Transitions of Care for People with Dementia: Predictive Factors and Health Workforce Implications

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Table of Contents

Summary

As the population ages, policymakers struggle to cope with the increasing demands for home care and institutional long-term care. This thesis project focuses on factors associated with the transition from home to institutional care for people with dementia. Using health administrative data at a population level, we construct a multivariable model that estimates the time between home care initiation after dementia diagnosis and placement in a long-term care home. From the model, we identify protective factors that allow people with dementia to remain at home for longer, with a particular emphasis on the health workforce and the contribution of formal and informal caregivers to delaying the transition from home to institutional care. Together, these results inform policymakers in capacity planning and in determining where investments should be targeted to maintain people with dementia at home, along with the associated health workforce implications.

Résumé

En raison du vieillissement de la population, les décideurs politiques ont des difficultés à gérer la demande croissante de soins à domicile et de soins institutionnels à long terme. Ce projet de thèse examine les facteurs associés à la transition entre les soins à domicile et les soins en établissement de santé pour les personnes atteintes de démence. À l'aide de données administratives sur la santé des populations, nous avons construit un modèle multivarié qui estime le délai, une fois le diagnostic de démence posé, entre le début des soins à domicile et le placement dans un foyer de soins de longue durée. À partir du modèle, nous identifions les facteurs protecteurs qui permettent aux personnes atteintes de démence de rester à la maison plus longtemps, en mettant l'accent sur le personnel de santé et la contribution des aidants professionnels ou naturels, pour retarder la transition entre les soins à domicile et les soins en établissement de santé. Pris ensemble, ces résultats informeront les décideurs politiques dans la planification de la capacité et pour déterminer où les investissements doivent être faits pour permettre aux personnes atteintes de démence de rester à la maison, incluant les implications pour les professionnels de santé.

List of Tables

List of Figures

Legend

ADL – activities of daily living

CCRS – Continuing Care Reporting System

CI – confidence interval

CIHI-DAD – Canadian Institute for Health Information Discharge Abstract Database

CPS – cognitive performance scale

HR – hazard ratio

HRH – human resources for health

IADL – instrumental activities of daily living

ICES – Institute for Clinical Evaluative Sciences

IQR – interquartile range

LHIN – Local Health Integration Network

LTC – long-term care

MAPLe – Method for Assigning Priority Level

MOHLTC – Ministry of Health and Long-Term Care

ODB – Ontario Drug Benefit database

OHIP – Ontario Health Insurance Plan

PSW – personal support worker

RAI-HC – Resident Assessment Instrument – Home Care

RPDB – Registered Persons Database

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1. Introduction and Research Question

Like most industrialized nations, Canada's population is aging due to a combination of longer life expectancy and lower birth rates, exacerbated by the cohort effects of the baby boom generation (CIHI, 2011). Indeed, the proportion of the Canadian population over 65 is predicted to increase from 16% in 2015 to 25% in 2036 before levelling off (StatCan, 2015; CIHI, 2011). A turning point of sorts was reached in 2015 when for the first time the proportion of seniors surpassed that of youth under 15 (StatCan, 2015). As a result, Canada faces the challenge of having to care for an ever-increasing number of seniors with fewer working-age people to support them.

As the population ages, people's health care needs tend to shift from acute to chronic conditions, and people typically experience a gradual functional decline that increases their need for assistive care (CIHI, 2011). It is important to note, however, that aging is a heterogeneous process: Some people can remain healthy and fit well into their 90s, while others experience functional decline at a much earlier age. While the senior population is healthier today than it has ever been (CIHI, 2011), nevertheless the growing population of seniors means a large increase in the absolute number of "frail elderly"—people who experience functional impairments due to chronic diseases, physical disabilities and/or cognitive decline that limit their ability to live independently (Lally, 2007). Of particular concern is the growing prevalence of dementia. Dementia refers to a group of symptoms affecting memory and brain function, severe enough to interfere with everyday functioning (ASC, 2016; Wong, 2016). The most common cause of dementia is Alzheimer's disease, followed by vascular dementia, Lewy body dementia, and frontotemporal dementia (Wong, 2016). Dementia incidence increases dramatically after age 65, and the number of Canadians with dementia is forecast to more than double between 2011 and 2031 (ASC, 2016).

Dementia is a key contributor to long-term care (LTC) home placement in Canada, with 45% of residents in LTC homes aged 45 and older estimated to have dementia as compared to only 0.8% of people living in private households in the community (Wong, 2016). The proportion is even higher in Ontario where as many as 71% of LTC residents have dementia (Tanuseputro, 2017). LTC homes (or institutional LTC) are residential facilities with 24-hour nursing and personal care, comparable to what is commonly referred to as "nursing homes" in other jurisdictions. They are used primarily to care for those who are unable to cope adequately at home. While LTC is not considered a medically necessary service under the Canada Health Act, each province and territory provides some degree of public funding for institutional LTC. For example, in Ontario, government expenditures on LTC represented 7.9% ($4.07

billion) of the overall provincial health budget for 2016, covering primarily nursing and personal care, specialized therapies, recreational programs, support services and food (OLTCA, 2017). Residents of LTC homes are expected to pay a portion of their "room and board" (roughly $1800 to $2600 per month, depending on the type of room), with subsidies available for those who cannot afford the accommodation charges (OLTCA, 2017). Residents may face additional out-of-pocket charges for medications or services not covered by private or provincial plans (OLTCA, 2017).

As an alternative to institutional LTC, individuals with dementia can often be supported at home through a combination of "formal" and "informal" home care, particularly in the early stages of the disease. Formal home care refers to services provided in the care recipient's home by personal support workers, nurses and other health care workers (Williams, 2010). Publicly-funded formal home care services exist to varying extents in every province and territory. For example, in Ontario, roughly 4 to 5% of provincial health spending is directed to home care, equivalent to approximately $2.5 billion in 2014-15 (Auditor General of Ontario, 2015). Services can be "short stay" for short-term acute needs (e.g., recovery after surgery) or "long stay" for chronic and complex needs. Only 60% of home care clients are seniors (aged 65 and over), but they represent the vast majority of long-stay clients (Auditor General of Ontario, 2015). Services are allocated according to strict eligibility criteria based on an assessment by a care coordinator, and even for those deemed eligible the services are frequently insufficient to meet all their needs. As a result, it is not uncommon for people to pay out-of-pocket for private home care services.

While formal home care services are important in supporting individuals with dementia in the community, informal care plays a significantly greater role. Informal care refers to unpaid care provided by a family member (typically a spouse), friend and/or neighbour (Williams, 2010). The estimated value of all informal care provided in Canada in 2009 was $25-$26 billion, far outweighing the public expenditures on formal home care (Hollander, 2009). According to the 2007 Statistics Canada General Social Survey, 2.7 million people aged 45 and above provided some degree of informal care in the previous 12 months (Keefe, 2011), which was equivalent to one-fifth of all people in that age group. Dementia greatly increases the demand for informal care: Care recipients with Alzheimer's disease or other forms of dementia received an average of 37 hours per week of informal care in 2012 vs. seven hours per week for those without dementia (Sinha, 2014). Providing informal care can be very rewarding and is typically done out of compassion and love; however, it can also be burdensome and stressful. According to an OECD report, "Intensive caregiving is associated with a reduction in labour force attachment for caregivers of working age, higher poverty rates, and a higher prevalence of mental health problems" (OECD, 2013, p. 180). Women are disproportionately affected as they represent the majority of informal caregivers (Keefe, 2011), and they also provide a higher intensity of care than their male counterparts (Sinha, 2013). As more and more women enter the workforce and families become smaller and more dispersed, fewer people will be available to be informal caregivers, putting even greater pressure on those who do provide care.

The demand for home care is significant, due to the fact that many seniors prefer to remain in their homes as they age rather than in hospitals or LTC homes (Keenan, 2010). In addition, it is often more cost-effective for the government to care for frail seniors in their homes as compared to LTC homes or hospitals. For example, a collection of "balance of care" projects in Ontario showed that between a third and a half of people assessed as requiring institutional LTC could actually be supported safely and cost-effectively in the community: The "tipping point" depends on the balance of need and the availability of health care workers to provide the necessary services in the community (Williams, 2009; Williams, 2016). Unfortunately, the dearth of information on the health workforce makes it difficult to accurately assess the supply side of the care equation. Responding adequately to the rising demand for care requires having the appropriate supply, mix and distribution of health care professionals (Moat, 2016), yet data are often lacking, particularly with respect to unregulated health workers like health care aides and personal support workers who provide the vast majority of both home care and LTC for seniors (Estabrooks, 2015). Furthermore, health care workers may need to develop new skills to manage the growing complexity of caregiver needs (HQO, 2016). The gendered nature of the care environment also needs to be considered, as the vast majority of caregivers for the elderly are female (Estabrooks, 2015). Yet rather than seeking out the necessary data, policymakers frequently ignore health workforce issues, to the point that the health workforce is often the "elephant in the room" when health policies are developed (Huyer, 2016).

Over the past 10 to 15 years, many jurisdictions have turned their focus to improving home care services. For example, in Ontario, the government introduced its Aging at Home Strategy in 2007 that increased funding for home care for seniors. The government's commitment to home care was further reinforced in its 2012 Action Plan for Health Care which established three priorities, the third being "the right care, at the right time, in the right place" which includes a commitment to "ensuring seniors receive the care they need as close to home as possible" (MOHLTC, 2012). These commitments were reiterated in Ontario's Action Plan for Seniors, released in 2013 (Ontario Seniors' Secretariat, 2013). Finally, the Patients First Act was passed in 2016 which, among other things, transferred responsibility for home care from Community Care Access Centres (CCACs) to the Local Health Integration Networks (LHINs) with the goal of improving services and increasing service integration while reducing costs (MOHLTC, 2016). At the federal level, the government committed $6 billion over 10 years for home care in its 2017 budget (Government of Canada, 2017) and negotiated transfer agreements with each province, with Ontario receiving $2.3 billion (Health Canada, 2017).

Supporting people at home as they age is a laudable goal, but achieving this requires more than just policy statements and money: It requires understanding the demographics and health status of the aging population, the factors that contribute to their transition to LTC, the interventions that have the greatest effect at delaying that transition, and last but certainly not least, the health human resource implications of shifting care to the community. To these ends, this thesis project will seek to examine the following overarching research question: **What are the predictive factors and health workforce implications associated with the transition from home care to institutional LTC for people with dementia?** In particular, the following specific objectives will be addressed:

1. create a predictive model using multivariable regression analysis to estimate time to LTC placement for people with dementia who are receiving formal home care services;
2. use the predictive model to identify the "protective" or modifiable factors that could be targeted to delay the transition and keep people with dementia at home longer, with a particular emphasis on factors that involve the health workforce (both formal and informal); and
3. explore how best to assess the health workforce implications stemming from policy changes designed to keep people with dementia at home longer.

The results of this study will provide a better understanding of the drivers for the transition from home care to LTC which will help policymakers in estimating future care demand. The results will also aid in identifying areas for intervention to support people with dementia at home longer, while highlighting the importance of assessing the associated health workforce implications to ensure that there is the capacity in the health workforce to deliver these interventions successfully and safely. Finally and perhaps most importantly, the results will benefit individuals with dementia, along with their caregivers and health care professionals, by providing them with a clearer understanding of their likely disease trajectory, from which they can make better-informed care decisions.

2. Background

2.1 Transitions of care

The term "transitions of care" refers to the continuity and coordination of health care when an individual physically moves between settings (e.g., from hospital to LTC home) or when responsibility for care is transferred between health care professionals within the same setting (e.g., from one department to another at a hospital) (Coleman, 2003). For the purposes of this thesis project, the transition of care being considered is the physical movement of individuals with dementia from their homes (where they are receiving publicly-funded formal home care services) to institutional LTC. A number of studies have used health administrative data and statistical analyses to determine factors associated with this transition, both in the general elderly population as well as community-dwelling individuals suffering from dementia. The approaches and conclusions of these studies will be summarized below, along with the study limitations and knowledge gaps that will be addressed by this thesis project.

2.2 Predictors of LTC home placement

2.2.1 Systematic reviews

Since 2000, three systematic reviews have been published to examine studies of factors influencing placement of the elderly (with or without dementia) in institutional LTC. In the first, Luppa *et al.* (2008) summarized 42 studies between 1986 and 2007 that used multivariate statistical analyses of health administrative data to identify predictors of LTC home placement for people with dementia. Only one study (Hébert, 2001) was from Canada; two thirds were from the United States, with the rest being from Europe or Australia, potentially limiting the relevance and applicability to the Canadian context. Demographic factors associated with an increased risk of institutionalization included advanced age of patients and their informal caregivers, being male, being unmarried, living alone, and (for the American studies) being white. Health-related factors included greater severity of dementia, greater cognitive and functional impairment, and other behavioural and psychological dementia-related problems such as aggression, depression and incontinence. Inconsistent results were found with respect to weekly caregiver hours. However, the health of the family caregiver was an important factor, with increased caregiver health problems associated with a higher risk of institutionalization. The sample sizes in the studies examined ranged from 30 to 5,831 community-dwelling individuals, and while the authors did not assess the quality of the studies, they noted "a lack of methodological strength in a large part of identified studies" (Luppa, 2008).

A second systematic review by Gaugler *et al.* (2009) also examined predictors of LTC home admission for people with dementia. They included 80 studies published up to 2006 (26 of which were reviewed in Luppa, 2008), with sample sizes ranging from 14 to 5,795 individuals in the community. A key inclusion criterion was that the study was a case-control or cohort design that attempted to identify predictors of institutionalization. Only two studies were Canadian (Hébert, 2001; Hogan, 1994), while nearly half were from the United States. Study quality was assessed using a 15-point checklist, and 29 of 80 studies were classified as "high quality" (scoring seven or above out or 15). Effects were examined across all 80 studies and within the high-quality studies only. Similar to Luppa *et al.* (2008), they found the most consistent predictors of institutionalization for people with dementia to be the severity of cognitive impairment, Alzheimer's disease diagnosis, functional impairment, behavioural symptoms, depression, and caregiver stress. On the other hand, they found that demographic variables (including age and gender), incontinence and service use did not consistently predict institutionalization. The authors noted that it was challenging to synthesize the results of the studies because of their variable quality, with just seven studies scoring nine or above on their 15-point quality checklist.

The final systematic review, also by Luppa *et al.* (2010), examined predictors of institutionalization in the general elderly population rather than people with dementia. They included 36 studies published between 1976 and 2007 that identified predictors by multivariate analyses using population-based samples. Only two studies were from Canada (Mustard, 1999; Shapiro, 1988) and 28 were from the United States. None of these studies was included in the earlier systematic reviews summarized above (Luppa, 2008; Gaugler, 2009). Sample sizes ranged from 207 to 487,383 individuals living at home, and in most studies the individuals were aged 65 and above. Study quality was assessed based on a checklist developed by the authors (similar to that used by Gaugler *et al.* (2009)), and predictive factors were assigned one of four levels of evidence (strong, moderate, weak or inconclusive) based on the number and quality of studies that reported an effect. Factors with strong evidence for predicting institutionalization were increased age, not owning one's home, being white, having low self-rated health status, functional and cognitive impairment, dementia, prior nursing home placement, and a high number of prescriptions. As for the Gaugler (2009) study, inconsistent results were noted for sociodemographic factors (gender, income and education), incontinence and prior hospital use. Only 21 of the 36 studies were found to be of high or moderate quality, leading the authors to note that the methodological quality of studies needs improvement.

2.2.2 Canadian studies

Very few quantitative studies have been conducted in Canada to examine the predictors of LTC placement, and almost all are from 2001 and earlier. Only two studies have been published examining people with dementia (Hébert, 2001; Hogan, 1994), while three other studies have looked at predictors for the general population without a specific emphasis on dementia (Gruneir, 2013; Mustard, 1999; Shapiro, 1988). The Hogan study followed 553 patients referred to the University of Calgary's Dementia Research Clinic and found that factors associated with predicting institutionalization included older age, being unmarried, greater cognitive impairment, more rapid progression of dementia, and greater functional impairments. The Hébert study used data from the Canadian Study of Health and Aging to follow the informal caregivers of 326 individuals with dementia in the community. They found that the factors associated with a shorter time to institutionalization were probable or possible Alzheimer's disease (as compared to other forms of dementia), disability in activities of daily living (ADLs), caregiver age (i.e., over 60 years old), the caregiver not being a spouse or child, and severe caregiver burden. An important gap in both studies was the absence of examining sex as a potential predictor.

Of the studies on the general population, both Mustard (1999) and Shapiro (1988) were considered in the systematic review by Luppa *et al.* (2010). The Gruneir (2013) study is by far the most recent of the Canadian studies, and it is notable because of the size of their cohort (71,303 individuals aged 76 years or older) and their use of multiple linked health administrative databases. Their focus was on gender differences in home care clients and admission to LTC in Ontario, and as such the study was primarily descriptive rather than predictive: The only finding they report related to predictors of LTC admission is that men were more likely to be admitted than women (Gruneir, 2013). The variables they described and the datasets they used have some relevance for this thesis project in terms of helping to guide the data collection and model specification described below in the Methodology section.

Finally, Laporte *et al.* (2017) examined factors associated with LTC waitlist placement in Ontario's North West LHIN. They examined a population of 2,469 community-dwelling individuals receiving publicly-funded home care services, of whom 367 were waitlisted for institutional LTC. The two groups were compared using variables from RAI-HC which they divided into three "blocks": care recipient characteristics, informal caregiver characteristics, and formal system characteristics. They found that all three "blocks" are significantly related to waitlist placement. As for the Gruneir (2013) study, many of the variables and methods employed by Laporte *et al.* are relevant to this thesis project and were helpful in developing the methodological approach used here.

2.2.3 Other relevant studies

A small number of studies have also been published that were not included in the systematic reviews described above. Four studies examined predictors of institutionalization in the general population (Friedman, 2005; Gaugler, 2007; Cai, 2009; Luppa, 2012a). One study was from Germany (Luppa, 2012a) while the others were from the United States, and sample sizes ranging from approximately 3,000 to 6,000 individuals. The Gaugler (2007) study was a meta-analysis that included 77 reports across 12 data sources with sample sizes up to 137,632. Similar to what was found in the systematic reviews, there were consistencies and inconsistencies between the studies. For example, all four studies identified advanced age, functional and cognitive impairment, living alone, and (for the American studies) being white as predictors of institutionalization. On the other hand, there was a lack of agreement among the studies with respect to sex, bowel incontinence, self-perceived health, psychiatric problems, home ownership, and depression, with some studies finding them relevant and others not.

Two additional studies focused specifically on community-dwelling individuals with dementia (Luppa, 2012b; Miller, 2011). Luppa *et al.* (2012b) examined 254 individuals with dementia aged 75 years and older who were part of the same cohort in the study described above (Luppa, 2012a). They found that nursing home placement correlated with being single or widowed, and higher severity of cognitive and functional impairment. Marital status was by far the strongest predictor, which they suggested relates to the likelihood of an informal caregiver (spouse or child) being present. The study by Miller *et al.* (2011) included 418 individuals with Alzheimer's disease with psychosis or agitation participating in a randomized controlled trial of anti-psychotic medications. Predictors of institutionalization included prior outpatient mental health use, functional and cognitive impairment, and being white.

2.2.4 Study limitations and knowledge gaps

While a number of studies have examined factors associated with the transition from home to LTC for people with dementia, there are various limitations and gaps associated with them (Table 1). First, the samples were not true population studies—the vast majority of the dementia studies included fewer than 1,000 individuals—and data sources were generally restricted to a defined cohort, such as people enrolled in a specific health care program. As a result, particular effects may be more difficult to assess due to a lack of power, and the results may not be representative of the general population. Second, while many of the studies used multivariable modeling (Cox proportional hazards or logistic regression) to identify predictors of LTC institutionalization, the models were not validated for their predictive ability, further limiting the generalizability of the results, and the studies tended to be more descriptive in nature. Third, there are very few Canadian studies, and the ones that have been carried out are more than 15 years old. This thesis addresses these gaps by conducting an up-to-date study for the Ontario context based on population level data, using a rigorous multivariable regression modelling approach to identify predictive factors.

2.3 Human resources for health

2.3.1 Health workforce implications of LTC and home care policies

Health care delivery is highly labour-intensive, and this is especially true for LTC where the majority of the services are for personal support and assistance rather than medical interventions. Indeed, two-thirds of the Ontario government's per diem funding for LTC homes in 2016 was for nursing and personal care (OLTCA, 2017). Despite the importance of the health workforce in health care delivery, health human resource issues are often overlooked or even actively ignored in health care policy proposals (Van Lerberghe, 2002; Huyer, 2016). A case in point is Ontario's Action Plan for Seniors (Ontario Seniors' Secretariat, 2013) which outlines a number of new initiatives to promote better health for seniors, including: "we will increase the number of exercise and falls prevention programs throughout the province" (p. 17); "we will improve access to home care by expanding personal support worker services through community support agencies" (p. 18); "primary care physicians will be encouraged to provide about 30,000 more house calls than the 228,000 currently provided" (p.19); and "we will provide more care at home across the province" (p. 19). The success of these important goals depends almost entirely on the health workforce being able to expand and adapt as necessary to implement the programs, for example through the implementation of supportive funding models and the development of competencies to work in the home. Yet there is little, if anything, in the strategy to suggest how health workforce considerations have been taken into account and how these recommendations with critical health workforce implications will be implemented.

When considering how health policies may impact the health workforce (and vice versa), issues of particular importance are the supply, distribution and mix of health care professionals (Moat, 2016). The World Health Organization has made health workforce issues in policy development a key focus for a number of years and recently released its Global Strategy on Human Resources for Health: Workforce 2030 (WHO, 2016). The strategy enumerates four key objectives:

1. To optimize performance, quality and impact of the health workforce through evidence-informed policies on human resources for health;

2. To align investment in human resources for health with the current and future needs of the population and of health systems, and to address shortages and improve the distribution of health workers;
3. To build the capacity of institutions at sub-national, national, regional and global levels for effective public policy stewardship, leadership and governance of actions on human resources for health; and
4. To strengthen data on human resources for health, for monitoring and ensuring accountability for the implementation of national and regional strategies, and the Global Strategy.

Of particular relevance to this thesis project are the second and fourth objectives. To the extent possible, the predictive model will be used to identify the formal home care services that have the greatest impact on delaying the transition to LTC, which will help guide policymakers in assessing current and future needs and in determining where best to invest to address those needs. In addition, the limitations of what can be done with the available health workforce data and suggestions for improvements will be considered. More broadly, the results from this thesis research will be used to highlight the importance of including a detailed assessment of the associated health workforce implications when developing policy recommendations.

2.3.2 Health workforce implications: literature review

There are very few studies in the literature that assess the implications of health policies on the health workforce, including policies that relate to aging at home and transitions of care. Many studies have been conducted to explore the impact of an aging population on the health workforce (see, for example, CHWS, 2005; IOM, 2008; Ricketts, 2011; Schofield, 2006); however, these studies generally try to model where the human resources gaps will be based on demographic projections, rather than assess the health workforce implications and needs that arise from a particular policy proposal aimed at responding to an aging population.

A review of the literature revealed a small number of published studies that assess the impact of health policies for seniors on the health workforce. In one, Stone and Bryant (2012) examined the impact of the U.S. Patient Protection and Affordable Care Act (ACA) on the health workforce. While they applaud the fact that “the ACA is the first comprehensive federal legislation to acknowledge gaps in the workforce caring for the elder population” (Stone, 2012, p. 188), they find that the Act’s provisions for addressing those gaps are inadequate. Among the challenges they enumerate are a lack of preparation in the workforce for the new models of service delivery the legislation specifies; a lack of training, support and accountability for effective care coordination and service integration; and a lack of the requisite skills, knowledge and competencies (Stone, 2012). They also point out that several provisions in the Act for developing the workforce have not had their funding approved, and in any case most of these provisions are demonstration projects with limited scope and duration. They remark that "many of the demonstration provisions in the ACA simply assume that participating organizations have the workforce capacity to implement successfully the new models being evaluated" and conclude that the reforms may be "doomed to failure" if these health workforce considerations are not appropriately addressed (Stone, 2012, p. 203).

A second study by Gleason and Coyle (2016) examined how the increased emphasis on home and community-based health care affects home health care aides in Massachusetts, and in particular the impact of the increased prevalence of individuals with mental and behavioural health conditions. They note that "though this expanding workforce [home health care aides] continues to bear the burden of home care for individuals with mental illness, they are rarely heard from in either policy or practice" (Gleason, 2016, p. 848). Through focus groups with home health care aides, the researchers outline the challenges the aides face in their daily work and propose strategies to address these challenges and ensure that the workforce is prepared and supported to respond to the ever-increasing number and complexity of clients.

Other more general studies have looked at the effects of technology and human resource management practices on the health workforce. Jennett *et al.* (2000) examined the potential effects of telehealth on the Canadian health workforce in a qualitative study that interviewed the project coordinators of 12 diverse telehealth projects from across Canada. They found that there were many workforce benefits to telehealth such as enhanced roles for health professionals, positive effects on recruitment and retention of staff, and reduced travel time, but there was a need for additional training and informal support networks to ensure successful adoption and implementation of telehealth programs. A second study considered the impact of decentralization on the health workforce (Kolehmainen-Aitken, 2004). The author notes that the human resource implications of decentralization and other reform measures are often ignored, with the focus instead being on financial and structural reform measures. Based primarily on the experiences in developing countries, a broad range of impacts were enumerated including staffing equity, health worker motivation and performance, and managerial effectiveness, along with strategies for addressing these impacts.

2.3.3 Study limitations and knowledge gaps

Despite the importance of human resources for health in health care delivery, it remains an understudied topic. An important gap in studies that do exist is the tendency to examine health workforce issues in isolation and not in connection with specific health policy proposals (Table 1). An in-depth exploration and analyses of these issues is beyond the scope of this thesis; instead, a health workforce lens will be applied in conducting and analyzing the research data, along with a discussion of approaches for identifying and assessing the health workforce implications of policy proposals that emphasize shifting care from LTC homes to the community.

3. Methodology

3.1 Research design

This project is a retrospective, population-based cohort study of community dwelling adults with dementia in Ontario who transition from home to institutional LTC. Using routinely-collected health administrative data from ICES (the Institute for Clinical Evaluative Sciences), a broad range of attributes were analyzed to construct a multivariable model that models the time between home care initiation and institutionalization, based on an individual's baseline characteristics at their first assessment for formal home care services following dementia diagnosis. The statistical approach used is referred to as a survival analysis, in which the outcome variable of interest is time until an event occurs (Clark, 2003). Because of the large number of variables that may impact the outcome, a multivariable analysis was used in which the effects of multiple factors can be assessed simultaneously and the relative contribution of each factor estimated (Bradburn, 2003). Specifically, the Cox proportional hazards model was employed, a survival analysis regression model that is the most commonly used multivariate approach for analyzing survival time data in medical research (Bradburn, 2003). The predictive modeling approach followed the guidelines by Harrell (2001) and Steyerberg (2009), which included full pre-specification of the predictor variables and use of flexible functions for continuous predictors.

This study received approval from the University of Ottawa Research Ethics Board (see Appendix 1) and through the ICES Privacy Impact Assessment process.

3.2 Conceptual framework

The conceptual framework for the multivariable model building is based on Andersen's behavioural model of health service use (Andersen, 1995) and Pruchno's conceptual framework for predicting institutionalization of people with Alzheimer's disease (Pruchno, 1990). Andersen's model suggests that people's use of health services is a function of predisposing, need and enabling characteristics of the individual (Andersen, 1995). *Predisposing variables* include demographic factors such as age, sex, marital status, socioeconomic status, and so on. *Need variables* relate to the individual's overall health and functional capacity. Finally, *enabling variables* include the availability and accessibility of health care services as well as family and community resources. Pruchno's framework for predicting institutionalization is similar, encompassing four factors: (1) demographic, (2) stressors (i.e., the patient's health status), (3) caregiver resources (including availability and quality of resources), and (4) caregiver burden or stress (Pruchno, 1990). Pruchno's consideration of caregiver burden or stress is effectively an elaboration of the enabling variables that Andersen describes. This framework of predisposing (demographic), need and enabling factors provides a useful classification for organizing the many variables that may affect the transition from home care to LTC; indeed, it was used by Luppa *et al.* (2008) to structure the results of their systematic review. Their framework was adapted for this thesis project and is presented in Figure 1. In particular, the enabling factors related to the health workforce will be a special focus of this study, with a specific emphasis on sex and gender.

3.3 Sample

3.3.1 Data collection

The data for this study were obtained from ICES, a non-profit research institute established by the Ontario government. ICES maintains the ICES Data Repository that consists of record-level, coded and linkable health datasets (www.ices.on.ca/Data-and-Privacy/ICES-data). These datasets include over 80 publicly-funded administrative health services records for the Ontario population dating back as early as 1986, with records for more than 13 million people (not included are First Nations, military personnel and migrants not covered by the Ontario Health Insurance Plan (OHIP)) (see Appendix 2 for a description of the ICES databases used in this study). As a prescribed entity under Ontario's Personal Health Information Protection Act, ICES is permitted to hold and use these data for research and evaluation purposes under strict privacy procedures.

3.3.2 Case ascertainment

The detailed process for creating the study cohort is described in Figures 2 & 3. Broadly speaking, the process involved three steps: (1) identifying the dementia population; (2) identifying those receiving long-stay home care after dementia diagnosis; and (3) determining their outcome (LTC home placement, death in the community, or alive in the community).

(1) Dementia population

All Ontarians diagnosed with dementia between July, 1, 1991 and Dec. 31, 2015 (the full timespan for which data are available) were identified through two approaches. First, a previously validated definition developed by ICES scientists (sensitivity 79.3%, specificity 99.1%) (Jaakimainen *et al.*, 2016) was used that draws on information from three ICES datasets: OHIP (Ontario Health Insurance Plan), ODB (Ontario Drug Benefit database), and CIHI-DAD (Discharge Abstract Database) (see Appendix 2 for a description of these datasets and Appendix 3 for the algorithm definition). This algorithm identified 645,373 individuals as having dementia. A second algorithm was used drawing on data from the CCRS (Continuing Care Reporting System) and RAI-HC (Resident Assessment Instrument – Home Care) datasets (datasets described in Appendix 2). Specifically, the algorithm searched for individuals with a dementia diagnosis (I1V or I1R flags in CCRS; J1G or J1H flags in RAI-HC) combined with a cognitive performance scale (CPS) score of 2 or higher (Fisher, in preparation). This approach identified an additional 39,303 cases for a total of 684,676 unique individuals. Individuals were excluded if their dementia diagnosis date was before July 1, 2007 to align with availability of RAI-HC data. It should be noted that while the date returned by these approaches is referred to here as the “dementia diagnosis date”, it is more precise to consider it the individual’s first interaction with the health care system in which dementia was recorded (i.e., “health care diagnosed dementia” as opposed to “physician diagnosed dementia”).

Relevant data from the Registered Persons Database (RPDB) were attached to each individual’s record based on the dementia diagnosis date, including age, sex, income quintile, rurality, death date, and other sociodemographic factors. Individuals were excluded if they were less than 65 or more than 104 years old at the dementia diagnosis date; if they had an invalid IKN (ICES key number, used for linking datasets); if their age or sex was unknown; or if they were not a resident of Ontario. Individuals under 65 years of age were excluded as they represent a relatively small proportion of individuals and generally have early onset dementia which is thought to have different risk factors than other types of dementia. Furthermore, most other studies examining the transition to LTC for people with dementia focus on the 65+ age group; thus, excluding individuals under 65 helps ensure comparability with other studies. In addition, for purposes of data quality, individuals 105 years and older at the index date are routinely excluded because of errors in RPDB (known as “RPDB creep”, typically due to a person’s death not being recorded correctly in the dataset).

(2) Home care population

In Ontario, adults requiring long-stay home care (defined as more than 60 days of uninterrupted service) or admission to a LTC home must receive a RAI-HC assessment by a trained case manager (MOHLTC, 2007). Provincial policy also states that long-stay home care clients are to be reassessed using RAI-HC at least every six months or when there is a significant change in the client’s condition (e.g., new disease diagnosis, functional and/or health declines, return from a hospital stay, change in caregiver status, etc.); however, in practice this policy is not always strictly followed.

To identify individuals with dementia receiving long-stay home care, the first RAI-HC assessment on or after the dementia diagnosis date was attached to each individual’s record, which represents the index event date. (Note that it is possible that some of these individuals were already receiving long-stay home care prior to dementia diagnosis, so both “incident” and “prevalent” home care recipients are included.) In addition, certain variables from RPDB that may have changed between dementia diagnosis and RAI-HC assessment were added again based on the RAI-HC assessment date (namely age, LHIN and income quintile). Together, these data allow for a baseline description of each individual at the index event date.

(3) Outcomes

The primary outcome for this study is time to LTC placement from the index event date (i.e., the first RAI-HC assessment after dementia diagnosis). Two methods were used to determine if and when an individual transitioned to a LTC home:

1. For the period Jan. 1, 2010 to May 31, 2016, individuals were cross-referenced against the CCRS database, which has complete records of all admissions to LTC homes beginning in 2010.
2. For the period prior to full implementation of CCRS in 2010, an algorithm was employed that searches the ODB and OHIP databases for two claims within 90 days of each other with location codes for LTC homes (OHIP: all services billed under a “W” code and where the institution (insttype =) is “NH” or “HF”; ODB: all claims made from LTC (LTC flag = 1)) (Ng, in preparation).

For individuals receiving home care, only LTC admission dates after the index RAI-HC assessment date were included, and if more than one LTC admission date was found, the earliest date was retained.

The secondary outcome, death, was determined from RPDB records. As detailed below, death in the community before transitioning to LTC was treated as a competing risk as it prevents individuals from experiencing the event of interest (i.e., placement in LTC).

To limit the cohort to individuals living in the community when diagnosed with dementia, anyone with a LTC admission date on or before the dementia diagnosis date was excluded. Individuals were also removed if they were diagnosed with dementia after June 30, 2015 (to align with availability of RAI-HC data) or if their death date was on or before the RAI-HC assessment date. For predictive modelling the follow-up period was one year after the index RAI-HC assessment or May 31, 2016, whichever was earlier. The timeline for cohort creation and follow-up is summarized in Figure 4.

3.3.3 Model specification

The RAI-HC dataset contains a wealth of information with data on up to 398 variables for every individual (https://datadictionary.ices.on.ca/Applications/DataDictionary/Library.aspx?Library=RAIHC). For model building and analysis, it is necessary to reduce and pre-specify the number of variables to help prevent type I errors (i.e., detecting an effect that is not present) that may result in overfitting the model (Collins, 2015). To this end, the most meaningful variables for predicting institutionalization were chosen based on the literature and expert opinion consensus. Briefly, the variables used in other studies examining the transition from home care to LTC (described above in the Background) were examined to create a preliminary list of potential variables to use in the present study. Potentially relevant variables (from the RAI-HC and RPDB datasets) that were not identified from other studies were also included in the list. The utility and appropriateness of including these variables was then discussed and debated in meetings with expert researchers to reduce the number of variables to the most relevant ones. The final list contained 69 variables and is presented in Table 2.

To clean the data, reduce complexity and facilitate analysis, a number of steps were undertaken (see Table 2 for further details and specific variables):

- the variable “sex” was converted from character to numeric values (M = 0, F = 1);
- age (a continuous variable) was flexibly modelled using a restricted cubic spline; i.e., a piecewise cubic function that is smooth at the knots and restricted to be linear in the tails. Specifically, a 5-knot spline was used with knots placed at fixed quantiles of the distribution (the 5th, 27.5th, 50th, 72.5th and 95th percentiles);
- all other continuous variables were converted to categorical;
- for certain categorical variables, the number of categories was reduced, and/or several variables were combined into a single variable;
- for variables with missing values, a category for “missing” was created if there was a significant number of missing values and it could not be assumed that a missing value was equivalent to “zero” or “no”; otherwise, if there were only 1 or 2 missing values they were treated as “zero” or “no”.

3.4 Measurement and Analysis

3.4.1 Multivariable model development

As a first step, the cohort was described statistically (using the analytical software package SAS 9.4® (SAS Institute Inc., Cary, North Carolina)) with respect to the chosen variables, to provide a detailed baseline picture of all the attributes associated with the individuals in the cohort at the index event date (i.e., first RAI-HC assessment for long-stay home care following dementia diagnosis) grouped by outcome. To obtain p-values between groupings, one-way analysis of variance was used for age, and chi-squared tests for all other variables.

Next, highly-correlated variables were identified using the PROC VARCLUS statement in SAS. In the first iteration, the full set of variables was tested with an eigenvalue threshold of 0.70, resulting in 56 clusters and the elimination of nine variables (detailed in Table 2). The PROC VARCLUS procedure was repeated with the remaining variables, resulting in 54 clusters and the elimination of one additional variable (Table 2).

The remaining candidate predictors were entered into a multivariable Cox proportional hazards regression model using the SAS PROC PHREG procedure, with time to LTC placement as the dependent variable. Individuals who were still alive in the community at the end of the follow-up period (one year after the index event or May 31, 2016, whichever was earlier) were censored. For the rest of the cohort, two outcomes were possible: LTC placement (the outcome of interest) or death in the community (the secondary outcome). Death in the community is a competing risk as it precludes the occurrence of the primary event of interest, namely LTC placement. Thus, the survival function (time to event) must be expressed using the cumulative incidence function as the Kaplan-Meier estimate yields biased results in the presence of a competing risk (So, 2014). The Fine and Gray subdistribution hazard model was used to model the cumulative incidence function (Fine, 1999) as this has been shown to provide better hazard estimates than the cause-specific hazard approach (Gondara, 2015) and is better suited for addressing questions related to incidence and prognosis (Austin, 2017).

A fundamental assumption of the Cox proportional hazards regression model is the absence of time by predictor interactions. For age (the only continuous variable), the proportionality assumption was assessed using plots of smoothed scaled Schoenfeld residuals versus time and by testing the time interaction term in the Cox model. As all the other variables were categorical, Schoenfeld residuals could not be used. Instead, time-dependent covariates were tested in the Cox model, and plots of the cumulative incidence function for each variable (stratified by category) were examined for intersecting curves which would indicate a violation of the proportional hazards assumption (Figure 6). No variables were found to violate the proportional hazards assumption.

The final model was derived by reducing the full model using stepwise backward elimination (Ambler, 2002). Briefly, the overall variance for the model was calculated by summing the squares of the β values for the individual variables, and the relative contribution of each variable to the overall variance was determined by dividing each variable's variance (i.e., β^2) by the total variance. Variables with the lowest contribution to the overall variance were removed progressively and the model was derived again at each step. The AIC (Akaike information criterion) value was used to compare the quality of each model, with the lowest AIC indicating the highest quality or preferred model. This process resulted in the elimination of 11 variables, leaving 48 predictors in the final model with 99 degrees of freedom.

3.4.2 Evaluation of model performance

Model discrimination was determined by calculating the concordance (or C) statistic (Pencina, 2015). The C statistic is equivalent to the area under the receiver operator characteristic (ROC) curve, which plots the probability of detecting true signal (sensitivity) and false signal (1–specificity) for an entire range of possible cutpoints (Hosmer, 2013). Values can range from 0.5 (random concordance) to 1.0 (perfect concordance). Model calibration was assessed by ranking and then dividing a random 20% sample of the cohort into 50 strata based on the observed risk of LTC placement at one year, and comparing with the predicted risk calculated from the regression model. The observed vs. predicted risk of LTC placement was also compared across meaningful variables both within and outside of model.

4. Results

4.1 Cohort description

The study cohort consisted of 163,983 community-dwelling individuals aged 65 and above who were diagnosed with dementia between July 1, 2007 and June 30, 2015 and receiving formal home care services (Figure 3). The average age was 83.3 ± 6.9, the median age was 84 (IQR = 9), and 62% of the cohort was female (Table 3). Home care services were accessed relatively quickly following dementia diagnosis: The median time from diagnosis to RAI-HC assessment was 84 days (IQR = 378) and the mean time was 294.7 days (S.D. = 447.6) (Figure 5). Within one year after the incident RAI-HC assessment (i.e., the follow-up period used for the predictive modeling), 43,097 individuals (26.2%) had transitioned to LTC while 20,655 (12.6%) had died in the community (Figure 3).

4.1.1 Baseline characteristics

The baseline characteristics of the full cohort are shown in Table 3, separated by outcome (i.e., alive in the community, in LTC, or dead in the community within one year of index event date). The 48 variables used in the predictive model building were used to describe the cohorts, with unadjusted results for key variables summarized below in relation to the conceptual model (Figure 1).

Predisposing factors. Individuals who transitioned to LTC ("LTC cohort") or who died in the community were older than those still alive in the community (84.5 ± 6.9 and 84.7 ± 7.0 vs. 82.5 ± 6.8; $p<0.001$). Men were more likely than women to die in the community: Fully half (49.6%) of those who died in the community were men, as compared to just over one-third (35.5%) who were still alive in the community after one year. In contrast, the proportion women in LTC was 1.6-fold greater than that of men (61.6% vs. 38.4%). Income was associated with LTC placement, with individuals in lower income quintiles more likely to enter LTC than those in higher income quintiles. On the other hand, being married (as opposed to widowed, divorced, separated or never married) was associated with remaining in the community: In the LTC cohort, only 32.0% were married as compared to 40.0% among those still alive in the community ($p<0.001$). Having a live-in informal caregiver was more common among those in the community, with only 42.9% of the LTC cohort living with an informal helper at the index event date as compared to 52.2% of those alive in the community ($p<0.001$).

Needs variables – health-related aspects. Increased cognitive impairment and behavioural issues were significantly more common among those placed in LTC. For example, only 27.9% of those alive in the community had a cognitive performance scale (CPS) score of 3 or above (on a scale of 0 to 6, with 6 being the highest level of impairment), as compared to over half (52.8%) of the LTC cohort ($p<0.001$).

Similarly, higher proportions of individuals demonstrating behavioural issues (i.e., wandering, verbally or physically abusive, resists care, changes in behavioural symptoms, and hallucinations) were consistently observed among those placed in LTC as compared to those alive in the community. With respect to comorbidities, only individuals with stroke, coronary heart disease, peripheral vascular disease, hip fracture and cancer appeared to be more highly represented in the LTC cohort. A similar pattern was observed among those who died in the community, with even greater associations for certain comorbidities such as coronary heart disease and especially cancer.

Needs variables – functional impairment. Essentially every measure of functional impairment was more highly associated with the LTC cohort (and statistically significant at p<0.001). For example, 18.3% of the LTC cohort experienced three or more falls in the 90 days preceding the RAI-HC assessment, as compared to 11.1% of those alive in the community. Individuals admitted to LTC were also more likely to be incontinent and to be less physically active. With respect to activities of daily living (ADLs) such as dressing, eating, toileting and bathing, the LTC cohort had a higher level of disability than those alive in the community, with consistently higher proportions for ADL scores of 2 and above (measured on a scale of 0 (independent) to 6 (total dependence)). The profile was similar for those who died in the community, except that those with an ADL of 6 were even more highly-represented among those who had died. For instrumental activities of daily living (IADLs) such as meal preparation, housework, managing medications and using the telephone, individuals with a score of 6 (i.e., total dependence) were a significantly greater proportion of those who were placed in LTC or died in the community as compared to those still alive.

Enabling resources. The data on informal help (hours of care per week) included a high proportion of missing values (19.3%) which were significantly associated with the LTC cohort (39.7%) and to a lesser extent those who died in the community (24.4%) vs. those still alive in the community (9.5%). Recalculating the informal help data after excluding the missing values suggested no correlation between hours of informal care and LTC placement, except at the highest level (42 hours and above) which was more highly represented in the LTC cohort as compared to those alive in the community. On the other hand, an increased number of hours of informal care appeared to correlate with death in the community. Formal care services also included a high proportion of missing values (10.9%) which were again consistently over-represented in the LTC cohort (19.5%) and those who died in the community (13.9%) as compared to those alive in the community (6.5%). Across the six groups of formal care services analyzed, the missing values belonged to the same individuals; furthermore, all of these individuals were also missing data on informal help. The RAI-HC manual notes that collection of these formal care data elements is not required in hospital settings (CIHI, 2010, p. 127); thus, these individuals may have received their RAI-HC assessment while awaiting discharge from hospital. Nevertheless, with the exception of meals services, there appeared to be an association between the absence of formal care services and LTC admission. Receiving nursing services appeared to have only a small association with remaining alive in the community, but they were highly associated with dying in the community. Finally, in terms of caregiver characteristics, having one's spouse as the primary caregiver correlated with a lower rate of LTC placement (24.0% vs 31.3% alive in the community) and a higher rate of dying in the community (34.3%). In addition, caregiver distress (as measured by the caregiver feeling she/he is unable to continue in the role) was much more evident in the LTC cohort (22.8% vs 13.8% alive in the community) and to a lesser extent among those who died in the community (19.1%).

The baseline characteristics associated with informal and formal care were examined in more detail. First, relevant variables were examined according to the informal helper's relationship with the care recipient (or "client" as per the RAI-HC assessment terminology) (Table 4a). The vast majority (98.5%) of clients had an informal caregiver, and just over half (56.0%) were a child or child-in-law of the care recipient. Care recipients with a spousal caregiver were significantly younger than all other categories (80.8 ± 6.5 vs. 83.3 ± 6.9 for the full cohort). Women represented 62.0% of all care recipients, yet among those whose primary caregiver was their spouse, 63.2% were men, indicating that spousal caregivers were much more likely to be women than men (assuming that the vast majority of marriages are heterosexual). Interestingly, a spousal caregiver was more likely to be unable to continue in the role than any other relation (25.8% for a spouse vs. 12.4% to 14.3% for all other relations; p<0.001). On the other hand, it was more common for children to be dissatisfied with support from the family (6.1% vs. 4.2% to 4.4%; p<0.001). Finally, spousal caregivers provided a higher level of care compared to other relations, with much higher proportions in all categories above 14 hours per week, while the lowest level of care was provided by friends and neighbours, and by relatives other than a spouse or child/child-in-law.

Second, relevant variables were also examined according to whether the informal caregiver lives with the client (Table 4b). Exactly half of the cohort had a live-in informal caregiver, split almost evenly between male and female care recipients (47.2% and 52.8%, respectively). However, significantly more women did not have a live-in caregiver (71.2%). Individuals with an informal caregiver tended to be younger than those without one (82.2 ± 6.8 vs. 84.4 ± 6.8; p<0.001). Perhaps not surprisingly, being married was closely associated with having a live-in caregiver (61.8% vs. 14.6% with no live-in caregiver), consistent with one's spouse commonly being the primary informal caregiver. Similarly, being widowed was strongly associated with not having a live-in caregiver (68.4%). Individuals in the lowest income quintile were also much less likely to have a live-in caregiver (25.8% vs. 18.6% with a live-in caregiver). Finally, similar to that observed for spousal caregivers, individuals with a live-in caregiver received a much higher level of informal care than those without a live-in caregiver.

Receipt of formal care services was stratified according to the sex of the care recipient (Table 5). Women received a higher level of formal care than men in the case of PSW, homemaking and meal services, perhaps a result of women generally receiving less informal care support than men as noted above. On the other hand, men were somewhat more likely to receive nursing support and therapy (physical, occupational and/or speech therapy).

4.1.2 Time to LTC placement

The transition to LTC over time was examined by plotting the cumulative incidence function for the full cohort and stratified by key variables (Figure 6). The cumulative incidence function represents the probability that the event of interest (i.e., LTC placement) has occurred by time *t*. Because of the presence of a competing risk (i.e., death in the community), the Fine and Gray method was used for the analysis (Fine, 1999). The cumulative incidence curves for males and females were essentially coincident (Figure 6c) and very similar to that for the full cohort (Figure 6a). On the other hand, the probability of LTC placement increased with increasing age, CPS score (cognitive impairment), and disability in ADLs and IADLs (although in the case of cognitive impairment, the CPS 4 curve was actually higher than the CPS 5 curve) (Figure 6b, d, e, f). The curves for the highest level of cognitive impairment (CPS score of 6) and ADL disability (ADL score of 6) were initially parallel to the other curves but became less steep after approximately 90-100 days. This anomalous behaviour is almost certain due to the low number of individuals in those categories (CPS 6 = 0.9% of cohort; ADL 6 = 1.3%) and their having an elevated risk of death (in both cases, more individuals experienced the competing risk than the outcome of interest).

Finally, the outcomes were examined for the cohort, stratified by key variables (Table 6). In general, predictors that had a greater association with the LTC cohort than the full cohort also correlated with a shorter time to LTC placement. For example, the median time to LTC placement for an ADL of 0 was 147 days, dropping to just 33 to 35 days for an ADL of 4, 5 or 6. Similarly, the median time for individuals with an IADL score of 0 was 171 days as compared to 52 days for an IADL score of 6, and 88.5 to 100 days for a CPS score below 3 vs. 36 days for a CPS score of 6. As previously noted, hours of informal care did not appear to have much of an association with LTC placement, except at the highest level (42 hours and above per week) where the median time was 88 days as compared to 113.5 to 133 days for all other categories; however, individuals who were missing an entry had a significantly faster time to LTC entry with a median of 33 days. Being married led to a longer time to LTC placement (median of 85 days) as compared to being widowed (69 days), divorced/separated (66 days) or having never been married (56 days). Finally, if a caregiver was unable to continue providing support, the median time to LTC placement was 48 days vs. 83 days for those still able to provide support.

4.2 Model development

As described in the Methodology section, a preliminary list of 69 variables was compiled for the predictive model based on a review of the literature and expert consensus (Table 2). To create a parsimonious model that still captures as much of the predictive information as possible, 21 variables were eliminated that were either highly correlated or provided a minimal contribution to the model's overall variance using the SAS PROC VARCLUS procedure and the Ambler stepdown process. The final model consisted of 48 variables with 99 degrees of freedom, of which 28 variables were dichotomous.

The adjusted hazard ratios (with 95% confidence intervals) for all variables were determined using Cox proportional hazards regression analysis (Table 7). The values represent the risk of LTC placement within one year of the index event date (i.e., first RAI-HC assessment following dementia diagnosis), accounting for death in the community as a competing risk. The results for key variables are summarized below in relation to the conceptual model (Figure 1).

Predisposing factors. Age did not appear to be a significant predictor of LTC admission after adjusting for other predictor variables. The continuous age variable was overall slightly predictive (HR = 1.03; 95% CI = 1.02–1.04), but there was no statistically significant age effect when expressed as a restricted cubic spline. As compared to being married, the risk was higher for individuals who were widowed (1.11; 1.07–1.15), divorced/separated (1.14; 1.08–1.20), or never married (1.11; 1.05–1.18). Consistent with marriage reducing the risk of LTC placement, having an informal helper who lives with the care recipient was also protective (0.87; 0.85–0.90). Higher income was associated with a decreased risk of LTC placement, with lower hazard ratios at the highest income quintiles. Living in a setting other than one's private home (such as an assisted living facility or group home) carried an increased risk of LTC placement (1.24; 1.20–1.29). Interestingly, individuals whose home environment contained hazards that limited access to the home or rooms in the home (e.g., due to stairs that the care recipient is unable to climb easily) had a lower risk (HR = 0.88 and 0.91, respectively; p<0.0001).

Needs variables – health-related aspects. Individuals with decreased cognitive ability and presence of behavioural symptoms generally had a higher risk of LTC placement. For example, having a CPS score of 3, 4 or 5 was strongly predictive (hazard ratios of 1.53, 1.35 and 1.35, respectively; p<0.0001), although a CPS score of 6 was less predictive (1.19; 1.04–1.37). Wandering was also strongly predictive (1.25; 1.20–1.29). An overall worsening in behavioural symptoms (as compared to the status 90 days before the assessment) was also predictive of LTC entry (1.14; 1.10–1.17). Having symptoms of depression (as measured by the interRAI depression rating scale (Burrows, 2000)) was not predictive of LTC admission. Similarly, of the 11 chronic diseases included in the model, almost none was predictive to any meaningful extent, with the exception of Parkinsonism (1.12; 1.07–1.17). On the other hand, an increasing number of medications was found to be protective (HRs of 0.87 to 0.89 for 5 or more medications; p<0.0001), as was receipt of hypnotic or analgesic medication (0.87; 0.85–0.89).

Needs variables – functional impairment. Functional impairment was consistently a strong predictor of LTC entry. For example, a high falls frequency (three or more in the last 90 days) had a hazard ratio of 1.24 (95% CI = 1.20–1.28), and bladder incontinence had a HR of 1.09 (1.06–1.12). Difficulties with ADLs and especially IADLs were also predictive. As compared to an ADL score of 0, the hazard ratio increased with increasing score up to 5 (peaking at 3 and 4: HR = 1.31; p<0.0001). However, there was no statistical difference for an ADL score of 6. The effect was more pronounced with the IADL scale, with hazard ratios between 1.43 and 1.54 for IADL scores of 3 to 6 (p<0.0001).

Enabling resources. No statistical association was found between prior hospital admissions and LTC entry. The level of informal care was predictive of LTC admission, with increasing hazard ratios for the highest levels of care (28-34 hours per week, 1.07; 35-41 hours per week, 1.06; and 42 hours or more per week, 1.15). Notably, the hazard ratio was highest for individuals for whom data on informal care was missing (3.55; 3.37–3.73), which may correspond to receiving no informal care. Among the formal care services examined, receipt of both PSW services (0.95; 0.92–0.97) and therapy (occupational, physical or speech) (0.82; 0.80–0.84) was associated with a lower risk of LTC entry while nursing (1.07; 1.04–1.10) and especially meals services (1.21; 1.16–1.25) had a higher risk. As previously noted, 10.9% of the cohort were missing data on formal care services; however, in almost all cases the hazard ratios associated with missing data were not significant and therefore not meaningful. Finally, with respect to informal caregiver characteristics, having one's spouse as the informal helper (as compared to child or child-in-law) was protective (0.93; 0.89–0.97), while “other relative” had a higher risk (1.09; 1.05–1.13) and friend/neighbour had no statistical difference. In addition, if the caregiver felt that she or he was unable to continue in the role, there was a much higher risk of LTC entry (1.21; 1.18–1.24). Conversely, if the caregiver was not satisfied with support from the family, the risk was lower (0.88; 0.84–0.92).

4.3 Model performance

For the purpose of assessing model performance, calculations were performed using a random 20% sample of the full cohort (32,868 individuals) and the time to event (LTC placement) was expressed in weeks instead of days (1 week = 1 to 7 days; 2 weeks = 8 to 14 days; etc.). These changes were necessary to reduce the computational complexity such that the analytical program could run in SAS (using the full cohort would have required more than two weeks of computing time). To ensure a statistically valid proportional hazards regression model, there should be at least 10 outcome events per independent variable (Peduzzi, 1995). In fact, 8,645 individuals in the random sample were placed in LTC (the outcome of interest); thus, there are well in excess of 10 events per variable (total of 48 variables and 99 degrees of freedom), indicating that the 20% sample size is more than adequate. The random sample was also found to be representative of the full sample when the baseline characteristics of both samples were compared (data not shown).

The predictive model was tested first for its discrimination; i.e., its ability to predict an individual’s risk ranking in terms of which individuals will be placed in LTC earlier vs. later or not at all. A concordance (or C) statistic value of 0.748 was calculated, roughly midway between random concordance (0.5) and perfect concordance (1.0).

A second important measure of model performance is its calibration; i.e., how closely the predicted risk approximates the observed risk, or in other words the ability of the model to accurately predict time to LTC placement. To assess calibration, the cohort was ranked based on the predicted one-year (52-week) risk of LTC entry (calculated from the regression model) and divided into 50 risk groups. The observed risk (i.e., cumulative incidence function) for the 50 groups versus time is shown in Figure 7. The mean predicted risk for each group was compared with the mean observed risk (Figure 8). A very close match between observed and predicted risk was noted for all risk groups, except for the two highest groups (49 and 50) where the predicted risk was approximately 15% higher than the observed risk. The outcomes by risk group and statistics on time to LTC placement are shown in Table 8 and Figure 9. As expected, the number of individuals experiencing the outcome of interest increased fairly consistently from the lowest risk group (1) to the highest (50), while the median time to LTC placement decreased from 278.5 days to just 29-30 days.

Calibration was also tested by comparing the predicted and observed risk of LTC placement for key variables both within and outside of the model (Figure 10). Once again, there was very close agreement between the observed and predicted risks for all variables examined. In the case of MAPLe score (Method for Assigning Priority Level, used in determining need for LTC placement (Hirdes, 2008)), the model over-predicted slightly at the lower MAPLe scores (1 and 2) but showed good agreement at the higher scores (3 to 5) (Figure 10f).

Finally, the utility of the model for estimating risk beyond one year was examined. The random 20% cohort was divided into risk deciles based on one-year predicted risk, and the observed outcomes up to five years post-index event date were plotted (Figure 11). The 10 cumulative incidence curves did not cross and maintained good separation across the full time period. Thus, it is likely that similar risk discrimination would be observed for regression models based on predicted risk at time points beyond one year as compared to that of the one-year risk model presented here.

5. Discussion

5.1 Predictive model for estimating risk of LTC placement

This study represents, to the best of our knowledge, the first use of population-level data to generate a predictive model estimating the risk of LTC placement for community-dwelling individuals with dementia receiving formal home care services. The use of population-level data allows for a very large sample size and significant statistical power: Data were obtained for nearly 164,000 individuals with dementia, of whom over 43,000 experienced the event of interest (i.e., LTC placement) within one year of their first RAI-HC assessment following dementia diagnosis. The use of RAI-HC data also allowed us to consider a wide range and number of predictors. An important aspect of the regression modelling was to include death in the community as a competing risk. Individuals who die in the community are obviously prevented from experiencing the outcome of LTC placement, and this competing risk must be taken into account in the predictive modelling to avoid incorrect risk estimates.

Our regression model demonstrated a high level of discrimination, which is a model's ability to differentiate individuals at high risk from those at low risk; that is, to rank individuals correctly based on risk of experiencing the outcome of interest. Discrimination is commonly measured by the C statistic, with values over 0.7 considered to be good models, and over 0.8 to be excellent models (Hosmer, 2013). The C statistic for our model was 0.748, indicative of a very strong fit, particularly in light of the fact that the study population was relatively similar in that it only included seniors with dementia and at risk of LTC placement, making it more challenging to discriminate individuals as compared to a more diverse population. The lack of perfect concordance indicates that there are additional variables that contribute to risk. However, because of the likely contribution of unmeasured confounders for which we have no data (such as an individual's resilience, social support network beyond simply the presence of an informal caregiver, or privately-paid formal care services), there will always be limits to the level of discrimination that a model such as this can achieve.

Model performance is also commonly assessed by its calibration, or how closely the predicted risk approximates the observed risk. We assessed calibration by dividing the cohort into 50 risk groups and comparing the average predicted and observed risk (i.e., cumulative incidence function) for each group (Figure 8). The predicted risk closely approximated the observed risk across almost all risk groups, with the exception of the two highest risk groups where the model over-predicted the risk. This is perhaps not unexpected due to the realities of the LTC system in Ontario. Demand for LTC exceeds current capacity, with 32,046 individuals on the wait list for LTC as of June, 2017 and an average time to placement for those on the wait list of 137 days (OLTCA, 2017). Even for those in greatest need of LTC placement, there are practical limits to how quickly they can move through the system and be placed, creating a kind of “ceiling effect” of how fast an individual can enter LTC that is not accounted for in the predictive model. The effect of these delays would presumably be less evident for the lower risk groups where the predicted time to LTC placement is longer; however, for the highest risk individuals who transition quickly to LTC, the effect of delays is likely significant relative to the predicted time to LTC placement. The data trends in Figure 9, in which the median time to LTC placement is plotted for the 50 risk groups, may also reflect this ceiling effect. As expected, the placement time decreases with increasing level of risk, but instead of continuing down to zero as the trend would predict, a floor of approximately 30 days is reached by around risk group 44. These constraints may be alleviated to some extent by the Ontario government’s recent decision to add 5,000 new LTC beds by 2021-22, and a total of 30,000 over the next decade, augmenting the roughly 78,000 beds that currently exist (Ministry of Seniors Affairs, 2017).

Model calibration was also assessed by comparing observed vs. predicted risk for a number of key variables (Figure 10). Again, excellent agreement was observed in all cases. Of particular note was the comparison with MAPLe score (Figure 10f). MAPLe is a decision-support tool based on a number of RAI-HC variables and used to prioritize individuals for LTC placement (Hirdes, 2008). In Ontario, only individuals with a MAPLe score of 4 or 5 are eligible for LTC (OLTCA, n.d.). Our predictive model included only a subset of the RAI-HC variables used to derive the MAPLe score, yet it performs as well as MAPLe in predicting risk of LTC entry, further validating the utility of our model for policymakers. In fact, our predictive model has a number of advantages over MAPLe, including the ability to discriminate a much higher number of risk groups (at least 10 and up to 50, as compared to 5 with MAPLe) and the use of a larger number of predictors to improve calibration.

The predictive model generated here estimates the risk of LTC placement one year after the first RAI-HC assessment following dementia diagnosis. A one-year time frame was chosen for several reasons. First, nearly 70% of all individuals in the cohort who entered LTC by the end of the maximum follow-up period did so within one year of the RAI-HC assessment (median time of 162 days, mean of 323.6 days); thus, one year captures the majority of primary outcomes observed. Second, a one-year timeframe is relevant from the patient’s and family’s perspective to assist with planning decisions in the immediate term. Third, because of the way the cohort was created, individuals can be followed for as little as 11 months and as much as nine years less a month (Figure 4b); thus, limiting the follow-up to one year ensures that almost all individuals can be followed for the full period. And finally, the computational intensity of the regression modelling increased significantly with increasing follow-up time, making it challenging to model a period of greater than one year. Regardless, it is highly likely that similar results would be obtained for follow-up periods up to five years, based on the results shown in Figure 11: Comparing the risk profiles for the full cohort divided into deciles based on the one-year predicted risk demonstrates that the risk discrimination holds true out to five years post-RAI-HC assessment as the curves do not cross and remain roughly parallel. Thus, predictive models estimating risk at any time point up to five years should generate the same risk rankings as that from the one-year model developed here.

As an alternative to using predicted risk at later time points, the power of a large population-level study such as this means that observed risk trajectories can be used for prognostication. As outlined in Figure 12, the predictive model estimates one-year risk of LTC placement, allowing the cohort to be divided into ranked groups based on predicted risk. The risk trajectory of each group beyond one year can then be determined based on observed data (as in Figure 11), instead of the predicted risks. To estimate the risk of a new individual, his or her predicted risk at one year is calculated using the predictive model and the individual then assigned to the appropriate risk group. The observed five-year risk trajectory of the assigned group can then be used for risk prognostication beyond one year, and in fact may be a more accurate and more easily interpretable indication of the likely risk trajectory since it is based on actual rather than predicted data. Indeed, this approach is currently being used by Doug Manuel and colleagues at the Ottawa Hospital Research Institute in the development of their Project Big Life health and life expectancy calculators (www.projectbiglife.ca) (Manuel, 2016).

5.2 Key factors influencing time to LTC placement

Based on the adjusted hazard ratios from the regression analysis (Table 7), the predictors associated with the greatest risk of LTC placement were cognitive impairment, behavioural symptoms and functional impairment. Important protective factors included marital status, whether an informal helper lives with the client, living arrangement, and variables related to informal care. On the other hand, age and sex (among other variables) had little or no significant effect on predicting risk. The sections below elaborate further on the key factors in relation to the conceptual model, with comparisons to results from other published studies. The first section examines the predisposing and needs variables, while the second section considers the enabling factors, with a specific emphasis on those related to formal and informal care. Finally, sex and gender considerations associated with formal and informal care variables are discussed.

5.2.1 Predisposing and needs variables

Several protective factors were noted among the predisposing factors included in the model, including marital status, whether an informal helper lives with the client, and variables related to living arrangement. As reported in other studies (Luppa, 2008; Gaugler, 2009), being married had a protective effect as compared to individuals who were widowed, divorced/separated, or never married. This result is not unexpected as one's spouse is often the primary caregiver. Consistent with this result, having a live-in informal caregiver was also protective. These effects speak to the importance of informal care in maintaining people with dementia at home and delaying their transition to institutional LTC (elaborated further in the next section under Enabling Factors). Living in a private home as compared to other arrangements such as assisted living, group homes and residential care also reduced the risk of LTC placement. Consistent with this result, home ownership has been shown to be associated with delaying entry into LTC (Gaugler, 2007; Cai, 2009). While people residing in private homes may have lower needs and/or a more supportive informal care network as compared to those in other settings, the protective effect may also reflect factors such as one's resilience and determination to remain independent despite functional and cognitive challenges, and/or having the financial means to pay for private in-home support services (all of which are variables that are not directly measured as part of the RAI-HC assessment). An unexpected result was that a lower risk of LTC placement was associated with a hazardous home environment affecting access to the home or access to rooms in the home (for example, due to stairs that the care recipient in unable to climb easily). This result may be indicative of a high level of personal resilience or independence which allows them to manage at home in spite of the hazard, and more generally contributes to a protective effect against LTC placement.

In terms of needs variables, the key predictive factors were cognitive impairment (worsening decision-making and elevated CPS score), behavioural symptoms (wandering and an overall worsening of behavioural symptoms), and functional impairment (increasing falls frequency, ADL score and especially IADL score). These results are consistent with those observed in other studies (Luppa, 2008; Gaugler, 2009). For CPS score, the hazard ratios peaked at a score of 3 (HR = 1.53) and then declined (HR = 1.35 for CPS score of 4 or 5, and 1.19 for CPS score of 6). A similar pattern was observed for ADL and IADL scores, which peaked in the mid range of the scales (score of 3 or 4) and then declined somewhat. This may be because individuals with the highest CPS and ADL/IADL scores are almost always completely bedridden (for example, a comatose individual has a CPS score of 6, while the highest ADL/IADL scores indicate total or near-total dependence) and therefore can be managed more easily at home with appropriate home care as compared to someone with dementia who is mobile. In addition, as functional and cognitive impairment often develops gradually, the fact that these individuals have managed to remain at home throughout their decline could be indicative of unmeasured confounders like privately-paid in-home care that would reduce the need for LTC placement. We also found that another measure of functional impairment, namely bladder incontinence, was predictive of LTC placement (albeit to a lesser extent), as compared to inconsistent results found from other studies (Luppa, 2008; Gaugler, 2009).

Receipt of three or more prescription medications in the week preceding the RAI-HC assessment had a protective effect on LTC placement, with an even greater effect at five or more medications. Interestingly, simply receiving hypnotic or analgesic medication was as protective as receiving 9 or more medications (although it is possible that individuals who received this medication also received multiple medications). According to the RAI-HC User's Manual (CIHI, 2010), hypnotic or analgesic medications produce an insensitivity to pain by causing partial or complete unconsciousness. This state is similar to extreme cognitive impairment which (as noted above) can reduce the need for LTC, thus creating a protective effect and perhaps explaining the result observed here. This result is notable as few published studies have examined medication use (including psychotropic drugs) as a predictor of LTC entry, and among those that did, inconclusive or conflicting results were reported (Gaugler, 2009).

Factors that had little or no effect on time to LTC placement were age and sex (female sex was only slightly protective with a hazard ratio of 0.97, p=0.0024). Inconsistent results have been reported in the literature with respect to age and sex (Luppa, 2008; Gaugler, 2009), with some studies finding an increased risk for males and for older persons, while others did not find a statistically significant effect. It is important to note that the hazard ratios from the regression model are adjusted for the effects of all the other variables in the model. Thus, while LTC residents are generally older and female, these variables on their own are not predictive of LTC entry. In general, the presence of comorbid conditions also had little, if any statistically significant effect on risk of LTC placement (either elevating or reducing risk). Small predictive effects (HRs of 1.04 to 1.06) were observed for stroke, coronary heart disease, peripheral vascular disease, arthritis and diabetes. The one exception was Parkinsonism with a hazard ratio of 1.12. Parkinson's disease often results in decreased cognitive ability, which may explain the increased risk of LTC placement associated with Parkinsonism. Similarly, coronary and circulatory diseases can also lead to impaired brain function, potentially increasing the need for LTC. In contrast to that observed in other published studies (Luppa, 2008; Gaugler, 2009), we found here that depression (as measured using the RAI Depression Rating Scale) had no effect on LTC placement. We also found that the number of hospital admissions in the 90 days preceding the RAI-HC assessment was not predictive of LTC entry, consistent with that reported in the literature (Gaugler, 2009).

5.2.2 Enabling factors – formal and informal care

Formal care services. The effect of various formal care services in the week preceding the RAI-HC assessment was examined. Receipt of PSW services only slightly reduced the risk of LTC placement, while receipt of nursing or homemaking services was associated with an increased risk. On the other hand, individuals receiving meals services and a basket of other services including volunteer, day care, day hospital and/or social worker were at higher risk of LTC placement while those receiving in-home therapy (physical, occupational and/or speech) were at lower risk. While it may be expected that more services would reduce the risk of LTC placement, it is also possible that individuals receiving more services may be at increased risk because their needs are greater (hence the higher level of services), complicating the interpretation. Another important limitation is that the RAI-HC assessment only captures the hours of services provided in the week before the assessment, and it is likely that the level and mix of services for many individuals changed as a result of the RAI-HC assessment, particularly for those who were not already receiving publicly-funded home care prior to the assessment. In addition, the high proportion of missing values (10.9% of the full cohort, and 19.5% of those who transitioned to LTC) makes interpretation challenging, as it cannot simply be assumed that a missing value means that no services were provided. As previously noted, one possibility is that individuals missing these data received their RAI-HC assessment while in hospital to determine their eligibility for home care post-discharge or for LTC admission, as the RAI-HC manual notes that collection of these data elements is not required in hospital settings “as these services are available to all clients in hospital settings and therefore do not discriminate the functional needs of individual clients” (CIHI, 2010, p. 127). Consistent with this, a recent CIHI report found that seniors who received their initial RAI-HC assessment in hospital were significantly more likely to be placed in institutional LTC than those who were assessed in the community (CIHI, 2017).

Informal caregiver characteristics. Several variables related to the informal caregiver were found to decrease the risk of LTC placement. First, the relationship between the informal caregiver and the care recipient was important: As compared to a child or child-in-law (the most common relationship at 56.0%

of all informal caregivers (Table 4a)), having a spousal caregiver decreased the risk of LTC entry while other relatives increased the risk (there was no statistical difference for a friend or neighbour as the primary informal caregiver). The protective effect of a spousal caregiver has also been shown in other studies (Luppa, 2008). Not unexpectedly, there was a significantly increased risk of LTC placement if the primary caregiver reported being unable to continue in the role (HR = 1.21), consistent with the importance of informal care in maintaining individuals with dementia in the home. On the other hand, if the primary caregiver was not satisfied with support from the family, the risk of LTC placement was decreased (HR = 0.88), suggesting that a lack of family support does not contribute to the caregiver feeling unable to continue in the role. It is possible that caregivers who are providing a higher level of care are more prone to voice their concern about lack of support, hence the apparent protective effect. Notably, the number of care recipients with a caregiver who was unable to continue in the role was very large, indicating a high population burden: The group included one in six of all care recipients (16.8%) and nearly one quarter (22.8%) of individuals who entered LTC within one year of the index RAI-HC assessment (Table 3).

We noted a number of interesting differences in the characteristics of the care recipients depending on the relationship of the informal caregiver (Table 4a). First, individuals with a spousal caregiver were significantly younger and much more likely to be male than those with another caregiver. This is presumably because as people grow older, it is more likely that their spouse dies or is unable to serve as the primary informal caregiver. Furthermore, since women have a longer life expectancy than men and tend to be younger than their husbands, they are more likely than men to be widowed by the time they develop dementia and need an informal caregiver, leading children or other relatives to become the primary caregiver more frequently for women. Spousal caregivers were also much more likely to be unable to continue in the role, presumably because of their advanced age and challenges stemming from their own health problems. They also provided the highest intensity of care in terms of hours of informal help, perhaps contributing to caregiver distress and burnout. On the other hand, a child or child-in-law caregiver was more likely to report not being satisfied with support from others. This may reflect family dynamics; for example, situations where one sibling (typically a daughter) becomes the primary caregiver and the other siblings contribute minimal support, leading to frustration and dissatisfaction on the part of the caregiver.

Hours of informal care. We expected that higher levels of informal care (as measured in hours received in the week preceding the RAI-HC assessment) would reduce the risk of LTC placement. However, there was little, if any statistically significant effect at all categories up to 41 hours per week, while the highest category (42 hours and above) was associated with an increased risk of LTC placement (HR = 1.15; 95% CI = 1.10–1.21). Inconsistent results have been reported in the literature with respect to informal caregiver hours and LTC placement (Luppa, 2008). It is possible the higher levels of informal (and formal) care may reduce the risk of LTC placement for some individuals while appearing to increase the risk for others. For example, a high level of care for someone with lower needs would presumably reduce their risk of LTC placement, while a high-needs individual receiving the same level of care may still transition to LTC because they cannot be maintained at home. These contradictory effects may cancel each other out to some extent in the predictive modeling, or at least contribute to inconsistent or confusing results. Further confounding the interpretation was the fact that individuals missing data on informal care (19.3% of the full cohort, and 39.7% of the LTC cohort) had an especially elevated risk of LTC placement (HR = 3.55; 95% CI = 3.37–3.73). One possible explanation is that the missing values in fact correspond to zero hours of informal care, which would then make any level of informal care protective in comparison. A visual examination of the characteristics of individuals with missing values for informal care (data not shown) did not reveal any obvious patterns: The overall profile was similar to that of the full cohort, except for the fact that everyone who was missing data on formal care services was also missing data on informal care hours. Regardless, the high proportion of missing values makes it difficult to derive any meaningful interpretation from the data on hours of informal care.

5.2.3 Sex and gender considerations – formal and informal care

The majority of home care recipients are women: Women represented 62.0% of the full cohort in this study and 61.6% of those who were placed in LTC within one year of the index event date (Table 3). The health and social needs of women and men vary, as do their end-of-life trajectories (Gill, 2010). Thus, it is important to consider sex and gender when applying the results from predictive models such as this, as conclusions can vary depending on whether the care recipient is male or female. Women also represent the majority of formal care providers and informal caregivers, and in particular spousal caregivers. Because of these important differences, we examined how some of the formal and informal care variables examined in the predictive model may relate to sex and gender.

Receipt of formal care services varied according to the sex of the care recipient (Table 5): Women were more likely to receive PSW, homemaking and meal services, while men were more likely to receive nursing and therapy services. These differences are consistent with the typical end-of-life trajectories of men and women (Gill, 2010). Specifically, men generally die earlier with more complex medical needs resulting from organ failure (hence the increased use of nursing and therapy services), while women tend to live longer with a prolonged decline due to frailty that necessitates personal support (PSW, homemaking and meal services) more so than nursing and therapy. Similarly, Gruneir *et al.* (2013) found that male home care clients presented with higher levels of need as compared to female clients. These differences need to be considered when deciding how to tailor the availability and provision of formal care services, as a one-size-fits-all solution will not necessarily be the most effective for both women and men.

With respect to informal care, we examined factors associated with sex for both the caregivers and the care recipients and how they relate to traditional gender-based caregiver roles. While the RAI-HC assessment does not directly collect information on the sex of the informal caregiver, it can be inferred from the data that the vast majority of spousal caregivers are women (Table 4a); furthermore, other studies have shown that the majority of informal caregivers (spousal or otherwise) are female (Keefe, 2011). Women also provide a higher intensity of care than do male caregivers (Sinha, 2013). As a result, women overall experience a greater caregiver burden; for example, among the non-economic social and physical costs of caregiving noted in the 2007 Statistics Canada General Social Survey (i.e., effects on social activities, changed holidays and less time with one's spouse or children), the impact in all cases was greater on women than on men (Keefe, 2011). Providing support services for informal caregivers is essential to help maintain them in that role. Support can take the form of labour policies such as flexible workplaces and paid caregiver leave; programs to enhance caregiver well-being including respite care, counselling and community support groups; and direct financial support through tax credits or allowances (OECD, 2011; CCC, 2017). Encouragingly, the Ontario government plans to increase support for caregivers as part of its updated Action Plan for Seniors (Ministry of Seniors Affairs, 2017); however, it is not clear how effective this will be as the specific commitment is only to create a new province-wide organization to provide caregivers with support and resources.

In terms of care recipients, a striking sex imbalance was noted in relation to whether the informal caregiver lives with the care recipient, with men much more likely to have a live-in caregiver than women (Table 4b). Consistent with one's spouse often serving as the primary informal caregiver, those with a live-in caregiver were much more likely to be married. Furthermore, care recipients with a live-in caregiver were younger, more often male, and received a higher level of informal care than those without. On the other hand, individuals without a live-in caregiver were much more likely to be in the lowest income quintile, presumably because they live alone as their spouse has died and they only have one income. As the vast majority of individuals without a live-in caregiver in the study cohort are female, it suggests that elderly women with dementia are at a greater risk of poverty than their male counterparts, restricting their access to paid formal care and other support services that may help sustain them at home and maintain their health. These caregiver and associated effects are especially evident in the characteristics of individuals in the highest risk groups for LTC placement (Appendix 4). In particular, individuals in the highest risk groups were less likely to be married, have a live-in informal caregiver or a spousal caregiver, and more likely to be female, in the lowest income quintile or have a caregiver who is unable to continue. These individuals presumably require more proactive interventions as they may be less likely to seek care on their own and lack a caregiver to advocate on their behalf. An understanding of the demographics of the care recipient population is clearly important in designing the appropriate range of services and interventions to help maintain them at home.

5.3 Model application to policy development and risk prognostication

An important outcome of this predictive model is its ability to help shape the development and implementation of health policy for home care and LTC. Governments across Canada at both the provincial/territorial and federal levels have created policies directed at maintaining seniors at home for longer, with the goal of delaying or obviating the need for institutional LTC. In particular, the federal government has committed $6 billion over 10 years for improved home care services (Government of Canada, 2017), and the Ontario Ministry of Seniors Affairs recently released an updated Action Plan for Seniors entitled “Aging with Confidence” (Ministry of Seniors Affairs, 2017) that includes a broad range of actions such as increased in-home health care, additional home care hours for services including PSWs, nurses, physical and speech therapy, and expanded community dementia programs. At the same time, the Ontario government announced its intention to create over 30,000 new LTC beds over the next decade, and 5,000 by 2021-22 (Ministry of Seniors Affairs, 2017).

The predictive model developed here can inform these policy changes by identifying the most important targets for intervention. The key factors associated with LTC placement identified by the model (i.e., cognitive impairment, behavioural symptoms and functional impairment) indicate the types of services and supports that should be expanded to maintain people at home longer. For example, the high hazard ratios associated with increased ADL and IADL dependency indicate the importance of providing supports to address people’s functional impairments. However, as the hazard ratios for IADL dependency are higher than for ADL dependency, it suggests that increasing IADL supports (e.g., assistance with housework and grocery shopping) should take precedence over ADL supports. Also, the higher risk associated with being single and not having a live-in caregiver emphasizes the importance of identifying and targeting people living alone to ensure they have the supports they need in their home. And finally, the importance of informal caregivers reinforces the need for programs and services to support them and prevent caregiver burnout.

The predictive model can also be used to estimate future demand for LTC, based on demographic projections and dementia incidence rates, and how that need may change as a result of increased home care services (or indeed, as a result of changes to any of the predictors included in the model). The Ontario government has committed to a substantial increase in LTC beds over the next decade which will help to address the current excess demand; however, it is possible that future demand will decline after the cohort effects of the baby boom generation have passed and the demographic pyramid loses its baby boom "bulge". Thus, while this policy decision may make for good politics, it is less clear whether it is the most efficient use of health care dollars and if the funds would be better spent on additional home care and supports for informal caregivers. Applying this model for future modelling would help determine the need for these planned investments.

Finally, the predictive model can be used by physicians and patients newly diagnosed with dementia to estimate risk of LTC placement. Physicians have few, if any tools beyond their own experience and instinct to advise patients and their families of what to expect regarding disease progression. Our predictive model fills this gap by creating an algorithm to determine an individual's one-year risk of LTC placement based on her or his RAI-HC assessment data following dementia diagnosis. As shown in Figures 11 and 12, the results of our study could potentially allow for longer-term prognostication by matching individuals to pre-defined risk groups based on their predicted one-year risk, and then using the observed risk of individuals in that risk group to predict disease and care trajectories for up to five years. To make the model more user-friendly for prognostication, an online interface similar to that used by the life expectancy calculator Project Big Life (www.projectbiglife.ca) could be created.

5.3.1 Health workforce implications

An essential consideration when developing these home care and LTC policies (and indeed, any health policy) is the implications for human resources for health (HRH). Successful implementation of health policies such as these depends heavily on having a sufficient number, distribution and mix of adequately trained and supported health workers from both the formal and informal care sectors in order to be feasible (Bourgeault, 2015; Huyer, 2016), and as such the implications for HRH need to be assessed. What exactly does it mean to assess the implications of a new policy on HRH? Nove *et al.* (2017)

distinguish between *impacts* and *implications*: Impacts are the effect of the initiative on the health workforce, while implications recognize that successful policy implementation depends on the health workforce and that HRH requirements need to be part of the planning and implementation process. They propose a health workforce impact assessment tool that begins by exploring the potential impacts on the following areas: health labour market dynamics; management and regulation of the health workforce; health worker education and training; and attitudes of and towards health workers. The tool then continues with a guided assessment of the initiative's potential dependency on the health workforce; a more detailed examination of health workforce impacts; an equity analysis; a stakeholder analysis; and legal and political considerations.

A structured tool such as the one proposed by Nove (2017) provides a valuable framework to begin investigating the health workforce impacts and implications of policy changes. However, an effective assessment of HRH implications depends on the availability of good quality health workforce data. One of the great strengths of the ICES data holdings is the linkages between datasets. For example, the RAI-HC data on formal care services is limited because it is self-reported and retrospective (services received in the week prior to the assessment), restricting the conclusions that could be drawn from this predictive model. However, the Ontario Home Care Database (HCD) records longitudinal data on specific home care services provided to clients. While it was beyond the scope of this thesis project, it would be interesting to link HCD data to the RAI-HC data to more fully explore the impact of specific home care services over time on the risk of LTC placement.

On the other hand, a significant gap exists with respect to information about the health workforce itself. The vast majority of home care (and institutional LTC) is provided by PSWs (Estabrooks, 2015), yet as the profession is unregulated there is no central organization responsible for their oversight. In an effort to better understand the PSW workforce, a registry was launched in 2012 to collect information about the training and employment status of Ontario's PSWs (Born, 2012). However, the registry was disbanded in 2016 over concerns about data quality (Zlomislic, 2016). The province recently announced plans to implement a new mandatory PSW registry beginning in 2018 (MOHLTC, 2017). While this is an encouraging development, it remains to be seen exactly what data will be collected and if/how the registry can be used to assist in PSW capacity planning and development (including whether it can be linked to other ICES data holdings). With respect to regulated health professions, the Ontario MOHLTC does maintain the Health Professions Database which contains demographic, geographic, educational and employment information on all regulated allied health professionals in the province; however, it is not linked with the suite of datasets at ICES.

In addition to the formal care sector, the health workforce includes many informal caregivers who play a significant role in maintaining seniors with dementia in their homes. While the RAI-HC questionnaire collects some information about informal caregivers, the data are limited, particularly with respect to caregiver sociodemographics, stressors, well-being and support which have been shown in other studies to be important in predicting risk of LTC admission (Luppa, 2008; Gaugler, 2009). A common test for caregiver burden is the Zarit Burden Interview (Zarit, 1985), consisting of 22 questions. A shortened version (12 items) and a screening version (4 items) of the tool have been derived that produce results comparable to the full version (Bedard, 2001) and could potentially be incorporated into RAI-HC to provide a more complete picture of caregiver burden. Another option would be to collect the OHIP number of the primary informal caregiver as part of the RAI-HC assessment (the caregiver's name is already part of the questionnaire). Having the caregiver's OHIP number would allow for data linkages within the ICES holdings, from which a detailed picture of the caregiver's health and socioeconomic status could be derived.

5.4. Limitations and strengths

Limitations. There are several limitations associated with this study related to the data. First, the dementia diagnosis date was ascertained from health administrative data; however, dementia develops progressively and was therefore likely present before the diagnosis date used in this study. In addition, individuals with dementia who do not seek out health care would not be identified from the data. Nevertheless, the diagnosis dates used here are valid "anchor points" as they presumably represent a change in the severity of dementia that was significant enough to trigger an interaction with the health care system. Second, we did not confirm that individuals who were admitted to LTC were long-stay clients rather than short-stay. However, as only 1% of LTC beds in Ontario are for short-term respite or convalescence care (OLTCA, 2017), it is reasonable to assume that almost all individuals who enter LTC are long-stay clients. Third, we did not distinguish between people receiving a RAI-HC assessment in different settings (e.g., private home vs. hospital) and for different purposes (i.e., long-stay home care vs. eligibility for LTC). As noted above, a recent CIHI study found that 12% of seniors who received a RAI-HC assessment were in a hospital setting, and that they had a significantly higher risk of LTC placement than those assessed in the community (CIHI, 2017). It would be interesting to separate these groups in future analyses to determine if the risk factors vary between the two groups. Finally, when creating our dementia cohort, we assumed that LTC admission follows RAI-HC assessment and ignored any LTC admission dates prior to the RAI-HC assessment. Thus, it is possible that the cohort includes some people who were already in LTC when they received their RAI-HC assessment. However, it is reasonable to assume that if there are any individuals in this category, it is a very small number. The purpose of the RAI-HC assessment is to determine an individual's eligibility for long-stay home care or for LTC admission; thus, if the RAI-HC assessment was conducted in a LTC facility, it was presumably because the individual was about to be discharged to the community and the purpose of the assessment was to determine home care needs.

Additional limitations relate to the study design and analysis. First, the analysis is based on data from a single point in time (i.e., the first RAI-HC assessment after dementia diagnosis). An advantage of this approach is that an individual's risk of LTC placement can be determined immediately based on a single RAI-HC assessment without the need for repeated assessments. However, it is conceivable that factors may change over time, including health status, functional ability and level of formal/informal care, resulting in changes to an individual's risk. This limitation is mitigated by modelling risk of LTC admission one year after the RAI-HC assessment, as factors are not likely to change significantly in this time frame. Future work could include a longitudinal analysis focussing on understanding the role of a few key variables (e.g., related to formal and informal care provision) in predicting risk of LTC placement. Second, there is the potential for reverse causality, particularly with respect to formal and informal care services. For example, individuals with the greatest needs (and therefore at highest risk of LTC placement) presumably receive a higher level of care, with the result that increased care appears to raise the risk LTC placement rather than reduce it. This concern is addressed to some extent in the regression model by controlling for confounders; however, there are likely unmeasured confounders that are not captured or indeed cannot be accurately assessed (e.g., individual resilience). Nevertheless, the model's high degree of discrimination and calibration suggests that these issues are not overly significant.

Strengths. The key strength of this study is its use of population-level data, which greatly improves the power of the study and the validity of the statistical analyses. We also assessed the model's performance in terms of discrimination and calibration and found that it performed very well in both measures, strengthening the validity of the conclusions drawn from the regression model. By contrast, regression models in published studies are seldom assessed for their performance. In addition, our regression analysis included a wide range of variables covering predisposing factors, needs variables and enabling resources, allowing for a diverse analysis of key factors contributing to LTC placement. Few other studies have been as comprehensive in their assessment of potential predictors. Importantly, we applied a sex and gender perspective to the analysis, highlighting the differences in informal and formal care for both the caregiver and care recipient. The sex- and gender-based differences we observed reinforce the importance of considering the distinct needs and experiences of men and women when developing policies and programs related to home care and LTC. Finally, our study draws attention to the importance of health workforce considerations in interpreting and applying the results from the predictive model. Policy development is often informed by studies such as this, yet issues related to human resources for health are rarely addressed, despite the importance of HRH in ensuring the successful implementation of many of these policy changes.

6. Conclusions

The predictive model generated here represents the first use of population-level data to estimate risk of LTC placement for individuals with dementia. We found that the predictors associated with the greatest risk of LTC placement were cognitive impairment, behavioural symptoms and functional impairment. Important protective factors included marital status, whether an informal helper lives with the client, living arrangement, and variables related to informal care. The validity of the results is supported by the model's strong performance in both discrimination and calibration. The in-depth analysis of formal and informal care variables in particular revealed not only details of their contribution to delaying the transition to LTC, but also important differences related to the sex of the caregiver and care recipient.

The results of this study are of great value to policymakers as they respond to decisions by governments across Canada to increase their investments in home care in response to an aging population and the increasing demand for home care services. In particular, the predictive model can help in identifying the types of services to expand in order to maintain individuals with dementia at home longer, and in estimating future demand for LTC. The model can also be used to determine the profiles of individuals with the greatest need for additional formal care services. As these services are highly dependent on human resources for health, we examined ways to assess the health workforce implications associated with an increased emphasis on home care. Health administrative data can be very helpful in these analyses, but there are limits to what can be achieved with the available data and opportunities to improve health workforce data should be explored further.

This study also benefits individuals newly diagnosed with dementia, along with their families and physicians. Being diagnosed with dementia is often stressful and frightening for the patient and family because of uncertainty about the disease progression. The predictive model can help physicians, patients and their families understand the risk of LTC placement and the interventions that can best support the patient at home, aiding them in decision-making and care planning.

6.1 Next steps

Building on the results of this study, several areas for further research and investigation could be pursued. First, inclusion of data on formal care services from the Home Care Database would allow for a more fulsome analysis of the impact of specific services in delaying the transition from home care to LTC, from which care packages could be derived to further guide policymakers in deciding where to increase investments in home care services. A longitudinal study could also be conducted to determine if and how services change over time, and the optimal points for intervention along the disease trajectory and transition of care pathway to reduce the risk of LTC placement.

Second, the health workforce implications of increased investments in home care could be examined in greater depth with the help of an expert panel of researchers who have worked extensively with health workforce stakeholders and have expertise in aging and in the use of health administrative data. Building on the care packages derived in the study proposed above, the expert panel could help guide and validate the care package development, and to identify at a high level the key factors that may impact the feasibility of implementing those care packages. The panel would also be able to point out the limitations of health workforce data and help identify strategies and opportunities for improving data collection and linkages.

Finally, the impact of this present study, as well as those proposed above, would be strengthened by incorporating caregiver and care recipient perspectives. Their input would provide a kind of reality check to validate the conclusions from the statistical analyses derived from health administrative data. Stakeholder focus groups could include representatives of the formal care sector (e.g., PSWs, home care nurses, etc.), whose input would be particularly valuable in assessing the health workforce implications of policy changes. Interviews with informal caregiver/care recipient dyads would further provide a human face to the numbers and could be structured to allow for a more detailed consideration of the predictors of LTC placement associated with informal care, in particular caregiver distress.

Table 1. Knowledge gaps addressed by this thesis project.

Limitations of current knowledge	**Results of thesis project**
Studies of people with dementia used sample sizes of fewer than 6,000 individuals (the vast majority had fewer than 1,000), limiting their power	Significantly larger cohort using ICES data (163,983 individuals with dementia receiving home care) linking multiple datasets to create much more comprehensive data sources spanning many sectors
Data sources restricted to a defined cohort, such as people enrolled in a specific health care program, limiting the generalizability of the conclusions	Study uses individual-level, population-based health administrative data from linked datasets, allowing the assessment of a very broad range of predictors and potential confounders, along with multiple outcomes (e.g., mortality as a competing risk), with results that are generalizable to the general population
Studies generally more descriptive in nature, and while multivariable models were often used to identify predictors, most lacked rigor and were not assessed for their predictive qualities (e.g., calibration and discrimination)	Survival analysis using a Cox proportional hazards regression model was used to identify modifiable predictive factors, with death as a competing risk. A rigorous methodology was followed including pre-specification of variables and model reduction; in addition, model performance was assessed by measuring discrimination and calibration.
Very few Canadian studies, and those that have been carried out are more than 15 years old	Study provides a much-needed up-to-date analysis for the current Ontario context, with relevance to other Canadian jurisdictions
Health workforce impacts rarely examined in health policy development, including policies directed at an aging population	Health workforce factors (both formal and informal) affecting the transition from home care to LTC are highlighted, along with a consideration of potential approaches to better identify and assess health workforce implications in policy development

Table 2. RAI-HC and RPDB variables used for predictive model building.

1. Predisposing factors				
Description	**Variable^**	**Scale**	**Variable Range**	**Comments**
Age at RAI-HC assessment*	**age_r1c**	Continuous	65 - 104 years old	Create a 5-knot spline. From RPDB.
Sex*	**sex**	Dichotomous	M / F	Change to numeric: M = 0, F = 1. From RPDB.
Marital status	**BB4**	Categorical	1 = Never Married 2 = Married 3 = Widowed 4 = Separated 5 = Divorced 6 = Other	Collapse to: 0 = Married 1 = Widowed 2 = Divorced; separated 3 = Never married 4 = Other
Income quintile at RAI-HC assessment*	**incquint_r1c**	Categorical	1 (low) to 5 (high)	Add category 6 = "missing". From RPDB.
Living arrangement	Change in Living Arrangement: Client Lives with Other Persons (**O2A**)	Dichotomous	0 = No / 1 = Yes	
	Informal Helper Lives with Client - Primary (**G1EA**)	Categorical	0 = Yes / 1 = No / 2 = No such helper	Collapse to dichotomous: 0 = no, no such helper; 1 = yes
	Where Lived at Time of Referral (**CC5**)	Categorical	1 = Private home/apt. with no home care services 2 = Private home/apt. with home care services 3 = Board and care/assisted living/group home 4 = Residential care facility 5 = Other	Collapse to: 0 = Private home/apt. with or without home care services 1 = categories 3 & 4 2 = Other/Missing (~23% missing)
Home environment hazards	Access to Home (**O1g**); Access to Rooms in Home (**O1h**)	Dichotomous	0 = No / 1 = Yes	Combine missing with "no"

^ Variables in **bold** were used for final regression modelling (see Table 7); variables in *italics* were dropped based on PROC VARCLUS or Ambler stepdown (as noted in the footnotes and the Comments column).

* From RPDB dataset.

** Variable dropped following PROC VARCLUS.

[#] Variable dropped based on Ambler stepdown.

Table 2 continued.

2a. Needs variables – health-related aspects				
Description	**Variable**	**Scale**	**Variable Range**	**Comments**
Cognitive deterioration / impairment	*Cognitive Skills-Decision Making (B2A)* **	Categorical	0=Independent 1=Modified independence 2=Minimally impaired 3=Moderately impaired 4=Severely impaired	Collapse to: 0 = Independent 1 = Modified independence; minimally impaired 2 = Moderately impaired 3 = Severely impaired *Dropped based on PROC VARCLUS.*
	Cognitive Skills-Worsening Decision Making (**B2B**)	Dichotomous	0 = No / 1 = Yes	
	Cognitive Performance Scale (**CPS**)	Categorical	0 - 6 scale	
CHESS scale	*CHESS_SCALE* **	Categorical	0 = No health instability (HI) 1 = Minimal HI 2 = Low HI 3 = Moderate HI 4 = High HI 5 = Very high HI	*Dropped based on PROC VARCLUS.*
Memory-related disease	*Memory Recall Ability - Short-term memory (B1A)* **; *Memory Recall Ability - Long-term memory (B1B)* **	Dichotomous	0 = Memory OK / 1 = Memory problem	*Dropped based on PROC VARCLUS.*
Behavioural and mental symptoms				
Changes in mood	*Mood Decline (E2)* **	Dichotomous	0 = No / 1 = Yes	*Dropped based on PROC VARCLUS.*
Wandering	Behavioural Symptoms: Wandering (**E3A**)	Categorical	0 = Did not occur in last 3 days 1 = Occurred, easily altered 2 = Occurred, not easily altered	Collapse to dichotomous: 0 = Did not occur in last 3 days 1 = Occurred *E3D dropped based on Ambler stepdown.*
Verbal disruption	Behavioural Symptoms: Verbally Abusive (**E3B**)			
Physical aggression	Behavioural Symptoms: Physically Abusive (**E3C**)			
Socially Disruptive / Inappropriate	*Behavioural Symptoms: Socially Inappropriate/ Disruptive (E3D)* $^{\#}$			
Resists Care	Behavioural Symptoms: Resists Care (**E3E**)			
Behaviour changes / problems	Changes in Behaviour Symptoms (**E4**)	Dichotomous	0 = No / 1 = Yes	

Table 2 continued.

Delusions / Hallucinations	*Problem Conditions - Delusions (K3F)* #*;* Problem Conditions - Hallucinations (**K3G**)	Dichotomous	0 = No / 1 = Yes	*K3F dropped based on Ambler stepdown*.
Depression (clinical)	Depression Rating Scale (**DRS**)	Categorical	0 - 14 scale	Collapse to 0, 1, 2, 3+ ("Clinical screen for depression if score of 3 or greater out of 14")
Comorbidities				
Stroke	Cerebrovascular Accident/Stroke (**J1A**)	Categorical	0 = Not present 1 = Present-Not subject to forces treatment or monitoring by home care professional 2 = Present-Monitored or treated by home care professional	Collapse to dichotomous: 0 = not present 1 = present (if any missing values, assume not present). *J1AA, J1B, J1J, J1O, J1Z dropped based on Ambler stepdown*.
Renal insufficiency	*Renal Failure (J1AA)* #			
Congestive heart failure (CHF)	*Congestive Heart Failure (J1B)* #			
Coronary heart disease (CHD)	Coronary Heart Disease (**J1C**)			
Peripheral vascular disease (PVD)	Peripheral Vascular Disease (**J1F**)			
Head Trauma	Head Trauma (**J1I**)			
Hemiplegia / Hemiparesis	*Hemiplegia/Hemiparesis (J1J)* #			
Multiple Sclerosis	Multiple Sclerosis (**J1K**)			
Parkinson's disease	Parkinsonism (**J1L**)			
Arthritis	Arthritis (**J1M**)			
Hip Fracture	Hip Fracture (**J1N**)			
Other Fractures (wrist, vertebral)	*Other Fractures (wrist, vertebral) (J1O)* #			
Any Psychiatric Diagnosis	Any Psychiatric Diagnosis (**J1S**)			
Cancer	Cancer, Not Including Skin Cancer (**J1X**)			
Diabetes	Diabetes (**J1Y**)			
Emphysema / COPD / Asthma	*Emphysema/COPD/Asthma (J1Z)* #			
Pharmaceuticals				
Number of Medications	Number of Medications - taken in last 7 days or since last assessment (**Q1**)	Continuous	0 - 8; 9 or more	Change to categorical: 0 = 0 to 2 (incl. missing: n = 1) 1 = 3 or 4 3 = 7 or 8 2 = 5 or 6 4 = 9+
Antipsychotic / Neuroleptic Medication	*Receipt of Psychotropic Medication - Antipsychotic/Neuroleptic (Q2A)* #	Dichotomous	0 = No / 1 = Yes	Include missing values with "no". *Q2A & Q2B dropped based on Ambler stepdown*.
Anxiolytic Medication	*Receipt of Psychotropic Medication - Anxiolytic (Q2B)* #			

Table 2 continued.

Antidepressant Medication	*Receipt of Psychotropic Medication - Antidepressant (Q2C) ***	Dichotomous	0 = No / 1 = Yes	*Q2C dropped based on PROC VARCLUS.*
Hypnotic Medication	Receipt of Psychotropic Medication - Hypnotic (**Q2D**)			

2b. Needs variables – functional impairment				
Description	**Variable**	**Scale**	**Variable Range**	**Comments**
Falls	Falls Frequency - in last 90 days or since last assessment (**K5**)	Continuous	0 - 8; 9 or more	Change to categorical: 0, 1, 2, 3+
Incontinence	Bladder Continence - in last 7 days (**I1A**)	Categorical	0 = Continent 1 = Continent with catheter 2 = Usually continent 3 = Occasionally incontinent 4 = Frequently incontinent 5 = Incontinent 8 = Did not occur	Collapse to: 0 = Continent; Continent with catheter; Did not occur 1 = Usually continent; occasionally incontinent 2 = Frequently incontinent; Incontinent
	*Worsening of Incontinence - in last 7 days (I1B) ***	Dichotomous	0 = No / 1 = Yes	*Dropped based on PROC VARCLUS.*
	*Bowel Continence - in last 7 days (I3) ***	Categorical	0 = Continent 1 = Continent with catheter 2 = Usually continent 3 = Occasionally incontinent 4 = Frequently incontinent 5 = Incontinent 8 = Did not occur	Collapse to: 0 = Continent; Continent with catheter; Did not occur 1 = Usually continent; occasionally incontinent 2 = Frequently incontinent; Incontinent *Dropped based on PROC VARCLUS.*
Stamina	*Stamina - Days (H6A) **: in a typical week in last 30 days, # of days client goes outside*	Categorical	0 = Every day 1 = 2-6 days a week 2 = 1 day a week 3 = No days	*Dropped based on PROC VARCLUS.*
	Stamina - Hours (**H6B**): hrs of physical activity in last 3 days	Dichotomous	0 = 2 or more hours 1 = <2 hours	Include any missing values with category 1 (<2 h)
Activities of Daily Living (ADL)	ADL Self-Performance Hierarchy Scale (**ADL_SELF**)	Categorical	0 - 6 scale	
	ADL Decline (**H3**)	Dichotomous	0 = No / 1 = Yes	
Instrumental Activities of Daily Living (IADLs)	IADL Difficulty Scale (**IADL_DIFF**)	Categorical	0 - 6 scale	

Table 2 continued.

3. Enabling resources				
Description	**Variable**	**Scale**	**Variable Range**	**Comments**
Hospitalizations	*Time Since Last Hospital Stay (CC4) ***	Categorical	0 = Presently in hospital 1 = No stays within 180 d 2 = Within last week 3 = Within 8-14 d 4 = Within 15-30 days 5 = >30 days ago	Collapse to: 0 = no stays within 180 d 1 = presently in hospital 2 = within last 30 days 3 = >30 days ago 4 = missing/unknown *Dropped based on PROC VARCLUS*.
	Number of Overnight Hospital Admissions - in last 90 days (**P4A**)	Continuous	0 - 8; 9 or more	Change to categorical: 0, 1, 2, 3+
	Number of ER Visits Without an Overnight Stay (P4B) $^{\#}$	Continuous	0 - 8; 9 or more	Change to categorical: 0, 1, 2, 3+ *Dropped based on Ambler stepdown*.
Informal care	Hours of Informal Help: Weekdays (G3A); Weekends (G3B)	Continuous		Combine G3A and G3B to get hours per week (G3); Split into categories (**G3_cat**): 0 = 0 – 6 1 = 7 – 13 2 = 14 – 20 3 = 21 – 28 4 = 29 - 34 5 = 35 - 41 6 = 42+ 7 = missing
Home care (and community care; formal services)	Formal Care - last 7 days: Home Health Aides (P1A); Visiting Nurses (P1B); Homemaking Services (P1C); Meals (P1D); Volunteer (P1E); Physical Therapy (P1F); Occupational Therapy (P1G); Speech Therapy (P1H); Day Care or Day Hospital (P1I); Social Worker in Home (P1J)	Continuous	Recorded as <var>_DAYS, <var>_HOURS, <var>_MINS (minutes rounded to nearest 10)	Combine into 6 variables: **PSW_RAI** = P1a **Nursing_RAI** = P1b **Homemaking_RAI** = P1c **Meals_RAI** = P1d **Therapy_RAI** = P1f, P1g, P1h (PT/OT/ST) **Other_RAI** = P1e (volunteer), P1i (day care/day hospital), P1j (social worker) Change to categorical: 0 = no services 1 = services received 2 = missing

Table 2 continued.

Caregiver attributes				
Relationship of caregiver to care recipient	Informal Helper Relationship with Client - Primary (**G1FA**)	Categorical	0 = Child or child-in-law 1 = Spouse 2 = Other Relative 3 = Friend / neighbour	Add category 4 = "missing"
Caregiver burden	A Caregiver is Unable to Continue (**G2A**); Caregiver is Not Satisfied with Support from Family (**G2B**); *Primary Caregiver Expresses Feeling of Distress, Anger, Depression (G2C)* [#]	Dichotomous	0 = No / 1 = Yes	*G2C dropped based on Ambler stepdown*.

Table 3. Baseline characteristics at index event date (RAI-HC assessment) for full cohort, grouped according to outcomes at one year post-index event date.

Variable	Value	Total		Alive in community		Placed in LTC		Died in community		p-value
		N=163,983		N=100,231		N=43,097		N=20,655		
1. Predisposing factors										
Age	Mean ± SD	83.3 ± 6.9		82.5 ± 6.8		84.5 ± 6.9		84.7 ± 7.0		<.001
	Median (IQR)	84 (79-88)		83 (78-87)		85 (80-89)		85 (80-90)		<.001
Age group	65-69	7,823	4.8%	5,701	5.7%	1,442	3.3%	680	3.3%	<.001
	70-74	15,412	9.4%	10,817	10.8%	3,123	7.2%	1,472	7.1%	
	75-79	29,395	17.9%	19,852	19.8%	6,491	15.1%	3,052	14.8%	
	80-84	43,252	26.4%	27,396	27.3%	10,648	24.7%	5,208	25.2%	
	85-89	41,896	25.5%	24,112	24.1%	12,175	28.3%	5,609	27.2%	
	90+	26,205	16.0%	12,353	12.3%	9,218	21.4%	4,634	22.4%	
Sex	Male	62,348	38.0%	35,536	35.5%	16,560	38.4%	10,252	49.6%	<.001
	Female	101,635	62.0%	64,695	64.5%	26,537	61.6%	10,403	50.4%	
Marital status	Married	62,657	38.2%	40,118	40.0%	13,796	32.0%	8,743	42.3%	<.001
	Widowed	82,274	50.2%	48,698	48.6%	23,691	55.0%	9,885	47.9%	
	Divorced / Separated	10,464	6.4%	6,434	6.4%	2,941	6.8%	1,089	5.3%	
	Never married	6,889	4.2%	3,937	3.9%	2,228	5.2%	724	3.5%	
	Other	1,699	1.0%	1,044	1.0%	441	1.0%	214	1.0%	
Income quintile	1 (low)	36,400	22.2%	21,810	21.8%	10,234	23.7%	4,356	21.1%	<.001
	2	34,210	20.9%	20,876	20.8%	8,889	20.6%	4,445	21.5%	
	3	32,093	19.6%	19,547	19.5%	8,500	19.7%	4,046	19.6%	
	4	31,425	19.2%	19,394	19.3%	8,021	18.6%	4,010	19.4%	
	5 (high)	29,147	17.8%	18,215	18.2%	7,204	16.7%	3,728	18.0%	
	Missing	708	0.4%	389	0.4%	249	0.6%	70	0.3%	
Changed living arrangement (whom client lives with)	No	147,400	89.9%	91,631	91.4%	37,374	86.7%	18,395	89.1%	<.001
	Yes	16,583	10.1%	8,600	8.6%	5,723	13.3%	2,260	10.9%	
Informal helper lives with client	No	81,912	50.0%	47,946	47.8%	24,619	57.1%	9,347	45.3%	<.001
	Yes	82,071	50.0%	52,285	52.2%	18,478	42.9%	11,308	54.7%	
Where lived at time of referral	Private home	105,960	64.6%	68,567	68.4%	24,561	57.0%	12,832	62.1%	<.001
	Assisted living / group home	17,769	10.8%	9,501	9.5%	5,843	13.6%	2,425	11.7%	
	Other/missing	40,254	24.5%	22,163	22.1%	12,693	29.5%	5,398	26.1%	
Access to home	No hazards	150,771	91.9%	92,625	92.4%	39,728	92.2%	18,418	89.2%	<.001
	Hazards present	13,212	8.1%	7,606	7.6%	3,369	7.8%	2,237	10.8%	
Access to rooms in home	No hazards	153,394	93.5%	93,466	93.3%	41,130	95.4%	18,798	91.0%	<.001
	Hazards present	10,589	6.5%	6,765	6.7%	1,967	4.6%	1,857	9.0%	

Table 3 continued.

Variable	Value	Total		Alive in community		Placed in LTC		Died in community		p-value
2a. Needs variables – health-related aspects										
Worsening decision making	No	85,824	52.3%	58,447	58.3%	17,605	40.8%	9,772	47.3%	<.001
	Yes	78,159	47.7%	41,784	41.7%	25,492	59.2%	10,883	52.7%	
Cognitive performance scale	0	10,156	6.2%	7,407	7.4%	1,692	3.9%	1,057	5.1%	<.001
	1	16,059	9.8%	11,499	11.5%	2,997	7.0%	1,563	7.6%	
	2	77,896	47.5%	53,521	53.4%	15,595	36.2%	8,780	42.5%	
	3	44,440	27.1%	21,616	21.6%	16,814	39.0%	6,010	29.1%	
	4	4,801	2.9%	1,855	1.9%	1,991	4.6%	955	4.6%	
	5	9,125	5.6%	3,964	4.0%	3,465	8.0%	1,696	8.2%	
	6	1,506	0.9%	369	0.4%	543	1.3%	594	2.9%	
Behavioural and mental symptoms										
Wandering	No	153,023	93.3%	95,011	94.8%	38,575	89.5%	19,437	94.1%	<.001
	Yes	10,960	6.7%	5,220	5.2%	4,522	10.5%	1,218	5.9%	
Verbally abusive	No	152,006	92.7%	93,907	93.7%	39,123	90.8%	18,976	91.9%	<.001
	Yes	11,977	7.3%	6,324	6.3%	3,974	9.2%	1,679	8.1%	
Physically abusive	No	160,745	98.0%	98,838	98.6%	41,826	97.1%	20,081	97.2%	<.001
	Yes	3,238	2.0%	1,393	1.4%	1,271	2.9%	574	2.8%	
Resists care	No	143,684	87.6%	90,045	89.8%	36,079	83.7%	17,560	85.0%	<.001
	Yes	20,299	12.4%	10,186	10.2%	7,018	16.3%	3,095	15.0%	
Changes in behaviour symptoms	No	138,715	84.6%	87,751	87.5%	33,792	78.4%	17,172	83.1%	<.001
	Yes	25,268	15.4%	12,480	12.5%	9,305	21.6%	3,483	16.9%	
Hallucinations	No	154,335	94.1%	95,207	95.0%	39,880	92.5%	19,248	93.2%	<.001
	Yes	9,648	5.9%	5,024	5.0%	3,217	7.5%	1,407	6.8%	
Depression rating scale	0	82,952	50.6%	51,836	51.7%	20,814	48.3%	10,302	49.9%	<.001
	1	23,358	14.2%	14,160	14.1%	6,278	14.6%	2,920	14.1%	
	2	21,806	13.3%	13,002	13.0%	5,986	13.9%	2,818	13.6%	
	3+	35,867	21.9%	21,233	21.2%	10,019	23.2%	4,615	22.3%	
Comorbidities										
Stroke	No	133,262	81.3%	83,052	82.9%	33,890	78.6%	16,320	79.0%	<.001
	Yes	30,721	18.7%	17,179	17.1%	9,207	21.4%	4,335	21.0%	
Coronary heart disease	No	125,117	76.3%	78,621	78.4%	31,890	74.0%	14,606	70.7%	<.001
	Yes	38,866	23.7%	21,610	21.6%	11,207	26.0%	6,049	29.3%	
Peripheral vascular disease	No	155,107	94.6%	95,614	95.4%	40,408	93.8%	19,085	92.4%	<.001
	Yes	8,876	5.4%	4,617	4.6%	2,689	6.2%	1,570	7.6%	
Head trauma	No	161,863	98.7%	99,008	98.8%	42,476	98.6%	20,379	98.7%	0.003
	Yes	2,120	1.3%	1,223	1.2%	621	1.4%	276	1.3%	
Multiple sclerosis	No	163,605	99.8%	99,970	99.7%	43,016	99.8%	20,619	99.8%	0.006
	Yes	378	0.2%	261	0.3%	81	0.2%	36	0.2%	
Parkinsonism	No	154,959	94.5%	94,847	94.6%	40,588	94.2%	19,524	94.5%	0.003
	Yes	9,024	5.5%	5,384	5.4%	2,509	5.8%	1,131	5.5%	
Arthritis	No	90,190	55.0%	54,738	54.6%	23,546	54.6%	11,906	57.6%	<.001
	Yes	73,793	45.0%	45,493	45.4%	19,551	45.4%	8,749	42.4%	

Table 3 continued.

Variable	Value	Total		Alive in community		Placed in LTC		Died in community		p-value
Hip fracture	No	155,506	94.8%	95,805	95.6%	40,106	93.1%	19,595	94.9%	<.001
	Yes	8,477	5.2%	4,426	4.4%	2,991	6.9%	1,060	5.1%	
Any psychiatric diagnosis	No	137,505	83.9%	83,399	83.2%	36,114	83.8%	17,992	87.1%	<.001
	Yes	26,478	16.1%	16,832	16.8%	6,983	16.2%	2,663	12.9%	
Cancer	No	148,777	90.7%	92,705	92.5%	38,819	90.1%	17,253	83.5%	<.001
	Yes	15,206	9.3%	7,526	7.5%	4,278	9.9%	3,402	16.5%	
Diabetes	No	124,420	75.9%	76,536	76.4%	32,596	75.6%	15,288	74.0%	<.001
	Yes	39,563	24.1%	23,695	23.6%	10,501	24.4%	5,367	26.0%	
Pharmaceuticals										
Number of medications	0-2	12,031	7.3%	7,927	7.9%	2,878	6.7%	1,226	5.9%	<.001
	3 or 4	16,890	10.3%	11,318	11.3%	3,822	8.9%	1,750	8.5%	
	5 or 6	26,050	15.9%	17,223	17.2%	6,029	14.0%	2,798	13.5%	
	7 or 8	28,381	17.3%	18,230	18.2%	6,780	15.7%	3,371	16.3%	
	9+	80,631	49.2%	45,533	45.4%	23,588	54.7%	11,510	55.7%	
Hypnotic Rx	No	122,153	74.5%	75,772	75.6%	31,409	72.9%	14,972	72.5%	<.001
	Yes	41,830	25.5%	24,459	24.4%	11,688	27.1%	5,683	27.5%	
2b. Needs variables – functional impairment										
Falls frequency (last 90 d)	0	84,969	51.8%	56,254	56.1%	18,977	44.0%	9,738	47.1%	<.001
	1	38,409	23.4%	22,844	22.8%	10,657	24.7%	4,908	23.8%	
	2	18,070	11.0%	9,966	9.9%	5,567	12.9%	2,537	12.3%	
	3+	22,535	13.7%	11,167	11.1%	7,896	18.3%	3,472	16.8%	
Bladder continence	Continent	77,726	47.4%	52,435	52.3%	16,812	39.0%	8,479	41.1%	<.001
	Usually continent	43,213	26.4%	26,910	26.8%	11,164	25.9%	5,139	24.9%	
	Incontinent	43,044	26.2%	20,886	20.8%	15,121	35.1%	7,037	34.1%	
Hrs of physical activity (last 3 d)	2+	91,028	55.5%	62,017	61.9%	20,364	47.3%	8,647	41.9%	<.001
	< 2	72,955	44.5%	38,214	38.1%	22,733	52.7%	12,008	58.1%	
ADL self scale	0	70,528	43.0%	52,811	52.7%	11,889	27.6%	5,828	28.2%	<.001
	1	25,398	15.5%	16,323	16.3%	6,318	14.7%	2,757	13.3%	
	2	29,522	18.0%	16,597	16.6%	8,824	20.5%	4,101	19.9%	
	3	15,055	9.2%	6,985	7.0%	5,715	13.3%	2,355	11.4%	
	4	12,621	7.7%	4,457	4.4%	5,542	12.9%	2,622	12.7%	
	5	8,793	5.4%	2,579	2.6%	4,060	9.4%	2,154	10.4%	
	6	2,066	1.3%	479	0.5%	749	1.7%	838	4.1%	
ADL decline	No	60,393	36.8%	43,858	43.8%	11,288	26.2%	5,247	25.4%	<.001
	Yes	103,590	63.2%	56,373	56.2%	31,809	73.8%	15,408	74.6%	
IADL difficulty scale	0	3,086	1.9%	2,625	2.6%	309	0.7%	152	0.7%	<.001
	1	4,631	2.8%	3,849	3.8%	515	1.2%	267	1.3%	
	2	13,121	8.0%	10,286	10.3%	1,912	4.4%	923	4.5%	
	3	9,852	6.0%	7,127	7.1%	2,010	4.7%	715	3.5%	
	4	26,148	15.9%	17,857	17.8%	5,799	13.5%	2,492	12.1%	
	5	57,963	35.3%	35,446	35.4%	15,273	35.4%	7,244	35.1%	
	6	49,182	30.0%	23,041	23.0%	17,279	40.1%	8,862	42.9%	

Table 3 continued.

Variable	Value	Total		Alive in community		Placed in LTC		Died in community		p-value
3. Enabling resources										
# of O/N hospital admissions (last 90 d)	0	94,639	57.7%	64,179	64.0%	20,810	48.3%	9,650	46.7%	<.001
	1	59,190	36.1%	31,299	31.2%	18,893	43.8%	8,998	43.6%	
	2	8,309	5.1%	3,905	3.9%	2,792	6.5%	1,612	7.8%	
	3+	1,845	1.1%	848	0.8%	602	1.4%	395	1.9%	
Hours of informal help (per week)	0-6	28,002	17.1%	19,625	19.6%	5,687	13.2%	2,690	13.0%	<.001
	7-13	26,337	16.1%	18,869	18.8%	4,967	11.5%	2,501	12.1%	
	14-20	23,189	14.1%	16,547	16.5%	4,099	9.5%	2,543	12.3%	
	21-28	16,352	10.0%	11,444	11.4%	2,953	6.9%	1,955	9.5%	
	29-34	11,811	7.2%	7,924	7.9%	2,336	5.4%	1,551	7.5%	
	35-41	10,072	6.1%	6,484	6.5%	2,042	4.7%	1,546	7.5%	
	42+	16,556	10.1%	9,837	9.8%	3,898	9.0%	2,821	13.7%	
	Missing	31,664	19.3%	9,501	9.5%	17,115	39.7%	5,048	24.4%	
PSW services (last 7 d)	No	83,064	50.7%	52,956	52.8%	21,043	48.8%	9,065	43.9%	<.001
	Yes	63,050	38.4%	40,707	40.6%	13,629	31.6%	8,714	42.2%	
	Missing	17,869	10.9%	6,568	6.6%	8,425	19.5%	2,876	13.9%	
Nursing services (last 7 d)	No	118,225	72.1%	77,014	76.8%	28,415	65.9%	12,796	62.0%	<.001
	Yes	27,894	17.0%	16,654	16.6%	6,257	14.5%	4,983	24.1%	
	Missing	17,864	10.9%	6,563	6.5%	8,425	19.5%	2,876	13.9%	
Homemaking services (last 7 d)	No	105,986	64.6%	67,891	67.7%	25,353	58.8%	12,742	61.7%	<.001
	Yes	40,132	24.5%	25,776	25.7%	9,319	21.6%	5,037	24.4%	
	Missing	17,865	10.9%	6,564	6.5%	8,425	19.5%	2,876	13.9%	
Meals services (last 7 d)	No	128,386	78.3%	82,941	82.7%	29,913	69.4%	15,532	75.2%	<.001
	Yes	17,732	10.8%	10,727	10.7%	4,758	11.0%	2,247	10.9%	
	Missing	17,865	10.9%	6,563	6.5%	8,426	19.6%	2,876	13.9%	
OT/PT/ST (last 7 d)	No	112,005	68.3%	70,236	70.1%	28,777	66.8%	12,992	62.9%	<.001
	Yes	34,113	20.8%	23,432	23.4%	5,895	13.7%	4,786	23.2%	
	Missing	17,865	10.9%	6,563	6.5%	8,425	19.5%	2,877	13.9%	
Other formal care services (last 7 d)	No	141,022	86.0%	90,140	89.9%	33,568	77.9%	17,314	83.8%	<.001
	Yes	5,097	3.1%	3,528	3.5%	1,104	2.6%	465	2.3%	
	Missing	17,864	10.9%	6,563	6.5%	8,425	19.5%	2,876	13.9%	
Relationship of caregiver to care recipient	Child	91,865	56.0%	55,364	55.2%	25,561	59.3%	10,940	53.0%	<.001
	Spouse	48,812	29.8%	31,377	31.3%	10,356	24.0%	7,079	34.3%	
	Other relative	13,323	8.1%	7,437	7.4%	4,373	10.1%	1,513	7.3%	
	Friend / neighbour	7,584	4.6%	4,535	4.5%	2,162	5.0%	887	4.3%	
	Missing	2,399	1.5%	1,518	1.5%	645	1.5%	236	1.1%	
Caregiver unable to continue	No	136,369	83.2%	86,391	86.2%	33,275	77.2%	16,703	80.9%	<.001
	Yes	27,614	16.8%	13,840	13.8%	9,822	22.8%	3,952	19.1%	
Caregiver not satisfied with support	No	155,357	94.7%	94,937	94.7%	40,858	94.8%	19,562	94.7%	0.779
	Yes	8,626	5.3%	5,294	5.3%	2,239	5.2%	1,093	5.3%	

Table 4a. Informal care baseline characteristics: Informal helper relationship with client.

Variable	Value	Informal helper relationship with client*									
		Total		**Child / child-in-law**		**Spouse**		**Other relative**		**Friend / neighbour**	
		n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
	Total	163,983	100%	91,865	56.0%	48,812	29.8%	13,323	8.1%	7,584	4.6%
Age of care recipient	Mean ± SD	83.3 ± 6.9		84.7 ± 6.5		80.8 ± 6.5		83.4 ± 7.8		82.9 ± 7.6	
	Median (IQR)	84 (79-88)		85 (81-89)		81 (76-85)		84 (78-89)		84 (78-88)	
Sex of care recipient	Male	62,348	38.0%	23,336	25.4%	30,870	63.2%	4,103	30.8%	2,911	38.4%
	Female	101,635	62.0%	68,529	74.6%	17,942	36.8%	9,220	69.2%	4,673	61.6%
Caregiver unable to continue	No	136,369	83.2%	79,700	86.8%	36,215	74.2%	11,419	85.7%	6,645	87.6%
	Yes	27,614	16.8%	12,165	13.2%	12,597	25.8%	1,904	14.3%	939	12.4%
Caregiver not satisfied with support from family	No	155,357	94.7%	86,222	93.9%	46,733	95.7%	12,757	95.8%	7,248	95.6%
	Yes	8,626	5.3%	5,643	6.1%	2,079	4.3%	566	4.2%	336	4.4%
Hours of informal help (last 7 days)	0-6	28,002	17.1%	17,784	19.4%	2,059	4.2%	4,053	30.4%	2,513	33.1%
	7-13	26,337	16.1%	17,503	19.1%	5,358	11.0%	2,122	15.9%	1,323	17.4%
	14-20	23,189	14.1%	13,214	14.4%	7,898	16.2%	1,304	9.8%	748	9.9%
	21-27	16,352	10.0%	7,930	8.6%	7,307	15.0%	695	5.2%	413	5.4%
	28-34	11,811	7.2%	5,546	6.0%	5,553	11.4%	470	3.5%	236	3.1%
	35-41	10,072	6.1%	4,560	5.0%	4,978	10.2%	334	2.5%	197	2.6%
	42+	16,556	10.1%	7,502	8.2%	8,082	16.6%	591	4.4%	375	4.9%
	Missing	31,664	19.3%	17,826	19.4%	7,577	15.5%	3,754	28.2%	1,779	23.5%

* For all variables, p<0.001.

Table 4b. Informal care baseline characteristics: Informal caregiver lives with client.

Variable	Value	Informal caregiver lives with client*					
		Total		No / no such helper		Yes	
		n	%	n	%	n	%
	Total	163,983	100.0%	81,912	50.0%	82,071	50.0%
Age of care recipient	Mean ± SD	83.3 ± 6.9		84.4 ± 6.8		82.2 ± 6.8	
	Median (IQR)	84 (79-88)		85 (80-89)		83 (78-87)	
Sex of care recipient	Male	62,348	38.0%	23,610	28.8%	38,738	47.2%
	Female	101,635	62.0%	58,302	71.2%	43,333	52.8%
Marital status	Married	62,657	38.2%	11,949	14.6%	50,708	61.8%
	Widowed	82,274	50.2%	56,027	68.4%	26,247	32.0%
	Divorced / Separated	10,464	6.4%	7,715	9.4%	2,749	3.3%
	Never married	6,889	4.2%	5,325	6.5%	1,564	1.9%
	Other	1,699	1.0%	896	1.1%	803	1.0%
Income quintile	1 (low)	36,400	22.2%	21,101	25.8%	15,299	18.6%
	2	34,210	20.9%	16,821	20.5%	17,389	21.2%
	3	32,093	19.6%	15,562	19.0%	16,531	20.1%
	4	31,425	19.2%	14,666	17.9%	16,759	20.4%
	5 (high)	29,147	17.8%	13,309	16.2%	15,838	19.3%
	Missing	708	0.4%	453	0.6%	255	0.3%
Hours of informal help (last 7 days)	0-6	28,002	17.1%	24,577	30.0%	3,425	4.2%
	7-13	26,337	16.1%	17,693	21.6%	8,644	10.5%
	14-20	23,189	14.1%	9,879	12.1%	13,310	16.2%
	21-27	16,352	10.0%	3,961	4.8%	12,391	15.1%
	28-34	11,811	7.2%	2,424	3.0%	9,387	11.4%
	35-41	10,072	6.1%	1,677	2.0%	8,395	10.2%
	42+	16,556	10.1%	2,720	3.3%	13,836	16.9%
	Missing	31,664	19.3%	18,981	23.2%	12,683	15.5%

* For all variables, $p<0.001$.

Table 5. Formal care baseline characteristics: Sex of care recipient.

Variable	Value	Sex of care recipient*					
		Total		Male		Female	
		n	%	n	%	n	%
	Total	163,983	100.0%	62,348	38.0%	101,635	62.0%
PSW	No services	83,064	50.7%	33,577	53.9%	49,487	48.7%
	Services rec'd	63,050	38.4%	21,218	34.0%	41,832	41.2%
	Missing	17,869	10.9%	7,553	12.1%	10,316	10.2%
Nursing	No services	118,225	72.1%	43,936	70.5%	74,289	73.1%
	Services rec'd	27,894	17.0%	10,860	17.4%	17,034	16.8%
	Missing	17,864	10.9%	7,552	12.1%	10,312	10.1%
Homemaking	No services	105,986	64.6%	42,094	67.5%	63,892	62.9%
	Services rec'd	40,132	24.5%	12,702	20.4%	27,430	27.0%
	Missing	17,865	10.9%	7,552	12.1%	10,313	10.1%
Meals	No services	128,386	78.3%	49,447	79.3%	78,939	77.7%
	Services rec'd	17,732	10.8%	5,349	8.6%	12,383	12.2%
	Missing	17,865	10.9%	7,552	12.1%	10,313	10.1%
Therapy (PT / OT / speech)	No services	112,005	68.3%	41,067	65.9%	70,938	69.8%
	Services rec'd	34,113	20.8%	13,730	22.0%	20,383	20.1%
	Missing	17,865	10.9%	7,551	12.1%	10,314	10.1%
Other	No services	141,022	86.0%	52,682	84.5%	88,340	86.9%
	Services rec'd	5,097	3.1%	2,114	3.4%	2,983	2.9%
	Missing	17,864	10.9%	7,552	12.1%	10,312	10.1%

* For all variables, $p<0.001$.

Table 6. Time to LTC placement by key variables.

	Time to LTC placement (days)			
Variable	**Mean**	**SD**	**Median**	**IQR**
Sex				
Male	111.6	101.6	77	156
Female	108.3	102.4	70	153
Age group				
65-69	119.0	104.8	84	166
70-74	121.3	105.5	89	171
75-79	114.7	103.1	81	164
80-84	111.7	102.1	76	158
85-89	108.1	101.7	70	151
90+	100.0	99.5	60	140
ADL self scale				
0	157.6	107.0	147	185
1	122.8	103.2	94	168
2	104.0	98.6	68	142
3	85.8	90.7	49	108
4	66.1	78.8	34	76
5	61.8	72.4	33	68
6	62.3	73.1	35	64
IADL difficulty scale				
0	175.3	108.6	171	184
1	179.7	104.0	177	181
2	163.8	105.9	157	181.5
3	146.4	105.3	130	181
4	131.6	108.1	105	184
5	106.9	101.4	70	150
6	90.9	93.3	52	118
Marital status				
Married	119.1	105.4	85	169
Widowed	106.8	101.2	69	150
Divorced/separated	101.0	96.1	66	131
Never married	92.5	94.7	56	115
Other	102.1	95.9	66	135
Informal helper lives with client				
No	102.4	99.1	64	141
Yes	119.1	105.3	85	169
Cognitive performance scale				
0	122.2	110.4	88.5	191
1	125.5	110.0	93	186
2	128.5	106.9	100	180
3	97.6	95.9	60	131
4	82.7	87.4	47	100
5	84.9	90.0	48	106
6	64.0	72.5	36	68

Table 6 continued.

Variable	Time to LTC placement (days)			
	Mean	SD	Median	IQR
Falls frequency (last 90 days)				
0	123.8	105.3	93	174
1	103.1	100.5	64	141
2	97.5	97.3	57	132
3+	92.5	95.0	54	124
Hours of informal care (per week)				
0-6	144.1	105.8	123	181
7-13	146.4	106.6	129	187
14-20	146.5	106.5	129	181
21-27	148.2	105.6	133	179
28-34	142.8	107.7	122	188.5
35-41	138.2	106.0	113.5	183
42+	119.6	103.2	88	166
Missing	61.6	72.9	33	68
Informal caregiver is unable to continue				
No	116.7	103.9	83	164
Yes	85.4	91.8	48	109
Informal caregiver not satisfied with support from family				
No	109.7	102.2	73	155
Yes	107.5	100.8	69	146

Table 7. Adjusted hazard ratios for one-year risk of LTC placement*.

Predictor	**Hazard Ratio (95% CI)**	**p value ^**
1. Predisposing factors		
Age (continuous: 65-104)	1.03 (1.02–1.04)	**<.0001**
Age knot 2 (27.5 percentile = 79)	0.98 (0.95–1.00)	0.0887
Age knot 3 (50 percentile = 84)	1.15 (0.99–1.33)	0.0676
Age knot 4 (72.5 percentile = 88)	0.76 (0.57–1.00)	0.0507
Female Sex (ref = male)	0.97 (0.94–0.99)	**0.0024**
Marital Status (ref = married)		
Widowed	1.11 (1.07–1.15)	**<.0001**
Divorced/separated	1.14 (1.08–1.20)	**<.0001**
Never married	1.11 (1.05–1.18)	**0.0006**
Other	1.04 (0.94–1.15)	0.4449
Income Quintile (ref = 1 / lowest)		
2	0.96 (0.93–0.98)	**0.0023**
3	0.98 (0.95–1.01)	0.2571
4	0.94 (0.91–0.97)	**<.0001**
5 (highest)	0.92 (0.89–0.95)	**<.0001**
missing	1.20 (1.05–1.38)	**0.0080**
Change in Living Arrangement (whom client lives with) (ref = no)	1.05 (1.02–1.08)	**0.0021**
Informal Helper Lives with Client (ref = no / no such helper)	0.87 (0.85–0.90)	**<.0001**
Where Lived at Time of Referral (ref = private home)		
Assisted living/group home/residential care	1.24 (1.20–1.29)	**<.0001**
Other	1.25 (1.22–1.28)	**<.0001**
Hazardous Home Environment (ref = no hazards)		
Access to Home	0.88 (0.85–0.92)	**<.0001**
Access to Rooms in Home	0.91 (0.86–0.95)	**<.0001**
Needs variables – health-related aspects		
Cognitive Skills - Worsening Decision Making (ref = no)	1.11 (1.08–1.13)	**<.0001**
Cognitive Performance Scale (ref = 0)		
1	1.07 (1.01–1.14)	**0.0222**
2	1.03 (0.98–1.09)	0.2144
3	1.53 (1.45–1.61)	**<.0001**
4	1.35 (1.26–1.46)	**<.0001**
5	1.35 (1.27–1.45)	**<.0001**
6	1.19 (1.04–1.37)	**0.0130**
Behavioural and mental symptoms		
Behavioural Symptoms (ref = no)		
Wandering	1.25 (1.20–1.29)	**<.0001**
Verbally abusive	1.08 (1.03–1.12)	**0.0005**
Physically abusive	0.90 (0.84–0.96)	**0.0014**
Resists care	0.98 (0.95–1.01)	0.1937
Changes in Behaviour Symptoms (ref = no)	1.14 (1.10–1.17)	**<.0001**
Problem Conditions - Hallucinations (ref = no)	1.08 (1.04–1.13)	**<.0001**
Depression Rating Scale (ref = 0)		
1	1.01 (0.98–1.04)	0.6853
2	1.00 (0.97–1.04)	0.8266
3+	0.99 (0.96–1.01)	0.3112

^ Statistically significant p-values (<0.05) indicated in **bold**.

Table 7 continued.

Predictor	**Hazard Ratio (95% CI)**	**p value**
Comorbidities (ref = not present)		
Cerebrovascular Accident / Stroke	1.06 (1.04–1.09)	**<.0001**
Coronary Heart Disease	1.05 (1.02–1.07)	**<.0001**
Peripheral Vascular Disease	1.06 (1.01–1.10)	**0.0110**
Head Trauma	0.90 (0.82–0.98)	**0.0112**
Multiple Sclerosis	0.89 (0.71–1.11)	0.2923
Parkinsonism	1.12 (1.07–1.17)	**<.0001**
Arthritis	1.05 (1.02–1.07)	**<.0001**
Hip Fracture	1.02 (0.97–1.06)	0.4908
Any Psychiatric Diagnosis	0.97 (0.94–1.00)	**0.0330**
Cancer	1.02 (0.98–1.05)	0.3993
Diabetes	1.04 (1.02–1.07)	**0.0005**
Pharmaceuticals		
Number of Medications (last 7 days) (ref = 0 to 2)		
3 or 4	0.92 (0.87–0.96)	**0.0006**
5 or 6	0.89 (0.85–0.93)	**<.0001**
7 or 8	0.87 (0.83–0.91)	**<.0001**
9+	0.88 (0.84–0.92)	**<.0001**
Receipt of Psychotropic Medication - Hypnotic (ref= no)	0.87 (0.85–0.89)	**<.0001**
Needs variables – functional impairment		
Falls Frequency (last 90 days) (ref = 0)		
1	1.06 (1.03–1.09)	**<.0001**
2	1.11 (1.08–1.15)	**<.0001**
3+	1.24 (1.20–1.28)	**<.0001**
Bladder Continence (last 7 days) (ref = continent)		
Usually continent / occasionally incontinent	1.04 (1.02–1.07)	**0.0010**
Frequently incontinent / incontinent	1.09 (1.06–1.12)	**<.0001**
Stamina (hours of physical activity in last 3 days) (ref = 2 or more)		
Less than 2	1.02 (1.00–1.04)	0.0891
ADL Scale (ref = 0)		
1	1.12 (1.08–1.16)	**<.0001**
2	1.21 (1.17–1.25)	**<.0001**
3	1.31 (1.25–1.36)	**<.0001**
4	1.31 (1.26–1.37)	**<.0001**
5	1.24 (1.18–1.31)	**<.0001**
6	0.96 (0.86–1.08)	0.4813
ADL Decline (ref = no)	1.09 (1.07–1.12)	**<.0001**
IADL Difficulty Scale (ref = 0)		
1	1.04 (0.91–1.20)	0.5571
2	1.25 (1.11–1.40)	**0.0002**
3	1.54 (1.37–1.74)	**<.0001**
4	1.51 (1.35–1.69)	**<.0001**
5	1.43 (1.27–1.60)	**<.0001**
6	1.48 (1.32–1.67)	**<.0001**

Table 7 continued.

Predictor	**Hazard Ratio (95% CI)**	**p value**
Enabling resources		
# of O/N Hospital Admissions (last 90 days) (ref = 0)		
1	0.98 (0.95–1.00)	0.0552
2	0.98 (0.93–1.02)	0.2866
3+	0.96 (0.87–1.05)	0.3360
Hours of Informal Care last 7 days) (ref = 0 to 6)		
7 - 13	1.00 (0.96–1.03)	0.7947
14 - 20	1.00 (0.96–1.04)	0.8388
21 - 27	1.03 (0.98–1.08)	0.2241
28 - 34	1.07 (1.02–1.13)	**0.0085**
35 - 41	1.06 (1.01–1.12)	**0.0321**
42+	1.15 (1.10–1.21)	**<.0001**
missing	3.55 (3.37–3.73)	**<.0001**
Formal Care Services (last 7 days) (ref = none of that type)		
PSW - received	0.95 (0.92–0.97)	**0.0001**
PSW - missing	0.12 (0.04–0.37)	**0.0002**
Nursing - received	1.07 (1.04–1.10)	**<.0001**
Nursing - missing	1.18 (0.22–6.36)	0.8491
Homemaking - received	1.04 (1.01–1.07)	**0.0123**
Homemaking - missing	2.07 (0.44–9.66)	0.3556
Meals - received	1.21 (1.16–1.25)	**<.0001**
Meals - missing	2.34 (0.68–8.12)	0.1801
Therapy - received	0.82 (0.80–0.84)	**<.0001**
Therapy - missing	0.51 (0.13–1.99)	0.3319
Other - received	1.16 (1.09–1.23)	**<.0001**
Other - missing	1.93 (0.36–10.44)	0.4439
Informal Helper Relationship with Client (ref = child or child-in-law)		
Spouse	0.93 (0.89–0.97)	**0.0004**
Other relative	1.09 (1.05–1.13)	**<.0001**
Friend/neighbour	1.00 (0.96–1.05)	0.8585
Missing	0.91 (0.83–0.98)	**0.0192**
A Caregiver is Unable to Continue (ref = able to continue)	1.21 (1.18–1.24)	**<.0001**
Caregiver is Not Satisfied with Support from Family (ref = satisfied)	0.88 (0.84–0.92)	**<.0001**

* Hazard ratios were calculated from a Cox proportional hazards regression model with LTC placement as the primary outcome and death as a competing risk. The model included 48 variables as described in Table 2. The study population comprised 163,983 individuals with dementia who received a RAI-HC assessment after dementia diagnosis. Individuals were followed for up to one year after RAI-HC assessment to determine outcomes (LTC placement or death in the community).

Table 8. Outcomes by risk group*.

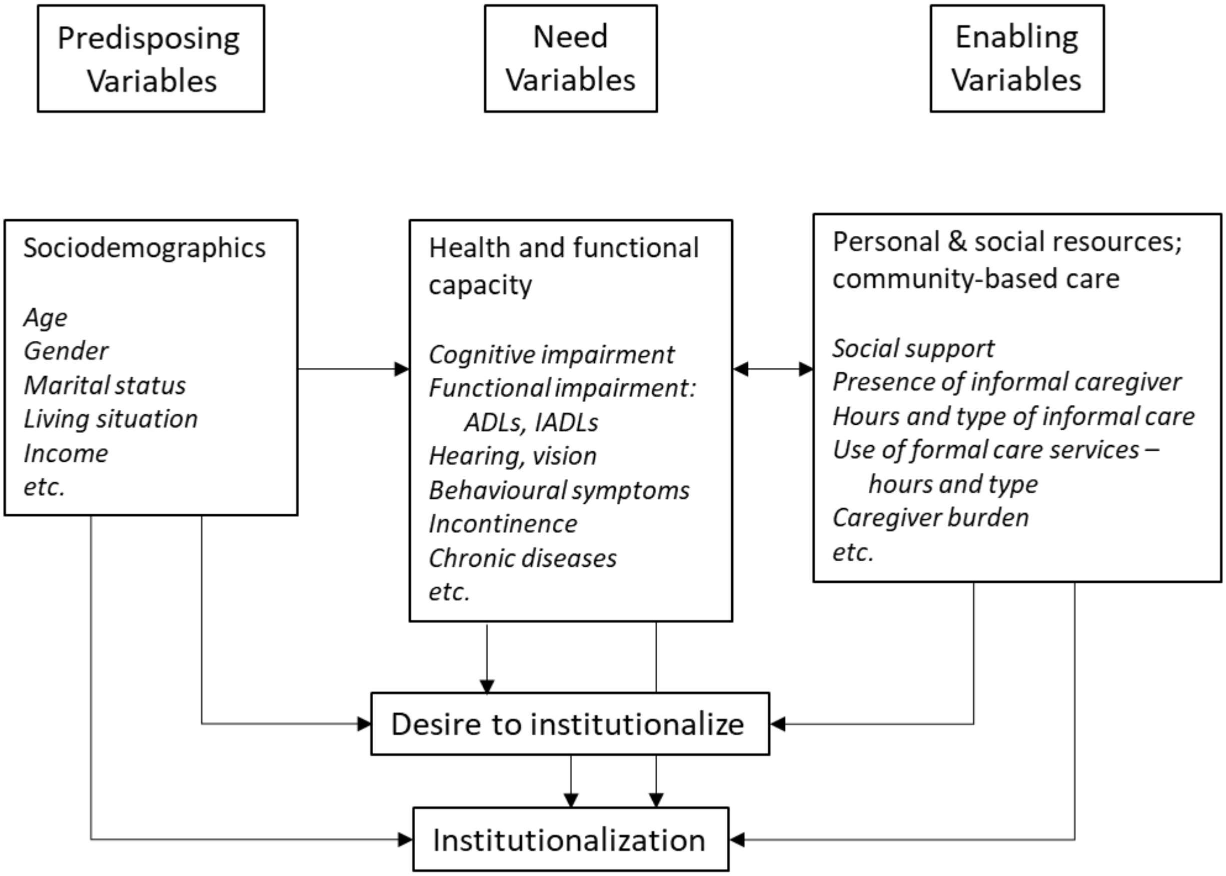
Risk Group	Total (n)	Outcome (n)			Time to LTC placement (days) for LTC cohort					
		alive	LTC	dead	mean	SD	median	Q1	Q3	IQR
1	657	575	34	48	241.0	93.7	278.5	164	313	149
2	657	574	38	45	209.2	100.5	234	135	306	171
3	658	547	39	72	204.1	109.0	202	140	303	163
4	657	552	47	58	192.7	112.4	177	93	297	204
5	657	535	55	67	191.9	102.5	214	108	270	162
6	658	534	56	68	185.7	99.0	169.5	104.5	280.5	176
7	657	536	62	59	181.8	106.0	187.5	91	263	172
8	658	535	59	64	183.2	116.2	174	70	287	217
9	657	520	72	65	190.1	109.2	198	79	277.5	198.5
10	657	528	71	58	168.4	102.6	155	79	260	181
11	658	518	77	63	180.3	102.6	193	86	264	178
12	657	495	92	70	184.5	102.8	179	99.5	261.5	162
13	657	507	85	65	175.9	101.8	177	92	246	154
14	658	499	81	78	144.4	103.3	117	47	222	175
15	657	478	100	79	166.0	101.7	154	74	239	165
16	658	494	83	81	162.8	103.5	145	67	249	182
17	657	474	111	72	152.7	106.7	146	55	246	191
18	657	474	99	84	167.5	108.6	170	65	249	184
19	658	449	130	79	161.9	105.4	158.5	69	246	177
20	657	479	101	77	155.7	100.0	156	61	219	158

* The 20% random sample of the full cohort was ranked and divided into 50 risk groups. The one-year outcomes for individuals in each risk group were determined, and for those who were placed in LTC, the time to LTC placement (mean and median) was calculated. The median time to LTC placement by risk group for the LTC cohort is plotted in Figure 9.

Table 8 continued.

Risk Group	Total (n)	Outcome (n)			Time to LTC placement (days) for LTC cohort					
		alive	LTC	dead	mean	SD	median	Q1	Q3	IQR
21	657	458	119	80	159.9	105.3	153	62	246	184
22	658	471	114	73	145.2	106.6	121.5	57	249	192
23	657	459	116	82	150.9	101.6	135	71.5	221.5	150
24	658	442	134	82	141.6	100.9	123.5	49	213	164
25	657	452	121	84	164.0	109.1	149	65	247	182
26	657	444	140	73	145.5	105.0	120	56.5	238.5	182
27	658	434	135	89	145.4	104.6	129	48	236	188
28	657	405	165	87	145.5	114.5	111	40	237	197
29	658	403	168	87	144.4	108.3	130.5	49.5	229.5	180
30	657	419	145	93	127.9	101.8	101	37	212	175
31	657	406	172	79	126.5	103.3	103	38	212	174
32	658	380	186	92	129.7	102.5	104	39	220	181
33	657	373	190	94	126.5	99.3	116.5	37	202	165
34	657	375	189	93	123.2	97.3	101	33	189	156
35	658	356	208	94	110.2	102.0	73	26	172	146
36	657	345	205	107	104.2	96.1	69	28	156	128
37	658	350	208	100	103.4	97.9	69	20.5	168	147.5
38	657	318	232	107	119.9	102.1	94	29	195.5	166.5
39	657	312	237	108	94.8	95.0	57	16	159	143
40	658	313	251	94	92.8	93.4	52	16	153	137
41	657	271	285	101	89.4	95.6	48	14	142	128
42	657	250	314	93	84.7	86.2	53.5	17	131	114
43	658	228	313	117	71.9	79.5	39	15	97	82
44	657	200	358	99	64.0	79.0	32	12	81	69
45	658	213	351	94	70.0	75.7	41	15	100	85
46	657	181	363	113	54.8	67.6	29	12	67	55
47	657	137	419	101	58.2	69.2	29	11	70	59
48	658	130	430	98	58.5	68.4	29.5	13	82	69
49	657	119	416	122	57.9	70.6	29.5	13	75.5	62.5
50	657	76	469	112	55.5	67.2	30	12	69	57

Figure 1. Conceptual framework of factors influencing institutionalization.



Adapted from Luppa, 2008.

Figure 2. Creation of dementia cohort.

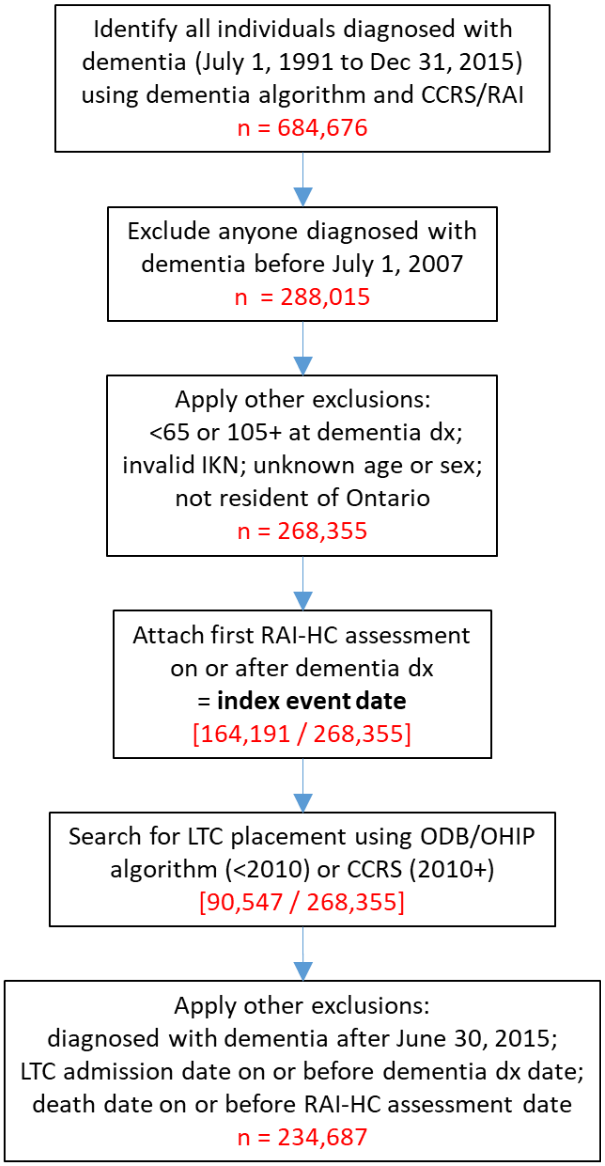


Figure 3. Creation of study cohort.

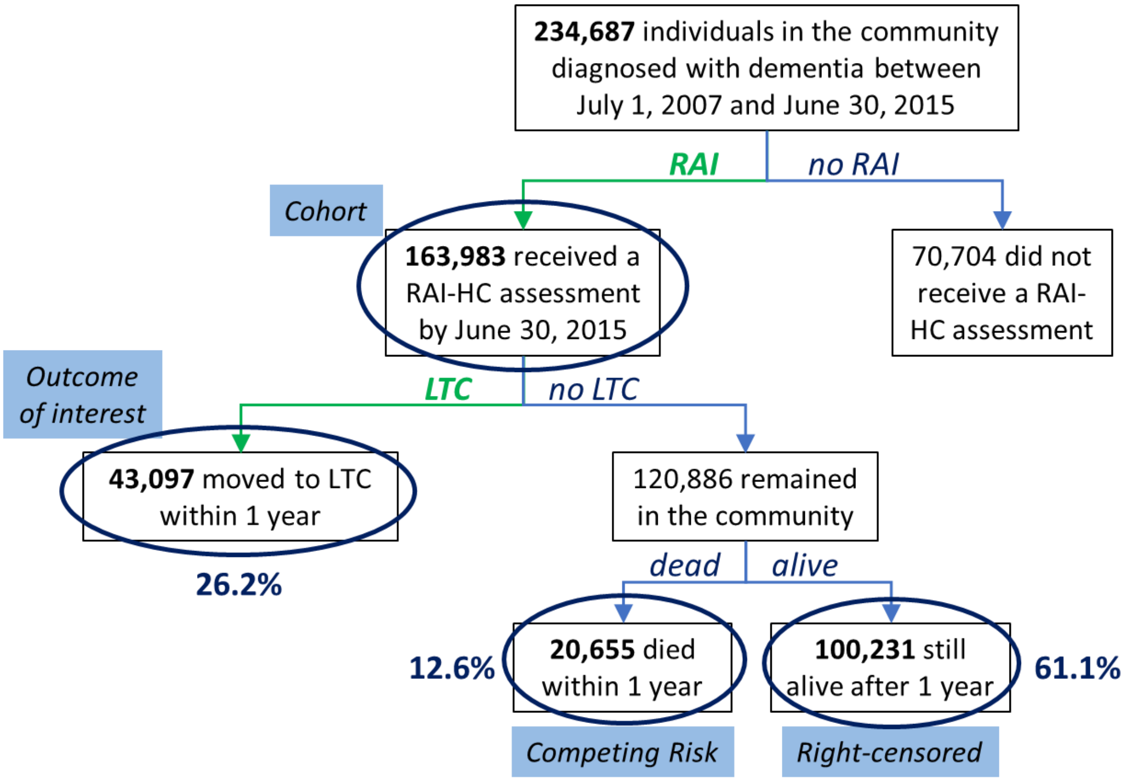


Figure 4. Timeline for cohort creation and follow-up.

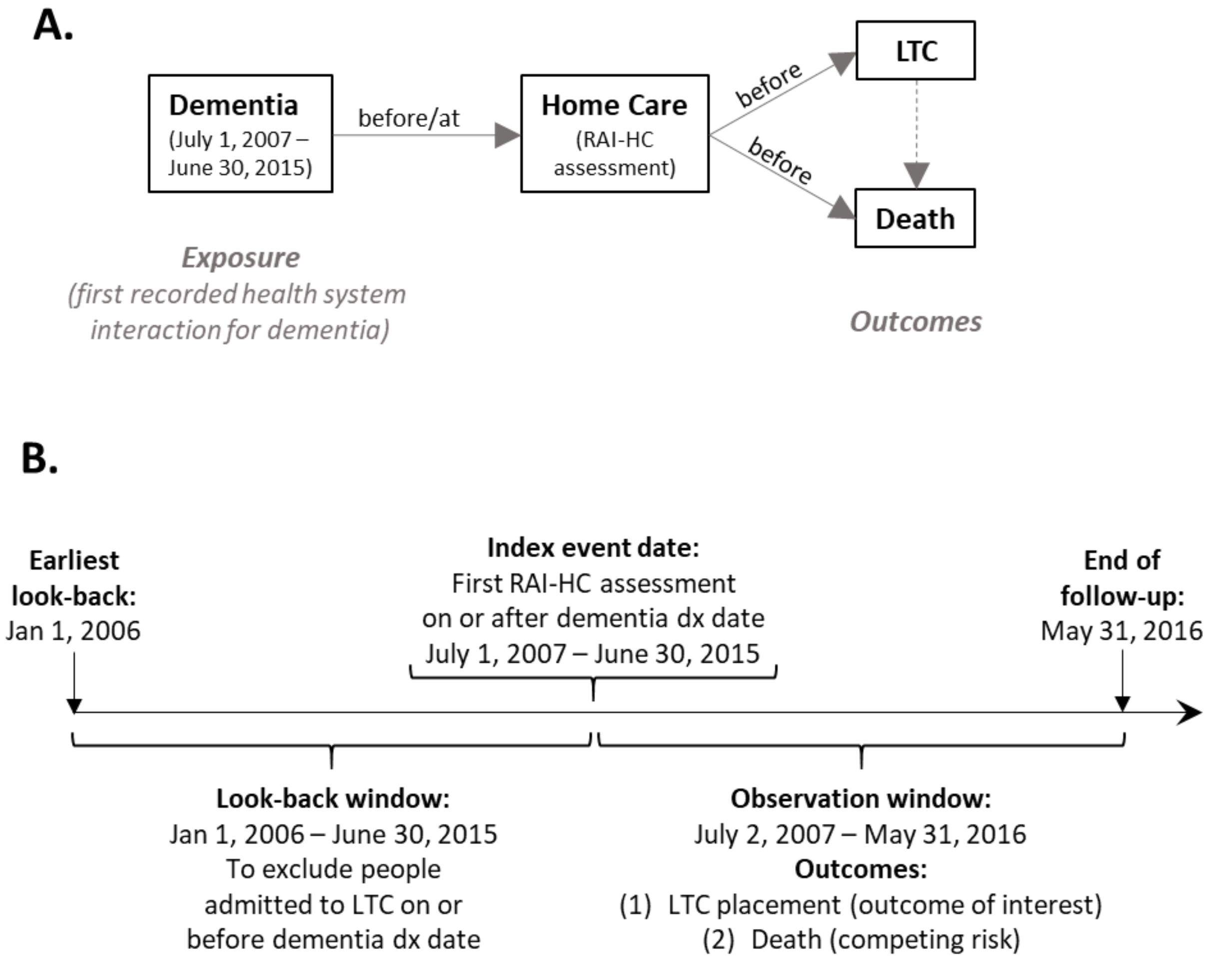


Figure 5. Time from dementia diagnosis to index event date.

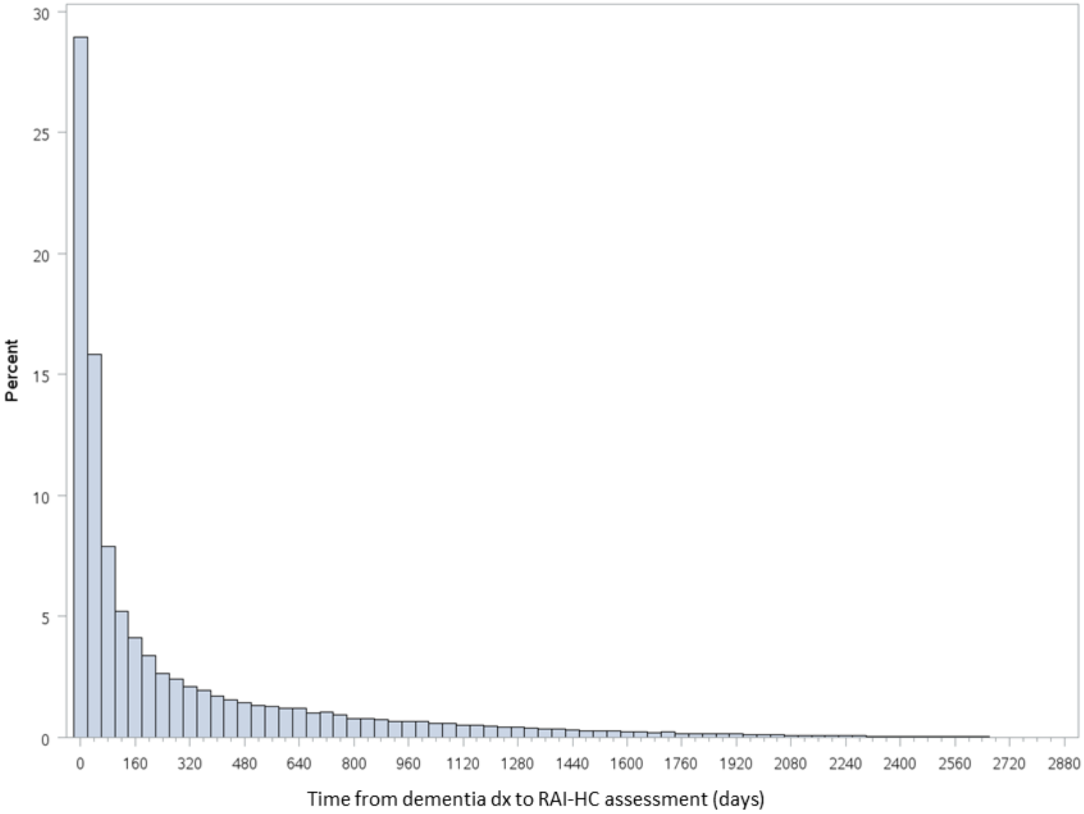


Figure 6. Cumulative incidence function plots for key variables.

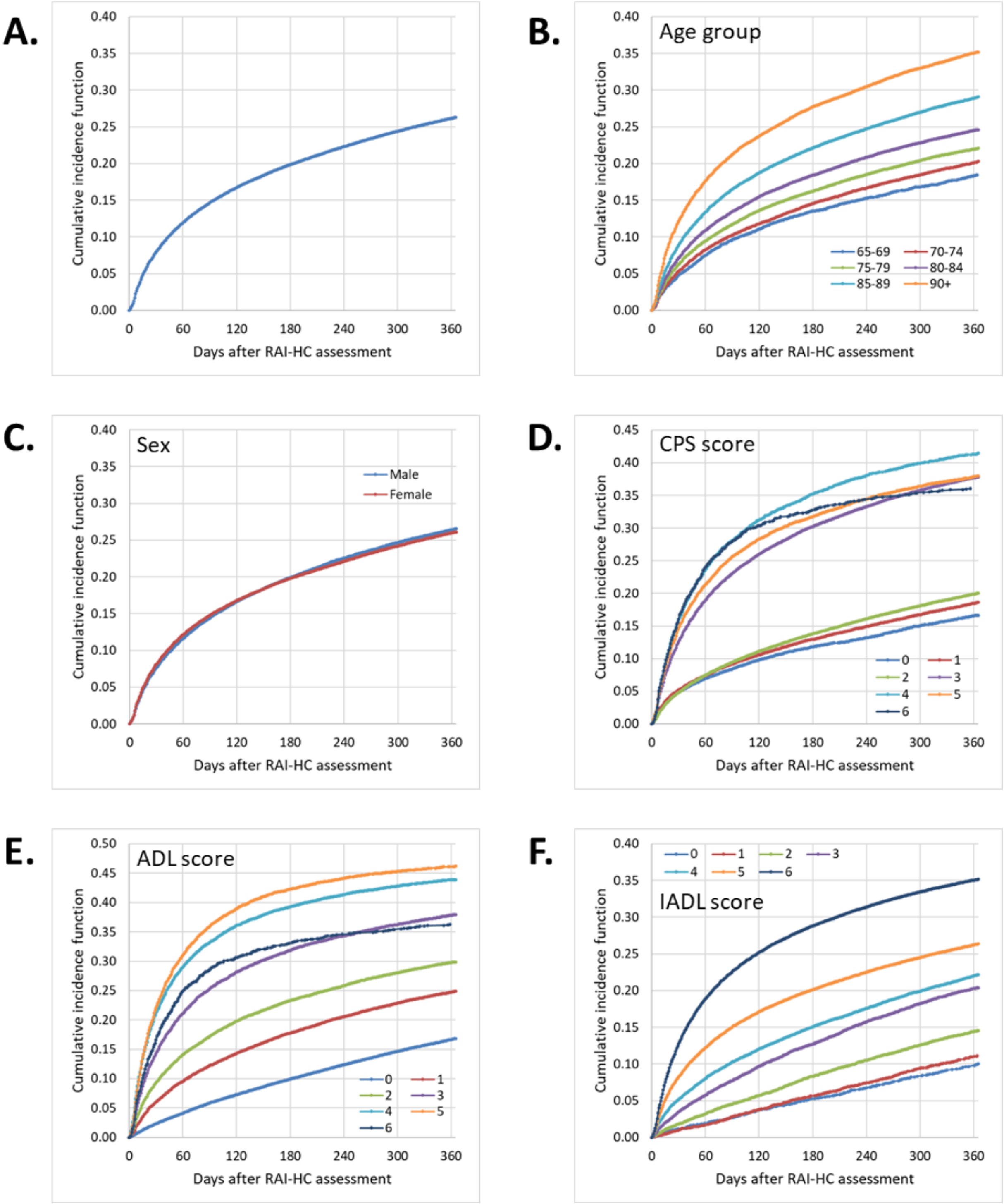


Figure 7. Cumulative incidence function plots by risk group.

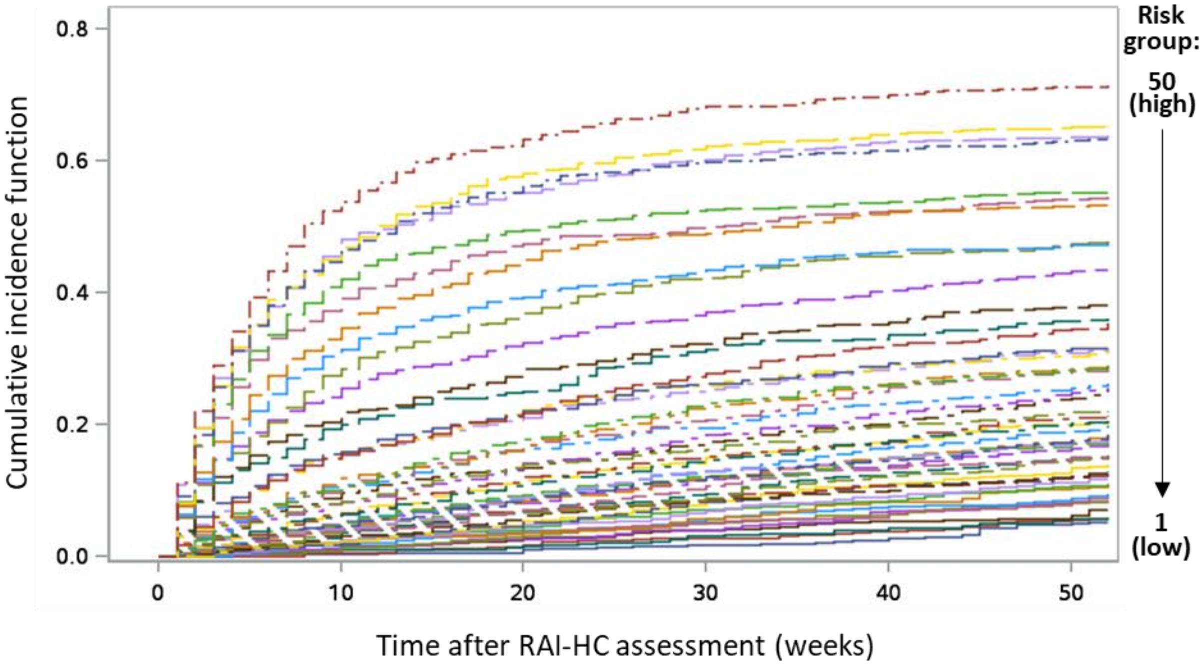


Figure 8. Model performance: observed vs. predicted risk.

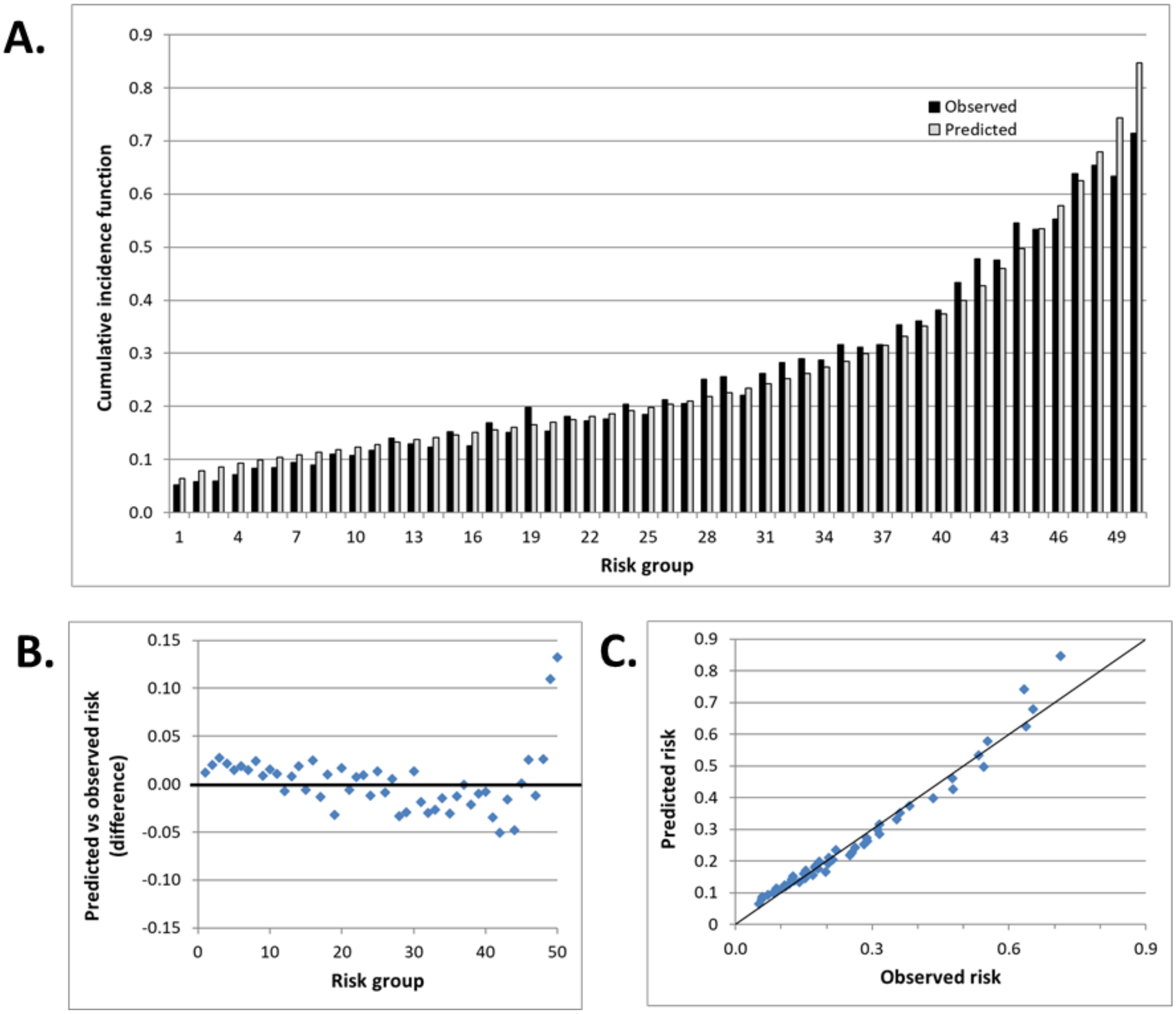


Figure 9. Time to long-term care placement by risk group.

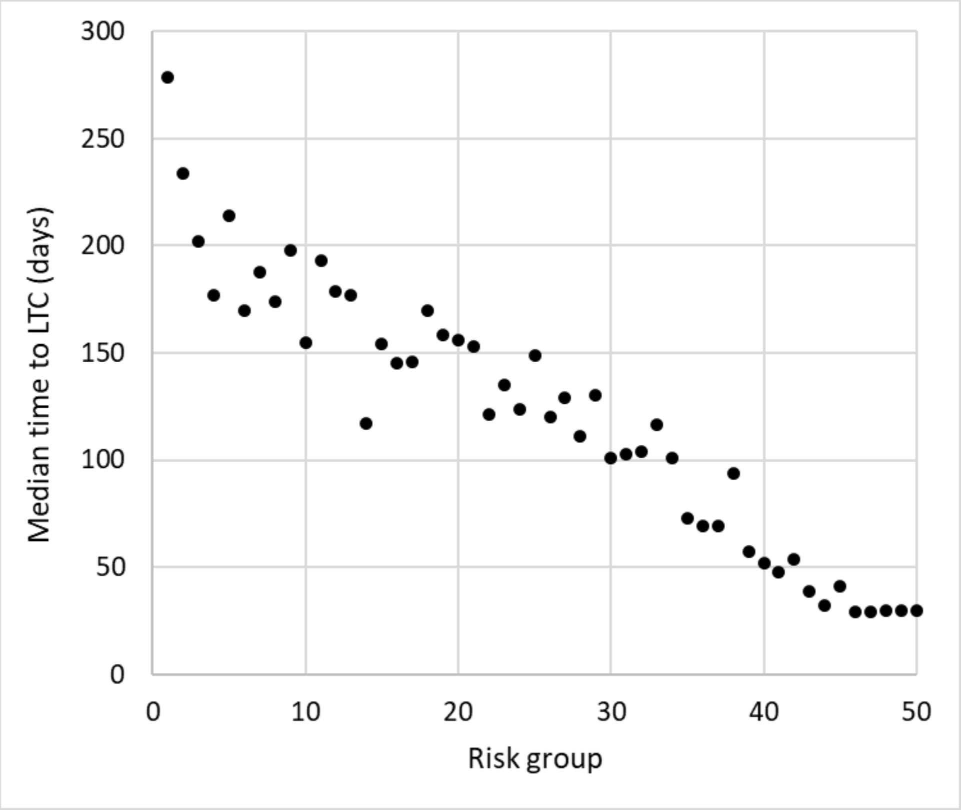


Figure 10. Observed vs. predicted risk by key variables.

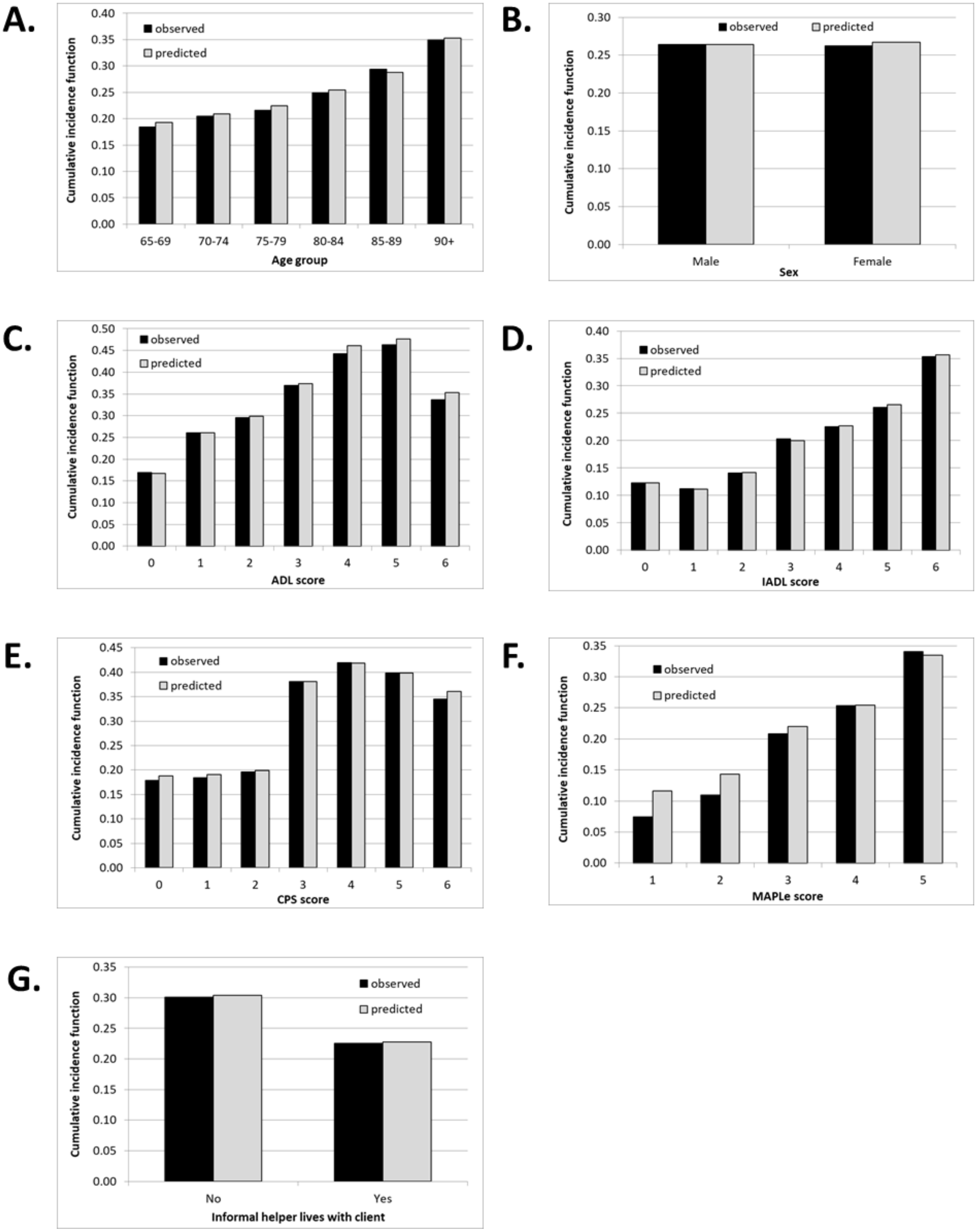


Figure 11. Five-year cumulative incidence function plots by risk decile.

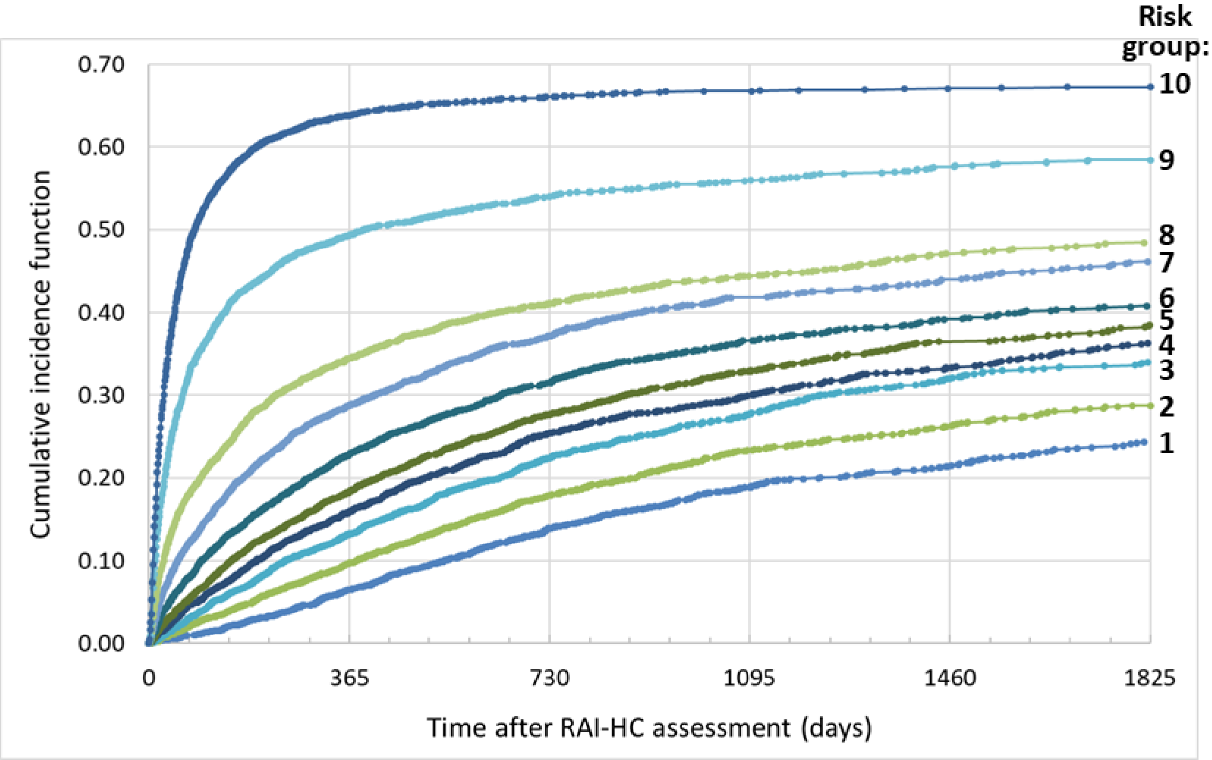
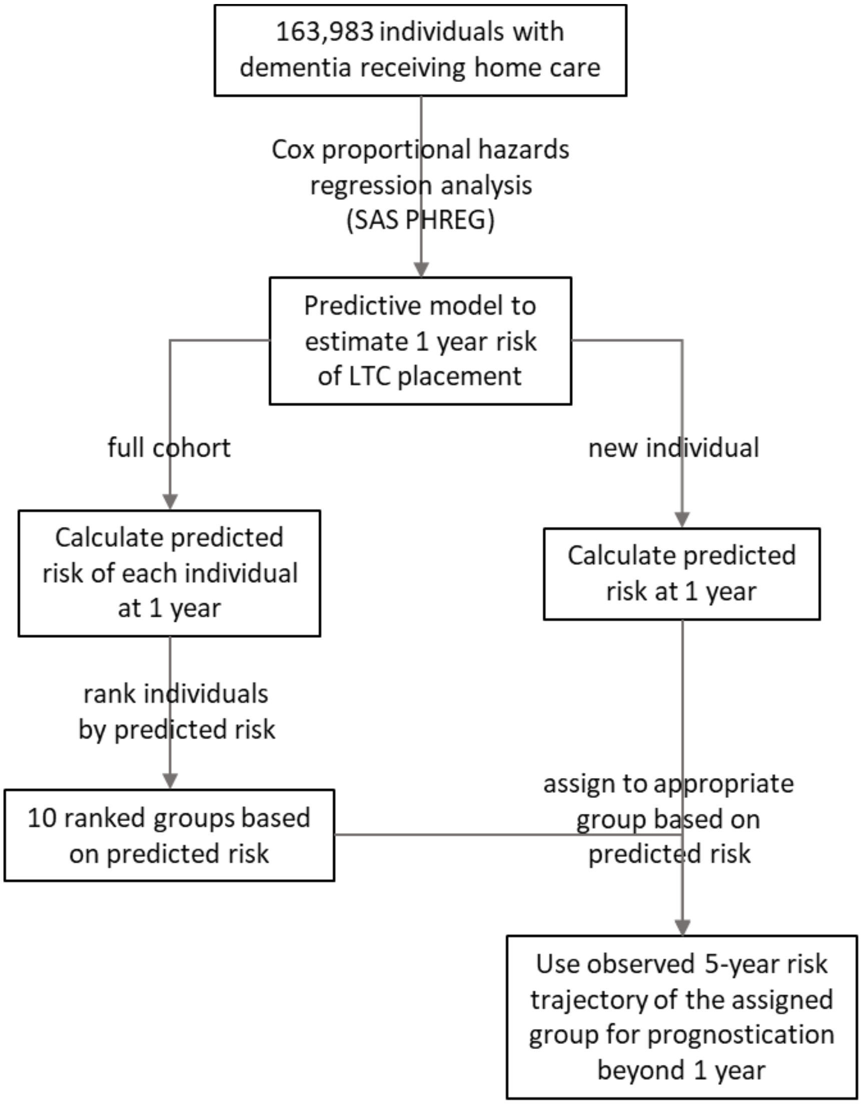


Figure 12. Application of predictive model for prognostication.



7. Appendices

Appendix 1. University of Ottawa REB approval

File Number: 12-16-02

Date (mm/dd/yyyy): 12/19/2016

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Ethics Approval Notice

Social Science and Humanities REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

First Name	Last Name	Affiliation	Role
Ivy	Bourgeault	Telfer School of Management	Supervisor
Amir	Attaran	Law / Law	Co-Supervisor
Gregory	Huyer	Telfer School of Management	Student Researcher

File Number: 12-16-02

Type of Project: Master's Thesis – Secondary use of data

Title: Transition of care for people with dementia: Predictive factors and health workforce implications

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
12/19/2016	12/18/2017	Approval

Special Conditions / Comments:
N/A

Appendix 2. ICES databases used in this study

Database	**Health Care Sector**	**Description**
Continuing Care Reporting System (CCRS)	Long-term care	Population-based resident information for over 600 publicly funded residential long-term care homes with 24-hour nursing care. Includes data collected from the Resident Assessment Instrument – Minimum Data Set (RAI-MDS). Years available: 1996–2016.
Canadian Institute for Health Information – Discharge Abstract Database (CIHI-DAD)	Acute care	Administrative, clinical, and demographic data on all hospital discharges in Ontario, using ICD coding scheme. Years available: 1988–2016.
Ontario Drug Benefit (ODB)	Prescription drugs	Drugs for those over 65 years, on social assistance, residents of LTC, home care recipients, Trillium drug program and special drugs program recipients for those qualifying for assistance. Years available: 1990–2017.
Ontario Health Insurance Plan (OHIP) Claims Database	Physician billings	Claims data for physicians in Ontario – includes claims in both inpatient and outpatient settings. Years available: 1991–2017.
Resident Assessment Instrument – Home Care (RAI-HC)	Home care	Data from the Ontario Association of Community Care Access Centres, responsible for providing all publicly funded home care. Years available: 2007–2015.
Registered Persons Database (RPDB)	Sociodemographics	Provides basic demographic information about anyone who has ever received an Ontario health card number, such as date of birth, sex, address, date of death (where applicable) and changes in OHIP eligibility status. Years available: 1990–2017.

Appendix 3. Definition of physician-diagnosed dementia

Any individual with one hospitalization billing OR three physician claims at least 30 days apart* within a two-year period** with any code/claim from either of the following datasets#:

- **CIHI-DAD:** ICD-9 (46.1, 290.0, 290.1, 290.2, 290.3, 290.4, 294.x, 331.0, 331.1, 331.5, 331.82); ICD-10 (F00.x, F01.x, F02.x, F03.x, G30.x)
- **OHIP:** 290, 331

OR: one dispensing record for the cholinesterase inhibitor subclass in **ODB** including donepezil (Aricept), galantamine (Reminyl, Reminyl ER, Razadyne, Razadyne ER), rivastigmine (Exelon), tacrine (Cognex), and memantine (Ebixa, Namenda) (ODB subclnam =: 'CHOLINESTERASE INHIBITOR').

* A separation of 30 days between claims is to avoid a misclassification of individuals experiencing a delirium during an acute illness (such as during a hospital admission)

**Date of last claim is considered to be the dementia diagnosis date. If a dementia diagnosis is ascertained by more than one method, the earliest ascertainment date is used.

CIHI-DAD: Canadian Institute of Health Information Discharge Abstract Database; OHIP: Ontario Health Insurance Plan physician claims database; ODB: Ontario Drug Benefit program database.

(Reference: Jaakkimainen, 2016)

Appendix 4. Baseline characteristics (selected variables) of individuals placed in LTC from two highest risk groups vs. full cohort (20% random sample)

Variable	Value	All	Risk group 49	Risk group 50
		n (%)	**n (%)**	**n (%)**
	Total	8,645 (100.0%)	416 (100.0%)	469 (100.0%)
Age	Mean ± SD	84.4 ± 6.9	86.2 ± 6.3	88.2 ± 6.1
	Median (IQR)	85 (80-89)	86 (82-91)	89 (85-93)
Time from dementia dx to RAI-HC assessment	Mean ± SD	215.0 ± 360.6	124.7 ± 266.5	106.7 ± 230.5
	Median (IQR)	52 (10-250)	30 (11-97)	26 (8-75)
Sex	Male	3,304 (38.2%)	138 (33.2%)	156 (33.3%)
	Female	5,341 (61.8%)	278 (66.8%)	313 (66.7%)
Marital status	Married	2,788 (32.2%)	84 (20.2%)	58 (12.4%)
	Widowed	4,781 (55.3%)	281 (67.5%)	358 (76.3%)
	Divorced / separated	594 (6.9%)	27 (6.5%)	26 (5.5%)
	Never married	401 (4.6%)	23 (5.5%)	26 (5.5%)
	Other	81 (0.9%)	<=5 (0.2%)	<=5 (0.2%)
Income quintile	1 (low)	2,089 (24.2%)	121 (29.1%)	152 (32.4%)
	2	1,775 (20.5%)	82 (19.7%)	93 (19.8%)
	3	1,723 (19.9%)	73 (17.5%)	90 (19.2%)
	4	1,555 (18.0%)	67 (16.1%)	67 (14.3%)
	5 (high)	1,460 (16.9%)	71 (17.1%)	63 (13.4%)
	Missing	43 (0.5%)	<=5 (0.5%)	<=5 (0.9%)
Informal helper lives with client	No / no such helper	4,907 (56.8%)	293 (70.4%)	384 (81.9%)
	Yes	3,738 (43.2%)	123 (29.6%)	85 (18.1%)
Cognitive skills - worsening decision making	No	3,510 (40.6%)	73 (17.5%)	60 (12.8%)
	Yes	5,135 (59.4%)	343 (82.5%)	409 (87.2%)
Cognitive Performance Scale	0	355 (4.1%)	6 (1.4%)	<=5 (0.2%)
	1	594 (6.9%)	12 (2.9%)	0 (0.0%)
	2	3,087 (35.7%)	27 (6.5%)	14 (3.0%)
	3	3,385 (39.2%)	267 (64.2%)	361 (77.0%)
	4	403 (4.7%)	39 (9.4%)	24 (5.1%)
	5	715 (8.3%)	61 (14.7%)	67 (14.3%)
	6	106 (1.2%)	<=5 (1.0%)	<=5 (0.4%)
Wandering	No	7,725 (89.4%)	358 (86.1%)	378 (80.6%)
	Yes	920 (10.6%)	58 (13.9%)	91 (19.4%)
Changes in behaviour symptoms	0	6,742 (78.0%)	304 (73.1%)	290 (61.8%)
	1	1,903 (22.0%)	112 (26.9%)	179 (38.2%)
Number of medications (last 7 days)	0 - 2	607 (7.0%)	8 (1.9%)	14 (3.0%)
	3 or 4	754 (8.7%)	18 (4.3%)	22 (4.7%)
	5 or 6	1,227 (14.2%)	37 (8.9%)	48 (10.2%)
	7 or 8	1,323 (15.3%)	47 (11.3%)	52 (11.1%)
	9+	4,734 (54.8%)	306 (73.6%)	333 (71.0%)
Falls frequency (last 90 days)	0	3,839 (44.4%)	115 (27.6%)	101 (21.5%)
	1	2,127 (24.6%)	127 (30.5%)	102 (21.7%)
	2	1,105 (12.8%)	80 (19.2%)	86 (18.3%)
	3+	1,574 (18.2%)	94 (22.6%)	180 (38.4%)
Bladder continence	Continent	3,353 (38.8%)	113 (27.2%)	89 (19.0%)
	Usually continent	2,257 (26.1%)	89 (21.4%)	98 (20.9%)
	Incontinent	3,035 (35.1%)	214 (51.4%)	282 (60.1%)
Hours of physical activity (last 3 days)	2 or more	4,088 (47.3%)	118 (28.4%)	131 (27.9%)
	Less than 2	4,557 (52.7%)	298 (71.6%)	338 (72.1%)

Appendix 4 continued.

Variable	Value	All	Risk group 49	Risk group 50
ADL self-performance scale	0	2,404 (27.8%)	<=5 (1.2%)	<=5 (1.1%)
	1	1,301 (15.0%)	30 (7.2%)	27 (5.8%)
	2	1,769 (20.5%)	86 (20.7%)	78 (16.6%)
	3	1,059 (12.2%)	79 (19.0%)	96 (20.5%)
	4	1,132 (13.1%)	124 (29.8%)	166 (35.4%)
	5	838 (9.7%)	87 (20.9%)	97 (20.7%)
	6	142 (1.6%)	<=5 (1.2%)	0 (0.0%)
ADL decline	No	2,260 (26.1%)	24 (5.8%)	12 (2.6%)
	Yes	6,385 (73.9%)	392 (94.2%)	457 (97.4%)
IADL difficulty scale	0	78 (0.9%)	0 (0.0%)	<=5 (0.2%)
	1	100 (1.2%)	0 (0.0%)	0 (0.0%)
	2	381 (4.4%)	0 (0.0%)	0 (0.0%)
	3	387 (4.5%)	7 (1.7%)	<=5 (1.1%)
	4	1,176 (13.6%)	42 (10.1%)	35 (7.5%)
	5	3,045 (35.2%)	118 (28.4%)	129 (27.5%)
	6	3,478 (40.2%)	249 (59.9%)	299 (63.8%)
Hours of informal care (per week)	0 to 6	1,143 (13.2%)	0 (0.0%)	0 (0.0%)
	7 to 13	983 (11.4%)	<=5 (0.2%)	0 (0.0%)
	14 to 20	786 (9.1%)	0 (0.0%)	0 (0.0%)
	21 to 26	590 (6.8%)	<=5 (0.2%)	0 (0.0%)
	27 to 34	487 (5.6%)	<=5 (0.2%)	0 (0.0%)
	35 to 41	395 (4.6%)	0 (0.0%)	0 (0.0%)
	42+	803 (9.3%)	0 (0.0%)	0 (0.0%)
	Missing	3,458 (40.0%)	413 (99.3%)	469 (100.0%)
PSW services (last 7 days)	No	4,250 (49.2%)	307 (73.8%)	402 (85.7%)
	Yes	2,674 (30.9%)	<=5 (0.2%)	0 (0.0%)
	Missing	1,721 (19.9%)	108 (26.0%)	67 (14.3%)
Nursing services (last 7 days)	No	5,684 (65.7%)	306 (73.6%)	402 (85.7%)
	Yes	1,240 (14.3%)	<=5 (0.5%)	0 (0.0%)
	Missing	1,721 (19.9%)	108 (26.0%)	67 (14.3%)
Homemaking services (last 7 days)	No	5,104 (59.0%)	306 (73.6%)	402 (85.7%)
	Yes	1,820 (21.1%)	<=5 (0.5%)	0 (0.0%)
	Missing	1,721 (19.9%)	108 (26.0%)	67 (14.3%)
Meals services (last 7 days)	No	5,984 (69.2%)	305 (73.3%)	402 (85.7%)
	Yes	940 (10.9%)	<=5 (0.7%)	0 (0.0%)
	Missing	1,721 (19.9%)	108 (26.0%)	67 (14.3%)
OT/PT/ST (last 7 days)	No	5,794 (67.0%)	308 (74.0%)	402 (85.7%)
	Yes	1,130 (13.1%)	0 (0.0%)	0 (0.0%)
	Missing	1,721 (19.9%)	108 (26.0%)	67 (14.3%)
Other services (last 7 days)	No	6,695 (77.4%)	307 (73.8%)	402 (85.7%)
	Yes	229 (2.6%)	<=5 (0.2%)	0 (0.0%)
	Missing	1,721 (19.9%)	108 (26.0%)	67 (14.3%)
Informal helper relationship with client	Child / child-in-law	5,139 (59.4%)	275 (66.1%)	325 (69.3%)
	Spouse	2,096 (24.2%)	59 (14.2%)	36 (7.7%)
	Other relative	867 (10.0%)	53 (12.7%)	85 (18.1%)
	Friend / neighbour	408 (4.7%)	24 (5.8%)	19 (4.1%)
	Missing	135 (1.6%)	<=5 (1.2%)	<=5 (0.9%)
A caregiver is unable to continue	No	6,649 (76.9%)	279 (67.1%)	302 (64.4%)
	Yes	1,996 (23.1%)	137 (32.9%)	167 (35.6%)
Caregiver is not satisfied with support from family	No	8,204 (94.9%)	402 (96.6%)	461 (98.3%)
	Yes	441 (5.1%)	14 (3.4%)	8 (1.7%)

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