without Louis Rochette's efforts. Louis, thank you kindly for taking the time to extract data, adjust, explain nuances and for helping navigate the gaps between SAS and R; it was an enormous help to have your poised support while learning on the job.

To my professors, fellow students and ROSA teammates, thank you for challenging me to think, communicate and be better as a researcher. Thank you to Dr Tibor Schuster for your generosity with your time; you were a reliable and insightful support in developing the methods and my thinking about this project. Dr Rashi Khare, thank you for passing on your wealth of knowledge and resources on Latent Class Analysis. Your animation in our discussions helped me understand the methodology and how to use it, which was invaluable in making this project possible. A deep thank you as well to Dr Sreenath Madathil for your help with coding, insights on reporting and thinking in greater depth about this study's results. To Dr Nadia Sourial, thank you for investing time and effort into my development as a statistical analyst and young researcher. You took time to explain things in depth, challenge me, provide opportunities and your expertise truly bolstered this thesis. Matthew Hacker Teper, thank you for sharing, for your consistent guidance and for your candour that helped me navigate my time in the department and writing this document. And to the ROSA team, if passion, insight and creativity were currencies, no one on the team would ever need to apply for grants again. It is a privilege to be pushed and supported by you all, thank you so much for the animated and productive discussions that aided in the development and completion of this thesis.

Sherrie Childs, thank you for the time and assistance you have provided over these three years; your patience, presence and responses have been an enormous help.

I am grateful to have a strong network of support outside of academia as well. To my family and friends, believing in me is among the greatest gifts I could receive from you; thank you. Zoë, Scott and Lori, thank you for helping ensure my dog was well cared-for and quite literally adding time to my days as this thesis was finalized. Thank you to Judith for all your help paving the way to submission of this thesis. And to Sydney, thank you for growing with me, for understanding and for listening; your friendship is second to none.

Preface

The master's thesis that follows is written and organized in compliance with the McGill University Graduate and Postdoctoral Studies guidelines on preparation of a master's thesis. This includes the following major sections:

- A review of relevant literature
- Detailed methods of the present study
- The results, which describe the research findings
- A scholarly discussion of the results of the study

Additional components of this document include the title page, abstracts in English and French, the table of contents, acknowledgements, this preface, an overview of the contributions of the authors and finally, a reference list detailing all sources cited in the document.

Contribution of authors

In total, seven persons contributed directly to this thesis project: Eva Margo-Dermer, Dr Isabelle Vedel, Dr Catherine Hudon, Dr Caroline Sirois, Dr Claire Godard-Sebillote, Dr Nadia Sourial and Louis Rochette. Thus, the contributions of Eva Margo-Dermer, the master's candidate and primary researcher, in relation to her supervisors and colleagues should be clarified.

- The review of relevant literature was written entirely by Eva Margo-Dermer with feedback and editorial assistance from Dr Vedel and Dr Hudon
- The methods were conceived jointly by Ms. Margo-Dermer, Dr Godard-Sebillotte, Dr Sourial and Dr Vedel, however, the methods section of this thesis was written entirely by Eva Margo-Dermer with feedback and editorial assistance from Dr Vedel and Dr Hudon
- Data analyses were exclusively run by Ms. Margo-Dermer; Louis Rochette aided extracting data from the administrative database
- Dr Godard-Sebillotte and Dr Sirois assisted with the interpretation of the latent class model, and the results section was written by Ms. Margo-Dermer with feedback and editorial assistance from Dr Vedel and Dr Hudon.
- The scholarly discussion was written by Ms. Margo-Dermer with feedback and editorial assistance from Drs Vedel and Hudon

Introduction

Older adults with dementia represent a heterogenous group of persons with high healthcare needs compared with older adults without dementia. These needs translate to greater use of ambulatory and hospital-based health services as well as increased needs for long-term care and higher mortality. Research on the differential needs of persons with dementia is preliminary and as such, there is a paucity of literature on ideal individual care planning and health systems planning to best meet the complex and differential needs of older adults with dementia.

As such, this study aimed to identify homogenous subgroups of healthcare users in a cohort of older adults with incident dementia and to describe the characteristics of each group.

Literature review

Aging and dementia

Canada is in a period of accelerated population aging, with seniors (persons aged 65 and over) expected to represent 25% of the population by 2036, compared with 14% in 2009 (1). Over the same time span, a near threefold increase in the population aged 80 years or over is also expected. (1) Population aging provides a setting for increased prevalence of dementia, which is a globally recognized public health priority (2). It is estimated that by 2031, more than 937 000 Canadians will be living with dementia (3) This would increase by 50% if mild cognitive impairment (MCI), which leads to dementia in approximately 60% of cases, were included in the estimated future prevalence of dementias and associated disorders (3).

Dementia

The Diagnostic and Statistical Manual (DSM-5) now defines dementia as a neurocognitive disorder, characterized as decline in one or more of six domains: attention, executive function, learning and memory, language, perceptual function and social cognition (4). These symptoms can cause significant changes to people's day-to-day functioning and as such, can be distressing not only to persons diagnosed with dementia but to their family members and caregivers as well (5). Neurocognitive declines relating to dementia are not predictable nor linear (6); neurocognitive changes are difficult both to adjust to or anticipate, and little is known in terms of speeds or sequences in which people with dementia will experience such changes (7). Moreover, approximately 90% of persons with dementia have behavioural and psychological symptoms of dementia (BPSD) during the progression of their illness (8); such symptoms include agitation, psychosis, and aggression. While these symptoms may vary in nature and severity, they can cause distress and risk for persons with dementia and their caregivers (9,10). Further to the extensive above-mentioned burdens, comorbid conditions to dementia commonly exacerbate patients' illness burden and negatively impact quality of life (11,12). Mortality is additionally known to be independently associated with dementia (13).

The complexities of dementia make its management correspondingly complex; while dementia treatments are generally centred on pharmacological intervention and clinical follow-up, non-pharmacological therapies including music and visual art therapies are increasingly favoured interventions for dementia (14,15). This is not a focus of the present study, however, the importance of treatments that do not have risks or side effects compared with pharmacological therapies – particularly which might contribute to further healthcare use – cannot be overstated (16).

Pharmacotherapy

Dementia diagnosis, treatment and management are rapidly evolving areas of research and clinical practice and so there is not yet consensus on gold standard interventions. This is especially apparent in the context of pharmacotherapy in dementia, where there is mixed evidence on the benefits of medications for symptomatic relief but also well-documented risks and side effects. This nuanced risk-benefit balance is further complicated by many patients being on non-dementia medications (17); use of multiple medications – polypharmacy – creates a setting for added health burden and complexities in management of dementia care (18).

The following section presents the medications that are most prescribed in a dementia context (acetylcholinesterase inhibitors, antipsychotics, benzodiazepines, antidepressants) and the impacts that they and polypharmacy have on healthcare use by persons with dementia.

Acetylcholinesterase inhibitors and memantine

Acetylcholinesterase inhibitors (AChEIs) and memantine are psychotropic medications commonly prescribed to persons with dementia as a means of delaying cognitive but have limited efficacy (19,20). These medications are thought to prevent prescribing of other psychotropics such as antipsychotics, which carry greater risks (21). The use of AChEIs in persons with dementia is complicated by the fact that many seniors with dementia are prescribed medications with anticholinergic effects (22): though not necessarily their primary targeted effects, these medications act on the acetylcholinesterase neurotransmitter system to lessen its effects, whereas AChEIs' targeted effects are the opposite (23). In addition to the limited effectiveness of AChEIs in preventing cognitive declines and potential interaction effects with anticholinergics, risks of cardiovascular events and gastro-intestinal disturbances are linked to their use (24,25). These risks can increase use of healthcare services, comorbidity burden and negatively impact quality of life.

Antipsychotics

Antipsychotic medications are often prescribed to persons with dementia to manage behavioral and psychological symptoms of dementia (BPSD) (26). While these medications can swiftly intervene with severe BPSD, the rates of prescription of antipsychotics for persons with dementia in long-term care is estimated at about 25%, with evidence for only 5%-15% of residents likely to benefit from an antipsychotic prescription (27). Latest evidence-based guidelines recommend deprescription of these medications for patients with dementia because of the risks and side effects associated with antipsychotics (28)], namely sedation and resulting fall-related injuries

(29), which in turn can lead to emergency and hospital use that hasten functional and cognitive declines (8,30).

Benzodiazepines

Benzodiazepines are similarly prescribed at high rates for persons with dementia, though evidence for their effectiveness is likewise limited and the potential harms are well-documented (29,31–34). Benzodiazepines' sedative effect can too lead to fall-related injuries (35). They are additionally linked to risks of pneumonia and to hastened cognitive decline (36,37). These all may result in increased healthcare use and furthermore, can lead to hastened declines during prolonged stays in clinical environments (8,38).

Antidepressants

Antidepressant medications may appropriately be prescribed to persons with dementia for depressed mood, which can either be a dementia symptom or due to a comorbid mood disorder (39). Selective serotonin reuptake inhibitors (SSRIs) are broadly favoured due to their relatively low side effect profile (40) but may still cause gastrointestinal distress, anxiety, sleep disturbances and contribute to polypharmacy-related risks (41,42).

Trazodone, an antidepressant which does not belong to traditional classes, has been prescribed as an alternative pharmacological intervention for BPSD intended to mitigate side effects (32,43). These benefits do not seem to transpire to clinical realities as falls and related injuries persist at rates comparable to antipsychotics and benzodiazepines (31,44).

Polypharmacy

Any medication comes with its own set of side effects or risks, but this may be complicated by interaction effects between medications (45). Evidence on the effect of polypharmacy in a dementia context is emerging yet, though research on the topic to date is not favourable; polypharmacy is common in persons with dementia and increases risk of healthcare use independently and with a dose-response effect (18,46). As such, a greater number of prescribed medications are independently associated with increased risk of healthcare use.

In short, medication use and use of multiple medications by persons with dementia is pervasive and borne from necessity for treatments of both dementia symptoms and comorbid disorders (8,12,13,18,33,40,44). The literature consistently demonstrates that despite clinical necessity, these interventions carry risk and potential to increase healthcare needs.

Health service use by persons with dementia

The prevalence of dementia and associated healthcare needs are increasing, but health systems are ill-prepared to meet these demands (47). Seniors with dementia have greater healthcare utilization than seniors without dementia and have substantial healthcare needs in the year following dementia diagnosis (48–51).

Primary care

Primary care is largely the first point of contact for persons with dementia and the most common setting for diagnosis (52,53). Primary care provides an ideal setting for dementia care as family physicians often have a near-complete portrait of patients' medical history, diagnoses, medications, establish relational continuity with patients (54,55) and sometimes are care providers for dementia patients’ caregivers as well (54,55); this can facilitate open dialogue and shared decision making to coordinate patients’ care and address caregivers’ needs (56). As such, continuity of care with the family physician is an important aspect of quality of care, which can prevent potentially avoidable use of healthcare services (57).

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Specialists & cognition specialists

Specialists are a highly used facet of healthcare by people with dementia (53). Community-dwelling persons with dementia moreover have up four times the utilization of cognition specialists (geriatricians, psychiatrists and neurologists) compared to persons without dementia (58). While specialist care can contribute to holistic healthcare services for persons with dementia, it is a setting which creates vulnerabilities for fragmentation of care (59). This fragmentation can consequently lead to acute exacerbations that require hospital-based care, increasing the overall healthcare use of persons with dementia (60).

Emergency department

Seniors with dementia have twice the acute (emergency) hospital use of seniors without dementia (61). Emergency department (ED) visits are common for persons with dementia, with some studies suggesting that upwards of 50% of dementia patients visit in emergency in the year following initial diagnosis (49). These visits are not only costly to health systems – which are often already at capacity – but an emergency department visit can be distressing to patients and caregivers alike (53,62,63). These visits may moreover be for acute episodes that would be better managed in ambulatory care (64). Emergency department physicians and staff might have insufficient information to ensure adequate care following discharge (65) and thereby may discharge patients to home environments in which there is poor support or coordination of care (49,66). This may precede further adverse events that lead to emergency visits and hospitalizations (8,49).

Hospital

Persons with dementia are more frequently hospitalized compared with persons without dementia, regardless of other morbidities (50,67). Hospitals are not ideal environments for dementia care as hospitalizations are costly to the healthcare system, disorienting to persons with dementia and are a consequence of potentially preventable exacerbations or injuries (67–70). Delirium is a common occurrence during hospitalizations of persons with dementia, which can extend their stays and increase cognitive declines (71).

Hospitalizations may be extended once the acute episode that led to hospitalization has been resolved, but patients' functional states make it so that a return home is not possible (72). This means that institutionalization is an appropriate next step, however, due to bed shortages in long-term care, these patients generally wait in hospital until a bed opens (73,74). This is referred to as alternate level of care and poses a problem not only to patients who are staying in hospitals for longer than their healthcare needs require, but likewise for a health system that is struggling to provide necessary services while simultaneously also providing potentially avoidable ones (47,57,72,75).

Long-Term Care

Long-term care is an appropriate care environment for some persons in advanced stages of dementia or with complex needs (27); with round-the clock nursing and supportive care , long-term care is higher intensity, can help alleviate caregiver burden and increases medication compliance (27,76). Despite the range of support available in long-term care, patients tend not want to leave home and might feel their autonomy is limited in this environment (77,78). There are long-term care bed shortages in Canada, resulting in long waitlists and the use of alternative levels of care (72–74,79). Furthermore, staffing shortages in long-term care highlight vulnerability to infections (80); the COVID-19 pandemic particularly highlights incongruities between resident needs and services staff can provide, which leaves already vulnerable persons with dementia further compromised (81).

Cost

Increasing prevalence of dementias are accompanied by an estimated doubling in the annual costs of dementia care from 10.4 billion in 2016 to 20.8 billion in 2031(82). The costs of this care are more than 5 times greater than for those without dementia, notwithstanding the estimated 38 million hours of unpaid care by informal caregivers of those with dementia (3). According to the Government of Canada, long-term care is the largest contributor to dementia-related costs (3).

Sociodemographics, comorbidities, healthcare and dementia

Several factors can explain the higher use of healthcare services by persons with dementia, including age, sex/gender, comorbidities, material deprivation and rurality (83–85).

Age

While dementia's greatest risk factor is age, dementia is not a normal part of aging (86). Misconceptions about normative aging versus dementia-related cognitive and functional declines can delay patients and caregivers seeking intervention and diagnosis (83). As such, an elder age at diagnosis may indicate that persons with dementia are being diagnosed at a later stage in their disease course, when it is later than ideal to initiate interventions that could prevent some healthcare use (87,88).

Sex & gender

Of those diagnosed with dementia in Canada aged 65 and older, 65% are women; women's lived experiences of dementia are different from those of men (89,90). Women are less likely to have a spousal caregiver and thus more likely to live alone, meaning that home support – if any for persons living alone– is provided by care workers, family or friends who reside outside of the home (91–93). Differences in care for women and men affected by other diseases is well-documented, but there is a paucity of research into differential care healthcare delivery in a dementia context (94). This has been recognized in a call to action for further research into sex differences in dementia diagnosis, treatment, and management, and in emerging research that recognizes sex- and gender-associated gaps in care (90).

Comorbidities

Dementia is often not the only diagnosis that patients have (12,95); comorbid conditions tend to increase the complexity of persons' needs, which in turn translates to a higher use of healthcare services (84,96). Comorbid conditions that make persons with dementia particularly vulnerable to higher use of healthcare services include psychiatric disorders, chronic pain, hypertension, diabetes, arthritis, and cardiovascular disease (13,97,98). As persons with dementia use more healthcare services (49,61), particularly if said services span different facets of ambulatory and hospital care, the complexities of providing continuous care and follow-up create vulnerabilities to fragmentation of care that can precede comorbidity decompensation (59,99,100). Moreover, comorbid conditions of persons with dementia independently increase healthcare use and do so proportionally to the level of comorbidity.

Material deprivation, rurality, and access to care

Access to resources facilitates dementia care but said access is not uniform across communities (101). Publicly funded programs are limited, but they are even less prevalent in remote or lower-socioeconomic areas (102). In communities with lesser access to health resources, the point of access for care can look different; patients without access to their family physician are likelier to refrain from seeking care, which can lead to delayed diagnosis and missed opportunities for interventions (85). Moreover, lesser access to specialized health services such as cognition specialists for complex cases can similarly contribute needs remaining unmet (102).

Differential use of health services between persons with dementia

Healthcare use by persons with dementia is non-homogenous and thus, it is important to understand differential use of healthcare services between persons with dementia. Prior studies studying healthcare use by older adults and persons with dementia using latent class analysis highlight differential use of services by simultaneously emphasizing differences between groups of healthcare users and the uniformity among those in the identified groups (103).

Janssen et al found 3 groups of healthcare users (N=530) with dementia and mild cognitive impairment in their 2016 observational study (104); the data were merged from longitudinal studies with caregiver-reported use of home care, ambulatory and hospital services. The classes were named the “low user”, “informal home care” and “formal home care” classes, and as the names suggest they differed primarily on their use of informal vs. formal caregiving resources.

A subsequent study of an international European cohort (105) likewise used latent class analysis to examine differing use of care services by persons with dementia (N=447), this time based on questionnaire responses by caregivers of persons with dementia. The analysis showed 4 groups of users: “needs met”, “psychological needs met”, “social needs met” and “social needs unmet”. While use of healthcare was not a primary interest in this study, it highlights important differences in needs and associated use of social services by persons with dementia. Additionally, a 2019 study of a nationally representative sample of older adults in China (N=2,981) identified 4 latent classes of healthcare users (103): older adults with relative health, lacking socialization, with many comorbidities and with high disability. The latter two groups had higher healthcare costs compared with the relative health group and those who lacked socialization.

Hasting et al.’s study from the United States on health service use by older persons using an administrative database (N=4,964) was conducted with longitudinal data to not only identify healthcare use groups but also to predict healthcare use based on latent class membership (106). Similarly to the above-mentioned studies using latent class analyses to identify care user groups of persons with dementia this study found five groups: a relatively well group, higher primary care users, highest primary care users with hospitalizations, emergency and hospital users, and the sickest elderly group. Furthermore, group membership was predictive of future healthcare use including returns to the emergency room and hospitalizations, which were highest for the sickest elderly group (106).

Gap & Objectives

While previous studies identify groups of healthcare users with dementia, there is yet to be such research that uses exhaustive samples of the population and a broad portrait of healthcare service use.

To answer to this gap, the study objectives of the present thesis were:

1- Identify different groups of healthcare users among a cohort of persons with dementia using latent class analysis of provincial administrative data.
2- Conduct a descriptive analysis of each identified group using data on healthcare use, medication use and sociodemographics.

Importance of this study

This study is the first to our knowledge to use administrative data and latent class analysis to identify healthcare utilization groups based on a near-complete cohort of persons with dementia and a broad inventory of use of Canadian health services known to affect management and patterns of care for people with dementia. A deepened understanding of different utilization by persons with dementia is crucial, as it will provide context for future research, help guide clinicians to adjust patients' care and implement necessary interventions by identifying patients' patterns of use to address factors underlying their healthcare utilization. This together will help minimize potentially avoidable healthcare utilization by people with dementia.

Methods

This population-based retrospective cohort study used provincial administrative data and latent class analysis. A retrospective design using this type of data was well-suited to the objective as analyses of a near-exhaustive cohort of persons with incident dementia and a broad set of health services gave a baseline understanding of dementia patients' differential healthcare utilization. Healthcare utilization groups were identified using latent class analysis (LCA) with several patient-level covariates and an array of healthcare use parameters. Research on healthcare utilization patterns of subgroups of people with dementia is preliminary, particularly as far as integration of associated covariates and comprehensive parameters of healthcare use. Latent class analyses are best-suited to research contexts in which latent variables are not measured nor known (107); LCA is therefore well-suited to the objective of identifying homogenous subgroups of healthcare users within a larger cohort. The main output of LCA was patient groups with similar patterns of healthcare utilization. The terms healthcare utilization "groups" and "classes" will be used interchangeably here and signify the same concept.

Data source

The incident dementia cohort analyzed in this study was from the Quebec public health agency (Institut national de santé publique du Québec - INSPQ) administrative database, which merges Quebec's health services databases on 1) individual demographics, 2) medical visits, 3) hospitalizations, 4) prescription medications and 5) deaths for a comprehensive repository of provincial population-level healthcare statistics (108). This represents a near-exhaustive health services database, covering upwards of 99% of Quebec's population of older adults (108).

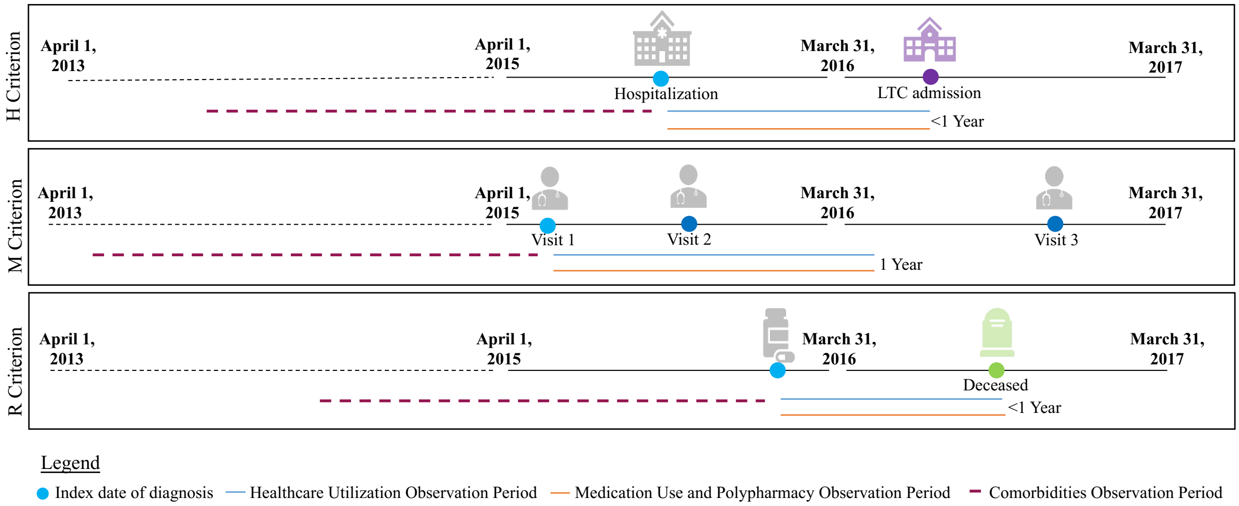
Population

Patients were eligible for this cohort if they had an index date of incident dementia diagnosis between April 1, 2015 and March 31, 2016 and were both aged 65+ and community-dwelling upon diagnosis. As done in previous studies, a validated algorithm (109) was used to identify new dementia cases and included patients on one of three criteria (Figure 1):

1) The H Criterion: One hospitalization with a dementia code from the hospitalization database. The index date of diagnosis is the date of hospitalization.
2) The M Criterion: Three or more physician visits with dementia billing codes in a 2-year period in the medical consultations database. The index date of diagnosis corresponds with the date of the first of the three visits.
3) The R Criterion: A medication profile consistent with dementia (acetylcholinesterase inhibitor or memantine use) from the prescription medication database. The index date of diagnosis is the date when these medications were initially dispensed to the patient.

Non-community-dwelling patients were excluded using the INSPQ algorithm, which identified those living in long-term care on the index date of dementia diagnosis (110). In Quebec, patients in assisted living (residential homes) receive comparable care to those with dementia dwelling immediately within their communities and as such, were included in the cohort.

Figure 1. Cohort inclusion criteria and associated observation period



Variables of Interest

The variables of interest to answer study objective 1 are listed and defined in Table 1. These variables are: 1) family physician visits, 2) cognition specialist visits, 3) other specialist visits, 4) emergency department use, 5) days in hospital, 6) 30-day readmissions to hospital, 7) days in alternate level of care, 8) long-term care admissions and 9) mortality. As defined in the introduction, alternate level of care is a designation for patients who are well enough to be discharged from hospital, but not well enough to return to independent living and therefore remain in hospital until a long-term care bed becomes available to them.

Table 1. Manifest variables in the latent class analysis

Manifest variable	Definition	Type
Family physician visits	Visit to family physicians in the year following index date of diagnosis; multiple billing codes on the same calendar date from the same physician will be amalgamated to represent one visit.	Count
Cognition specialist visits	Visits to psychiatrists, geriatricians and neurologists in the year following index date of diagnosis; multiple billing codes on the same calendar date from the same physician will be amalgamated to represent one visit.	Count
Other specialist visits	Visits to any other physician in the year following index date of diagnosis; multiple billing codes on the same calendar date from the same physician will be amalgamated to represent one visit.	Count
Emergency department (ED) visits	Visits to ED in the year following index date of diagnosis.	Count
Days in hospital	Number of days spent in hospital in the year following index date of diagnosis; admissions spanning less than 24 hours counted as 1 day.	Count
30-day readmissions to hospital	Admission to hospital less than 30 days after discharge in the year following index date of diagnosis; 30 days calculated as of the date of hospital admission.	Count
Days in alternate level of care (ALC)	Number of days spent in ALC in the year following index date of diagnosis.	Count
Long-term care admission	Whether the patient was admitted to long-term care in the year following index date of diagnosis.	Binary
Mortality	Whether the patient died in the year following index date of diagnosis; censored in the latent class analysis for patients who were admitted to long-term care, re-introduced without censoring in descriptive analysis.	Binary

Table 2. Covariates in the latent class analysis

Covariate	Definition	Type
Age	Age at index date of diagnosis	Continuous
Sex	Biological sex	Binary
Material deprivation score	Proxied by the Pampalon index, which is scored on 6 factors relating to material deprivation; scored from 1 (least deprived) to 5 (most deprived). Derived from patients' postal codes.	Ordinal
Marc Simard comorbidity index score	Marc Simard comorbidity index score excluding dementia at index date of diagnosis; scored from 0-18. Includes the following comorbidities: neurological disorders, alcohol abuse, drug use, depression, psychoses, ulcer disease, hypertension, chronic obstructive pulmonary disease, cardiac arrythmias, peripheral vascular disorders, myocardial infarction, congestive heart failure, valvular disease, cerebrovascular disease, pulmonary circulation disorders, coagulopathy, diabetes (uncomplicated), diabetes (complicated), anemia, tumor without metastasis, metastatic cancer, hypothyroidism, liver disease, renal disease, fluid and electrolyte disorders, rheumatoid arthritis, paralysis, obesity, weight loss and HIV/AIDS.	Ordinal
Cohort inclusion criterion	Whether the patient was included in the cohort based on the1) R criterion 2) M criterion or, 3) H criterion.	Categorical

* Diagnostic criterion for all psychological and physical comorbidities in the present study: 1) 1 hospital code, OR 2) 2 separate physician codes in the 2 years prior to the index date of dementia diagnosis.

The covariates in the latent class analysis were age, sex, socio-economic status, physical comorbidities, and patients' cohort inclusion criterion. Socio-economic status was proxied using the validated Pampalon Index (Pampalon et al., 2011), which uses 6 indicators to capture a material deprivation score based on persons' home addresses. Physical comorbidities were represented in the latent class analyses using the Marc Simard index, an index developed and validated at INSPQ (111). This comorbidity index combines the Charlson and Elixhauser indices to scale comorbidity scores according to severity and significance of 30 different illnesses and has better predictive capacity of mortality than either the Charlson or Elixhauser indices alone (111). Table 2 lists and defines these covariates.

Lastly, variables used to answer objective 2 and conduct the descriptive analysis of the identified latent classes were psychotropic medication use (acetylcholinesterase/memantine antipsychotics, benzodiazepines, antidepressants), polypharmacy and presence of specific psychological and physical comorbidities. These variables are listed and defined in Table 3.

Table 3. Variables added in the descriptive analysis

Variable	Definition	Type
Acetylcholinesterase inhibitor or Memantine use	Whether the patient was dispensed an acetylcholinesterase inhibitor or Memantine in the year following the index date of diagnosis.	Binary
Antipsychotic use	Whether the patient was dispensed antipsychotic medication in the year following the index date of diagnosis.	Binary
Benzodiazepine use	Whether the patient was dispensed benzodiazepine medication in the year following the index date of diagnosis.	Binary
Antidepressant use	Whether the patient was dispensed antidepressant medication in the year following the index date of diagnosis.	Binary
Polypharmacy	Total number of medications dispensed to patient in year following index date of diagnosis based on medications' chemical names; includes both chronic and acute use.	Count
Psychological comorbidities*	Mood disorder	Binary
	Psychotic disorder	Binary
	Another mental disorder	Binary
Physical comorbidities*	Neurological Disorders	Binary
	Alcohol Abuse	Binary
	Drug Use	Binary
	Ulcer Disease	Binary
	Hypertension	Binary
	Chronic Pulmonary Disease	Binary
	Cardiac Arrythmias	Binary
	Peripheral Vascular Disorders	Binary
	Myocardial Infarction	Binary
	Congestive Heart Failure	Binary
	Valvular Disease	Binary
	Cerebrovascular Disease	Binary
	Pulmonary Circulation Disorders	Binary
	Coagulopathy	Binary
	Diabetes, Uncomplicated	Binary
	Diabetes, Complicated	Binary
	Anemia	Binary
	Tumor without Metastasis	Binary
	Metastatic Cancer	Binary
	Hypothyroidism	Binary
	Liver Disease	Binary
	Renal Disease	Binary
	Fluid and Electrolyte Disorders	Binary
	Rheumatoid Arthritis	Binary
	Paralysis	Binary
	Obesity	Binary
	Weight loss	Binary
	HIV/AIDS	Binary

Data Extraction

Figure 1 summarizes the timelines upon which cohort inclusion criteria, healthcare utilization, medication use, and comorbidities were measured for this cohort.

Persons who were community-dwelling, aged over 65 and whose index dates of dementia diagnosis (based on the H, M or R criteria) fell between April 1, 2015 and March 31, 2016 were included.

Data on healthcare service use and prescription medications was collected for one year following the index date of diagnosis of dementia for each patient. This period was selected because 1) healthcare needs are higher in the year following diagnosis (51) and 2) a year-long observation period accounts for seasonal effects.

The "healthcare utilization period" was measured for 1 year following the index date of diagnosis (e.g.: a person diagnosed on October 22, 2015, would have their healthcare utilization measured from the index date to October 21, 2016). Variables extracted from the "healthcare utilization period", or the year following the index date of diagnosis, were:

- Family doctor, cognition specialist and other specialist visits in the year following the index date of diagnosis, excluding a visit on the indexed date of diagnosis.
- Emergency visits and hospitalizations; only healthcare utilization after the index date of diagnosis was measured; consequently, emergency department visits and hospitalizations that coincided with the index date of dementia diagnosis were excluded from analyses.
- Long-term care admissions and mortality were modeled alongside healthcare utilization data. Both are competing risks for utilization; healthcare utilization by patients living in long-term care were not measured following admission as their round-the-clock care was markedly different from that of community-dwelling patients. Furthermore, mortality

following long-term care admission was censored from latent class analyses but re-introduced in the descriptive analysis.

Each person's age, sex material deprivation score – which, by convention, is a quintile – and cohort inclusion criterion were extracted based on index date of diagnosis. Lastly, all measured psychological and physical comorbidities were measured in the 2-year period prior to the index date of diagnosis; patients were considered to have a diagnosis of the measured conditions if they had either one hospital-based code or two physician codes identifying them as having the comorbidity of interest in the 2 years preceding index date of dementia diagnosis (111). For example, if a person with an index date of diagnosis on August 5, 2015 had one hospital-based code for hypertension between August 5, 2013 and their index date, they would be considered to have comorbid hypertension.

Data Analysis

Latent class analysis (objective 1)

To answer objective 1, Latent class analyses were performed with the R Software Version 3.5.1 using the poLCA package (112). This mixture modeling technique analyzes data to find natural divergences and patterns in order to group similar observations without assumptions of variable distributions or pre-determined thresholds (113).

Latent class modeling is predicated on the idea that an unobserved (latent) variable can be modeled on a set of observed (manifest) variables (112). In this case, the latent variable is healthcare utilization group, and the manifest variables were components of healthcare utilization, long-term care admissions and mortality, all of which were measured. The observed subjects (patients with dementia) were assumed to belong to one class within a set of latent classes (113); the number of classes is not known prior to analyses, nor are the distributions of subjects within these classes (114).

While LCA does not hold assumptions on the distribution of variables, there are assumptions about the observations and the inter-relation of variables. Firstly, a key assumption of LCA is that observed subjects belong to only one latent class (112). Additionally, manifest variables are assumed to be independent of one another and uncorrelated within each latent class (112). In the context of this study, this means the latent class analysis assumes that each person had only one pattern of healthcare use in the first year following dementia diagnosis and that the components of their healthcare utilization were both independent of and uncorrelated to one another. This analysis integrated observed baseline patient-level covariates to impact prior probabilities of latent class membership. This is a purposeful "violation" of the assumption that all observed subjects have identical prior probabilities of latent class membership (112) by integrating baseline characteristics known to impact healthcare use (83–85).

For the first part of the analysis, the manifest variables and covariates were input to identify latent healthcare utilization classes. The healthcare utilization components and patient-level characteristics were the manifest variables and covariates, respectively. The latter were input in a single step with healthcare utilization variables to enable latent classes to converge on baseline, patient-level factors that would be associated with persons' differing prior probabilities of latent class membership.

Latent class analyses are iterative by nature (112) and thus, the analysis was run starting with a basic one-class model. Then, the number of classes output were increased by one at a time until the best fit was achieved. Two of the primary indications that a good fit was been achieved are homogeneity and latent-class separation (115). The first represents the idea that all subjects within a particular latent class are alike. The second is that the conditional probabilities of each manifest variable are different between classes. In the context of this study, this means that persons in each latent class had a similar healthcare utilization pattern and that this pattern differed from that of patients in other latent classes. The covariates added patients' prior probabilities of class membership, which were affected by underlying factors including age, sex, socio-economic status, and comorbidities.

Selection of the best model (objective 1)

Several statistical measures of goodness of fit can be compared between latent class models to determine the number of classes that is best suited (107). Two of the more common measures, which were used in this study, are the AIC (Akaike Information Criterion) and BIC (Bayesian Information Criterion), both of which will output lesser values for better-fitting models. While these are both statistical parameters of model fit, substantive interpretation by experts is also an important way to assess the clinical relevance and applicability of the latent class model (116). A geriatrician, community pharmacist, family physician and public health physician were consulted in the substantive interpretation of latent class solutions to choose the most clinically relevant model.

In short, the first part of the statistical analysis modelled latent healthcare utilization classes on seven components of healthcare utilization, long-term care admissions and mortality. Five covariates were also modelled in a single step to account for baseline characteristics and factors that affect healthcare utilization, and the solutions were assessed using both statistical indications of model fit and expert input to choose the best-fitting and most clinically relevant model.

Healthcare use by latent class (objective 1)

Conditional probabilities of the manifest variables for each latent class were reported. The median and range of use of each measured facet of care healthcare use according to the latent classes into which persons in the cohort were classified were reported to further illustrate the patterns of healthcare use identified in the latent classes.

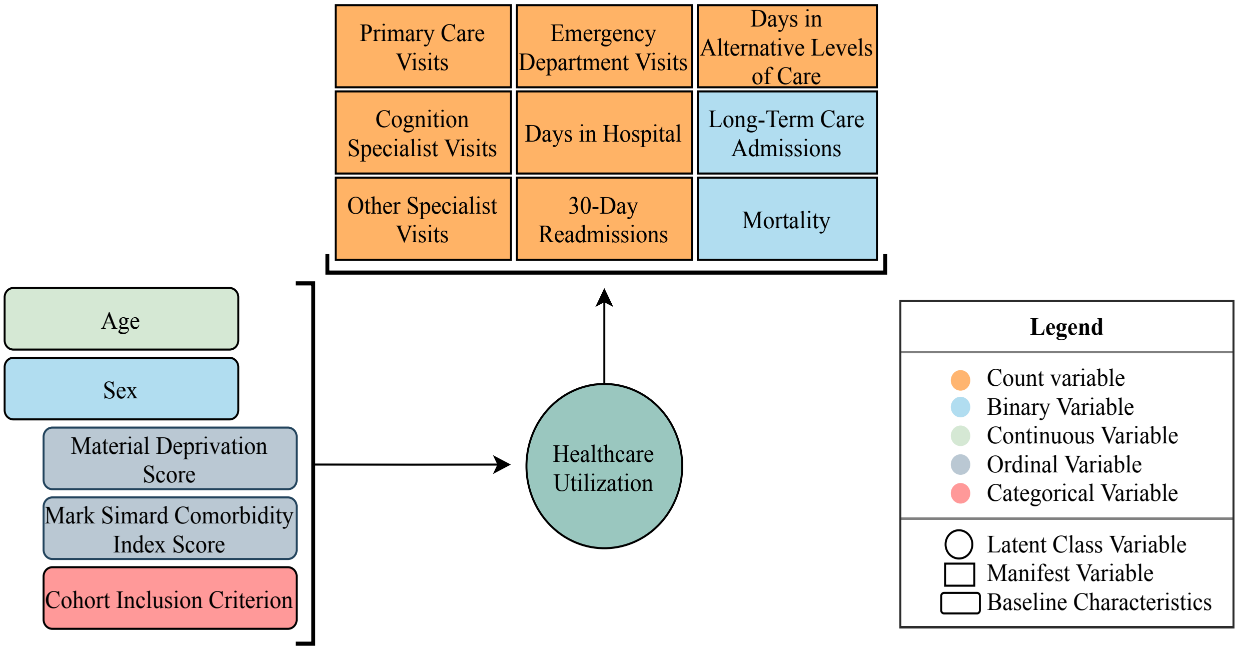
Characteristics of each class (objective 2)

Factors hypothesized to relate to the latent variable (healthcare utilization group) were examined using descriptive analyses in a subsequent step to the Latent Class Analysis. Healthcare utilization groups were described based on the observed groups derived from the Latent Class Analysis; as such, this step was a description of healthcare utilization groups based upon the characteristics, prescriptions, comorbidities and healthcare use of the persons who were classified into each of the groups. The variables assessed by group in this step were: age, sex, cohort inclusion criterion, psychotropic medication use (antipsychotics, benzodiazepines, antidepressants, acetylcholinesterase inhibitors), polypharmacy, psychological comorbidities (mood disorders, psychosis and other mental illness) and 28 physical comorbidities (those included in the Marc Simard Index). Median use of all measured facets of healthcare based on cohort members' classification into healthcare utilization groups were additionally used to describe the groups in this step.

All variables listed in Tables 1 and 2 were formatted identically across analyses, except for mortality, which was censored in the latent class analysis for persons admitted to long-term care but re-introduced without censoring in the descriptive analysis.

Figure 2 is the latent class model diagram depicting the relationship between the latent class variable, manifest variables, and covariates of interest in this study.

Figure 2. Latent Class Model Diagram



Results*:*

Characteristics of the Cohort

The INSPQ algorithm identified 15,584 persons diagnosed with index dates of dementia diagnosis between April 1, 2015 and March 31, 2016. The age of persons in the cohort ranged from 65 to 106 years (Median: 82, Mean: 81.63 [SD: 7.29]), with more than half (62.5%) of the cohort aged 80 and above years at diagnosis. The cohort was 60.8% female.

Of the persons included in the cohort whose Material Deprivation Score was measured, there was a skew towards higher deprivation; this variable was the only incomplete variable of interest (NA=3127, 20.1% of total cohort).

Nearly half of the cohort (7,540 persons or 48.4%) were identified by the M criterion, which is 3 physician visits in a span of 2 years with a dementia code; the least number of persons (3,192 or 20.5%) were identified with the H criterion, a hospitalization with a dementia code.

In the year following diagnosis, 2173 persons (13.9%) were admitted to long-term care and 1,611 (10.4%) died. The characteristics of the cohort are summarized in Table 4.

Table 4. Characteristics of the cohort

N Total=15,584

Age	**Median (Min; Max)**				**Mean (SD)**	
	82 (65.00;106.00)				81.63 (7.29)	
	65-69	**70-74**	**75-79**	**80-84**	**85-89**	**90+**
N (% of Cohort)	958 (6.1)	1913 (12.3)	2968 (19.0)	3934 (25.2)	3602 (23.1)	2209 (14.2)
Sex	**Female**				**Male**	
N (% of Cohort)	9443 (60.6)				6141 (39.4)	
Material Deprivation	**1 (lower)**	**2**	**3**	**4**	**5 (higher)**	**NA**
N (% of Cohort)	2104 (13.5)	2087 (13.4)	2617 (16.8)	2744 (17.6)	2905 (18.6)	3127 (20.1)
Cohort Inclusion Criterion	**H Criterion***		**M Criterion****		**R Criterion*****	
N (% of Cohort)	3192 (20.5)		7540 (48.4)		4852 (31.1)	
Long-Term Care Admissions						
N (% of Cohort)				2173 (13.9)		
Survival	**1 Year**			**Died in Community**	**Died in Long-Term Care**	
N (% of Cohort)	13973 (89.7)			1177 (7.6)	434 (2.8)	

* 1 hospitalization with dementia code
** 3 physician visits with dementia codes
*** prescription profile consistent with dementia

Latent Class Solutions

Between 1 and 5 latent class solutions were fit. The 4- and 5-class solutions were considered as the best fit; upon interpretation of the two, the 4-class solution was chosen based on both statistical model fit criteria and clinical relevance.

As demonstrated in Table 5, the Akaike Information Criterion (AIC) lowered with each class solution from 1 to 4, then increased at the 5-class solution. Conversely, the Bayesian Information Criterion (BIC) was lowest at the 2-class solution; while this indicates that the chosen 4-class solution was a lesser fit based on the BIC, this criterion is more sensitive to a larger number of parameters (such as a large sample size and many manifest variables) and thus, the AIC was prioritized as a statistical indication of model fit. The model fit criteria are summarized in Table 5.

The 4-class model was likewise the most clinically relevant solution; the healthcare utilization (HCU) groups captured more nuance than the 2- or 3-class solutions yet demonstrated clearer-cut classes than the 5-class solution. Thus, the groups identified with the 4-class solution were labelled:

1) Low Users
2) Ambulatory Centric Users
3) High Acute Hospital Users
4) Long-Term Care Destined Users

Table 5. Akaike Information Criterion (AIC) and Bayesian Information Criterion (BIC) by class solution.

	1-Class Solution	**2-Class Solution**	**3-Class Solution**	**4-Class Solution**	**5-Class Solution**
AIC	356671.1	343796.2	340999.9	340251	353716.7
BIC	364240.9	358989.4	363816.4	370690.9	391780.0

Table 6 provides an overview and comparison between the healthcare utilization groups resulting from the five assessed latent class solutions.

Table 6. Overview of groups in assessed latent class solutions.

	1-Class Solution	2-Class Solution	3-Class Solution	4-Class Solution	5-Class Solution
Group 1	Full cohort	Higher users	Ambulatory users	Low users	Low Users
Group 2	-	Lower users	Hospital-centric users	Ambulatory-centric users	Unclear
Group 3	-	-	LTC*-destined users	High acute hospital users	Unclear
Group 4	-	-	-	LTC*-destined users	Unclear
Group 5	-	-	-	-	LTC*-destined Users

*LTC: Long-Term Care

Latent Classes

The following section sequentially presents the groups from the 4-class solution and the characteristics that differentiate their healthcare use from one another. Tables 7-11 present the characteristics of each identified latent class; sociodemographic characteristics are summarized by group in Table 7, Table 8 presents a summary of the conditional probabilities of manifest variables and subsequently, the medians and ranges of healthcare utilization are summarized in Table 9. The prevalences of use for each medication class of interest and polypharmacy are summarized in Table 10 and then, the prevalence of all measured psychological and physical comorbidities, as well as the medians and ranges of comorbidity index scores are found in Table 11.

Finally, Table 12 provides a summary of each of these four healthcare utilization groups' sociodemographic characteristics, relative conditional probabilities, median use of healthcare services, medication use and comorbidities.

Group 1: Low Users

Sociodemographic characteristics

The Low Users were the largest healthcare utilization group (N=5,673 persons or 36.4% of the cohort); they were the second youngest (median age: 83 years) and had an under-representation of males (31.0% of the group, compared with 39.4% in the total cohort). 18.9% of the group were identified with the H criterion (hospitalization with a dementia code), 39.6% were identified with the M criterion (3 physician visits) and 41.5% were identified with the R criterion (prescription profile consistent with dementia).

Conditional probabilities of manifest variables

In terms of conditional probabilities of healthcare use, the Low Users had the lowest probabilities of most manifest variables. For ambulatory care, Low Users had: the second-lowest probability of using family physicians (76.6%), and the lowest probabilities of frequent family physician use (10.4% probability of 8 or more visits), cognition specialist use (15.5% probability) and of visiting other specialist physicians (56.2% probability) compared with other groups. As for hospital-based care, Low Users had the lowest probability of ED use (23.7%), frequent ED use (0.5% probability of 4+ visits), hospitalization (1.3% probability), 30-day hospital readmissions (0% probability) and of ALC use (0.4% probability). This group also had the second-highest probability of long-term care admission (4.1%) and the second-lowest probability of mortality (4.2%) in the year following index date of dementia diagnosis.

Healthcare utilization

The persons classified into the Low User Group had the lowest median use of all measured facets of ambulatory and hospital care: family physician use (median: 2 visits), cognition specialist use (median: 0 visits), other specialist physician use (median: 1 visit), emergency department use (median: 0 visits), hospitalizations (median: 0) and days in hospital (median: 0). The persons classified as Low Users had the second-highest percentage of long-term care admissions (4.0%) and the second-lowest percentage of mortality (4.9%). No persons classified in the Low Users had 30-day hospital readmissions and as with all groups, the median number of days in ALC was 0.

Medication use

This group were the lowest antipsychotic (20.1% prevalence), benzodiazepine (27.0%) and antidepressant (32.3%) users but were the second-highest acetylcholinesterase inhibitor users (61.4%). They had the lowest number of medications of all groups (median: 9 medications dispensed in the year following diagnosis).

Comorbidities

The Low Users had the lowest prevalence of all measured psychological and physical comorbidities; these include mood disorders (57.6% prevalence), psychosis (13.2%), hypertension (22.5%), chronic pulmonary disease (4.2%), cardiac arrythmias (8.5%), myocardial infarction (1.3%), congestive heart failure (2.4%) and diabetes (uncomplicated: 11.7% prevalence; complicated: 1.2% prevalence). They had a median score of 0 on the Marc Simard comorbidity index and a median of 1 comorbidity.

Group 2: Ambulatory-Centric Users

Sociodemographic Characteristics

The Ambulatory Centric Users were the second-largest group (N=4,288 persons or 27.5% of the cohort). They were the youngest (median age: 78 years) and had an over-representation of males (49.5% of the group compared with 39.4% of the cohort). 11.3% of the group were identified with the H (hospitalization) criterion, 58.9% with the M (physician visit) criterion and 29.8% with the R (prescription) criterion.

Conditional probabilities

This group had the highest conditional probability of visiting a family physician (89.3% probability of 1+ visits), cognition specialists (51.9% probability of 1+ visits) and other specialist physicians (98.2% probability of 1+ visits). The Ambulatory Centric Users also had the second-highest probability of frequent use of family physicians (15.7% probability of 8+ visits). For hospital based-care, this group had the second-lowest probability of visiting ED (53.9%) of frequent emergency department use (5.1%) and of hospitalization (14.8%). Same as the Low Users, they had the lowest conditional probabilities of 30-day readmissions (0%) and of ALC use (0.4%). The Ambulatory Centric Users also had the lowest probability of long-term care admission (0.2%) and of mortality (0%) in the year following index date of dementia diagnosis.

Healthcare utilization

The persons classified as Ambulatory Users had the highest median use of all facets of ambulatory care: family physicians (median: 4 visits), cognition specialists (median: 1 visit) and other specialist physician (median: 5 visits). Conversely, the members of this group had relatively low use of hospital-based care: they had the second-lowest emergency department use (median: 1 visit), and – same as the persons classified into the Low User group – the lowest median hospitalizations (median: 0), days in hospital (median: 0 days), 30-day readmissions (median: 0) and use of alternate level of care (median: 0 days). Of the persons in the Ambulatory-Centric group there were only 2 long-term care admissions and no deaths during the observation period.

Medication use

This group had the same lowest prevalence of antipsychotic use as the Low Users (20.1%), second-lowest benzodiazepine and antidepressant use (28.2% and 39.3% prevalence, respectively) and the highest acetylcholinesterase inhibitor use (61.8%, similar to the Low Users' 61.4% prevalence). This group also has the second-lowest number of medications (median: 11).

Comorbidities

The Ambulatory Users had the second-highest prevalence of mood disorders (64.4%), the highest prevalence of neurological disorders (10.4%) and tumours without metastasis (13.5%), and the second-lowest prevalence of hypertension (25.1%), chronic pulmonary disease (7.8%), cardiac arrythmias (14.5%), myocardial infarction (2.6%), congestive heart failure (3.9%) and diabetes (15.5% uncomplicated; 2.4 complicated). This group also had a median of 2 comorbidities and a score of 1 on the Marc Simard index.

Group 3: High Acute Hospital Users

Sociodemographic

The High Acute Hospital Users were the second-smallest group (N=3680 persons or 23.6% of the cohort). The median age was 83 years and 39.2% of the group were male, which is comparable to the cohort at 39.4%. 33.1% were identified with the H criterion, 41.6% with the M criterion and 25.3% with the R criterion.

Conditional probabilities

This group had the second-highest conditional probability of visiting family physicians (81.5%), highest probability of frequent family physician use (21.0%), second lowest of cognition specialist use (22.8%), second-highest probability of other specialist use (80.6%). This group also had the highest conditional probabilities of emergency use (98.7%), frequent emergency use (30.0% of 4+ visits), hospitalization (96.3%) and of 30-day readmissions (28.1%), and the second-highest conditional probability of spending time in an alternate level of care (1.2%). The High Acute Hospital Users also have a 0.91% CP of LTC admission and the highest probability of mortality (26.1%).

Healthcare utilization

The High Acute Hospital Users had varied ambulatory care use; they had mid-level family physician use (median: 3 visits), the lowest cognition specialist use (median: 0 visits), and the second-highest use of other specialists (median: 3 visits). They had the highest hospital use with medians of 2 emergency department visits, 1 hospitalization, 15 days in hospital, no 30-day readmissions or days in ALC, the latter two of which were the medians for all groups. The High

Acute Hospital Users had no long-term care admissions and the highest mortality at 25.4% in the year following index date of diagnosis.

Medication use

This group were the overall highest medication users; they had the second-highest antipsychotic use (36.8%), highest benzodiazepine and antidepressant use (38.8% and 43.3%, respectively), and the second-lowest acetylcholinesterase inhibitor use (43.0%). These users also had the highest median number of medications (median: 15).

Comorbidities

The High Acute Hospital Users had the highest prevalence of mood disorders (65.0%) and the most measured physical comorbidities including hypertension (32.4%), chronic pulmonary disease (14.0%), cardiac arrythmias (22.0%), myocardial infarction (5.1%), congestive heart failure (12.2%), uncomplicated diabetes (19.0%) and complicated diabetes (4.2%). Same as the Ambulatory-Centric Users, this group also had a median of 2 comorbidities and a score of 1 on the Marc Simard index, respectively.

Group 4: Long-Term Care Destined Users

Sociodemographic

The Long-Term Care Destined Users were the smallest group with 1,943 persons (12.5% of the cohort). They were the oldest group (median age: 85) and 42.1% of group members were male. 21.6% of the cohort were identified with the H criterion (hospitalization), 63.7% with the M criterion (physician visits) and 14.7% with the R criterion (prescription profile).

Conditional probabilities

This group had the lowest conditional probability of all the groups of using family physicians (73.0%) and the second lowest of frequent family physician use (14.3% for 8+ visits). They also had the second-highest probability of cognition specialist use (24.1%) and second lowest of other specialist use (73.4%). As for the Long-Term Care Destined Users' use of hospital-based care, they had the second-highest probability of emergency use (95.3%), second-highest conditional probability of frequent emergency use (29.1%), the highest of hospitalization (96.3%, same as the High Acute Hospital Users), second-highest of 30-day readmissions (27.6%) and highest of alternate level of care use (46.6% probability of spending 1 or more days in alternative levels of). This group also had the highest conditional probability of long-term care admission, at 99.8% and mortality was censored for all persons in the cohort admitted to long-term care (1,942 out of 1,943 persons) in the latent class analyses, as healthcare utilization was not measured following admission.

Healthcare utilization

This group had the lowest median family physician visits (median: 2 visits) and cognition specialist visits (0 visits). They also had the second-lowest visits to other specialists (median: 2 visits). The Long-Term Care Destined Users had the highest emergency department use (median: 2 visits), and similar to the High Acute Hospital Users, they had the highest hospitalizations (median: 1) and the second-highest days in hospital (median: 13 days). As with the rest of the groups, the median numbers of 30-day admissions and days in alternate level of care were zero.

Only 1 person classified into this group was not admitted to long-term care and the group had the second-highest mortality (20.5%).

Medication use

The Long-Term Care Destined users were mid-level (along with the Ambulatory Users) medication users; they were the highest antipsychotic users (43.0%), second-highest benzodiazepine and antidepressant users (33.6% and 42.5%, respectively) and the lowest acetylcholinesterase inhibitor users (31.9%). They had the second-highest median number of medications (12 medications dispensed in the year following diagnosis).

Comorbidities

The Long-Term Care Destined Users had the second-lowest prevalence of mood disorders (63.3%) and the highest prevalence of psychosis (21.5%), other psychological disorders (48.3%), cerebrovascular disease (8.9%) and obesity (1.9%, which is identical to the High Acute Hospital group). They had the second-highest prevalence of the following comorbidities: hypertension (29.6%), chronic pulmonary disease (10.4%), cardiac arrythmias (20.5%), myocardial infarction (3.0%), congestive heart failure (8.9%) and diabetes (uncomplicated: 17.7%; complicated 3.1%).

Table 7. Sociodemographic characteristics by group

	Low Users N= 5673 (36.4%)	**Ambulatory Centric** N= 4288 (27.5%)	**High Acute Hospital** N= 3680 (23.6%)	**Long-Term Care Destined** N= 1943 (12.5%)
Sex				
N Male (%)	1757 (31.0)	2123 (49.5)	1443 (39.2)	818 (42.1)
Age (Years)				
Median (Min; Max)	83 (65; 106)	78 (65; 99)	84 (65; 103)	85 (65; 102)
Cohort Inclusion Criterion, N (%)				
H: Hospitalization	1070 (18.9)	486 (11.3)	1217 (33.1)	419 (21.6)
M: Physician Visits	2247 (39.6)	2524 (58.9)	1531 (41.6)	1238 (63.7)
R: Prescription Profile	2356 (41.5)	1278 (29.8)	932 (25.3)	286 (14.7)

Table 8. Conditional probabilities of manifest variables by group

	Low Users N= 5673 (36.4%)	**Ambulatory Centric** N= 4288 (27.5%)	**High Acute Hospital** N= 3680 (23.6%)	**Long-Term Care Destined** N= 1943 (12.5%)
Family Physician				
1 Or More Visits (%)	76.6	88.3	81.5	73.0
8 Or More Visits (%)	10.4	15.7	21.0	14.3
Cognition Specialist				
1 Or More Visits (%)	15.5	51.9	22.8	24.1
Other Specialists				
1 Or More Visits (%)	56.2	98.2	80.6	73.4
Emergency Department				
1 Or More Visits (%)	23.7	53.9	98.7	95.3
4 Or More Visits (%)	0.5	5.1	30.0	29.1
Days In Hospital				
1 Or More (%)	1.3	16.8	96.3	67.3
30-Day Readmissions				
1 Or More (%)	0	0	28.1	27.6
Days In ALC				
1 Or More Days (%)	0.4	0.4	1.2	46.6
Long-Term Care				
Admission (%)	4.1	0.2	0.9	99.8
Mortality				
Death (%)	4.2	0.0	26.1	0.1

Table 9. Healthcare utilization summary by group

	Low Users N= 5673 (36.4%)	Ambulatory Centric N= 4288 (27.5%)	High Acute Hospital N= 3680 (23.6%)	Long-Term Care Destined N= 1943 (12.5%)
Family Physician Visits				
Median (Min; Max)	2 (0; 47)	4 (0; 61)	3 (0; 72)	2 (0; 60)
Cognition Specialist Visits				
Median (Min; Max)	0 (0; 30)	1 (0; 55)	0 (0; 124)	0 (0; 70)
Other Specialist Visits				
Median (Min; Max)	1 (0; 161)	5 (0; 173)	3 (0; 166)	2 (0; 156)
Emergency Department Visits				
Median (Min; Max)	0 (0; 10)	1 (0; 18)	2 (0; 20)	2 (0; 26)
Hospitalizations				
Median Number (Min; Max)	0 (0; 2)	0 (0; 11)	1 (0; 9)	1 (0; 26)
Median Days (Min; Max)	0 (0; 189)	0 (0; 219)	15 (0; 272)	13 (0; 282)
30-Day Readmissions				
Median (Min; Max)	0 (0; 0)	0 (0; 9)	0 (0; 8)	0 (0; 27)
Days In ALC				
Median (Min; Max)	0 (0; 280)	0 (0; 81)	0 (0; 135)	0 (0; 282)
Long-Term Care Admission				
Admitted (%)	229 (4.0)	2 (0.0)	0 (0.0)	1942 (99.9)
Mortality				
Deaths (%)	276 (4.9)	0 (0.0)	936 (25.4)	399 (20.5)

Table 10. Medication use summary by group

	Low Users N= 5673 (36.4%)	Ambulatory-Centric N= 4288 (27.5%)	High Acute Hospital N= 3680 (23.6%)	Long-Term Care-Destined N= 1943 (12.5%)
Medication, N (% of Group)				
Antipsychotics	1143 (20.1)	862 (20.1)	1353 (36.8)	835 (43.0)
Benzodiazepines	1533 (27.0)	1208 (28.2)	1429 (38.8)	653 (33.6)
AChEIs*	3483 (61.4)	2650 (61.8)	1581 (43.0)	620 (31.9)
Antidepressants	1833 (32.3)	1686 (39.3)	1595 (43.3)	825 (42.5)
Number Of Medications				
Median (Min; Max)	9 (0; 38)	11 (0; 40)	15 (0; 51)	12 (0; 50)

*AChEIs: Acetylcholinesterase Inhibitors

Table 11. Psychological and physical comorbidities summary by group

	Low Users N= 5673 (36.4%)	**Ambulatory-Centric** N= 4288 (27.5%)	**High Acute Hospital** N= 3680 (23.6%)	**Long-Term Care Destined** N= 1943 (12.5%)
Comorbidity Index Score				
Median (Min; Max)	0 (0; 17)	1 (0; 16)	1 (0; 18)	0 (0; 17)
N Comorbidities				
Median (Min; Max)	1 (0; 15)	2 (0; 14)	2 (0; 17)	1 (0; 12)
Psychological Comorbidity				
Mood Disorder	3270 (57.6)	2761 (64.4)	2391 (65.0)	1230 (63.3)
Psychosis	747 (13.2)	591 (13.8)	711 (19.3)	417 (21.5)
Other	1881 (33.2)	1685 (39.3)	1726 (46.9)	938 (48.3)
Physical Comorbidities				
Alcohol Abuse	42 (0.7)	36 (0.8)	62 (1.7)	31 (1.6)
Drug Use	13 (0.2)	7 (0.2)	12 (0.3)	9 (0.5)
Ulcer Disease	11 (0.2)	21 (0.5)	31 (0.8)	11 (0.6)
Hypertension	1274 (22.5)	1076 (25.1)	1191 (32.4)	576 (29.6)
Chronic Pulmonary Disease	236 (4.2)	335 (7.8)	517 (14.0)	203 (10.4)
Cardiac Arrythmias	484 (8.5)	623 (14.5)	811 (22.0)	399 (20.5)
Peripheral Vascular Disorders	119 (2.1)	159 (3.7)	218 (5.9)	94 (4.8)
Myocardial Infarction	72 (1.3)	112 (2.6)	188 (5.1)	59 (3.0)
Congestive Heart Failure	136 (2.4)	168 (3.9)	450 (12.2)	172 (8.9)
Valvular Disease	129 (2.3)	156 (3.6)	227 (6.2)	100 (5.1)
Cerebrovascular Disease	159 (2.8)	233 (5.4)	305 (8.3)	172 (8.9)
Pulmonary Circulation Disorders	45 (0.8)	61 (1.4)	129 (3.5)	42 (2.2)
Coagulopathy	31 (0.5)	69 (1.6)	108 (2.9)	44 (2.3)
Diabetes, Uncomplicated	666 (11.7)	666 (15.5)	700 (19.0)	344 (17.7)
Diabetes, Complicated	66 (1.2)	104 (2.4)	154 (4.2)	61 (3.1)
Anemia	312 (5.5)	316 (7.4)	509 (13.8)	223 (11.5)
Tumor Without Metastasis	189 (3.3)	581 (13.5)	480 (13.0)	192 (9.9)
Metastatic Cancer	60 (1.1)	188 (4.4)	166 (4.5)	59 (3.0)
Hypothyroidism	221 (3.9)	203 (4.7)	283 (7.7)	135 (6.9)
Liver Disease	23 (0.4)	56 (1.3)	72 (2.0)	37 (1.9)
Renal Disease	176 (3.1)	236 (5.5)	400 (10.9)	187 (9.6)
Fluid/Electrolyte Disorders	126 (2.2)	119 (2.8)	242 (6.6)	106 (5.5)
Rheumatoid Arthritis	78 (1.4)	116 (2.7)	110 (3.0)	54 (2.8)
Paralysis	15 (0.3)	31 (0.7)	31 (0.8)	11 (0.6)
Obesity	20 (0.4)	46 (1.1)	69 (1.9)	37 (1.9)
Weight Loss	57 (1.0)	62 (1.4)	88 (2.4)	37 (1.9)
HIV/Aids	1 (0.0)	5 (0.1)	9 (0.2)	1 (0.1)

In summary, the Low Users were the largest group, had an under-representation of males, were of average age compared with the total cohort and had the highest prevalence of inclusion in the cohort based on a medication profile consistent with dementia. The persons classified as Low Users had the least use of all hospital-based services, lowest polypharmacy and lowest prevalence of all measured comorbidities.

Ambulatory-Centric users were the second-to-largest group, had an over-representation of males, were the youngest and had the lowest prevalence of inclusion in the cohort based on the hospitalization with dementia code criterion. The persons in this group had the highest use of ambulatory care and lowest mortality, relatively low medication use and relatively high comorbidities.

Comparatively, High Acute Hospital Users were the second-smallest group and had the highest prevalence of cohort inclusion from the hospitalization with dementia code criterion. The persons classified into the group had the highest hospital use on all measured facets of care save for ALC use, highest mortality and higher comorbidities.

Finally, Long-Term Care-Destined Users' primary characteristic was admission to long-term care in the year following diagnosis (except for one person classified into this group). They were the eldest group and had the highest prevalence of inclusion based on 3 physician visits with a dementia code. The Long-Term Care-Destined users additionally had the highest use of ALC and 20% mortality in the year following diagnosis. They had high use of medications and the highest prevalence of psychosis.

The characteristics of the four identified healthcare utilization groups are summarized in Table 12.

Table 12. Summary of healthcare utilization groups

	Low Users **N= 5673 (36.4%)**	**Ambulatory-Centric** **N= 4288 (27.5%)**	**High Acute Hospital** **N= 3680 (23.6%)**	**Long-Term Care Destined** **N= 1943 (12.5%)**
Gender	Under-representation of males (31.0%)	Over-representation of males (49.5%)	39.2% male	42.1% male
Age	Median 83	Youngest; median: 78	Median 84	Eldest; median 85
Cohort inclusion	Highest prevalence R criterion, lowest prevalence M criterion.	Lowest prevalence H criterion.	Highest prevalence H criterion.	Highest prevalence M criterion, lowest prevalence R criterion.
Conditional probabilities of healthcare use	Highest conditional probability of zero or non-frequent use of family physicians, lowest for all other use, 4% probability of LTC admission and mortality.	Highest conditional probability of use of all ambulatory care variables.	Highest conditional probability of frequent family physician use, ED use, frequent ED use, hospital use and readmissions.	46.6% conditional probability of ALC use: equivalent probability to High Acute Hospital of frequent ED use and 30-day readmissions.
Healthcare use	Not the highest users of any facet of care, including family physicians.	Highest family physician and specialist users, lowest mortality.	Highest hospital users and highest (26%) mortality.	High ED and hospital use as well, 20% mortality.
Psychotropic medication use	Higher acetylcholinesterase inhibitor use.		Higher antipsychotic, benzodiazepine, and antidepressant use.	
Polypharmacy	Lowest number of medications	Lower number of medications	Highest number of medications	Higher number of medications
Number of comorbidities	Lower comorbidity index score and number of comorbidities.	Higher comorbidity index scores and number of comorbidities. .		Lower comorbidity index score and number of comorbidities
Comorbid diagnoses	Lowest prevalence of all psychological and physical comorbidities.	Highest prevalence of metastasis and neurological. disorders.	Highest prevalence of most comorbidities. Notably: hypertension, myocardial infarction, congestive heart failure, cardiac arrythmias, chromic pulmonary disease, diabetes.	Highest prevalence of psychosis. Relatively high physical comorbidity with prevalence nearly as high as in the High Acute Hospital Users. This includes all comorbidities noted for the High Acute Hospital group.

Discussion

The present study adds to growing literature on differential use of health services by persons with dementia and is the first to our knowledge to use latent-class with near-complete cohort of persons with incident dementia and to include such a comprehensive set of ambulatory and hospital-based health service use parameters. This study identified four homogenous healthcare utilization groups, highlighting the heterogeneity of healthcare use among persons with incident dementia.

The mean age of this incident dementia cohort was 81.63 years (SD: 7.29), which is in line with previous Canadian provincial dementia cohorts' ages (58,64,117). As is also typical of dementia cohorts identified through administrative databases in Canada, 60% of the persons in the cohort were female (57,117). Likewise, 10.4% mortality of the cohort in the year following diagnosis was similar to comparable literature on trajectories of care of persons with dementia (58).

The latent class analysis identified 4 distinct healthcare utilization groups: Low Users (36.4% of the cohort), Ambulatory-Centric Users (27.5%), High Acute Hospital Users (23.6%) and Long-Term Care-Destined Users (12.5%). The Low Users had an under-representation of males when compared with the complete cohort, and were the overall lowest users, lowest comorbidity group and had the least polypharmacy of the groups. Ambulatory-Centric Users were the youngest group (median age: 78), had an over-representation of males (compared with the cohort) and relatively low comorbidity, and additionally were the highest users of family physicians, cognition specialists and other specialists, which were all measured facets of ambulatory care. The High Acute Hospital Users had the highest hospital use (emergency department visits, days in hospital and 30-day readmissions), mortality (26% of group), number of medications (median: 15), highest prevalence of antipsychotic, benzodiazepine, and antidepressant use, and had the highest prevalence of most comorbidities of interest, both physical and psychological. The Long-Term Care-Destined Users were the oldest group (median age: 85), had 99% admissions to long-term care, had high hospital use, the highest alternative le use and relatively high comorbidity.

Latent Class Analysis Groups

Low Users

Low User groups are consistently found across studies that use latent class analysis and examine healthcare use by older adults or persons with dementia (103,105,105,106,118). While this evidence suggests that lower healthcare user groups identified by latent class analysis may have lesser needs (105,106), it is also likely that part of this group has barriers to adequate healthcare and thus are Low Users with unmet needs (119,120). As such, the following section will explore possible facilitators to Low Users having met needs and barriers for Low Users with unmet needs that make up this group.

The Low Users' sociodemographic characteristic that distinguishes the group from the other three is that the group was 69% women (compared with 60% for the cohort). A partial possible explanation for this characteristic appears in a recent study on sex differences in dementia care in Ontario, Canada (117); women were found to use more home care services compared with men with dementia. This may be a realm of care in which their needs are being met, thereby preventing them from consulting physicians as much as the Ambulatory-Centric group. The Low Users were additionally the group with the greatest prevalence of identification for the cohort via the prescription criterion; medication profiles consistent with dementia are more common at earlier stages of dementia to prevent cognitive decline (121) and as such, the possibility of not having reached a severe stage of dementia is consistent with the possibility that Low Users had relatively low healthcare needs.

Nonetheless, a second subgroup of the Low Users may not have their needs met to the same extent. Older women are less likely to have spousal caregivers compared with men due to longevity of women and common age gaps between married partners (122). In the context of Low Users, this means that women perhaps did not have their care coordinated by caregivers in a manner that prompted them to seek and access all necessary care. Further sociodemographic factors can contribute to high needs not translating into higher use of services: these include cultural norms, reduced mobility, transportation, proximity to healthcare services (8,91,123) Additionally, perceived needs being lesser than clinically necessary ones and negative experiences when seeking care can deter patients from accessing health services (91,123).

Ambulatory-Centric Users

The Ambulatory-Centric Users were the youngest of the four identified classes, which may mean that they benefitted from earlier diagnosis of dementia. The most notable differences between the Low User and Ambulatory-Centric groups were the lower age and higher use of primary care (family physicians) and secondary care (cognition and non-cognition specialists) by the ambulatory-centric users, which suggests that these patients' healthcare utilization might have a closer follow-up of their conditions. This group also had an over-representation of men. The group's higher use of specialists coupled with its over-representation of men is also consistent with the aforementioned study in Ontario, Canada which found that men were more likely to visit non-cognition specialists (117). As previously highlighted, older men are more likely to have a spousal caregiver as compared with women (122); this may enable coordination of more appropriate care than that of the low user group and is perhaps a partial explanation of different proportions of women and men between the low users and ambulatory-centric users groups. These patients may be benefitting from closer follow-up to coordinate adequate care in the community (124,125).

High Acute Hospital Users

The high acute hospital users had the highest prevalence of most comorbidities, highest polypharmacy and highest mortality compared with the other 3 healthcare utilization groups. These comorbid conditions may explain why they are higher users, particularly of hospital services.

The High-Acute Hospital Users were most identified for the cohort with the hospitalization inclusion criterion of the groups. This contrasted with the ambulatory-centric users' least prevalent inclusion criterion being hospitalization codes is consistent with the possibilities of common and severe exacerbations versus adequate follow-up in community. Dementia independently increases healthcare use and risk of mortality (13). The cumulative burden of dementia and comorbidities make this group perhaps the most medically vulnerable of the 4 identified in this study as their needs are considerable but available resources may not promote adequate follow-up and coordination of care (126,127). As such, they are likely to benefit from interventions targeted to their complex health needs.

Long-Term Care Destined

The long-term care destined group were the smallest of the healthcare utilization groups found in this latent class analysis. Age is a predictor of long-term care admission, which is consistent with this group being the eldest of the latent classes (median age: 85) (128). It is possible that this group's diagnosis as dementia patients was delayed and thus that they were more advanced in their illness. They were the highest antipsychotic users prior to admission, which a recent study in Ontario which found that many antipsychotic prescriptions of long-term care residents with dementia were initiated prior to admission (129).

Strengths:

This study has strengths that make it a valuable addition to literature on differential healthcare use by persons with dementia, highlighting the heterogeneity of use and needs in this group. Latent class analysis in the context of healthcare use by older adults is an innovative method that is focused on emphasizing the differential needs of individuals within a heterogenous cohort (130,131).

This is the first time to our knowledge that healthcare utilization patterns were grouped using administrative data that identified a near-exhaustive cohort of persons with incident dementia and comprehensive measures of healthcare use. This gave way to a comprehensive analysis looking at several dimensions of ambulatory and hospital-based healthcare, which illustrates a larger picture of the patterns of use by the different groups. More generally, this study adds to a growing body of research on heterogeneous and equitable healthcare delivery for people with dementia.

Limitations:

This study likewise has limitations; as in any administrative database analysis, persons who were misdiagnosed, undiagnosed and not known to the healthcare system for dementia were not included in the cohort. Indeed, 20.5% of the cohort were identified by the algorithm with a hospitalization dementia code, though hospitalizations for dementia are improbable at onset.

The data analyzed in this study was likewise cross-sectional, which limits the possibility of inferring causality between measured parameters in the study. Medication use was additionally based on dispensing and not on compliance, nor whether the prescriptions were for medications to be taken on as-needed bases.

Healthcare use in salaried environments was not measured, which includes memory clinics, home care, nurses, social workers, non-pharmacological treatments such as music therapy, as well as informal caregiving. While one of the inherent assumptions of latent class analysis is that the observed or manifest variables are not inter-related, use of different facets of healthcare use in the present study were indeed related. For example, persons who were hospitalized in the year emergency department following index date of diagnosis must have visited the emergency as well, meaning that the emergency and days in hospital had inter-relation. This violation of an assumption of Latent Class Analysis is common in recent related literature, implying that the trade-off of violation of this assumption is acceptable given the benefits of looking at subgroups of varied cohorts. Finally, due to the ongoing pandemic limiting access to the INSPQ data, intended statistical analysis outputs on robustness of the latent class model were not possible and descriptive analysis stopped short of including the Material Deprivation of the identified healthcare utilization groups.

Implications and Recommendations

This study contributes to an improved understanding of the healthcare use patterns of patients with dementia in the year following diagnosis and the factors that underlie these patterns. Latent-class analysis provides context for subgroups considered in the context of larger, heterogeneous cohorts of persons (131). Thus, rather than looking at a heterogeneous cohort with one-size-fits-all solutions, latent class analysis studies account for similarities and differences between subgroups and their associated care use, which might reflect their differential care needs. While the healthcare needs of people with dementia are heterogeneous, healthcare policy, programs and interventions can err towards "one-size-fits-all" solutions; this study provides context for necessary adaptations to policy, programs and interventions to address differing health and social needs within the dementia population.

Further research looking at subgroups of persons with dementia and their specific or contrasting needs, in turn will enable better care planning to minimize potentially preventable healthcare utilization and optimize more favourable factors that underlie healthcare utilization.

Interventions

This study highlights the heterogeneous use of health services by people with dementia, which moreover, likely highlights a heterogeneity of needs in the year following diagnosis. Health and social care professionals must be open and adaptable to the heterogeneous needs of their patients to best support their care (123,132). Ambulatory care, hospital-based care, long-term care and medications were interventions for dementia measured in the present study, however, preventative approaches might be better suited to minimize unnecessary or preventable healthcare use through course of illness.

Firstly, screening and diagnostic tools for timely diagnosis of dementia are paramount to coordination and planning of care (133,134) Secondly, persons with dementia prefer to stay home rather than be institutionalized (e.g.: long-term care) , which can be better facilitated with comprehensive home care services and caregiver supports that can prevent increased healthcare use (77,135). Thirdly, persons who might particularly benefit from further intervention to prevent unnecessary use of healthcare are those with complex needs; such interventions include case management, advanced care planning (should they be hospitalized or need an increased level of care such as nursing home or long-term care) and community-based supports including as home care and art therapy(132,136–139),

While the interventions above have potential to mitigate burden of dementia on affected individuals, their caregivers and the healthcare system alike, the context of differential healthcare use in the present study highlights the importance of tailored interventions and care planning for heterogeneous needs. In latent class analysis healthcare studies, patients are each classified into only one group; in reality, patients may move between groups over time. The present study highlights the heterogeneity of use within a cohort of persons with dementia, but it is likewise essential for care providers to be mindful that diverse needs must be accommodated on individual bases as well.

Future Research

Future studies must be done to confirm the findings and further describe distinct healthcare utilization groups and understand the factors associated with group membership. Clinical data to understand social and medical needs of persons with dementia such as their living situation, use of home care and comorbidity burden would better identify unmet needs and targeted, holistic interventions. Moreover, longitudinal studies that look not only at care patterns but care trajectories to understand how patients' needs evolve would enable development of targeted interventions for persons' needs through the course of their illness and not simply at one time.

While this study provides rich preliminary information on healthcare utilization groups and their differential use of services, qualitative studies that give voice to patients with dementia and their caregivers' experiences such as decisions to seek healthcare, the barriers they encounter and experiences when seeking care would give a better-rounded view of healthcare utilization by people with dementia. Lastly, gender disparities in dementia care are an emerging topic; sex- and gender-based analyses of healthcare utilization can further help confront inequities by providing further insights into the differential needs of men and women with dementia.

Conclusion

This study provides important context on the heterogeneous healthcare use of people with dementia following diagnosis. The latent class analysis identified four groups of healthcare users: Low, Ambulatory-Centric, High Acute Hospital and Long-Term Care-Destined Users. The descriptive analysis moreover gave context to the sociodemographic, medication and comorbidity burdens that further defined characteristics of group membership. The identification of subgroups with defined characteristics in a heterogeneous cohort of persons with dementia sets a precedent for interventions targeted to the distinct needs of individuals rather than "one-size-fits-all" solutions.

References

1. Statistics Canada. Population Projections for Canada (2018 to 2068), Provinces and Territories (2018 to 2043), Section 2 – Results at the Canada level, 2018 to 2068 [Internet]. 2019. Report No.: 2019001. Available from: https://www150.statcan.gc.ca/n1/pub/91-520-x/2019001/sect02-eng.htm

2. World Health Organization. Dementia: a public health priority. United Kingdom; 2012.

3. Alzheimer Society of Canada. Prevalence and Monetary Costs of Dementia in Canada. Toronto; 2016 p. 70.

4. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. 2013.

5. Gitlin LN, Bruneau M. Supporting everyday functioning of people living with dementia: The role of care partners. In: Dementia Rehabilitation [Internet]. Elsevier; 2021 [cited 2021 Aug 14]. p. 189–211. Available from: https://linkinghub.elsevier.com/retrieve/pii/B9780128186855000118

6. Nielsen KD, Boenink M. Ambivalent anticipation: How people with Alzheimer's disease value diagnosis in current and envisioned future practices. Sociol Health Illn. 2021 Feb;43(2):510–27.

7. Moon F, Kissane DW, McDermott F. Discordance between the perceptions of clinicians and families about end-of-life trajectories in hospitalized dementia patients. Palliat Support Care. 2021 Jun;19(3):304–11.

8. Canadian Academy of Health Sciences. Improving the quality of life and care of persons living with dementia and their caregivers. Ottawa (ON): The Expert Panel on Dementia Care in Canada, CAHS; 2019.

9. Cloak N, Al Khalili Y. Behavioral And Psychological Symptoms In Dementia [Internet]. 2020. Available from: https://www.statpearls.com/articlelibrary/viewarticle/81923/?utm_source=pubmed&utm_campaign=CME&utm_content=81923

10. Maust DT, Kales HC, McCammon RJ, Blow FC, Leggett A, Langa KM. Distress Associated with Dementia-Related Psychosis and Agitation in Relation to Healthcare Utilization and Costs. Am J Geriatr Psychiatry. 2017 Oct;25(10):1074–82.

11. Nelis SM, Wu Y-T, Matthews FE, Martyr A, Quinn C, Rippon I, et al. The impact of co-morbidity on the quality of life of people with dementia: findings from the IDEAL study. Age Ageing. 2019 May 1;48(3):361–7.

12. Rajamaki B, Hartikainen S, Tolppanen A-M. The effect of comorbidities on survival in persons with Alzheimer's disease: a matched cohort study. BMC Geriatr. 2021 Dec;21(1):173.

13. Taudorf L, Nørgaard A, Brodaty H, Laursen TM, Waldemar G. Dementia increases mortality beyond effects of comorbid conditions: A national registry-based cohort study. Eur J Neurol. 2021 Jul;28(7):2174–84.

14. Lam HL, Li WTV, Laher I, Wong RY. Effects of Music Therapy on Patients with Dementia—A Systematic Review. Geriatrics. 2020 Sep 25;5(4):62.

15. Reel CD, Allen RS, Lanai B, Yuk MC, Potts DC. Bringing Art to Life: Social and Activity Engagement through Art in Persons Living with Dementia. Clin Gerontol. 2021 Jun 8;1–11.

16. Parajuli DR, Kuot A, Hamiduzzaman M, Gladman J, Isaac V. Person-centered, non-pharmacological intervention in reducing psychotropic medications use among residents with dementia in Australian rural aged care homes. BMC Psychiatry. 2021 Dec;21(1):36.

17. Eshetie TC, Nguyen TA, Gillam MH, Kalisch Ellett LM. Medication Use for Comorbidities in People with Alzheimer's Disease: An Australian Population-Based Study. Pharmacother J Hum Pharmacol Drug Ther. 2019 Dec;39(12):1146–56.

18. Mueller C, Molokhia M, Perera G, Veronese N, Stubbs B, Shetty H, et al. Polypharmacy in people with dementia: Associations with adverse health outcomes. Exp Gerontol. 2018 Jun;106:240–5.

19. Fink HA, Jutkowitz E, McCarten JR, Hemmy LS, Butler M, Davila H, et al. Pharmacologic Interventions to Prevent Cognitive Decline, Mild Cognitive Impairment, and Clinical Alzheimer-Type Dementia: A Systematic Review. Ann Intern Med. 2018 Jan 2;168(1):39.

20. Knight R, Khondoker M, Magill N, Stewart R, Landau S. A Systematic Review and Meta-Analysis of the Effectiveness of Acetylcholinesterase Inhibitors and Memantine in Treating the Cognitive Symptoms of Dementia. Dement Geriatr Cogn Disord. 2018;45(3–4):131–51.

21. Tan ECK, Johnell K, Bell JS, Garcia-Ptacek S, Fastbom J, Nordström P, et al. Do Acetylcholinesterase Inhibitors Prevent or Delay Psychotropic Prescribing in People With Dementia? Analyses of the Swedish Dementia Registry. Am J Geriatr Psychiatry. 2020 Jan;28(1):108–17.

22. Green AR, Segal J, Boyd CM, Huang J, Roth DL. Patterns of Potentially Inappropriate Bladder Antimuscarinic Use in People with Dementia: A Retrospective Cohort Study. Drugs - Real World Outcomes. 2020 Jun;7(2):151–9.

23. Carnahan RM, Lund BC, Perry PJ, Chrischilles EA. The Concurrent Use of Anticholinergics and Cholinesterase Inhibitors: Rare Event or Common Practice?: ANTICHOLINERGICS AND CHOLINESTERASE INHIBITORS. J Am Geriatr Soc. 2004 Dec;52(12):2082–7.

24. Ah Y, Suh Y, Jun K, Hwang S, Lee J. Effect of anticholinergic burden on treatment modification, delirium and mortality in newly diagnosed dementia patients starting a cholinesterase inhibitor: A population-based study. Basic Clin Pharmacol Toxicol. 2019 Jun;124(6):741–8.

25. Campbell NL, Perkins AJ, Gao S, Skaar TC, Li L, Hendrie HC, et al. Adherence and Tolerability of Alzheimer′s Disease Medications: A Pragmatic Randomized Trial. J Am Geriatr Soc. 2017 Jul;65(7):1497–504.

26. Ohno Y, Kunisawa N, Shimizu S. Antipsychotic Treatment of Behavioral and Psychological Symptoms of Dementia (BPSD): Management of Extrapyramidal Side Effects. Front Pharmacol. 2019 Sep 17;10:1045.

27. Canadian Institute for Health Information. Dementia in long-term care: Policy changes and educational supports help spur a decrease in inappropriate use of antipsychotics and restraints. [Internet]. 2018. Available from: https://www.cihi.ca/en/dementia-in-canada/dementia-across-the-health-system/dementia-in-long-term-care#admission

28. Bjerre LMB, Lemay GL, McCarthy L, Raman-Wilms L, Rojas-Fernandez C. Deprescribing antipsychotics for behavioural and psychological symptoms of dementia and insomnia. Can Fam Physician. 2018;64:11.

29. Ralph SJ, Espinet AJ. Use of antipsychotics and benzodiazepines for dementia: Time for action? What will be required before global de-prescribing? Dementia. 2019;18(6):2322–39.

30. Mudge AM, O′Rourke P, Denaro CP. Timing and Risk Factors for Functional Changes Associated With Medical Hospitalization in Older Patients. J Gerontol A Biol Sci Med Sci. 2010 Aug 1;65A(8):866–72.

31. Bronskill SE, Campitelli MA, Iaboni A, Herrmann N, Guan J, Maclagan LC, et al. Low-Dose Trazodone, Benzodiazepines, and Fall-Related Injuries in Nursing Homes: A Matched-Cohort Study. J Am Geriatr Soc. 2018;66(10):1963–71.

32. Iaboni A, Seitz DP, Fischer HD, Diong CC, Rochon PA, Flint AJ. Initiation of antidepressant medication after hip fracture in community-dwelling older adults. Am J Geriatr Psychiatry. 2015;23(10):1007–15.

33. Tampi RR, Tampi DJ. Efficacy and Tolerability of Benzodiazepines for the Treatment of Behavioral and Psychological Symptoms of Dementia: A Systematic Review of Randomized Controlled Trials. Am J Alzheimers Dis Dementiasr. 2014 Nov;29(7):565–74.

34. Wucherer D, Eichler T, Hertel J, Kilimann I, Richter S, Michalowsky B, et al. Potentially Inappropriate Medication in Community-Dwelling Primary Care Patients who were Screened Positive for Dementia. J Alzheimers Dis. 2016 Nov 19;55(2):691–701.

35. Brandt J, Leong C. Benzodiazepines and Z-Drugs: An Updated Review of Major Adverse Outcomes Reported on in Epidemiologic Research. Drugs RD. 2017 Dec;17(4):493–507.

36. Borda MG, Jaramillo-Jimenez A, Oesterhus R, Santacruz JM, Tovar-Rios DA, Soennesyn H, et al. Benzodiazepines and antidepressants: Effects on cognitive and functional decline in Alzheimer's disease and Lewy body dementia. Int J Geriatr Psychiatry. 2021 Jun;36(6):917–25.

37. Taipale H, Tolppanen A-M, Koponen M, Tanskanen A, Lavikainen P, Sund R, et al. Risk of pneumonia associated with incident benzodiazepine use among community-dwelling adults with Alzheimer disease. Can Med Assoc J. 2017 Apr 10;189(14):E519–29.

38. Fogg C, Griffiths P, Meredith P, Bridges J. Hospital outcomes of older people with cognitive impairment: An integrative review. Int J Geriatr Psychiatry. 2018 Sep;33(9):1177–97.

39. Kettunen R, Taipale H, Tolppanen A-M, Tanskanen A, Tiihonen J, Hartikainen S, et al. Duration of new antidepressant use and factors associated with discontinuation among community-dwelling persons with Alzheimer's disease. Eur J Clin Pharmacol. 2019 Mar;75(3):417–25.

40. Burke AD, Goldfarb D, Bollam P, Khokher S. Diagnosing and Treating Depression in Patients with Alzheimer's Disease. Neurol Ther. 2019 Dec;8(2):325–50.

41. Nørgaard A, Jensen-Dahm C, Gasse C, Hansen ES, Waldemar G. Psychotropic Polypharmacy in Patients with Dementia: Prevalence and Predictors. J Alzheimers Dis. 2017;56(2):707–16.

42. Oh E. Depression in Patient with Dementia [Internet]. Johns Hopkins Medicine: Geriatric Workforce Enhancement Program. 2015. Available from: https://www.hopkinsmedicine.org/gec/studies/depression_dementia.html

43. Schwasinger-Schmidt TE, Macaluso M. Other Antidepressants. In: Macaluso M, Preskorn SH, editors. Antidepressants: From Biogenic Amines to New Mechanisms of Action [Internet]. Cham: Springer International Publishing; 2019. p. 325–55. Available from: https://doi.org/10.1007/164_2018_167

44. Abi-Jaoude E, Stall NM, Rochon PA. Psychotropic drugs for the behavioural and psychological symptoms of dementia: no free ride. Can Med Assoc J. 2018 Nov 26;190(47):E1374–5.

45. Lee EA, Brettler JW, Kanter MH, ..., Gibbs NE. Refining the Definition of Polypharmacy and Its Link to Disability in Older Adults: Conceptualizing Necessary Polypharmacy,

Unnecessary Polypharmacy, and Polypharmacy of Unclear Benefit. Perm J [Internet]. 2020 [cited 2021 Aug 15]; Available from: https://www.thepermanentejournal.org/issues/2020/winter/7325.html

46. Ruangritchankul S, Peel NM, Hanjani LS, Gray LC. Drug related problems in older adults living with dementia. Vaismoradi M, editor. PLOS ONE. 2020 Jul 31;15(7):e0236830.

47. Canadian Institute for Health Information. How Canada Compares: Results From The Commonwealth Fund's 2017 International Health Policy Survey of Seniors - Accessible Report. Ottawa (ON): CIHI; 2018.

48. Gillespie SM, Wasserman EB, Wood NE, Wang H, Dozier A, Nelson D, et al. High-Intensity Telemedicine Reduces Emergency Department Use by Older Adults With Dementia in Senior Living Communities. J Am Med Dir Assoc. 2019 Aug;20(8):942–6.

49. LaMantia MA, Stump TE, Messina FC, Miller DK, Callahan CM. Emergency department use among older adults with dementia. Alzheimer Dis Assoc Disord. 2016;30(1):35.

50. Shepherd H, Livingston G, Chan J, Sommerlad A. Hospitalisation rates and predictors in people with dementia: a systematic review and meta-analysis. BMC Med. 2019 Dec;17(1):130.

51. Sivananthan S, Lavergne M, McGrail K. Caring for dementia: A population-based study examining variations in guideline-consistent medical care. Alzheimers Dement. 2015;11(8):906–16.

52. Pham ANQ, Voaklander D, Wagg A, Drummond N. Epidemiology of dementia onset captured in Canadian primary care electronic medical records. Fam Pract. 2021 Jun 28;cmab056.

53. Warrick N, Prorok JC, Seitz D. Care of community-dwelling older adults with dementia and their caregivers. Can Med Assoc J. 2018 Jul 3;190(26):E794–9.

54. Haggerty JL. Continuity of care: a multidisciplinary review. BMJ. 2003 Nov 22;327(7425):1219–21.

55. Moore A, Frank C, Chambers LW. Role of the family physician in dementia care. Can Fam Physician. 2018;64.

56. Miller LM, Whitlatch CJ, Lyons KS. Shared decision-making in dementia: A review of patient and family carer involvement. Dementia. 2016 Sep;15(5):1141–57.

57. Godard-Sebillotte C, Strumpf E, Sourial N, Rochette L, Pelletier E, Vedel I. Primary care continuity and potentially avoidable hospitalization in persons with dementia. J Am Geriatr Soc. 2021;69(5):1208–20.

58. Bronskill SE, Maclagan LC, Walker JD, Guan J, Wang X, Ng R, et al. Trajectories of health system use and survival for community-dwelling persons with dementia: a cohort study. BMJ Open. 2020 Jul;10(7):e037485.

59. Smith R, Martin A, Wright T, Hulbert S, Hatzidimitriadou E. Integrated dementia care: A qualitative evidence synthesis of the experiences of people living with dementia, informal carers and healthcare professionals. Arch Gerontol Geriatr. 2021 Nov;97:104471.

60. Kar N. Lack of community care facilities for older people and increased rate of admission and length of stay in hospitals. J Geriatr Care Res. 2015;2(2):4.

61. Feng Z, Coots LA, Kaganova Y, Wiener JM. Hospital And ED Use Among Medicare Beneficiaries With Dementia Varies By Setting And Proximity To Death. Health Aff (Millwood). 2014 Apr;33(4):683–90.

62. Boustani M, Unützer J, Leykum LK. Design, implement, and diffuse scalable and sustainable solutions for dementia care. J Am Geriatr Soc. 2021 Jul;69(7):1755–62.

63. Watkins S, Murphy F, Kennedy C, Dewar B, Graham M. Caring for an older person with dementia in the Emergency Department (ED): An Appreciative Inquiry exploring family member and ED nurse experiences. J Clin Nurs. 2019 Aug;28(15–16):2801–12.

64. Godard-Sebillotte C, Le Berre M, Schuster T, Trottier M, Vedel I. Impact of health service interventions on acute hospital use in community-dwelling persons with dementia: A systematic literature review and meta-analysis. MacLure K, editor. PLOS ONE. 2019 Jun 21;14(6):e0218426.

65. Israni J, Lesser A, Kent T, Ko K. Delirium as a predictor of mortality in US Medicare beneficiaries discharged from the emergency department: a national claims-level analysis up to 12 months. BMJ Open. 2018 May;8(5):e021258.

66. Legramante JM, Morciano L, Lucaroni F, Gilardi F, Caredda E, Pesaresi A, et al. Frequent Use of Emergency Departments by the Elderly Population When Continuing Care Is Not Well Established. Bugiardini R, editor. PLOS ONE. 2016 Dec 14;11(12):e0165939.

67. Afonso-Argilés FJ, Meyer G, Stephan A, Comas M, Wübker A, Leino-Kilpi H, et al. Emergency department and hospital admissions among people with dementia living at home or in nursing homes: results of the European RightTimePlaceCare project on their frequency, associated factors and costs. BMC Geriatr. 2020 Dec;20(1):453.

68. Anderson TS, Marcantonio ER, McCarthy EP, Herzig SJ. National Trends in Potentially Preventable Hospitalizations of Older Adults with Dementia. J Am Geriatr Soc. 2020 Oct;68(10):2240–8.

69. Miller J, Campbell J, Moore K, Schofield A. Elder care supportive interventions protocol: reducing discomfort in confused, hospitalized older adults. J Gerontol Nurs. 2004;30(8):10–8.

70. Wolf D, Rhein C, Geschke K, Fellgiebel A. Preventable hospitalizations among older patients with cognitive impairments and dementia. Int Psychogeriatr. 2019 Mar;31(3):383–91.

71. Fick DM, Steis MR, Waller JL, Inouye SK. Delirium superimposed on dementia is associated with prolonged length of stay and poor outcomes in hospitalized older adults: Delirium Superimposed on Dementia. J Hosp Med. 2013 Sep;8(9):500–5.

72. Kuluski K, Im J, McGeown M. "It's a waiting game" a qualitative study of the experience of carers of patients who require an alternate level of care. BMC Health Serv Res. 2017 Dec;17(1):318.

73. Costa A, Hirdes J. Clinical Characteristics and Service Needs of Alternate-Level-of-Care Patients Waiting for Long-Term Care in Ontario Hospitals. Healthc Policy Polit Santé. 2010 Aug 16;6(1):32–46.

74. Sutherland J, Crump R. Alternative Level of Care: Canada's Hospital Beds, the Evidence and Options. Healthc Policy Polit Santé. 2013 Aug 19;9(1):26–34.

75. Mahsr EB, Cook S, Crowe L, Drimer N, Ireland L, Ccfp DM, et al. How long are Canadians waiting to access specialty care? Can Fam Physician. 2020;66:11.

76. Health Canada. Long-term facilities-based care [Internet]. 2004. Available from: https://www.canada.ca/en/health-canada/services/home-continuing-care/long-term-facilities-based-care.html

77. Karlsen C, Ludvigsen MS, Moe CE, Haraldstad K, Thygesen E. Experiences of community-dwelling older adults with the use of telecare in home care services: a qualitative systematic review. JBI Database Syst Rev Implement Rep. 2017 Dec;15(12):2913–80.

78. Narushima M, Kawabata M. "Fiercely independent": Experiences of aging in the right place of older women living alone with physical limitations. J Aging Stud. 2020 Sep;54:100875.

79. Canadian Health Coalition. Seniors' Care [Internet]. 2021. Available from: https://www.healthcoalition.ca/project/seniors-care/

80. Abbasi J. "Abandoned" Nursing Homes Continue to Face Critical Supply and Staff Shortages as COVID-19 Toll Has Mounted. JAMA. 2020 Jul 14;324(2):123.

81. Cadieux M-A, Garcia LJ, Patrick J. Needs of People With Dementia in Long-Term Care: A Systematic Review. Am J Alzheimers Dis Dementiasr. 2013 Dec;28(8):723–33.

82. Public Health Agency of Canada. Dementia in Canada, including Alzheimer's disease: Highlights from the Canadian Chronic Disease Surveillance System [Internet]. 2017.

Available from: https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-highlights-canadian-chronic-disease-surveillance.html

83. Cations M, Radisic G, Crotty M, Laver KE. What does the general public understand about prevention and treatment of dementia? A systematic review of population-based surveys. Werner P, editor. PLOS ONE. 2018 Apr 19;13(4):e0196085.

84. Mondor L, Maxwell CJ, Hogan DB, Bronskill SE, Gruneir A, Lane NE, et al. Multimorbidity and healthcare utilization among home care clients with dementia in Ontario, Canada: A retrospective analysis of a population-based cohort. Brayne C, editor. PLOS Med. 2017 Mar 7;14(3):e1002249.

85. Petersen JD, Wehberg S, Packness A, Svensson NH, Hyldig N, Raunsgaard S, et al. Association of Socioeconomic Status With Dementia Diagnosis Among Older Adults in Denmark. JAMA Netw Open. 2021 May 18;4(5):e2110432.

86. van der Flier WM. Epidemiology and risk factors of dementia. J Neurol Neurosurg Psychiatry. 2005 Dec 1;76(suppl_5):v2–7.

87. Helvik A-S, Engedal K, Šaltytė Benth J, Selbæk G. Time from Symptom Debut to Dementia Assessment by the Specialist Healthcare Service in Norway. Dement Geriatr Cogn Disord Extra. 2018 Mar 27;8(1):117–27.

88. Thyrian JR, Hertel J, Wucherer D, Eichler T, Michalowsky B, Dreier-Wolfgramm A, et al. Effectiveness and Safety of Dementia Care Management in Primary Care: A Randomized Clinical Trial. JAMA Psychiatry. 2017 Oct 1;74(10):996.

89. Mielke MM, Ferretti MT, Iulita MF, Hayden K, Khachaturian AS. Sex and gender in Alzheimer׳s disease - Does it matter? Alzheimers Dement. 2018 Sep;14(9):1101–3.

90. Nebel RA, Aggarwal NT, Barnes LL, Gallagher A, Goldstein JM, Kantarci K, et al. Understanding the impact of sex and gender in Alzheimer׳s disease: a call to action. Alzheimers Dement. 2018;14(9):1171–83.

91. Bieber A, Nguyen N, Meyer G, Stephan A. Influences on the access to and use of formal community care by people with dementia and their informal caregivers: a scoping review. BMC Health Serv Res. 2019 Dec;19(1):88.

92. Eichler T, Hoffmann W, Hertel J, Richter S, Wucherer D, Michalowsky B, et al. Living Alone with Dementia: Prevalence, Correlates and the Utilization of Health and Nursing Care Services. Monastero R, editor. J Alzheimers Dis. 2016 May 10;52(2):619–29.

93. Ydstebø AE, Benth JŠ, Bergh S, Selbæk G, Vossius C. Informal and formal care among persons with dementia immediately before nursing home admission. BMC Geriatr. 2020 Dec;20(1):296.

94. Sourial N, Arsenault-Lapierre G, Margo-Dermer E, Henein M, Vedel I. Sex differences in the management of persons with dementia following a subnational primary care policy intervention. Int J Equity Health. 2020 Dec;19(1):175.

95. Griffith LE, Gruneir A, Fisher K, Panjwani D, Gandhi S, Sheng L, et al. Patterns of health service use in community living older adults with dementia and comorbid conditions: a population-based retrospective cohort study in Ontario, Canada. BMC Geriatr. 2016;16(1):177.

96. Snowden MB, Steinman LE, Bryant LL, Cherrier MM, Greenlund KJ, Leith KH, et al. Dementia and co-occurring chronic conditions: a systematic literature review to identify what is known and where are the gaps in the evidence?: What is known about dementia and chronic conditions? Int J Geriatr Psychiatry. 2017 Apr;32(4):357–71.

97. Browne J, Edwards DA, Rhodes KM, Brimicombe DJ, Payne RA. Association of comorbidity and health service usage among patients with dementia in the UK: a population-based study. BMJ Open. 2017 Mar;7(3):e012546.

98. Bunn F, Burn A-M, Goodman C, Robinson L, Rait G, Norton S, et al. Comorbidity and dementia: a mixed-method study on improving health care for people with dementia (CoDem). Health Serv Deliv Res. 2016 Feb;4(8):1–156.

99. Kupeli N, Leavey G, Harrington J, Lord K, King M, Nazareth I, et al. What are the barriers to care integration for those at the advanced stages of dementia living in care homes in the UK? Health care professional perspective. Dementia. 2018 Feb;17(2):164–79.

100. Santiago JA, Potashkin JA. The Impact of Disease Comorbidities in Alzheimer's Disease. Front Aging Neurosci. 2021 Feb 12;13:631770.

101. Morgan DG, Crossley M, Kirk A, D'Arcy C, Stewart N, Biem J, et al. Improving access to dementia care: Development and evaluation of a rural and remote memory clinic. Aging Ment Health. 2009 Jan 1;13(1):17–30.

102. Dal Bello-Haas V, Cammer A, Morgan D, Stewart N, Kosteniuk J. Rural and remote dementia care challenges and needs: perspectives of formal and informal care providers residing in Saskatchewan, Canada. Rural Remote Health [Internet]. 2014 Aug 1 [cited 2021 Aug 16]; Available from: https://www.rrh.org.au/journal/article/2747

103. Ye L, Luo J, Shia B-C, Fang Y. Multidimensional Health Groups and Healthcare Utilization Among Elderly Chinese: Based on the 2014 CLHLS Dataset. Int J Environ Res Public Health. 2019 Oct 14;16(20):3884.

104. Janssen N, Handels RLH, Koehler S, Ramakers IHGB, Hamel REG, Olde Rikkert MGM, et al. Combinations of Service Use Types of People With Early Cognitive Disorders. J Am Med Dir Assoc. 2016 Jul;17(7):620–5.

105. Janssen N, Handels RL, Köhler S, Gonçalves-Pereira M, Marques MJ, Irving K, et al. Profiles of Met and Unmet Needs in People with Dementia According to Caregivers′ Perspective: Results from a European Multicenter Study. J Am Med Dir Assoc. 2020 Nov;21(11):1609-1616.e1.

106. Hastings SN, Whitson HE, Sloane R, Landerman LR, Horney C, Johnson KS. Using the Past to Predict the Future: Latent Class Analysis of Patterns of Health Service Use of Older Adults in the Emergency Department. J Am Geriatr Soc. 2014 Apr;62(4):711–5.

107. UCLA: Statistical Consulting Group. Latent Class Analysis in Mplus [Internet]. Statistical Computing Seminars 2016; 2016. Available from: http://www.ats.ucla.edu/stat/mplus/seminars/lca/

108. Blais C, Jean S, Sirois C, Rochette L, Plante C, Larocque I, et al. Quebec integrated chronic disease surveillance system (QICDSS), an innovative approach. Chronic Dis Inj Can. 2014;34(4).

109. Jaakkimainen R, Bronskill S, Tierney M. Identification of physician-diagnosed Alzheimer′s disease and related dementias in population-based administrative data: a validation study using family physicians′ electronic medical records. J Alzheimers Dis. 2016;(54):337–49.

110. Godard-Sebillotte C, Sourial N, Hardouin M, Rochette L, Pelletier E, Gamache P, et al. Development of two hierarchical algorithms identifying the 65+ community-dwelling population in the provincial administrative database in Quebec. Canadian Association for Health Services and Policy Research Annual conference; 2019; Halifax, NS.

111. Simard M, Sirois C, Candas B. Validation of the Combined Comorbidity Index of Charlson and Elixhauser to Predict 30-Day Mortality Across ICD-9 and ICD-10. Med Care. 2018;56(5):441–7.

112. Linzer DA, Lewis JB. poLCA: An R package for polytomous variable latent class analysis. J Stat Softw. 2011;42(10):1–29.

113. Flaherty B, Kiff C. Latent class and latent profile models. In: Handbook of Research Methods in Psychology: Vol 3. American Psychological Association; 2012. p. 391–404.

114. Hadzi-Pavlovic D. Finding patterns and groupings: II. Introduction to latent profile analysis and finite mixture models. Acta Neuropsychiatr. 2010;22(1):40–2.

115. Martin KG. Latent Class Analysis. Data Analysis Brown Bag Series; 2015.

116. Hardigan PC. An application of latent class analysis in the measurement of falling among a community elderly population. Open Geriatr Med J. 2009;2(1):12.

117. Sourial N, Vedel I, Godard-Sebillotte C, Etches J, Arsenault-Lapierre G, Bronskill SE. Sex Differences in Dementia Primary Care Performance and Health Service Use: A Population-Based Study. J Am Geriatr Soc. 2020 May;68(5):1056–63.

118. Whitson HE, Johnson KS, Sloane R, Cigolle CT, Pieper CF, Landerman L, et al. Identifying Patterns of Multimorbidity in Older Americans: Application of Latent Class Analysis. J Am Geriatr Soc. 2016 Aug;64(8):1668–73.

119. Mazurek J, Szcześniak D, Urbańska K, Dröes R-M, Rymaszewska J. Met and unmet care needs of older people with dementia living at home: Personal and informal carers′ perspectives. Dementia. 2019 Aug;18(6):1963–75.

120. Morrisby C, Joosten A, Ciccarelli M. Do services meet the needs of people with dementia and carers living in the community? A scoping review of the international literature. Int Psychogeriatr. 2018 Jan;30(1):5–14.

121. Parsons C, Lim WY, Loy C, McGuinness B, Passmore P, Ward SA, et al. Withdrawal or continuation of cholinesterase inhibitors or memantine or both, in people with dementia. Cochrane Dementia and Cognitive Improvement Group, editor. Cochrane Database Syst Rev [Internet]. 2021 Feb 3 [cited 2021 Aug 15];2021(2). Available from: http://doi.wiley.com/10.1002/14651858.CD009081.pub2

122. Lee SM, Edmonston B. Living Alone Among Older Adults in Canada and the U.S. Healthcare. 2019 May 7;7(2):68.

123. Kenning C, Daker-White G, Blakemore A, Panagioti M, Waheed W. Barriers and facilitators in accessing dementia care by ethnic minority groups: a meta-synthesis of qualitative studies. BMC Psychiatry. 2017 Dec;17(1):316.

124. Lai SH, Tsoi T, Tang CT, Hui RJY, Tan KK, Yeo YWS, et al. An integrated, collaborative healthcare model for the early diagnosis and management of dementia: Preliminary audit results from the first transdisciplinary service integrating family medicine and geriatric psychiatry services to the heart of patients′ homes. BMC Psychiatry. 2019 Dec;19(1):61.

125. Morton T, Wong G, Atkinson T, Brooker D. Sustaining community-based interventions for people affected by dementia long term: the SCI-Dem realist review. BMJ Open. 2021 Jul;11(7):e047789.

126. Ha NHL, Yap Lin Kiat P, Nicholas SO, Chan I, Wee SL. Evaluating the Outcomes of a Hospital-to-Community Model of Integrated Care for Dementia. Dement Geriatr Cogn Disord. 2020;49(6):598–603.

127. Røsvik J, Rokstad AMM. What are the needs of people with dementia in acute hospital settings, and what interventions are made to meet these needs? A systematic integrative review of the literature. BMC Health Serv Res. 2020 Dec;20(1):723.

128. Harrison JK, Walesby KE, Hamilton L, Armstrong C, Starr JM, Reynish EL, et al. Predicting discharge to institutional long-term care following acute hospitalisation: a systematic review and meta-analysis. Age Ageing. 2017 Jul 1;46(4):547–58.

129. Bronskill SE. Improving medication and outcomes for older frail residents of long-term care facilities. 2017.

130. Dufour I, Dubuc N, Chouinard M, Chiu Y, Courteau J, Hudon C. Profiles of Frequent Geriatric Users of Emergency Departments: A Latent Class Analysis. J Am Geriatr Soc. 2021 Mar;69(3):753–61.

131. Wiegelmann H, Wolf-Ostermann K, Brannath W, Arzideh F, Dreyer J, Thyrian R, et al. Sociodemographic aspects and health care-related outcomes: a latent class analysis of informal dementia care dyads. BMC Health Serv Res. 2021 Dec;21(1):727.

132. Polacsek M, Goh A, Malta S, Hallam B, Gahan L, Cooper C, et al. ′I know they are not trained in dementia′: Addressing the need for specialist dementia training for home care workers. Health Soc Care Community. 2020 Mar;28(2):475–84.

133. The Alzheimer′s Association. 2020 Alzheimer′s disease facts and figures. Alzheimers Dement. 2020 Mar;16(3):391–460.

134. National Academies of Sciences, Engineering, and Medicine. Future Directions for the Demography of Aging: Proceedings of a Workshop. 2018

135. Lau JH, Abdin E, Jeyagurunathan A, Seow E, Ng LL, Vaingankar JA, et al. The association between caregiver burden, distress, psychiatric morbidity and healthcare utilization among persons with dementia in Singapore. BMC Geriatr. 2021 Dec;21(1):67.

136. Jethwa KD, Onalaja O. Advance care planning and palliative medicine in advanced dementia: a literature review. BJPsych Bull. 2015 Apr;39(2):74–8.

137. Khanassov V, Pluye P, Vedel I. Case management for dementia in primary health care: a systematic mixed studies review based on the diffusion of innovation model. Clin Interv Aging. 2014 Jun;915.

138. Popa L-C, Manea MC, Velcea D, Şalapa I, Manea M, Ciobanu AM. Impact of Alzheimer′s Dementia on Caregivers and Quality Improvement through Art and Music Therapy. Healthcare. 2021 Jun 9;9(6):698.

139. Poppe M, Burleigh S, Banerjee S. Qualitative Evaluation of Advanced Care Planning in Early Dementia (ACP-ED). Forloni G, editor. PLoS ONE. 2013 Apr 10;8(4):e60412.