Home and Community-Based Service Utilization Patterns for Seniors with Alzheimer's Disease and Related Dementias

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Lawrence S. Bloomberg Faculty of Nursing
University of Toronto

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Abstract

**Background:** Half a million Canadians are living with Alzheimer’s disease and related dementias. Approximately half these individuals live in the community, supported by informal caregivers. In this population, utilization of formal services is low and patterns of utilization are not well understood. Previous studies examining predictors of service use have examined services in isolation however, often multiple services are utilized, with little coordination between services.

**Purpose:** The purpose of this study was to provide a better understanding of the community-based services utilized concurrently by seniors with dementia and their caregivers.

**Methods:** Administrative data were utilized to conduct a secondary analysis. Using latent class analysis, cases were categorized into patterns of home and community-based health and support service use. Multinomial logistic regression was employed to identify predictors of identified service use patterns.

**Results:** A broad range of services were utilized by seniors with dementia in this sample. Services supporting patients’ functional needs were utilized most frequently, while services addressing patients’ medical needs, rehabilitation and caregiver relief were used less often.
Utilization of all services, except nursing and occupational therapy, varied by level of cognitive impairment. Seven unique patterns of home and community-based service use were identified. Key patient and caregiver characteristics impacting service use patterns included living arrangement, functional impairment, location of care, cognitive impairment, age, continence, and caregiver relationship.

**Conclusions:** The majority of community-based seniors with dementia did not access formal services. For those who did access formal services, availability of informal caregivers, living arrangement, caregiver relationship and location of care impacted the pattern of service use. A proactive approach to supporting caregivers and reducing the impact of functional limitations is recommended. Further research is needed to understand caregivers’ decision-making processes affecting service utilization and to assess the impact of patterns of service utilization on both patient and caregiver outcomes.
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1 Background

In 2010, the Alzheimer Society of Canada published Rising Tide: The Impact of Dementia on Canadian Society, which outlined the economic and societal impact of dementia in Canada and called for the development of a national dementia plan. Currently, half a million Canadians are living with Alzheimer’s disease or a related dementia, and based on expected population changes and knowledge of dementia risk factors, this number is projected to grow to 1.1 million by 2038 [Alzheimer Society of Canada (ASC), 2010]. Most people with dementia and their caregivers prefer to receive care at home, in familiar surroundings, with family nearby (Chu, Edwards, Levin & Thomson, 2000). However, dementia is currently the main cause of institutionalization among the elderly in Canada [Canadian Institute of Health Information (CIHI), 2010].

While presently, approximately 50% of persons with dementia live in the community, over the next 25 years, the percentage of seniors with dementia living in their own homes is projected to increase to 62% (ASC, 2010; CIHI, 2010). This shift will likely result in a substantial increase in demand for long-term community-based care. Additionally, greater geographical distance between family members along with informal caregivers’ competing priorities imply that demand for formal long-term care services for persons will increase (Wattmo, Londos & Minthon, 2014). With the institutional long-term care sector already experiencing bed shortfalls, 42% of the Alternate Level of Care (ALC) population in Ontario hospitals having a dementia diagnosis (Chambers & Eisner, 2013) and more than half of LTC beds occupied by seniors with dementia (CIHI, 2010), the impact of dementia on the system is significant. Gaining a better understanding of how seniors with dementia utilize home and community-based services and whether specific patient and caregiver characteristics impact patterns of service use is of great importance for service planning and resource allocation.

1.1 Alzheimer’s Disease and Related Dementias

Dementia is a syndrome caused by brain tissue disease in which multiple cortical functions are affected (Kinnard, 2012). Dementia is characterized by impaired cognitive functioning and includes a range of brain diseases, which are typically chronic and progressive in nature. Dementia affects an individual’s ability to perform high level functions including self-
management of other chronic conditions as well as an individual’s ability to perform important
daily self-care activities such as bathing and dressing [Alzheimer’s Society Ontario (ASO),
2012]. These functional impairments are a major source of disability and can lead to caregiver
burden, hospitalization, home care utilization and institutionalization (Hill, Fillit, Thomas &
Chang, 2006).

Alzheimer’s disease is the most common form of dementia in Canada and has no known cause or
cure. Alzheimer’s disease and related dementias (ADRD), including vascular dementia,
frontotemporal lobe dementia, and Lewy body dementia, cause chronic, progressive deterioration
in all functions and eventually lead to complete disability and death (ASO, 2012).

1.1.1 Impact of ADRD in Ontario

Approximately 400,000 Canadians are living with ADRD, while in Ontario, over 200,000
seniors have a dementia diagnosis (ASC, 2010; Hopkins, 2010). The prevalence of dementia
varies across different regions in Ontario, dependent on local population demographics (ASO,
2012). The actual number of seniors living with dementia in Ontario may be much higher, as
formal diagnosis rates have been reported to range from 20% to 50% [All-Party Parliamentary
Group on Dementia (APPGD), 2012; Bradford, Kunik, Schulz, Williams & Sing, 2009; Eichler
et al., 2014; Prince, Bryce & Ferri, 2011].

Approximately half of individuals with ADRD live in the community and are cared for by family
members and friends (Lindsay & Anderson, 2004; Markle-Reid & Browne, 2001; McAiney,
Hillier, Stolee, Harvey & Michael, 2012). Of those living in the community nearly two-thirds
live with their primary caregiver who is most often their spouse or an adult child [Alzheimer’s
Society Ontario (ASO), 2005; Gill, Camacho, Poss, Bronskill & Wodchis, 2011]. These informal
caregivers provide the bulk of care for their family member with dementia. A 2005 profile of
Ontario home care patients with ADRD reported an average informal caregiver provides
approximately 30.4 hours of care a week, with formal care services providing an additional 6.8
hours of care (ASO, 2005). Dementia places a significant demand on both formal and informal
health care services and, therefore, is associated with substantial financial and opportunity costs
for caregivers and the health system (Gill et al., 2011).
1.1.2 Clinical Course of ADRD

The progression of ADRD varies by person and can span anywhere from three to 20 years, with an average life expectancy following diagnosis of between eight and ten years (Feldman & Kertesz, 2001). Alzheimer’s disease is best conceptualized as a continuum with individuals experiencing symptoms and functional deficits at varying rates. The Functional Assessment Staging (FAST) method focuses on an individual’s level of functioning and ability to complete the activities of daily living. Seven global stages ranging from “Normal” to “Severe Alzheimer’s disease” have been identified with 16 sub-stages delineating functional changes being mapped to these seven more global stages (Reisberg et al., 1996). Movement through the continuum is not necessarily linear with many individuals experiencing overlap between stages. The clinical course of Alzheimer’s disease has been outlined by Reisberg and Franseen (1999) and is summarized in Table 1.

Table 1: Functional Assessment Stages, Clinical Characteristics and Clinical Diagnosis in Alzheimer’s disease

<table>
<thead>
<tr>
<th>FAST Stage</th>
<th>Clinical Characteristics</th>
<th>Clinical Diagnosis</th>
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<tr>
<td>1</td>
<td>No deficits noted</td>
<td>Normal adult</td>
</tr>
<tr>
<td>2</td>
<td>Subjective deficit in word finding or recalling location of objects</td>
<td>Age-associated memory impairment</td>
</tr>
<tr>
<td>3</td>
<td>Deficits noted in demanding employment settings</td>
<td>Mild cognitive impairment</td>
</tr>
<tr>
<td>4</td>
<td>Requires assistance in complex tasks (i.e., handling finances, planning and preparing meals, ordering from menu)</td>
<td>Mild Alzheimer’s disease</td>
</tr>
<tr>
<td>5</td>
<td>Requires assistance choosing proper attire</td>
<td>Moderate Alzheimer’s disease</td>
</tr>
<tr>
<td>6a</td>
<td>Requires assistance dressing</td>
<td>Moderately severe Alzheimer’s disease</td>
</tr>
<tr>
<td>6b</td>
<td>Requires assistance bathing properly</td>
<td>Moderate Alzheimer’s disease</td>
</tr>
<tr>
<td>6c</td>
<td>Requires assistance with toileting</td>
<td>Severe Alzheimer’s disease</td>
</tr>
<tr>
<td>6d</td>
<td>Urinary incontinence</td>
<td></td>
</tr>
<tr>
<td>6e</td>
<td>Fecal incontinence</td>
<td></td>
</tr>
<tr>
<td>7a</td>
<td>Speech ability limited to approximately 6 words</td>
<td></td>
</tr>
<tr>
<td>7b</td>
<td>Intelligible vocabulary limited to a single word</td>
<td></td>
</tr>
<tr>
<td>7c</td>
<td>Unable to ambulate independently</td>
<td></td>
</tr>
<tr>
<td>7d</td>
<td>Unable to sit up independently</td>
<td></td>
</tr>
<tr>
<td>7e</td>
<td>Unable to smile</td>
<td></td>
</tr>
<tr>
<td>7f</td>
<td>Unable to hold head up</td>
<td></td>
</tr>
</tbody>
</table>

Stage one, “Normal” and stage two, “Normal Aged Forgetfulness”, characterize individuals with either no deficit or normal changes in memory associated with aging. Stage three, “Mild Cognitive Impairment”, encompasses individuals who have subtle deficits in cognitive performance such as repeated questions, declining job performance, and difficulty mastering new skills.

A formal diagnosis of Alzheimer’s disease is most likely to be made in stage four, “Mild Alzheimer’s disease”, as difficulties completing instrumental activities of daily living (IADL) such as managing personal finances and grocery shopping become more evident. In this stage, individuals can continue to live independently, however they may require increased levels of formal support and / or informal support from family and friends to manage adequately. In stage five, “Moderate Alzheimer’s disease”, individuals begin to demonstrate deficits in key self-care activities such as dressing and have difficulty remembering major events and aspects of their lives. In this stage, many can no longer manage key IADL tasks such as food preparation and financial management on their own in the community without assistance. In stage six, “Moderately Severe Alzheimer’s disease”, the ability to perform basic self-care activities is highly compromised. Care needs increase rapidly in this stage as the individual experiences progressive functional decline in several activities of daily living (ADL) beginning with requiring assistance dressing (stage 6a) to fecal incontinence (stage 6e). Cognitive deficits are also severe at this point, with individuals displaying little to no knowledge of major aspects of their current circumstances. Once reaching stage seven, “Severe Alzheimer’s disease”, individuals require continuous assistance with basic activities of daily life. Most stage seven individuals are institutionalized due to overwhelming care needs. At this stage, the person with dementia loses their ability to speak, to ambulate and to remain seated upright. Most succumb to the illness during stage seven with the most common causes of death being aspiration pneumonia and infected decubitus ulcers. As this study focuses on individuals with a diagnosis of Alzheimer’s disease living in the community, further discussion will focus on individuals in stages four, five and six.
1.2 Dementia Care

The dementia illness experience is subjective, unique to each affected individual, and is determined by biological, social and psychological factors. Appropriate care for persons with dementia varies with the individual, their disease stage, and specific impairments (ASC, 2010) and unmet or partially met care needs can have serious consequences such as negative mental health states, nursing home placement and death (Gaugler, Kane, Kane & Newcomer, 2005a; Turcotte, 2014). The progressive nature of dementia, as described above, results in a caregiving situation where demands on caregivers are persistent and steadily increasing. Therefore, a wide range of community-based and institutional services are necessary to support persons with dementia and their family caregivers from the point of diagnosis until end-of-life. While there are a broad range of services available to persons with dementia and their caregivers along the disease trajectory, in Canada these services are often uncoordinated and delivered with little standardization and continuity (ASC, 2010), making the care of persons with dementia in the community more difficult.

Presently, most individuals living with dementia have not received a formal diagnosis. In high-income countries, like Canada, the United States and the United Kingdom, only 20-50% of individuals with dementia have a documented diagnosis (APPGD, 2012; Bradford et al., 2009; Eichler et al., 2014; Prince et al., 2011). As medical treatments and services are often only available for those with a formal diagnosis, timely detection of ADRD is a crucial step to supporting persons with dementia, their families and caregivers (Eichler et al., 2014). Persons with dementia typically enter the healthcare system at a point of crisis, leading to intensive use of high level care which could have been prevented if earlier interventions had been instituted (ASC, 2010; McAiney et al., 2012; Vetter et al., 1998). Studies evaluating interventions implemented early in the dementia trajectory have indicated that early intervention can assist individuals with dementia to maintain their independence, remain in the community longer, prevent crisis situations and reduce barriers to accessing appropriate care (Gaugler, Kane, Kane & Newcomer, 2005b; Littlewood, Seymour & Owen, 2010; McAiney et al., 2012; Peacock & Forbes, 2003).
Following diagnosis, persons living with ADRD, and their caregivers, need a range of health care and social support services that are responsive to changes in their health throughout the disease trajectory [Alzheimer’s Society of Toronto (AST), 2010]. Education, referrals to community resources, on-going monitoring and caregiver skill training are just some of the initial interventions thought to benefit early stage ADRD patients (Peacock & Forbes, 2003). As community-dwelling persons with dementia receive much of their care from their informal care system, involving these individuals in the early stages can allow for long-term care planning, the development of improved caregiving strategies to cope with functional and behavioural difficulties and the development of therapeutic relationships with case managers and other service providers (Chu et al., 2000; McAiney et al., 2012).

Care needs of persons with dementia increase significantly as the disease progresses, with increasing cognitive decline resulting in escalating functional impairments. In Canada, most informal caregivers assist with several activities of daily living (ADLs), such as bathing and toileting, as well as instrumental activities of daily living (IADLs) such as shopping and housekeeping (Smale & Dupuis, 2004). Informal caregivers of persons with dementia provide significantly more hours of care than caregivers of seniors without dementia [Health Council of Canada (HCC), 2012; Sinha & Bleakney, 2014]. As the disease progresses to later stages and functional and cognitive status decline, more hours of care are required to support the individual with dementia in the community (Peacock & Forbes, 2003). However, much of the additional burden is borne by informal caregivers with only a slight increase in the hours of formal care provided with increasing disease severity (Sinha & Bleakney, 2014).

Formal community-based long-term care services consist of services that are provided in the home or community, paid for with public or private funds, which provide planned temporary relief for the primary caregiver through the provision of substitute care (Markle-Reid & Browne, 2001). Typically, dementia caregivers are low users of formal care services (Smale & Dupuis, 2004). Reasons for low service use include reluctance to use formal services, lack of knowledge of formal services available, feelings that formal services are unnecessary or unwillingness to use formal services due to inconvenience, cost or perceived quality (Brodaty, Thomson, Thompson & Fine, 2005). However, case management has been found to increase the use of formal services in persons with dementia and their caregivers (Challis, von Abendorff, Brown, Chesterman &
Hughes, 2002; Peacock & Forbes, 2003). The positive therapeutic relationship established by case managers can aid in building the resilience of caregivers and improve service utilization rates to help seniors with dementia to remain in their homes and communities longer (Challis et al., 2002; Chu et al., 2000; Kinnard, 2012).

1.2.1 The Dementia Care Continuum

Dementia care exists along a continuum of increasing care intensity, starting with individuals who are first diagnosed and living at home with or without informal caregivers, to individuals living at home supported by informal care and/or formal community-based services, to individuals receiving full care in residential long-term care facilities (ASC, 2010).

1.2.1.1 Community-Based Care

Community-based dementia care consists of two main types of services: home health services and community support services. In Ontario, publicly funded home health services are accessed through and managed by the Community Care Access Centers (CCACs). Services available through the CCAC include assessment and case management, nursing care, personal care and housekeeping, therapies such as physiotherapy, occupational therapy, speech therapy, social work, dietetics, medical equipment and supplies, as well as respite care (Home Care and Community Services Act, 1994).

Community support services (CSSs) are those services delivered in the home or community by organizations which assist people with health or social problems to maintain the highest possible level of social functioning and quality of life (Ploeg et al., 2009). Examples of CSSs include adult day services, friendly visiting, security checks, transportation services, meal delivery and disease-specific organizations such as the Alzheimer’s Society which provide information, education and referral services. Access to some of these services is provided through the CCACs, while additional private services and programs are also available to support persons with dementia and their caregivers.

In 2010, the Alzheimer’s Society of Toronto undertook a project to summarize current community support services and identify gaps in community-based dementia care (AST, 2010). This report outlined services that should be considered “core” for dementia care as well as
services that could be considered complementary. Core services spanned the continuum of dementia and were identified as central to the care and well-being of people with ADRD and their caregivers. Community-based services recommended as core services include dementia-specific adult day services with and without overnight stay, assistive living programs for persons with dementia, dementia-specific case management, dementia-specific counseling, dementia-specific education programs, support groups for families caring for persons with dementia, dementia-specific personal care/personal support, dementia-specific homemaking/home help, dementia-specific respite, dementia-specific friendly visiting, psycho-geriatric mental health services, and memory clinics for persons with dementia. Currently generic (i.e. not dementia-specific) versions of many of these services are currently available with more dementia-specific services becoming increasingly available through funding under the Behavioural Supports Ontario project.

The Behavioural Supports Ontario program began in 2010 when the Ontario Ministry of Health and Long Term Care set out to develop a framework of care to improve outcomes for persons with responsive behaviours, their families, health care providers and the health system (Gutmanis, Snyder, Harvey, Hillier & LeClair, 2015). In recognition of the increase in individuals with responsive behaviours across the health system, in 2011, 40 million dollars were invested to develop a cross-sectoral system of supports and services aimed to meet the needs of seniors with cognitive impairments as well as complex, challenging behaviours. Goals of the project were threefold; 1) to improve system coordination and management, 2) to provide integrated service delivery to improve efficiency and access to services and 3) to develop capacity by increasing the knowledge and skills of care providers (Gutmanis et al., 2015). Using the framework, each health region in Ontario developed a unique plan which addressed local needs taking into account gaps in care, the local policy environment and opportunities for collaboration. Examples of system and service improvements undertaken through this funding included: training and education new and existing frontline staff, development of in-house behavioural support staff in many long-term care homes as well as mobile outreach teams, and the development of assessment and skill building tools as well as new care pathways (Gutmanis et al., 2015). In 2016, an additional 10 million dollars were invested to enhance services in place and hire additional staff across the program.
Often in the community, the family physician is the primary facilitator of care for community-based management of dementia with support from specialist providers such as neurologists, psychiatrists and geriatricians as well as community services (Frank, Feldman & Schulz, 2011). However, for persons with dementia to take advantage of the community services available, primary care physicians or family caregivers need to be aware of the dementia-specific resources available, the eligibility criteria for each service and how to navigate the referral process. Research suggests referrals and information to these services are not consistently provided and that community health and support services are underused, largely due to a lack of awareness of the services available (McAiney et al., 2012; Ploeg et al., 2009; Smale & Dupuis, 2004; Strain & Blandford, 2002; Vetter et al., 1998). Additionally, dementia services in Ontario vary significantly by Local Health Integration Network (LHIN) resulting in variation in coordination, availability and continuity of services and the need for local knowledge of services available (Dudgeon, 2010).

Through their First Link™ referral program, the Alzheimer Society of Ontario can reduce this knowledge burden on patients and primary care providers. For patients with a diagnosis of ADRD, with the appropriate consent, primary care providers can submit a referral to First Link™ and staff from the local Alzheimer’s Society will proactively contact the person with dementia and their caregiver to introduce services and arrange follow-up. This reduces the burden on patients and families to follow up with their local Alzheimer Society chapter when overwhelmed by a new diagnosis (Frank et al., 2011). Services provided by the Alzheimer Society can include: educational sessions and information, counseling services, respite care and programs tailored to stimulate and engage persons with dementia. Additionally, the Alzheimer Society can link persons with dementia and their families to supports and services in their communities. Services used by Ontario dementia caregivers most frequently include adult day-away programs, homemaker services, Alzheimer’s disease support groups, case management, in-home respite services and home health care (Smale & Dupuis, 2004). Unfortunately, First Link is not equally funded and supported across all Ontario LHINs at this time, resulting in variation in access to and knowledge of these services (G. Torys, personal communication, 29 Aug 2014).
1.2.1.2 Institution-Based Care

While it is preferable for persons with ADRD to remain at home to maintain their social network, preserve environmental landmarks and enjoy a better quality of life (Luppa et al., 2010), when cognitive or functional impairments become too great, institutional care can be necessary (Gill et al., 2011). However, institutional care is not always utilized appropriately. In 2007-2008, one in six seniors that were newly admitted to residential care had low levels of cognitive impairment and low levels of functional impairment and therefore may have been suitable for community-based care (CIHI, 2010). As admission to nursing homes has been associated with declining health status, increased mortality and emotional challenges for families (Gaugler, Yu, Krichbaum & Wymna, 2009), it is important to ensure institutional care is only utilized when necessary.

1.2.2 Service Utilization in Community-Based Dementia Care

For an individual to remain in the community, self-care abilities, informal care and formal care must be sufficient in total (Poss, 2006). As self-care abilities of individuals with dementia progressively decline, informal and formal care must make up the deficits. As care needs increase, formal care services are needed to supplement care provided by family caregivers and to support them to continue caregiving (Toseeland, McCallion, Gerber & Banks, 2002; Toseeland et al., 1999; Zhu et al., 2008). However, the balance of care between formal and informal care can be delicate and needs vary among persons with dementia living in the community. Research has found that the more family (informal) support available to an individual, the less likely older adults are to utilize formal care services early in the care trajectory (Chen & Thompson, 2010; Mitchell & Krout, 1998). This can lead to negative outcomes, such as earlier time to institutionalization, as caregivers become burnt out (Chen & Thompson, 2010; Gaugler et al., 2000; Gaugler et al., 2005a). On the other hand, a lack of adequate informal care has been found to be associated with a move to institution-based care, hospital admission and death for persons with dementia (Kuzuya et al., 2011). These findings highlight the complex interplay between formal and informal care and the importance of both the timing and mix of home and community-based services in supporting the person with dementia and their informal caregiver(s).
Home and community-based services for persons with dementia need to address a wide range of functional, cognitive and supportive care needs over the dementia trajectory [National Collaborating Center for Mental Health (NCCMH), 2007]. Four key elements identified as integral to providing effective dementia care in the community include: optimizing physical health and function, engaging in daily activities, maintaining quality of life and supporting caregivers (Gitlin, Winter, Dennis, Hodgson & Hauck, 2010). Home and community-based services which address these core elements include both health (medical and psychological) and supportive services (Smale & Dupuis, 2004; Toseland et al., 1999; Weber, Pirraglia & Kunik, 2011).

1.2.2.1 Home and Community-Based Support Services

Ideally, community-based care of individuals with dementia includes coordinated and integrated delivery of home and community-based services based on an individualized assessment and care plan (NCCMH, 2007). Home and community-based services of benefit to persons with dementia and their caregivers include visiting nursing, personal support and homemaking, physiotherapy, occupational therapy, physician visits, meal services, respite care and friendly-visiting. An overview of each service is provided below including a description of service provider roles in dementia care and service utilization rates by persons with dementia living in Ontario.

Personal Support and Homemaking.

Unregulated care providers provide support with personal and supportive care needs such as assistance with dressing, bathing, toileting, cooking or meal preparation, medication reminders and companionship. In Ontario, these care providers are known as Personal Support Workers (PSWs). From the caregiver perspective, personal care and homemaking services have been found to be essential for supporting vulnerable older adults in the community (Weaver, 2014). In Ontario, depending on whether individuals meet eligibility criteria, personal support and homemaking services can be provided through home care agencies under contract with the CCACs, by CSS agencies or by private caregiver services. Ontario service data demonstrates that in 2007-2008 only 23.8% of persons with physician-diagnosed dementia received personal care or homemaking visits through CCAC home care programs (Gill et al., 2011). Service utilization
rates for personal support and homemaking services provided through CSS agency programs or private caregivers could not be located.

**Meal Services.**

Utilization of meal delivery services such as Meals on Wheels can address some of the issues associated with nutrition and safety in individuals with dementia, especially for those living alone (Gould & Basta, 2013). Concerns of family caregivers related to nutrition and cooking often include safety when cooking, access to food, ability to prepare meals as well as maintaining independence (Keller et al., 2008). Meal delivery services provide complete meals that can improve nutritional intake and reduce the risk of fire or injury due to unsafe cooking practices. Having meals delivered also provides a regular check-in on individuals with dementia by non-health community volunteers. While only a small proportion of Ontario caregivers utilize meal services (7.3%), those who do access the service do so regularly, receiving meals on average 12.5 days per month (Smale & Dupuis, 2004).

**Community-based Respite Care.**

Respite care is the provision of short-term and/or temporary relief to those who are caring for loved ones who might otherwise require placement outside the home (Canadian Healthcare Association, 2012). Respite can take place in various locations including the care recipient’s home, community settings or institutions and therefore can be classified as either a community-based, or a home-based service (Phillipson, Jones & Magee, 2014).

**Adult Day Services.** Adult day services are community-based programs which provide day services for persons with dementia including supervised therapeutic activities, health monitoring, socialization, medical care and other social services. The key objectives of adult day services are to provide a period of respite for family caregivers and to provide psychological benefits to persons with dementia through social activities and therapy (Femia, Zarit, Stephens & Green, 2007; Gaugler et al., 2003a; Gould & Basta, 2013). However, services offered at each program are not consistent. Additionally, some programs may not accept patients with specific medical needs, behavioural problems or that are in early or advanced stages of dementia (AST, 2010; Gould & Basta, 2013). In an Ontario-based study of dementia caregivers, almost half (44.1%) of
caregivers reported accessing adult day services in the previous month and, on average, patients and their caregivers used the service 8 days per month (Smale & Dupuis, 2004).

**Short-Stay Residential Respite.** Short-stay residential respite care refers to temporary care provided in long-term care homes which allows family caregivers relief from providing daily care (Donath, Winkler & Gräßel, 2009). In Ontario, access to short stay respite beds in long-term care facilities (LTCF) is managed by Community Care Access Centers for stays between 7 to 60 days [Ontario Ministry of Health and Long-Term Care (MOHLTC), 2006]. Additionally, there are private options for respite within retirement homes across the province. For publicly-funded short stay respite in LTCF the costs of all necessary personal support and nursing care are covered by provincial health care insurance. However, users of short-stay LTCF beds are required to pay accommodation costs of $38.19 per day of stay (MOHLTC, 2016a). International usage rates of SRC are between 3% and 28%, with Ontario users at the low end of the range (7.3%) (Donath et al., 2009; Smale & Dupuis, 2004).

**Formal In-Home Respite Services.** In-home respite services provided by formal care providers can assume many forms. In Ontario, some CCACs offer in-home respite hours provided by personal support workers while other CCACs no longer offer this service but provide linkage and referrals to CSS agencies providing in-home respite care (T. Lindsay, personal communication, January 5, 2015). Additionally, Veteran Affairs Canada offers housekeeping, grounds maintenance and personal care under the umbrella of in-home respite as these services contribute to reducing total burden on caregivers of persons with dementia [Veterans Affairs Canada (VAC), 2009; VAC, 2013]. Of caregivers accessing publicly-funded community support services, the majority (74%) utilize in-home personal support and homemaking services as a form of respite (Sussman & Regeher, 2009). However, as previously indicated, only 23.8% of Ontarians with physician diagnosed dementia are accessing formal personal support/homemaking services through home care programs (Gill et al., 2011). Service utilization rates for in-home respite services offered through CSS agencies and Veterans Affairs could not be located.
Friendly (Volunteer) Visiting.

In addition to formal in-home respite services offered through home care, some community support agencies provide friendly visiting/socialization programs. Friendly visiting programs provide trained volunteers who engage individuals in meaningful activities to allow the primary caregiver some personal time and decrease the social isolation of the person with dementia (Alzheimer Society of Niagara Region, 2016). Volunteers do not provide personal care or homemaking services during their visits. In Ontario, friendly visiting programs are used by just 8% of caregivers (Smale & Dupuis, 2004). However, this low rate of utilization may be related to the perception that these programs are one of the least accessible community-based programs regardless of the size of community (Smale & Dupuis, 2004).

1.2.2.2 Home and Community-Based Health Care Services

Physician Visits.

Primary care physician visits are the most common outpatient service utilized by persons with dementia. Practice recommendations from the third Canadian Consensus Conference on Dementia (2007) emphasized that the role of primary care physicians in the care of individuals with dementia includes detection, diagnosis and management of dementia. This requires that physicians be aware of community services available and make appropriate referrals, a role that is especially critical in rural communities (Morgan, Innes & Kosteniuk, 2011). A study of Ontario health service use found 95.8% of persons with dementia accessed their primary care practitioners within the year and visited, on average, 13 times during the year (Gill et al., 2011).

Visiting Nursing.

The role of visiting nurses in supporting persons with dementia and their caregivers in the community can be broad, incorporating patient assessment, health teaching, direct nursing care and therapeutic relationship skills. Aspects of nursing care identified as important to community-based care of persons with dementia include health assessment, medication review and management as well as patient and caregiver education and support (Gitlin et al., 2010). Additionally, support from specialist nurses can be beneficial for continence issues and in supporting persons with dementia and their caregivers through end-of-life care in later stages of
dementia. Despite the many roles for nurses in home-based dementia care, in 2007, nursing visits were received by only 13.7% of Ontario seniors with physician diagnosed dementia (Gill et al., 2011).

**Physiotherapy.**

Physiotherapists play an important role in assessing, promoting and maintaining safety, mobility and independence for community-dwelling persons with dementia. Through individualized assessments, physiotherapists analyze and identify remediable factors related to mobility and physical functioning. Additionally, through the creation and monitoring of tailored home-exercise programs physiotherapists can increase fitness, improve physical and cognitive functioning and increase positive behaviours in those with dementia (Heyn, Abreu & Ottenbacher, 2004; NCCMH, 2007; Pitkälä et al., 2013a; Pitkälä, Savikko, Poysti, Strandberg & Laakkonen, 2013b; Suttanon et al., 2010; Suttanon et al., 2012). However, access to physiotherapy services has been identified as one of the most unmet service needs in the dementia population (Raivio et al., 2007; Smale & Dupuis, 2004). In Ontario, only 9.7% of persons with dementia received physiotherapy visits over the course of the 2007/2008 fiscal year (Gill et al., 2011).

**Occupational Therapy.**

For individuals with dementia living in the community, occupational therapy can improve daily functioning and social participation resulting in higher confidence and a sense of well-being for caregivers (Graff et al., 2008). In home-based care, occupational therapists work with persons with dementia and their caregivers to assess patient routines and interests, develop communication and problem-solving strategies, recommend home modifications, and select adaptive aids to improve their ability to perform activities of daily living (Graff et al., 2006; Graff et al., 2008; NCCMH, 2007). Occupational therapy also has a role in skill training and education for informal and formal caregivers (NCCMH, 2007). In Ontario, 12.1% of patients with physician diagnosed dementia received at least one in-home occupational therapy visit in fiscal year 2007/2008 (Gill et al., 2011).
1.2.3 Dementia Services in Ontario

In Ontario, persons with dementia and their caregivers are intensive users of less discretionary, formal health care services across the continuum of care (Gill et al., 2011). The use of acute care, hospitals, physician services, home care services and institutional long-term care have all been found to be significantly higher in persons with dementia than those without a dementia diagnosis (Gill et al., 2011). However, utilization rates of the more discretionary, community-based support services in this population remains low (Phillipson et al., 2014; Smale & Dupuis, 2004; Toseland et al., 2002; Vetter et al., 1998).

Recently, the quality and structure of dementia services in Ontario has received greater attention due to the growing impact of person with dementia on the healthcare system and emphasis on patient-centered care [AST, 2010; Behaviour Supports Ontario (BSO), 2013; Gill et al., 2011; Walker, 2011]. In 2011, the Ontario Ministry of Health and Long-Term Care invested in Behavioural Supports Ontario (BSO), a province-wide initiative focused on enhancing health care services for seniors with challenging and complex behaviours (BSO, 2013). Ongoing funding for this initiative, announced in 2016, allows service providers to maintain current services and to hire more specialized health care providers (Ontario Ministry of Health and Long-Term Care, 2016b). Having the tools to deal with responsive behaviours in individuals with dementia is critically important to retaining these individuals in the community, as some of the most powerful factors influencing transitions to institutional settings in this population include wandering, resisting care, and physically abusive behaviours (CIHI, 2010). The BSO investment spanned the continuum of dementia care involving primary care practitioners, Community Care Access Centers, acute care hospitals and long-term care facilities, recognizing that the right place for dementia care is specific to the individual and their care-giving situation. While community-dwelling persons with dementia are not the only target population of this initiative, those individuals with dementia and responsive behaviours benefit from these programs and services.

Programming under the BSO initiative built upon Ontario’s 2007-2011 Aging at Home strategy, which aimed to reduce the number of alternate level of care (ALC) patients in Ontario hospitals and expand community living options for seniors through enhanced home care and community
support services (Ontario Ministry of Health and Long-Term Care, 2008). Over four years, $1.1 billion was invested to improve community-based health service delivery. As community-dwelling persons with dementia have a high risk of being designated ALC when hospitalized, and approximately a quarter of the population is hospitalized each year (Gill et al., 2011), funds provided through this strategy supported dementia-specific programming such as case management for seniors with mental health issues, TeleChek services, family support workers through the Alzheimer’s Society and volunteer training (Central West LHIN, 2010).

1.3 Home and Community-Based Care in Ontario

Home care services in Canada include a range of health and supportive services received at home which are entirely or partially paid for by a national/provincial or territorial health plan. These services enable individuals who are incapacitated, either in whole or in part, to live in their home environment. In Ontario, Community Care Access Centers (CCACs) arrange access for all publicly-funded home care services. Home care services managed by the CCACs include nursing, personal support and homemaking, physiotherapy, occupational therapy, speech-language pathology, social work, dietetics, medical supplies and dressings, and medical equipment (MOHLTC, 2006).

Community-based services provide assistance to individuals who require help to function in the community because of disability, illness or limitations related to aging. Community-based health care services include primary care, outpatient care or clinic care. Community-based support services include those services which assist individuals with basic and instrumental activities of daily living, provide socialization opportunities or provide respite for family caregivers. In Ontario, these services are fully or partially funded by the Ministry of Health and Long-Term Care and are delivered by Community Support Services (CSS) agencies. CSS agencies are community-based, not-for-profit organizations that rely heavily on volunteers. Community-based support service availability and funding varies by community with some services requiring user fees. Key community support services available in Ontario which can be beneficial for community-based care of persons with dementia include: meal services, transportation services, caregiver support services, respite, homemaking, adult day services, home maintenance and repair services, hospice services, palliative care consultation services, palliative education,
Alzheimer’s services including education coordinators and psychogeriatric resource consultants, friendly-visiting services, security checks, and social and recreational services (MOHLTC, 2006). Currently there is no common pathway for caregivers to access both health and social services in the community, however, in Ontario, CCACs can provide information about, and referrals or linkages to, local CSS agencies (MOHLTC, 2006).

1.4 Study Purpose

The purpose of this study was to provide a better understanding of the services utilized concurrently by a vulnerable subset of seniors living in the community, individuals with dementia and their caregivers. Knowledge gained from this study provides a better understanding of services utilized at a regional level allowing for more effective planning of service availability and more efficient use of limited home care resources. Additionally, understanding the predictors of service utilization allows for targeted care planning at the individual level to ensure appropriate services are offered at the right time to patients and their caregivers.
Chapter 2

2 Health Service Use by Seniors with Alzheimer’s Disease and Related Dementias

In this chapter, a review of literature pertaining to the use of home and community-based services by seniors with Alzheimer’s disease and related dementias is presented. First, Andersen’s Behavioral model of Health Service Use, the conceptual framework which underpins the study, is described. Next, methods employed to perform the literature review are described and factors influencing the use of home and community-based services are identified. Finally, the hypothesized model, based on the review of the literature, is presented and four research questions are proposed.

2.1 Conceptual Framework

2.1.1 Andersen’s Behavioral Model of Health Service Use

Andersen’s Behavioral Model of Health Service Use was the conceptual framework selected to underpin this study and to organize this review of the literature. In this model, Andersen (1995) posits that there are factors which predispose an individual to utilize health services (predisposing factors), factors which facilitate or impede service use (enabling factors) and factors which determine the need for care (need factors). Originally developed to understand families’ use of health services (Andersen, 1968), this model has undergone multiple revisions (Andersen & Newman, 1973/2005; Andersen, 1995) and has been applied to a wide range of populations and contexts (Bubitsch, Gohl & von Lengerke, 2012). Toseland et al. (2002) examined the applicability of the Behavioral Model for the examination of community-based service use in a dementia population and concluded that the model was able to explain a large proportion of the variation in health and support service use.

Service utilization by individuals with dementia are influenced by both caregiver and care recipient factors. As dementia progresses, individuals with dementia become more reliant on informal caregivers as well as health and social services. Thus, informal caregivers can be key in determining which types of services are utilized. While the original Behavioral Model (1968) was developed to understand factors at the individual level, researchers have adapted and revised...
the model to include both patients and their caregivers in recognition of the importance of the family as the unit of care in the community (Bass & Noelker, 1987; Beeber, Thorpe & Clippe, 2008; Douglass & Fox, 1999; Hawranik, 1998; Hong, 2010; Toseland et al., 2002). Following this rationale, both caregiver and care recipient factors were included as predictors of service use in this study.

Past research examining predictors of service utilization for individuals with dementia and their caregivers has produced mixed and often conflicting results. Study design limitations such as focusing on utilization of a single service (Gill, Hinrichsen & DiGiuseppe, 1998; Phillipson et al., 2014) or employing an aggregate measure of services used (Boersma, Eefsting, van den Brink & van Tilburg, 1997; Forbes, Morgan & Janzen, 2006; Gill et al., 1998; Robinson, Buckwalter & Reed, 2005; Toseland et al., 2002), oversimplifies the reality of service utilization in the community. Examining the use of a single service in isolation without controlling for the use of other home and community support services can be problematic as the use of some services have been found to be significantly associated with use of others (Hong, 2010; Skarupski et al., 2008). Furthermore, eligibility criteria for various home and community-based services differ. Therefore, not all individuals with dementia qualify for all services, making aggregate measures of service use an inappropriate outcome. Additionally, research utilizing aggregate measures assume greater (or less) service utilization is the goal. However, individuals with dementia and their caregivers may not have a need for all services measured. Finally, within the literature, only few studies differentiate between health and social service utilization (Toseland et al., 2002) or discretionary versus non-discretionary services (Chen & Thompson, 2010; Chen, Thompson, Berkowitz, Young & Ward, 2011, Chen & Berkowitz, 2012; Mitchell & Krout, 1998) in their analyses.

For these reasons, all factors identified in the literature as influencing the use of any of the home and community-based services described in Chapter 1 were included in the hypothesized model.
2.2 Factors Influencing the Use of Home and Community-based Services

2.2.1 Literature Review Methods

Research studies available on the Medline, Cumulative Index for Nursing and Allied Health Literature (CINAHL), PsycINFO, and EMBASE databases were searched. Across all databases the search results were limited to English language articles published from 1997 to present. Articles were reviewed if 1) the population was greater than 65 years of age and cognitively impaired, 2) health service utilization was examined as an outcome, and 3) the population resided in the community. Articles were excluded if 1) the data analyzed was collected before 1990, 2) the study focused on caregiver interventions or outcomes or 3) the population resided in a nursing home. Bibliographies of retrieved studies were also searched until no unique articles could be identified.

Across the selected databases, 1,304 abstracts were identified using the search strategy outlined in Appendix A. Three hundred and sixteen duplicates were removed. Following a review of the titles and abstracts for each article, 581 articles were excluded, leaving 137 manuscripts for full-text review. Based on the identified inclusion and exclusion criteria, 63 manuscripts were selected for inclusion in this review. A further 17 articles were identified through hand-searching reference lists. Overall, 80 articles were included in this literature review.

2.2.2 Predisposing Factors

Within the Behavioral Model predisposing factors are defined as those demographic, social and belief factors which influence one’s likelihood of utilizing services (Babitsch et al., 2012). Both care recipient and caregiver sociodemographic factors have been identified as influencing formal service use in seniors. Care recipient sociodemographic factors identified in the literature as influencing service use in the dementia population include:

- **age** (Beeber et al., 2008; Bruggenjürgen et al., 2016; Douglass & Fox, 1999; Forbes et al., 2003; Graessel, Luttenberger, Bleich, Adabbo & Donath, 2011; Hawranik, 1998; Hawranik & Strain, 2001; Hawranik, 2002; Herrmann et al., 2006; Janssen et al., 2016; Kosloski, Montgomery & Karner, 1999; Phillipson et al., 2014; Roelands, Van Oyen, 2003)
Depoorter, Baro & van Oost, 2003; Skarupski et al., 2008; Strain & Blandford, 2002; Tuokko, Maccourt & Heath, 1999; Vecchio, Fitzgerald, Radford & Fisher, 2016; Wattmo, Londos & Minthon, 2014; Wee, Liu, Goh, Chong & Aravindhan, 2014; Wimo et al., 2011; Zhu et al., 2008),

- **sex** (Boersma et al., 1997; Douglass & Fox, 1999; Forbes et al., 2003; Forbes et al., 2008; Gottlieb & Johnson, 2000; Herrmann et al., 2006; Herron & Rosenberg, 2017; Phillipson et al., 2014; Roelands et al., 2003; Skarupski et al., 2008; Strain & Blandford, 2002; Sun, Roff, Klemmack & Burgio, 2008; Tuokko et al., 1999; Vecchio et al., 2016; Wattmo, Paulsson, Minthon & Londos, 2013; Wattmo et al., 2014; Zhu et al., 2008);

- **education level** (Douglass & Fox, 1999; Gill et al., 1998; Wee et al., 2014), and

- **marital status** (Boersma et al., 1997; Douglass & Fox, 1999; Friedman, Shih, Langa & Hurd, 2015; Herron & Rosenberg, 2017).

In caregivers,

- **age** (Gill et al., 1998; Forbes et al., 2008; Markle-Reid & Browne, 2001; Phillipson et al., 2014; Robinson, Buckwalter & Reed, 2013; Wee et al., 2014),

- **sex** (Kosloski et al., 1999; Montgomery, Marquis, Schaefer & Koloski; 2002; Phillipson et al., 2014; Strain & Blandford, 2002; Wee et al., 2014; Wimo et al., 2011),

- **education level** (Beeber et al., 2008; Forbes et al., 2003; Gill et al., 1998; Strain & Blandford, 2002; Toseland et al., 2002),

- **ethnicity** (Ayalon & Huyck, 2002; Chow, Ross, Fox, Cummings & Lin, 2000; Friedman et al., 2015; Kosloski et al., 1999; Kosloski, Schaefer, Allwardt, Montgomery & Karner, 2002; Low, Anstey, Lackersteen & Camit, 2011; Markle-Reid & Browne, 2001; Montgomery et al., 2002; Phillipson et al., 2014; Toseland et al., 2002; Valle, Yamada & Barrio, 2004; Xiao, Habel & De Bellis, 2015), and
Of the caregiver predisposing factors, caregiver relationship is most often found to be predictive of service utilization. Caregiver relationship can impact the use of formal care in the home as well as the use of community-based services such as adult day services (Cho et al., 2009; Douglass & Fox, 1999; Montgomery et al., 2002; Phillipson et al., 2013; Robinson et al., 2013; Wattmo et al., 2013). Multiple aspects of the caregiver relationship are postulated to be related to service use. First, men with dementia are less frequently widowed and, therefore, are likely to receive more intensive informal care from spousal caregivers resulting in less service use (Boersma et al., 1997; Phillipson et al., 2014). Wives are more likely to see the caregiving role as an extension of marital duties and have more emotional difficulty turning the care of their spouse or household chores over to professionals (Phillipson & Jones, 2011b; Robinson et al., 2005; Wattmo et al., 2013). However, wives are also more likely to have their own health issues due to their more advanced age (Cho et al., 2009). Child caregivers are more likely to have competing demands including work, marital responsibilities, and their own children, which is usually associated with increased service use (Cho et al., 2009; Montgomery et al. 2002; Wattmo et al., 2013). Finally, spousal caregivers may experience more resistance to the use of services from persons with dementia and thus suffer more guilt related to the use of formal services (Robinson et al., 2013; Neville et al., 2015).

2.2.3 Enabling Factors

Enabling factors include resources accessible to the caregiver and persons with dementia which support or impede the use of services. Enabling variables found to impact service use in dementia populations include:
• **living arrangement** (Douglass & Fox, 1999; Edwards & Morris, 2007; Eichler et al., 2016; Forbes et al., 2003; Gerves, Chauvin & Bellanger, 2014; Gill et al., 1998; Hawranik, 1998; Hawranik & Strain, 2001; Hawranik, 2002; Herron & Rosenberg, 2017; Houde, 1998; Janssen et al., 2016, Markle-Reid & Browne, 2001; Michalowsky et al., 2016; Robinson et al., 2005; Roelands et al., 2003; Skarupski et al., 2008; Strain & Blandford, 2002; Toseland et al., 2002; Tuokko et al., 1999; Vecchio et al., 2016; Wattmo et al., 2013; Wee et al., 2014; Zhu et al., 2008),

• **income level** (Beeber et al., 2008, Edwards & Morris, 2007; Forbes et al., 2003; Kosloski, Montgomery & Youngbauer, 2001; Montgomery et al., 2002; Phillipson et al., 2014; Skarupski et al., 2008; Wee et al., 2014),

• **knowledge of services** (Brodaty et al., 2005; Donath et al., 2009; Markle-Reid & Browne, 2001; Morgan, Semchuk, Stewart & D’Arcy, 2002; Neville et al., 2015; Noyes, Daley & French, 2000; Phillipson & Jones, 2011a; Phillipson et al., 2014; Strain & Blandford, 2002; Toseland et al., 2002; Vetter et al., 1999, Xiao et al., 2015), and

• **geographic location** (Armstrong, Zhu, Hirdes & Stolee, 2015; Douglass & Fox, 1999), including rurality (Beeber et al., 2008; Forbes et al., 2006; Herron & Rosenberg, 2017; Koller et al., 2010; Morgan et al., 2002; Phillipson et al., 2014; Sambrook et al., 2004; Strain & Blandford, 2002; VAC, 2009; Vecchio et al., 2016; Wenger et al., 2002).

Several related components of geographical location impact service utilization for persons with dementia. While Forbes et al. (2006) found few differences in overall home and community-based care utilization rates (aggregate measure) between Canadians living in rural versus urban locations, closer examination of the services accessed identified differences in the types of services utilized in rural versus urban settings. In this study, those in rural areas received more social care (personal support, homemaking, meal preparation and respite care) while those in urban areas received more professional care service (Forbes et al., 2006). Similarly, Armstrong et al. (2015) identified variation in access to community-based rehabilitation professionals based on location of care. Due to health human resources constraints, certain professional services may simply not be offered in rural areas (VAC, 2009). Alternatively, transportation concerns, including the distance to travel, may be a barrier to utilization for some caregivers (Morgan et
al., 2002). Additionally, as a result of reduced access to experts in diagnosis and management of dementia, those living in rural areas may not have access to or knowledge of appropriate community services to meet their needs (Koller et al., 2010; Morgan et al., 2002).

2.2.4 Need Factors

Need factors are health-related factors which are assessed either by the individual (perceived need) or a professional (assessed need). By considering the caregiver/care recipient the unit of care, need factors can be generated from either the care recipient or caregiver perspective. Services can be utilized for many different reasons including requirements for active treatment (e.g. wound care), emotional or social support (e.g. recreation and socialization programs), and caregiver respite. Care recipient need factors identified as influencing utilization of services include:

- **cognitive status** (Cox, 1997; Douglass & Fox, 1999; Edwards & Morris, 2007; Farre et al., 2016; Gerves et al., 2014; Gottlieb & Johnson, 2000; Hawranik, 1998; Hawranik, 2002; Herrmann et al., 2006; Markle-Reid & Browne, 2001; Norberg, von Strauss, Kareholt, Johansson & Wimo, 2005; Phillipson et al., 2014; Roelands et al., 2003; Robinson et al., 2005; Robinson et al., 2013; Skarupski et al., 2008; Strain & Blandford, 2002; Vecchio et al., 2016; Vetter et al., 1998; Wattmo et al., 2013; Wimo et al., 2011; Wimo et al, 2013; Wolfs et al., 2010; Zhu et al., 2006; Zhu et al., 2008),

- **recent cognitive decline** (Wilson et al., 2007),

- **number of comorbidities** (Beeber et al., 2008; Bruggenjurgen et al., 2016; Farre et al., 2016; Gill et al., 1998; Mondor et al., 2017; Wimo et al., 2011; Zhu et al., 2006; Zhu et al., 2008),

- **polypharmacy** (Wattmo et al., 2013; Wattmo et al., 2014),

- **psychotropic medication use** (Lindsey, 2009),

• **behavioural and psychological symptoms of dementia** (Beeber *et al.*, 2008; Douglass & Fox, 1999; Farre *et al.*, 2016; Gill *et al.*, 1998; Herrmann *et al.*, 2006; Levesque, Cossette, Potvin & Benigeri, 2000; Markle-Reid & Browne, 2001; Montgomery *et al.*, 2002; Robinson *et al.*, 2005; Robinson *et al.*, 2013; Toseland *et al.*, 2002; Vecchio *et al.*, 2016; Vetter *et al.*, 1998; Zhu *et al.*, 2008), and

• **recent behaviour decline** (Gaugler *et al.*, 2010).

Functional status elements found to have an impact on health service utilization in dementia include:


• **recent ADL decline** (Wattmo *et al.*, 2014),

• **continence** (Hawranik & Strain, 2001; Houde, 1998; Jansen *et al.*, 2009),

• **pain** (Achterberg *et al.*, 2013), and

• **falls** (Gill *et al.*, 1998; Koller *et al.*, 2010; Robinson *et al.*, 2005; Scherer *et al.*, 2008).
Additionally, recent health service use including emergency department visits (Houde, 1998) and hospitalizations (Forbes et al., 2003; Houde, 1998) have been demonstrated to impact future home and community services use.

Caregiver need factors associated with service use include:

- **caregiver distress** (Cox, 1997; Douglass & Fox, 1999; Gill et al., 1998; Hawranik, 2002; Kosloski et al., 2001; Levesque et al., 2000; Neville et al., 2015; O’Connell, Hawkins, Ostaszkiewicz & Millar, 2012; Phillipson et al., 2014; Strain & Blandford, 2002; Toseland et al., 2002; Vetter et al., 1998; Wolfs et al., 2010), and

- **caregiver commitment** (Gottlieb & Johnson, 2000; Markle-Reid & Browne, 2001).

Paradoxically, many factors which indicate high need for persons with dementia (and their caregivers) have been associated with non-use, brief use or use of only specific types of services (Gill et al., 1998; Phillipson et al., 2014). Researchers have suggested that this phenomenon may be related to high needs causing a barrier to utilization of specific services due to service eligibility requirements (Markle-Reid & Browne, 2001). For example, program admission may require that the person with dementia must be able to participate in group activities or may not have behavioural issues.

### 2.3 Patterns of Service Utilization

Determinants of utilization of individual home and community-based services by older adults and their caregivers have been investigated in previous studies. In most of these studies, service use was examined utilizing variable-specific methods resulting in an incomplete picture of interrelations among concurrent services. However, two studies were identified in which health service utilization patterns were examined in individuals with dementia (Beeber et al., 2008; Janssen et al., 2016). In these studies, it was demonstrated that none of the identified classes of service users utilized only one service, providing support for the further examination of concurrent service use.
2.4 Hypothesized Model

Based on the review of the literature, a hypothesized model of factors influencing patterns of service utilization for seniors with Alzheimer’s disease and related dementias was developed. In the model, predisposing, enabling and need factors are hypothesized to influence the latent variable, service user type, which is identified from the observed pattern of home and community-based health care, home and community-based support services and institution-based health and support services utilized. An illustration of this model can be found in Figure 1.

**Figure 1: Hypothesized model of factors influencing patterns of service use for seniors with Alzheimer’s disease and related dementias**

2.5 Research Questions

Four research questions are addressed in this study:

1. Which home and community-based services do Ontario seniors with Alzheimer’s disease and related dementias and their caregivers utilize?

2. Do services utilized vary by stage of cognitive impairment?
3. What patterns of service utilization can be identified in community-based seniors with Alzheimer’s disease and related dementias?

4. What impact do patient and caregiver characteristics have on patterns of service use for community-based seniors with Alzheimer’s disease and related dementias?
Chapter 3

3 Methods

In Chapter 3 the methods used to address the four study research questions are described. First, the research design and data sources are reported. Then, measurement of study concepts and coding of study variables are outlined. Next, data analysis methods used to address study research questions are described. Finally, ethical considerations are examined.

3.1 Research Design

In this study, a secondary analysis of a subset of data from the innovations in data, evidence and applications for Persons with Neurological Conditions (ideasPNC) project was conducted to address study research questions. A non-experimental, descriptive correlational design was utilized. A descriptive correlational design was chosen to answer the research questions as little is currently known about how this population engages with the health care system overall. This design allows for exploration of service use patterns and the identification of relationships between service use and patient and caregiver characteristics. A two-step modeling approach was employed to a) classify overall patterns of health and support service use for community-based seniors with Alzheimer’s disease and related dementias and b) identify predictors of service use patterns.

3.2 Data Sources

The ideasPNC project was a national population health study funded by the Public Health Agency of Canada (2010-2013) which examined the characteristics and needs of individuals with neurological conditions across numerous care settings. The ideasPNC database is housed and maintained by interRAI Canada at the University of Waterloo. All individuals included in the ideasPNC dataset received an interRAI assessment during one of the following health care interactions: long-stay home care admission (RAI-HC), long-term care facility admission (RAI-MDS 2.0), hospital-based mental health admission (RAI-MH) or complex continuing care admission (RAI-MDS 2.0) (White, 2013).
The *ideasPNC* dataset includes the entire population of individuals assessed for publicly-funded home care services using the RAI-HC assessment instrument in Ontario, Nova Scotia and the Yukon Territory between January 1, 2001 and June 30, 2011 and their associated service records from the Home Care Reporting System (January 2001 to July 2011), Continuing Care Reporting System (April 2003 to August 2011), National Ambulatory Care Reporting System (April 2003 to March 2011), Ontario Mental Health Reporting System (October 2005 to November 2010), National Rehabilitation Reporting System (January 2001 to August 2011), and Discharge Abstract Database (April 2004 to March 2011). These data files were linked using a unique linking variable, generated by CIHI, which allows for cases to be matched across databases while maintaining patient privacy. The subset of data extracted for this study was drawn from the HCRS, CCRS and NACRS databases. Figure 2 illustrates the *ideasPNC* dataset available data and the sample selected for this study.

![Figure 2: Available Data and Sample Dataset Coverage](image)

**Figure 2: Available Data and Sample Dataset Coverage**


### 3.2.1 Study Population and Sample Inclusion Criteria

For this study, a subset of the *ideasPNC* dataset which included all Ontario seniors, 65 years and older, living with Alzheimer’s disease or a related dementia who received home and community-
based care for at least 60 days was selected. As home care is not an insured service under the Canada Health Act (1985), there is significant variability in services provided across Canadian provinces. Therefore, to ensure all included cases would have access to the services funded by the Province of Ontario, the sample was restricted to those patients assessed in Ontario. In addition, as significant changes to the structure of Ontario’s home and community sector occurred in 2007, including the amalgamation of 42 CCACs into 14 CCACs aligned with the boundaries of the Local Health Integration Networks, as well as the start of additional funding provided by the Ontario Ministry of Health and Long-Term Care to support aging at home, only patients who received a RAI-HC assessment in Ontario between January 1st, 2007 and March 31st, 2011 were included in the study sample.

Patients who had a diagnosis of Alzheimer’s disease or a related dementia were identified through the pick list of disease diagnoses in Section J of the RAI-HC. In previous studies, diagnostic information in Section J of the RAI-HC has been demonstrated to be highly accurate, identifying cases of Alzheimer’s disease or related dementia (ADRD) with a sensitivity of 0.76 (95% CI: 0.75, 0.76) and a specificity of 0.89 (95% CI: 0.89, 0.89) (Foebel et al., 2013). Those cases with either a diagnosis of either Alzheimer’s disease (item J1g) or Dementia other than Alzheimer’s disease (item J1h) were included in this study sample. The dementia diagnosis did not have to be the focus for home care treatment to be included in the sample.
Only those individuals aged 65 or older were eligible for inclusion in the study sample. The lower limit of 65 years was selected because research has shown that early-onset dementia (symptom onset prior to age 65) has been associated with significantly different service utilization patterns (Bakker et al., 2013). Initial examination of age information revealed some irregularities in calculated age values provided by CIHI in the ideasPNC dataset. Additional sources of age information were considered resulting in the exclusion of 35 cases. More detailed information regarding this process and the information utilized is given in Section 4.4.

![Client Care Model](image)

**Figure 3: Client Care Model**

Figure from: Office of the Auditor General Ontario. (2015). Chapter 3, Section 3.01 CCACs – Community Care Access Centres – Home Care Program. Toronto, ON; Queen’s Printer for Ontario.

To identify those patients with at least two community-based RAI-HC assessments, an observation window of 15 months was selected for the study. This time frame for reassessment was chosen based on the provincial guidelines for reassessment outlined in the Client Care Model (Waterloo Wellington Community Care Access Centre, 2012). The Client Care Model (CCM), pictured in Figure 3, provides guidelines for case management intensity including the frequency of RAI-HC reassessments, with the time between intervals increasing with greater
patient stability. In the CCM, individuals are classified into five main categories based on their most recent RAI-HC assessment as well as care coordinator judgement regarding required case management intensity. Four of the five patient categories are eligible to receive CCAC services, while the fifth category, “well”, represents the portion of the population who does not require service. The four categories of patients who are eligible for services in Ontario are: 1) short-stay - those patients able to direct their own care with time-limited, predictable trajectories; 2) community independence - those patients capable of self-management who require some support to remain independent; 3) chronic - those patients with stable, predictable needs, with a reliable support network who require support to manage their health conditions and prevent decline, and 4) complex - those patients with multiple health conditions which are unstable and who have little to no informal support. According to the standards of care developed as a part of the CCM, complex patients are to be reassessed with the RAI-HC every 3 to 6 months, chronic patients every 6 months and community independence patients every 12 months.

However, a 2015 examination of Ontario CCACs conducted by the Ontario Auditor General’s office found that many patients were not being reassessed within the prescribed timelines, with up to 50% of community independence patients not being reassessed within one year (Office of the Auditor General Ontario, 2015). Additionally, for much of the study data, these guidelines would not yet have been in effect as the CCM was not initiated until 2010 and was not fully implemented across all CCACs until 2013. Prior to implementation of the CCM, care coordinators reassessed all patients based on clinical judgement. Therefore, to ensure patients with less acute care needs were not underrepresented in the dataset, a 90-day grace period was chosen for this study to allow for delays in reassessment. Furthermore, as home and community-based service utilization questions (Section P) are not mandatory when the RAI-HC is completed in institutional settings, final assessments conducted in hospital or long-term care were removed from the dataset.

Of the sample of 27,592 unique patients, 25,999 had two or more RAI-HC assessments completed within the 12-month guideline. An additional 1,593 patients only had a second RAI-HC assessment completed between months 12 and 15. Of those patients who had two or more assessments within 12 months 5,226 had an additional assessment within the 12 to 15-month period. This additional assessment was included in the dataset as their final study assessment.
Therefore, all Ontario seniors assessed with the RAI-HC assessment instrument between January 1st, 2007 and March 31st, 2011 were included in the sample provided they met the following inclusion criteria: 1) had a diagnosis of Alzheimer’s disease or other dementia, 2) was 65 years or older at the time of their assessment, and 3) had at least two community-based RAI-HC assessments completed within a 15-month time frame. In addition to the inclusion criteria, cases were excluded if the patient received CCAC services for less than 60 days. Based on these criteria 68,137 assessments were included in the dataset representing 27,592 unique individuals.

3.3 Data Quality

A description of the subset of databases used in this study including a discussion of data quality and missing data is presented in this section.

3.3.1 Home Care Reporting System

The Home Care Reporting System (HCRS) is a national longitudinal database which contains data about persons receiving publicly funded home care in Canada. Data collected includes patient-level demographic, clinical, functional and resource utilization information. Data in the HCRS are primarily collected at the point of care by regulated health professionals using the Resident Assessment Instrument for Home Care (RAI-HC). HCRS data is reported to be of good quality, exhibiting expected patterns of consistency within and across records (CIHI, 2012a). For most items, non-response rates are low as valid responses are mandatory. However, for those elements which are not mandatory, missing rates can be as high as 75% (CIHI, 2012a).

Additionally, approximately 20% of Ontario HCRS records lack a discharge record submission limiting the databases’ ability to be used longitudinally to draw conclusions about patients’ complete home care episode (CIHI, 2012a). HCRS service use variables are mandatory variables and are utilized in CIHI data quality audits (CIHI, 2012a).

3.3.1.1 Resident Assessment Instrument for Home Care

The RAI-HC provides the clinical data for the HCRS and was fully implemented in Ontario home care in 2006. The RAI-HC has undergone significant reliability and validity testing both internationally and in Canada, confirming the instrument has both high reliability and validity (Carpenter et al., 2004; Landi, et al., 2000; Morris et al., 1997). All home care patients expected
to be on service 60 days or longer are assessed with the RAI-HC at admission with reassessments completed at regular intervals throughout the year as well as when there is a significant change in patient status (CIHI, 2012a). However, it is not uncommon for delays in regular reassessments to occur due to competing priorities and heavy caseloads of care coordinators (Poss, 2006).

Formal and informal service utilization variables drawn from the RAI-HC have been utilized as both predictors and outcomes in numerous studies (Björkgren, Fries & Shugarman, 2000; Carpenter et al., 2004; Gill et al., 2011; Poss, Hirdes, Fries, McKillop & Chase, 2008; Sorbye, Finne-Soveri, Ljunggren, Topinkova & Bernabei, 2005; Vu et al., 2014). The RAI-HC service utilization items are self-reported estimates of formal and informal care over the past 7 days. While it is possible that self-reported data can result in biased estimates due to difficulties with recall, international reliability and validity testing revealed strong (kappa=0.75) inter-rater reliability for these items (Morris et al., 1997). Another study examining the validity of self-reported service utilization data among community-dwelling seniors found no significant differences between self-reported data and service records (Carsjö, Thorslund & Wärneryd, 1994). Additionally, these service use variables have been used for the development of the Resource Utilization Groups-III (RUG-III)/home care case mix grouping for community care (Björkgren et al., 2000) which was subsequently validated using Canadian administrative service records (Poss et al., 2008). A key advantage of using the RAI-HC service utilization items to measure home and community-based service use is that both publicly provided and privately purchased services are captured. This results in a more complete picture of community-based service use than publicly funded home care service records alone.

3.3.2 Continuing Care Reporting System

The Continuing Care Reporting System (CCRS) is a national longitudinal database which contains data pertaining to hospital-based continuing care and long-term care facilities in Canada. Data collected includes demographic, clinical, functional and resource utilization information. An evaluation of Ontario data submitted to CCRS found the database to be reliable, valid, complete and free from coding errors for both long-term care and complex continuing care settings (Hirdes et al., 2013). For this study, only CCRS records representing short stay respite or convalescent care admissions to long-term care facilities were of interest.
3.3.3 National Ambulatory Care Reporting System

The National Ambulatory Care Reporting System (NACRS) is a national database which contains data pertaining to all hospital and community-based ambulatory care including day surgery, outpatient clinics and emergency department care. Data categories include demographic, clinical, administrative, financial and service variables including information on patient discharge disposition, death and transfers (CIHI, 2012b). Emergency department reporting has been mandatory in Ontario since 2000 with 188 facilities submitting individual level data to the Canadian Institute for Health Information annually (CIHI, 2012b). CIHI’s quality control process for data submission to NACRS identifies and flags any inconsistencies in the abstracts submitted (CIHI, 2012b). Data re-abstraction studies conducted with NACRS data have revealed some issues with date/time elements (e.g. registration time or triage time), demographic elements, and diagnosis/intervention elements (CIHI, 2012b). However, none of these variables are utilized in this study.

3.3.4 Missing Data

Missing data can pose an issue for studies utilizing administrative data (Shi, 2008). While latent class analysis (LCA) allows for missing data in indicator variables, when covariates are included in the model, missing data is a concern. In SAS® Version 9.4, missing data on latent class indicators are handled in the PROC LCA procedure with data assumed to be missing at random (Lanza, Collins, Lemmon & Schafer, 2007). To ensure the same sample is utilized for both the LCA and multinomial logistic regression analysis, all covariates were examined for missing data and for any variable with greater than 10% of data missing, alternate sources of information were sought. The only variable with greater than 10% of data missing was patient education level. As this study utilizes multiple data sources which contain interRAI assessments (e.g. HCRS, CCRS) and interRAI assessments were designed to have shared core items, additional sources of information were available to reduce the amount of missing data on education level as this variable was considered to be consistent over time. Data which remained missing after all sources of information were exhausted were recoded as “unknown” and included in the model.

For RAI-HC assessments completed in hospital, section P, Service Utilization, is not a mandatory field. In some cases, assessors do not complete the section leaving the values missing,
while others report zero hours of service received. In this sample, 147 cases had missing data on all section P variables. All these assessments were completed in hospital where home and community-based services would not be provided. Therefore, for RAI-HC reassessments in the sample which were completed in hospital, home and community-based service use variables were recoded from missing to zero.

3.4 Measurement

Variables for the study have been selected based on the Hypothesized model of factors influencing service use patterns for seniors with Alzheimer’s disease and related dementias pictured in Figure 1. This model expands on Beeber and colleagues’ (2008) model to incorporate all potential predictors of service utilization identified in the literature and to broaden the services studied to reflect a cross-sectoral focus including home, community and institution-based care. Data were available in the ideasPNC database for most concepts in the model. However, data were not available for the concepts income level, knowledge of services and four caregiver-related concepts including: age, sex, education level, and ethnicity. The revised hypothesized model which was tested in this study is shown in Figure 4.

![Figure 4: Revised hypothesized model of factors influencing patterns of service use for seniors with Alzheimer’s disease and related dementias](image-url)
The hypothesized latent class measurement model, illustrated in Figure 5, expands on the model above to identify the home and community-based health service, home and community-based support service and institution-based health and support services used to identify the patterns of service utilization. Potential measures of home and community-based health services included measures of nursing services, physician services (including physician or clinic visits), physiotherapy, and occupational therapy. Potential measures of home and community-based support service use included measures of informal support, personal support, homemaking, adult day services, meal services, and volunteer services. Potential measures of institution-based health service use included measures of emergency department visits and short stay long-term care facility (LTCF) admissions. In the model, the latent variable, service user type (service utilization pattern), is represented by an oval. The indicator variables, individual services used, are represented by squares and measurement error is represented by circles. To provide a clear link between the *Revised Hypothesized Model of Factors Influencing Patterns of Service Use for Seniors with Alzheimer’s Disease and Related Dementias* and the *Hypothesized Measurement Model of Home and Community-Based Service Use Patterns for Seniors with Alzheimer’s Disease and Related Dementias*, indicator variables are grouped in the model by service type.

Figure 5: Hypothesized Measurement Model of Home and Community-Based Service Use Patterns for Seniors with Alzheimer’s Disease and Related Dementias
3.4.1 Health Service Utilization

Eleven measures of patients’ (and caregivers’) use of formal health and supportive care services and one measure of informal care were examined for inclusion in the latent class model as indicator variables. These variables measure three broad categories of health and supportive care services: home and community-based health care services, home and community-based support services, and institution-based health and support services. Home and community-based health care services and home and community-based support service variables were drawn from all RAI-HC re-assessments included in the study observation window. Institution-based health and support service measures were drawn from the NACRS and CCRS databases. As latent class analysis requires categorical indicator variables, all continuous measures of service utilization were recoded into categorical variables. Study measurement model concepts are summarized in Table 2 with operational definitions provided below.

Table 2: LCA measurement model concepts, data sources, and variables

<table>
<thead>
<tr>
<th>Model Concept</th>
<th>Data Source</th>
<th>Original Variable</th>
<th>Study Variable Coding</th>
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</thead>
<tbody>
<tr>
<td><strong>Home and Community-Based Support Services</strong></td>
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</table>
| Informal Care               | HCRS        | G3 - Extent of informal help for IADLs and ADLs over the last 7 days (hours).      | 1 = Low informal care (20hr/week or less)  
2 = High informal care (21hr/week or more) |
| Personal Support Services   | HCRS        | P1a - Extent of care or care management in last 7 days: Home health aides (days)    | 1 = Low personal support (5 days/week or less)  
2 = High personal support (6 days/week or more) |
| Homemaking Services         | HCRS        | P1c - Extent of care or care management in last 7 days: Homemaking services (days).| 1 = No homemaking services  
2 = Utilized homemaking services |
| Meal Services               | HCRS        | P1d - Extent of care or care management in last 7 days: meals (days).               | 1 = No meal services  
2 = Utilized meal services |
| Adult Day Services          | HCRS        | P1i - Extent of care or care management in last 7 days: day care or day hospital (days). | 1 = No adult day services  
2 = Utilized adult day services |
| Volunteer Services          | HCRS        | P1e - Extent of care or care management in last 7 days: volunteer services (days).  | 1 = No service  
2 = Utilized volunteer services |
<table>
<thead>
<tr>
<th>Model Concept</th>
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<th>Study Variable Coding</th>
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<tr>
<td>Home and Community-Based Health Care Services</td>
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</table>
| Nursing Services              | HCRS        | P1b - Extent of care or care management in last 7 days: Visiting nurses (days).      | 1 = No nursing services  
2 = Utilized nursing services                             |
| Physiotherapy (PT) Services   | HCRS        | P1f - Extent of care or care management in last 7 days: Physiotherapy (days).        | 1 = No PT services  
2 = Utilized PT services                                   |
| Occupational Therapy (OT) Services | HCRS        | P1g - Extent of care or care management in last 7 days: Occupational Therapy (days). | 1 = No OT services  
2 = Utilized OT services                                   |
| Physician Services            | HCRS        | P2t - Special treatments, therapies, and programs received or scheduled during the last 7 days: Physician or clinic visit | 1 = No physician services  
2 = Utilized physician services                              |
| Institution Health Care Services |                  |                                                                                     |                                                            |
| Emergency department visit(s) | NACRS       | Count of admissions                                                                 | 1 = No ED visits  
2 = Any ED visit(s)                                          |
| Short Stay LTCF admission(s)  | CCRS        | Count of admissions                                                                 | 1 = No short stay LTCF admissions  
2 = Any short stay LTCF admissions                            |

Note: CCRS=Continuing Care Reporting System, ED=Emergency Department, HCRS=Home Care Reporting System, LTCF=Long-Term Care Facility, NACRS = National Ambulatory Care Reporting System; OT=Occupational Therapy, PT=Physiotherapy

3.4.1.1 Home and Community-Based Support Services

The **hours of informal care**, including assistance with instrumental and personal activities of daily living provided by family, friends and neighbours in the past 7 days is measured in Section G of the RAI-HC. The hours of care provided across five weekdays and the hours of care provided across the weekend were summed to give a total number of hours of informal care provided in the past week. The highest intensity of informal care received during the observation window was selected and recoded into a dichotomous variable representing high vs low levels of informal care. As 98% of the sample received informal care from family or friends during the observation window, the intensity of help received was examined. Aligning with the Canadian Institutes of Health Information (2010) examination of informal care, those receiving 21 hours of informal care or more per week were categorized as “high informal care” while those receiving
20 hours or less of informal care were categorized as “low informal care”. Study variable response options include: (1) low informal care, and (2) high informal care.

The number of days that personal support services by a home health aide was received in the past 7 days is measured in Section P of the RAI-HC. Personal support services are defined in the RAI-HC user’s manual as “hands on ADL support” and “simple monitoring” provided by a home health aide (Morris et al., 2010). For each RAI-HC reassessment included in the service utilization dataset, the frequency of personal support services was examined. The highest frequency of personal support services received during the observation window was selected and recoded into a dichotomous variable for inclusion in the model. Initially, personal support services were categorized as (1) no personal support services received and (2) personal support services received. However, as more than three quarters of the sample received personal support services during the observation window, frequency of service use was examined further and this variable was recoded to improve class separation. Study variable response options included: (1) “low personal support” - those receiving personal care services 5 days per week or less, and (2) “high personal support” - those receiving personal care services on 6 or more days per week.

The number of days that homemaking services were received in the past 7 days is measured in Section P of the RAI-HC. Homemaking services are defined in the RAI-HC user’s manual as “IADL support usually in the form of housekeeping services, shopping and meal preparation” (Morris et al., 2010). For each RAI-HC reassessment included in the service utilization dataset, the intensity of homemaking services provided was examined. The highest intensity of care received during the observation window was selected and recoded into a categorical variable for inclusion in the model. Study variable response options include: (1) no homemaking services, and (2) utilized homemaking services received.

The number of days that meal services were utilized in the past 7 days is measured in Section P of the RAI-HC as a continuous measure. Meal services are defined in the RAI-HC user’s manual as organizations which deliver prepared meals to the patient for immediate or later consumption (Morris et al., 2010). For each RAI-HC reassessment included in the service utilization dataset, the frequency of meal services was examined. The highest intensity of care received during the observation window was selected and recoded into a categorical variable for inclusion in the model.
model. Study variable response options include: (1) no meal services, or (2) utilized meal services.

The number of days on which the patient attended adult day services (day care or day hospital) in the past 7 days is measured in Section P of the RAI-HC. Adult day services are defined in the RAI-HC user’s manual as programs, which take place outside of the home, where the patient “receives social, recreational, medical or functional support” (Morris et al., 2010). For each RAI-HC reassessment included in the service utilization dataset, the frequency of adult day services use was examined. The highest frequency of utilization received during the observation window was selected and recoded into a categorical variable for inclusion in the model. Study variable response options include: (1) no adult day services, or (2) utilized adult day services.

The number of days agency-supervised volunteer services were received in the past 7 days is measured in Section P of the RAI-HC. Agency-supervised volunteer services are defined in the RAI-HC user’s manual as individuals with a “formal arrangement with an agency/group that provides volunteer programs” with a “formalized role as a volunteer that may include training, background reviews” (Morris et al., 2010). Examples of volunteer programs include friendly-visiting, hospice volunteers and church visitors. For each RAI-HC reassessment included in the service utilization dataset, the intensity of volunteer services use was examined. Utilization of volunteer services at any time during the observation window was recorded and dichotomized for inclusion in the model. Study variable response options include: (1) no volunteer services, and (2) utilized volunteer services.

3.4.1.2 Home and Community-Based Health Care Services

The number of days nursing services were received in the community in the past 7 days is measured in Section P of the RAI-HC. In Ontario, community-based nursing services can be delivered in patient homes or in nursing care clinics. For each RAI-HC reassessment included in the service utilization dataset, the intensity of nursing care was examined. The highest frequency of nursing services received during the observation window was selected and recoded into a dichotomous variable for inclusion in the model. Study variable response options include: (1) no nursing services or (2) utilized nursing services.
The number of days **physiotherapy** services were received in the community in the past 7 days is measured in Section P of the RAI-HC. Physiotherapy services are defined in the RAI-HC user’s manual as “therapy services that are provided or directly supervised by a qualified physiotherapist” and would, therefore, include exercise programs developed by a physiotherapist (PT) and carried out by a physical therapy assistant (PTA) or home health aide (Morris et al., 2010). Physiotherapy services included in this variable can be received in the home or in the community on an outpatient basis and can be privately paid or publicly funded. For each RAI-HC reassessment included in the service utilization dataset, the frequency of physiotherapy was examined. Utilization of physiotherapy services at any time during the observation window was recorded and recoded into a categorical variable for inclusion in the model. Study variable response options include: (1) no PT services, and (2) utilized PT services.

The number of days **occupational therapy** services were received in the community in the past 7 days is measured in Section P of the RAI-HC. Occupational therapy services are defined in the RAI-HC user’s manual as “therapy services that are provided or directly supervised by a qualified occupational therapist” and would therefore include programs developed by an occupational therapist and carried out by an occupational therapy assistant (OTA) or home health aide (Morris et al., 2010). Occupational therapy services included in this variable can be received in the home or in the community and can be privately paid or publicly funded. For each RAI-HC reassessment included in the service utilization dataset, the frequency of occupational therapy was examined. Utilization of occupational therapy services at any time during the observation window was recorded and recoded into a categorical variable for inclusion in the model. Study variable response options include: (1) no OT services, and (2) utilized OT services received.

**Community-based physician services** utilized in the past 7 days are reported in the RAI-HC. In this variable, both visits to a physician’s office or clinic as well as any home visits from a physician would be captured. For each RAI-HC reassessment included in the service utilization dataset, the utilization of physician or clinic visits was examined. Utilization of community-based physician services at any time during the observation window was recorded and recoded into a categorical variable for inclusion in the model. Study variable response options include: (1) no physician services, and (2) utilized physician services.
3.4.1.3 Institution-Based Health and Support Services

The number of emergency department visits made by the patient within the observation window was extracted from NACRS as a numerical summation of contacts with the emergency department. Visits to the ED included all contacts, planned or unplanned, which resulted in admission to hospital, admission to mental health inpatient services, or discharge home. This count data was recoded into a dichotomous variable for inclusion in the model. Study variable response options include: (0) no ED use, or (1) any ED use.

Finally, the number of short-stay admissions to long term care facilities (LTCF) for short-stay respite (less than 60 days) or convalescent care (less than 90 days) within the observation window was extracted from CCRS as a numerical summation of admissions. This count data was recoded into a dichotomous variable for inclusion in the model. Study variable response options include: (1) no short-stay LTCF admissions, and (2) any short-stay LTCF admissions.

3.4.2 Predictors of class membership

Predictors of class membership reflect three categories of patient and caregiver characteristics: predisposing factors, enabling factors and need factors. All predictors of class membership were drawn from the baseline RAI-HC assessment. All variables were examined for missing data, outliers and dubious records. Tables 3 to 5 outline the model concepts, ideasPNC dataset variables and their original data source, as well as the measures and variable coding utilized in this study.

3.4.2.1 Predisposing Factors

Predisposing factors hypothesized to influence class membership are summarized in Table 3. Model concepts are listed along with the original data source and measurement items. Further measurement details and operational definitions for each study variable are discussed below.
To protect the personal health information of individuals, personal identifiers were removed from the dataset by CIHI prior to its release to the ideasPNC research team. Thus, variables which require this information were pre-calculated by CIHI. The care recipient age at the time of assessment was one of these pre-calculated variables. This variable utilized the RAI-HC variable A1 (date of assessment) and BB2a (birthdate) to calculate the patient’s age. The formula used by CIHI to calculate age at assessment was:

\[
\frac{[A1 - BB2a \text{ (at the 15th of the month of BB2a)}]}{365.25}
\]
Upon examination of this variable, some questionable values were identified \([\text{mean age}=82.9 (6.6), \text{min}=65 \text{ max}=110]\). An alternate source of age information (age at case opening) available in the HCRS dataset was used to calculate the year of birth and validate age at assessment. As only birth year could be calculated and not exact dates of birth, a maximum of one year difference in birth year was set to allow for errors due to rounding. In 243 cases a discrepancy was noted between the birth years calculated from the age at assessment and age at case opening variables \([\text{mean difference}=6.7(5.7), \text{min}=2, \text{max}=33]\). In cases with CCRS records \((n=88)\), year of birth was calculated and compared with HCRS values. Using the same criteria to compare year of birth, in all 88 cases the year of birth documented in the CCRS was congruent with the year of birth calculated from the age at case opening variable in the HCRS. Therefore, for all cases, age at baseline was re-calculated utilizing the year of birth drawn from age at case opening. This newly calculated variable showed that \(n=35\) cases were less than 65 years old at time of assessment. These cases were deleted from the sample as they no longer met the study inclusion criteria leaving a final study population of 27,592. To meet the assumption of linearity between continuous variables and the logit function in multinomial logistic regression, the continuous age variable was categorized with three response options: (1) 65 to 74 years, (2) 75 to 84 years, and (3) 85 years and older. This variable is included in the model using dummy variables with “65 to 74 years” as the reference category.

Care recipient sex, marital status and education were extracted from the HCRS database for inclusion in the model as categorical variables. All variables were examined for dubious values, coding errors and missing data. To capture care recipient sex, the HCRS variable BB1 (Sex) was recoded and included in the dataset. Response options include: (0) male and (1) female.

**Care recipient marital status** was captured from the HCRS variable BB4 (Marital status). Those coded as never married, widowed, separated, divorced or other were recoded to “not married”. A dichotomous variable with response options (0) not married, (1) and married / common-law was included in the analysis dataset.

To measure care recipient education, the HCRS variable BB6 (Education: highest level completed) was examined. Upon inspection of this variable, a significant amount of data were missing or unknown \([n=5,952 (21.6\%)]\). As per the RAI-HC user’s manual, the code (9) -
unknown is only to be used when the assessor has been unsuccessful in trying to determine education level (Morris et al., 2010). As one’s level of education attained is not a variable expected to change over the course of the care recipient’s health care episode, other sources of data for education were considered. First, to reduce the amount of unknown/missing codes, all alternate RAI-HC assessments were examined and the highest level of education coded was selected. Through this process, education level was identified for 968 cases with missing data. To further reduce the amount of unknown/missing codes, an alternate source of education information was considered from the CCRS dataset variable AB7 (Education: highest level completed). Education level was identified for a further 1,278 of the cases with missing data, leaving 13% (n=3,706) of all cases with missing education information. As no further sources of education information could be identified, the variable was recoded for inclusion in the dataset with the response options: (1) elementary school or less, (2) high school, (3) any post-secondary education, and (4) unknown. This variable is included in the model using dummy variables with “elementary school or less” as the reference category.

**Relationship [of the primary caregiver] to the care recipient** was captured through the HCRS variable G1fA (Relationship to client) with response options: (1) child, (2) spouse and (3) other. Caregivers captured under the category “other” include other relatives such as grandchildren, siblings, nieces, nephews etc., as well as friends and neighbours (Morris et al., 2010). As few cases in the sample (n=205) reported “no such caregiver”, these cases were also included in the category “other”. This variable is included in the model using dummy variables with “spouse” as the reference category.

### 3.4.2.2 Enabling Factors

Enabling factors hypothesized to influence class membership are summarized in Table 4. Model concepts are listed along with the original data source and measurement items. Further measurement details and operational definitions of study variables are provided below.

For this study, three enabling factors were included: living arrangement, geographic location and rurality. All data for enabling factors were extracted from the HCRS. **Living arrangement** was extracted from RAI-HC variables G1eA (Lives with client: primary helper) and G1eB (Lives with client: secondary helper) as a dichotomous variable with response options of (0) lives alone
or (1) lives with caregiver. In the RAI-HC an informal caregiver is coded as living with the patient only if they share the same house or apartment. Living in an adjacent residence or separate apartment in the same house is not considered living together (Morris et al., 2010). For this study, cases are considered to live alone if, for both the primary and secondary caregiver, responses to variable G1e (Lives with client) are “no” or “no such caregiver”.

Table 4: Enabling Factors: Model concepts, data sources, variables and measurement

<table>
<thead>
<tr>
<th>Model Concept</th>
<th>Original Data Source</th>
<th>ideasPNC Dataset Variable</th>
<th>Original Response Options</th>
<th>Variable Coding in Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living arrangement</td>
<td>HCRS</td>
<td>G1eA, G1eB Lives with client</td>
<td>0 = no 1 = yes 2 = no such helper</td>
<td>0 = lives alone 1 = lives with caregiver</td>
</tr>
<tr>
<td>Rurality</td>
<td>HCRS</td>
<td>Rurality</td>
<td>0 = urban location 1 = rural location</td>
<td>0 = urban location 1 = rural location</td>
</tr>
</tbody>
</table>

**Geographic location** accounts for the Local Health Integration Network (LHIN) in which each patient resides. Response options include 14 categories, one for each of the 14 health regions. A series of dummy variables identifying in which health region care was provided was included in the model with the largest group, Health Region 4, serving as the reference category.

**Rurality** is a measure of population density captured in the ideasPNC dataset. To protect the confidentiality of individuals in the dataset, this variable was pre-calculated by CIHI using a dataset internal to CIHI, the CIHI Geographic Dimension Table. This dataset is based on Statistics Canada’s Postal Code Conversion File and Health Regions: Boundaries and Correspondence with Census Geography product (CIHI, personal communication, 18 January...
2017). Response options include (0) urban location and (1) rural location. Together the geographic location and rurality variables account for differences in the availability of services across the province based on geography, funding and local funding priorities.

3.4.2.3 Need Factors

Both care recipient and caregiver need factors are included in the model. Assessed care recipient need factors reflect clinical issues and complexity as well as past health service use. Fourteen clinical and two health service use need factors are included in the model. Two variables reflecting caregiver psychosocial needs are also included. Need factors hypothesized to influence class membership are summarized in Table 5. Model concepts are listed along with the original data source and measurement items. Further measurement details and operational definitions of study variables are provided below.

Table 5: Need Factors: Model concepts, data sources, variables and measurement

<table>
<thead>
<tr>
<th>Model Concept</th>
<th>Data Source</th>
<th>ideaspnc Dataset Variable</th>
<th>Original Response Options</th>
<th>Variable Coding in Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive status</td>
<td>HCRS</td>
<td>Cognitive Performance Scale</td>
<td>Cognitive Performance Scale</td>
<td>0 = Intact</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Includes: B1a Short term memory</td>
<td>1 = Borderline intact</td>
<td>0 = Intact to mild impairment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>B2a Cognitive skills for daily decision making</td>
<td>2 = Mild impairment</td>
<td>1 = Moderate to severe impairment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>C2 Making self understood</td>
<td>3 = Moderate impairment</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>H2g – Eating</td>
<td>4 = Moderately severe impairment</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5 = Severe impairment</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>6 = Very severe impairment</td>
<td></td>
</tr>
<tr>
<td>Recent cognitive decline</td>
<td>HCRS</td>
<td>B2b Worsening of decision making as compared to status of 90 days ago</td>
<td>0 = No</td>
<td>0 = No cognitive decline</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 = Yes</td>
<td>1 = Decline in either decision-making or communication</td>
</tr>
<tr>
<td></td>
<td>HCRS</td>
<td>C4 Worsening in communication as compared to status of 90 days ago</td>
<td>0 = No</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 = Yes</td>
<td></td>
</tr>
<tr>
<td>Model Concept</td>
<td>Data Source</td>
<td>ideasPNC Dataset Variable</td>
<td>Original Response Options</td>
<td>Variable Coding in Study</td>
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<td>---------------------------------------</td>
<td>-------------</td>
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<td>---------------------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td>Number of comorbidities</td>
<td>HCRS</td>
<td>J1a-ac</td>
<td>0 = No</td>
<td>Comorbidity count</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disease/infection that doctor has indicated is present and affects client’s status, requires treatment, symptom management or if disease is monitored by a home care professional or is the reason for a hospitalization in the last 90 days.</td>
<td>1 = Condition is present but not subject to focused treatment or monitoring</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 = Condition is present and is subject to focused treatment or monitoring</td>
<td></td>
</tr>
<tr>
<td>Polypharmacy</td>
<td>HCRS</td>
<td>Q1</td>
<td>Count variable from 0-9.</td>
<td>1 = Less than five medications</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Number of medications: record the number of different medicines, including eye drops, taken regularly or on an occasional basis in the last 7 days</td>
<td>Those taking 9 or more medications is coded as 9.</td>
<td>2 = Five to eight medications</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3 = Nine or more medications</td>
</tr>
<tr>
<td>Psychotropic medication use</td>
<td>HCRS</td>
<td>Psychotropic medications taken in the last 7 days:</td>
<td>0 = No</td>
<td>0 = No psychotropic medication use</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Q2a - Antipsychotic / neuroleptic</td>
<td>1 = Yes</td>
<td>1 = Any psychotropic medication use</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Q2b - Anxiolytic</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Q2c - Antidepressant</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Q2d - Hypnotic or Analgesic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model Concept</td>
<td>Data Source</td>
<td>ideasPNC Dataset Variable</td>
<td>Original Response Options</td>
<td>Variable Coding in Study</td>
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<td>---------------------------------------</td>
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</tr>
<tr>
<td>Dementia type</td>
<td>HCRS</td>
<td>J1g Alzheimer’s disease</td>
<td>0 = No</td>
<td>0 = Other dementia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>J1h Dementia other than</td>
<td>1 = Condition is present</td>
<td>1 = Alzheimer’s disease</td>
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<tr>
<td></td>
<td></td>
<td>Alzheimer’s disease</td>
<td>but not subject to</td>
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<td></td>
<td></td>
<td></td>
<td>focused treatment or</td>
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<td></td>
<td></td>
<td></td>
<td>monitoring</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>2 = Condition is present</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>and is subject to focused</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>treatment or monitoring</td>
<td></td>
</tr>
<tr>
<td>Behavioural and Psychological</td>
<td>HCRS</td>
<td>Behavioural</td>
<td></td>
<td>Count of symptoms</td>
</tr>
<tr>
<td>Symptoms of Dementia</td>
<td></td>
<td>E3a Wandering</td>
<td>0 = Did not occur in last</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>E3b Verbally abusive</td>
<td>3 days</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>behavioural symptoms.</td>
<td>1 = Occurred, easily</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>E3c Physically abusive</td>
<td>altered</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>behavioural symptoms.</td>
<td>2 = Occurred, not easily</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>E3d Socially inappropriate /</td>
<td>altered</td>
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<tr>
<td></td>
<td></td>
<td>disruptive behavioural</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>symptoms. E3e Resists</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>care.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological</td>
<td>HCRS</td>
<td>Psychological</td>
<td>0 = No</td>
<td>Categorical:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>K3f Delusions</td>
<td>1 = Yes</td>
<td>0 = No BPSD reported</td>
</tr>
<tr>
<td></td>
<td></td>
<td>K3g Hallucinations</td>
<td></td>
<td>1 = Any BPSD reported</td>
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<tr>
<td></td>
<td></td>
<td>E1a A feeling of sadness</td>
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<td></td>
<td></td>
<td>or being depressed.</td>
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<td></td>
<td></td>
<td>E1c Expressions of what</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>appear to be unrealistic</td>
<td></td>
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<td></td>
<td></td>
<td>fears.</td>
<td></td>
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<td></td>
<td></td>
<td>E1d Repetitive health</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>complaints. E1e Repetitive</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>anxious complaints /</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>concerns. E1g Recurrent</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>crying, tearfulness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model Concept</td>
<td>Data Source</td>
<td>ideasPNC Dataset Variable</td>
<td>Original Response Options</td>
<td>Variable Coding in Study</td>
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<td>-----------------------------</td>
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<td>--------------------------</td>
</tr>
<tr>
<td>Recent behaviour decline</td>
<td>HCRS</td>
<td>E4 Behavioural symptoms have become worse or are less well tolerated by family as compared to 90 days ago.</td>
<td>0 = No 1 = Yes</td>
<td>0 = No 1 = Yes</td>
</tr>
</tbody>
</table>
| IADL assistance required    | HCRS        | IADL Hierarchy Scale  
Includes:  
H1Ba Meal preparation  
H1Bb Ordinary housework  
H1Bc Finances  
H1Bd Medication management  
H1Bf Shopping | IADL Hierarchy Scale  
0 = Independent  
1 = Single support area  
2 = Support in some areas  
3 = Support in most areas  
4 = Dependent in some areas  
5 = Dependent in most areas  
6 = Dependent | 0 = Dependent in 2 IADLs or less  
1 = Dependent in 3 IADLs or more |
| ADL assistance required     | HCRS        | ADL Hierarchy Scale  
Includes:  
H2i Personal hygiene  
H2j Toilet use  
H2c Locomotion in home  
H2g Eating | ADL Hierarchy Scale  
0 = Independent  
1 = Supervision  
2 = Limited  
3 = Extensive  
4 = Maximal  
5 = Dependent  
6 = Total dependence | 0 = Independent or supervision only  
1 = Any physical assistance required |
<p>| Recent ADL decline          | HCRS        | H3 ADL status has become worse as compared to status 90 days ago. | 0 = No 1 = Yes           | 0 = No 1 = Yes           |</p>
<table>
<thead>
<tr>
<th>Model Concept</th>
<th>Data Source</th>
<th>ideasPNC Dataset Variable</th>
<th>Original Response Options</th>
<th>Variable Coding in Study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Continence</strong></td>
<td></td>
<td>1a Bladder continence</td>
<td>0 = Continent&lt;br&gt;1 = Continent with catheter&lt;br&gt;2 = Usually continent&lt;br&gt;3 = Occasionally incontinent&lt;br&gt;4 = Frequently incontinent&lt;br&gt;5 = Incontinent&lt;br&gt;8 = Did not occur\</td>
<td>1 = Continent&lt;br&gt;2 = Bladder incontinence only&lt;br&gt;3 = Bowel incontinence</td>
</tr>
<tr>
<td></td>
<td>HCRS</td>
<td>I3 Bowel continence</td>
<td>0 = Continent&lt;br&gt;1 = Continent with catheter&lt;br&gt;2 = Usually continent&lt;br&gt;3 = Occasionally incontinent&lt;br&gt;4 = Frequently incontinent&lt;br&gt;5 = Incontinent&lt;br&gt;8 = Did not occur\</td>
<td></td>
</tr>
<tr>
<td><strong>Pain</strong></td>
<td></td>
<td>K4a Frequency with which client complains or shows evidence of pain</td>
<td>0 = No pain&lt;br&gt;1 = Less than daily&lt;br&gt;2 = Daily&lt;br&gt;3 = Daily – multiple episodes.</td>
<td>0 = No daily pain&lt;br&gt;1 = Daily pain</td>
</tr>
<tr>
<td></td>
<td>HCRS</td>
<td>K5 Number of times fell in last 90 days.</td>
<td>Count variable from 0-9.&lt;br&gt;Above 9 falls is coded as 9.</td>
<td>0 = No recent falls&lt;br&gt;1 = Any recent falls</td>
</tr>
<tr>
<td><strong>Recent falls</strong></td>
<td>HCRS</td>
<td>P4b Number of times visited emergency room without an overnight stay in last 90 days</td>
<td>Count variable from 0-9.&lt;br&gt;9 ED visits and above coded as 9.</td>
<td>0 = No recent ED visits&lt;br&gt;1 = Any recent ED visits</td>
</tr>
<tr>
<td><strong>Recent emergency department use</strong></td>
<td>HCRS</td>
<td>P4a Number of times admitted to hospital with an overnight stay in last 90 days</td>
<td>Count variable from 0-9.&lt;br&gt;9 hospitalizations and above is coded as 9.</td>
<td>0 = No recent hospital admissions&lt;br&gt;1 = Any recent hospital admissions</td>
</tr>
<tr>
<td>Model Concept</td>
<td>Data Source</td>
<td>ideasPNC Dataset Variable</td>
<td>Original Response Options</td>
<td>Variable Coding in Study</td>
</tr>
<tr>
<td>---------------------------</td>
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</tr>
</tbody>
</table>
| Caregiver distress        | HCRS        | **G2a** A caregiver is unable to continue in caring activities | 0 = No  
1 = Yes               | 0 = No caregiver distress  
1 = Caregiver in distress |
|                           | HCRS        | **G2c** Primary caregiver expresses feelings of distress, anger or depression | 0 = No  
1 = Yes               | 0 = No caregiver distress  
1 = Caregiver in distress |
| Caregiver commitment      | HCRS        | **O2b** Client or primary caregiver feels that client would be better off in another living environment | 0 = No  
1 = Client only  
2 = Caregiver only  
3 = Client and caregiver | 0 = Committed to current living arrangement  
1 = Considering alternate living arrangement |

Care recipient **cognitive status** was measured using the Cognitive Performance Scale (CPS). The CPS is a clinically meaningful scale derived using the Minimum Data Set (MDS) (precursor to MDS 2.0) and has been validated against two standard tests of cognition, the Mini-Mental State Examination (MMSE) and the Test for Severe Impairment (TSI) (Morris et al., 1994; Hartmaier, Sloane, Guess, Koch, Mitchell & Phillips, 1995). The CPS uses five items to classify patients into seven categories of cognitive impairment ranging from intact (0) to very severe cognitive impairment (6). To meet the assumption of linearity between continuous variables and the logit function in multinomial logistic regression, CPS was recoded to align with the clinical stages of dementia (Vancouver Coastal Health, 2010). Study variable response options are: (1) mild impairment - includes those in the early stages of dementia with a CPS between 0 and 2, (2) moderate impairment - includes those in mid-stage dementia, with a CPS score of 3 to 4, (3) severe impairment - includes those in late- to end-stage dementia with a CPS of 5 to 6. This variable is included in the model using dummy variables with a reference category of “mild impairment”.

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**Decline in cognitive status** was measured using two single items from the RAI-HC. Item B2b (worsening of decision making) is a dichotomous variable which compares current decision-making abilities to decision-making abilities from 90 days ago to ascertain whether there has been a decline in decision making (Morris et al., 2010). To determine if there has been a decline in communication abilities, item C4 (communication decline) compares the current abilities of the care recipient to make themselves understood with their abilities from 90 days ago (Morris et al., 2010). In this study, cases were considered to have declined cognitively if there is a decline in either decision-making or communication abilities. The two single items were summed to create a variable with the following response options: (0) no cognitive decline, or (1) decline in either decision-making or communication.

Multi-morbidity is defined as the co-occurrence of multiple diseases or medical conditions within an individual (Huntley, Johnson, Purdy, Valderas & Salisbury, 2012). Multi-morbidity can be measured in two broad ways: 1) simple unweighted disease or prescription counts and 2) indices which assess morbidity burden by differentially weighting conditions based on mortality, severity or predicted resource utilization (Huntley et al., 2012). Section J of the RAI-HC collects data on the presence of diseases which have a relationship with the patient’s current health status, medical treatments, need for nurse monitoring or risk of death (Morris et al., 2010). However, as no information is collected in the RAI-HC on the severity of these conditions, calculating multi-morbidity indices such as the Charlson Comorbidity Index or the Adjusted Clinical Groups System is not possible. Additionally, evidence has shown that combining simple count measures are almost as effective at predicting health care utilization as the more complicated indices (Huntley et al., 2012). Therefore, to quantify multi-morbidity the number of disease diagnoses recorded in the pick-list of the RAI-HC was utilized. First, the diagnoses recorded in Section J of the RAI-HC were dichotomized. All conditions which were recorded in the assessment as present were given a value of one regardless of whether the condition was subject to focused treatment or monitoring. All diagnoses (J1a to J1ab), except for J1g (Alzheimer’s disease) and J1h (Dementia other than Alzheimer’s disease), were then summed to create a continuous variable, **number of comorbidities**, with a theoretical range of zero to 26. These two conditions were excluded from the disease count because they are included in the model elsewhere as a measure of dementia type.
Next, to capture **polypharmacy**, the number of medications taken by a patient was drawn from Section Q of the RAI-HC. Item **Q1** (number of medications) reports the number of different medications, including eye drops, taken regularly or on an occasional basis over the preceding week (Morris *et al.*, 2010). As RAI-HC variable coding results in a ceiling value of nine, the variable was categorized with study variable response options: (1) less than 5 medications, (2) five to eight medications, and (3) nine or more medications.

In addition to the overall count of medications taken by the care recipient on a regular basis, **psychotropic medication use** was captured using four dichotomous variables from the RAI-HC. The four variables document the use of 1) antipsychotics and neuroleptics (**Q2a**), 2) anxiolytics (**Q2b**), 3) antidepressants (**Q2c**), and 4) hypnotics or analgesics (**Q2d**) in any form, in any setting (including home, emergency department etc.) over the past 7 days. Psychotropic medication is a broad term used to encompass medications that affect mental function, behaviour and experience (Lindsey, 2009). These medications are typically prescribed to patients with dementia to manage behavioural and psychological symptoms of dementia. A dichotomous variable was created for inclusion in the model with response options (0) no psychotropic medication use, (1) any psychotropic medication use.

**Dementia type** was included in the model using the disease variables Alzheimer’s disease (**J1g**) and dementia other than Alzheimer’s disease (**J1h**) of the RAI-HC. Response options include (0) dementia other than Alzheimer’s disease, or (1) Alzheimer’s disease.

Due to the documented influence of **behavioural and psychological symptoms of dementia** on patient morbidity, caregiver burden, quality of life and costs of care (Cerejeira, Lagarto & Mukaetova-Ladinska, 2012), including a variable which captured the presence of BPSD in order to assess their influence on patterns of service utilization was of great importance. Currently, interRAI does not have an approved scale measuring the presence or severity of BPSD. Therefore, two validated scales, the Behavioural Pathology in Alzheimer’s disease (BEHAVE-AD) (Reisberg, Borenstein, Salob, Ferris, Franssen, & Georgotas, 1987) and the Neuropsychiatric Inventory (NPI) (Cummings *et al*., 1994) were examined in order to establish whether items in the RAI-HC could be used to measure this factor.
The Behavioural Pathology in Alzheimer’s disease (BEHAVE-AD) developed by Reisberg and colleagues (1987) is a clinically validated instrument designed to be used during interviews with patients and their caregivers to quantify BPSD. Another validated scale, the Neuropsychiatric Inventory (NPI) is also widely used to evaluate the presence and severity of BPSD. In a study examining the concurrent validity of the NPI and the BEHAVE-AD, no difference was found in the ability of the instruments to quantify behavioural symptoms (Cummings et al., 1994). While both the BEHAVE-AD and NPI address similar global symptom categories (delusions, hallucinations, activity disturbances, aggression, affective disturbance, anxiety/phobias and day/night disturbances), the BEHAVE-AD was chosen as the comparator for the development of a measure of BPSD in this study because the greater level of detail provided allowed for better conceptual matching with RAI-HC items. Furthermore, the shorter look-back window (two weeks) of the BEHAVE-AD more closely aligned with the RAI-HC time-line (3 days) as the NPI examines symptoms exhibited in the previous month.

To capture the **behavioural and psychological symptoms of dementia (BPSD)**, 12 variables were selected from the RAI-HC which align with the items in the Behavioral Pathology in Alzheimer’s disease (BEHAVE-AD) instrument. RAI-HC variables considered for in the measurement of BPSD included mood and behaviour variables from Section E1 (Indicators of depression, anxiety, sad mood), E3 (Behavioural symptoms) and K3 (Problem conditions – Mental Health). Variables in these sections were examined for conceptual alignment with questions and categories of the BEHAVE-AD. Psychometric testing was not within the scope of this study. Items were identified in the RAI-HC which addressed all global categories in the BEHAVE-AD except Diurnal Rhythm Disturbances. See Table 6: *Cross-walk of Behavioural and Psychological Symptoms of Dementia between BEHAVE-AD and RAI-HC instruments* for a full description of items included. Three variables from section E1 were not selected for inclusion in the measure, E1b (persistent anger with self or others), E1h (withdrawal from activities of interest), and E1i (reduced social interaction), as they did not align with any of the items from the BEHAVE-AD. All variables from sections E3 and K3 were included. Based on this cross-walk between the BEHAVE-AD instrument items and the RAI-HC variables, a sum measure of behavioural and psychological symptoms was created. This continuous variable has a theoretical range of zero to twelve. To meet the assumption of linearity between continuous
variables and the logit function in multinomial logistic regression, BPSD was dichotomized with response options: (0) no BPSD reported, and (1) any BPSD reported.

As the RAI-HC variables included in the BPSD variable only measure the presence of symptoms in the last 3 days, a single variable was included to measure a **decline in behaviour** over a more extended period. Item E4 from the RAI-HC is a dichotomous variable that measures whether behavioural symptoms have worsened or are less well tolerated by family over the past 90 days (Morris et al., 2010). This variable was included as a dichotomous variable in the model.

Care recipient functional status was included using the Instrumental Activities of Daily Living Hierarchy Scale, the Activities of Daily Living (ADL) Hierarchy Scale and a measure of recent ADL decline from the RAI-HC. **IADL assistance required** was measured using the IADL Hierarchy Scale (Morris, Berg, Fries, Steel, & Howard, 2013). This scale includes five variables to assess an individual’s ability to perform key tasks (**H1a** meal preparation, **H1b** housework, **H1f** shopping, **H1c** managing finances and **H1d** managing medications) necessary for independent living. When completing the RAI-HC, care coordinators assess both the patient’s actual performance of IADLs in the past 7 days and their capability to perform the task. The IADL Hierarchy Scale utilizes this second assessment of capability to perform tasks to reduce bias resulting from the impact of social norms such as who performs housework or prepares meals in a couple (Morris et al., 2013). Although response options require the assessor to make a judgement to classify the individual as having no difficulty, some difficulty (e.g. needs some help, is very slow etc.) or great difficulty (e.g. little or no involvement in this activity is possible) with tasks, reliability testing for these items have demonstrated substantial agreement (weighted kappa = 0.76) among independent assessors (Morris et al., 1997).

Capacity to complete physical IADLs (such as shopping, housework and meal preparation) are typically the first areas requiring assistance, followed by the cognitive IADLs (such as managing finances, managing medications) (Morris et al., 2013). Additionally, those with higher levels of cognitive impairment, such as those seen in dementia, are more likely to be at the higher end of the IADLH (Morris et al., 2013). Therefore, the scale was dichotomized for inclusion in the study model with response options (0) dependent in less than 2 IADLs (IADLH = 4 or less) and (1) dependent in 3 or more IADLs (IADLH = 5 or more).
### Table 6: Cross-walk of Behavioural and Psychological Symptoms of Dementia between BEHAVE-AD and RAI-HC instruments

<table>
<thead>
<tr>
<th>Global Symptom Category</th>
<th>BEHAVE-AD&lt;sup&gt;1&lt;/sup&gt;</th>
<th>RAI-HC&lt;sup&gt;2&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A. Delusions</strong></td>
<td>1. People are stealing things                                                        K3f Delusions – fixed false beliefs not shared by others that the client holds even when there is obvious proof or evidence to the contrary (e.g. belief he or she is terminally ill; belief that spouse is having an affair; belief that food is poisoned).</td>
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<tr>
<td></td>
<td>2. One’s house is not one’s home</td>
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<tr>
<td></td>
<td>3. Caregiver is an imposter</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Delusion of abandonment</td>
<td></td>
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<tr>
<td></td>
<td>5. Delusion of infidelity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6. Suspiciousness/paranoia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7. Delusion other than above</td>
<td></td>
</tr>
<tr>
<td><strong>B. Hallucinations</strong></td>
<td>8. Visual hallucinations                                                             K3g Hallucinations – False perceptions that occur in the absence of any real stimuli. An hallucination may be auditory, visual, tactile, olfactory, or gustatory.</td>
<td></td>
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<tr>
<td></td>
<td>9. Auditory hallucinations</td>
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<tr>
<td></td>
<td>10. Olfactory hallucinations</td>
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<tr>
<td></td>
<td>11. Haptic (sense of touch) hallucinations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>12. Other hallucinations</td>
<td></td>
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<tr>
<td><strong>C. Activity Disturbances</strong></td>
<td>13. Wandering – e.g. away from home or caregiver                                      E3a Wandering – moved about with no discernible, rational purpose, seemingly oblivious to needs or safety.</td>
<td></td>
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<tr>
<td></td>
<td>14. Purposeless activity</td>
<td>E3d Socially inappropriate/disruptive behaviour – includes disruptive sounds, excessive noise, screams, self-abusive acts, or sexual behaviour or disrobing in public, smearing or throwing food or feces, rummaging through other’s belongings, repetitive behaviours, rising early and causing distress to others.</td>
</tr>
<tr>
<td></td>
<td>15. Inappropriate activity – e.g. storing and hiding objects in inappropriate places, such as throwing clothing in wastebasket or putting empty plates in the oven, inappropriate sexual behaviour such as inappropriate exposure.</td>
<td></td>
</tr>
<tr>
<td><strong>D. Aggressiveness</strong></td>
<td>16. Verbal outbursts                                                                  E3b Verbally abusive behavioural symptoms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>17. Physical threats and/or violence                                                  E3c Physically abusive behavioural symptoms</td>
<td></td>
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<td></td>
<td>18. Agitation – e.g. non-verbal anger; negativity including refusal to bathe, dress, continue walking, take medications etc.</td>
<td>E3e Resists care – resists taking medications / injections, pushed caregiver during ADL assistance in eating or changes in position.</td>
</tr>
<tr>
<td><strong>E. Diurnal Rhythm Disturbances</strong></td>
<td>19. Day/night disturbance</td>
<td>No variable matching this category</td>
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</tr>
<tr>
<td><strong>F. Affective Disturbance</strong></td>
<td>20. Tearfulness (or whimpering or other ‘crying sounds’)</td>
<td><strong>E1g Recurrent crying, tearfulness</strong></td>
</tr>
<tr>
<td></td>
<td>21. Depressed mood, other – e.g. occasional statement “I wish I were dead” or “I’m going to kill myself” or “I feel like nothing” without clear affective concomitants</td>
<td><strong>E1a A feeling of sadness or being depressed – e.g. life is not worth living, nothing matters, would rather be dead than live this way etc.</strong></td>
</tr>
<tr>
<td><strong>G. Anxieties and Phobias</strong></td>
<td>22. Anxiety regarding upcoming events – e.g. repeated queries and/or other activities regarding upcoming events e.g. when are we going?</td>
<td><strong>E1e Repetitive anxious complaints/concerns (non-health related) – e.g. persistently seeks attention/reassurance regarding schedules, meals, laundry, clothing, relationship issues.</strong></td>
</tr>
<tr>
<td></td>
<td>23. Other anxieties – e.g. regarding money, the future, being away from home, health, memory etc.</td>
<td><strong>E1d Repetitive health complaints – e.g. persistently seeks medical attention, obsessive concern with body functions, vital signs</strong></td>
</tr>
<tr>
<td></td>
<td>24. Fear of being left alone</td>
<td><strong>E1c Unrealistic fears – e.g. fear of being abandoned, left alone, being with others, afraid of nighttime.</strong></td>
</tr>
<tr>
<td></td>
<td>25. Other phobias - e.g. fear of crowds, travel, darkness, strangers, bathing etc.</td>
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Table created from:
ADL assistance required was measured using the ADL Hierarchy Scale (Morris et al., 1999). The ADL Hierarchy (ADLH) Scale reflects the level of progressive functional decline by utilizing four ADLs which reflect early (H2i personal hygiene), middle (H2h toilet use and H2c locomotion), and late (H2g eating) functional loss. This scale has a theoretical range of zero (independent) to six (total dependence) with higher scores indicating greater progressive decline in ADL performance. To meet the assumption of linearity of continuous variables and the logit function in multinomial logistic regression, ADL impairment was dichotomized with the following response options: (0) independent/supervision required (ADLH = 2 or less) and (1) any physical assistance required (ADLH = 3 or more).

Recent ADL decline was measured using item H3 from the RAI-HC. Item H3 is a dichotomous variable that measures whether ADL status has worsened as compared to the previous 90 days (Morris et al., 2010). This variable is included in the model as a dichotomous variable.

Continence was captured through a three-category measure of bladder and bowel continence created from two RAI-HC variables, I1 (bladder continence) and I3 (bowel continence). The two original variables were recoded to reflect (0) bladder continence (I1 original codes 0, 1, 2 or 8) versus (1) bladder incontinence (I1 original codes 3, 4, 5) and (0) bowel continence (I3 original codes 0, 1 or 8) versus (1) bowel incontinence (I3 original codes 3, 4, 5). These variables were then utilized to create one overall continence variable. Response options include: (1) continent (bladder = 0, bowel = 0), (1) bladder incontinence only (bladder = 1, bowel = 0), or (3) bowel incontinence (bladder = 1, bowel = 1). This variable is included in the model using a series of dummy variables with a reference category of “continent”.

A dichotomous variable indicating the existence of daily pain was created by recoding item K4a (pain frequency) from the RAI-HC. Response options include (0) no daily pain (original codes 0 or 1) or (1) daily pain (original codes 2 or 3).

Recent falls was captured using a single item from the RAI-HC. Item K5 (falls frequency) measures the number of falls (up to 9) in the past 90 days (Morris et al., 2010). Response options include: (0) no recent falls, or (1) any recent falls.
Prior health service use was incorporated in the model using two single items from the RAI-HC. **Recent emergency department (ED) use** was included using item P4b which measures the number of ED visits without an overnight stay in the past 90 days (Morris et al., 2010). The variable was recoded into a dichotomous variable with study response options: (0) no recent ED visits, and (1) any recent ED visits.

**Recent hospital use** was included using item P4a, which measures the number of hospital admissions with an overnight stay in the past 90 days (Morris et al., 2010). The variable was recoded into a dichotomous variable with response options: (0) no recent hospital admissions, and (1) any recent hospital admissions.

Finally, two variables reflecting caregiver needs were included in the model: caregiver distress and caregiver commitment to current living arrangement. **Caregiver distress** was measured following the definition provided by CIHI (2010) wherein a caregiver is considered to be in distress if one or both of the following are present: 1) a caregiver cannot continue in caring activities (Item G2a) or 2) if the caregiver expresses feelings of distress, anger or depression (Item G2c). Using these two variables a dichotomous variable was created with the response options (0) no caregiver distress or (1) caregiver in distress.

**Caregiver commitment to current living arrangement** was measured using a single item from the RAI-HC. Item O2b (living arrangement) assesses whether, considering the patient’s current condition, the caregiver or the patient feels the patient would be better off living in another living environment (Morris et al., 2010). This variable was recoded to reflect only the caregiver’s perspective and included in the model as a dichotomous variable. Study response options are (0) caregiver committed to current living arrangement or (1) caregiver considering alternate living arrangement.

### 3.5 Dataset Creation

CCAC service plans and authorization for publicly-funded home care services are established based on the RAI-HC assessment and any associated referral documentation (Office of the Auditor General of Ontario, 2015). Furthermore, RAI-HC service utilization data are retrospective, reporting services utilized in the past seven days. Therefore, to establish
temporality in the analysis dataset, patient and caregiver factors influencing service patterns were drawn from the baseline RAI-HC assessment while service use data were drawn from all follow-up RAI-HC assessment(s) as well as institution-based service records from NACRS and the CCRS databases.

3.5.1 Observation window

To construct the observation window for analysis, the final RAI-HC assessment conducted in the community was selected as the anchor. All RAI-HC assessments completed up to 15 months prior to the final assessment date were identified. The first RAI-HC assessment conducted within the 15-month window was designated as the baseline assessment with the date of assessment being the index assessment date. All institution-based service records occurring between the index assessment and final assessment dates were added to the analysis dataset. Figure 6 depicts the study design regarding the timelines and data sources.

![Figure 6: Study Observation Window](image)

3.5.2 Service utilization

For each Ontario senior living with dementia and receiving home and community-based care, a comprehensive picture of overall service utilization was created by linking service data from institution-based community care to their home and community-based service use. Home care and community support service variables were drawn from Section P (Service Utilization), of all follow-up RAI-HC assessment(s) within the study observation window and linked to records from the Continuing Care Reporting System (CCRS) and National Ambulatory Care Reporting System (NACRS) databases. In both the CCRS and the NACRS, for each patient, all unique
episodes within the study observation window were counted and summary values were included in the analysis dataset. Below is a detailed description of the procedures for extracting and linking data from each of the three datasets.

The **HCRS** includes assessment records for patients interacting with the publicly funded home care system. Patients access the home care system for several reasons including short-term acute services, long-term supportive community care, rehabilitation services, palliative care and long-term care applications. All follow-up records within the study observation window were selected for inclusion in the study dataset. The baseline record was not included in the service utilization dataset as any services reported would have been utilized prior to the index assessment date.

The **NACRS** includes records of ambulatory care including day surgery, outpatient clinics and emergency department (ED) care. Patients attend the emergency department for many reasons including urgent/emergent care, transfers from other institutions as well as planned visits for follow-up care. First, emergency department visits were identified using Management Information System (MIS) functional center codes for Emergency, General Emergency, Observation, Trauma, Urgent Care and Emergency Mental Health Service care centers. All cases within the observation window with an appropriate MIS functional center code were extracted. The number of ED visits occurring within the observation window were summed and added to the study dataset using the unique CIHI identifier.

The **CCRS** includes records of all hospital-based continuing care admissions as well as all long-term care (LTC) facility admissions for any reason including short-stay admissions for respite or convalescent care. Using the unique patient identifier provided by CIHI, all CCRS records within the observation window for sample patients were identified. All LTC facility admissions within the observation window for sample patients were identified using the LTC sector code (4) in the CCRS. For each case with one or more admissions to LTC within the observation window, the length of stay for each admission was calculated using the facility admission and discharge dates. Short stay admissions were defined as those episodes of care where a patient was admitted to and discharged from a LTC facility within the observation window, had a length of stay of 95 days or less, and had a community-based discharge destination (home with support, home without
support, retirement home). The number of short stay admissions and total length of stay within the observation window were added to the study dataset.

3.5.3 Patient and Caregiver Characteristics

Patient and caregiver characteristics were extracted from the baseline RAI-HC assessment and linked with service utilization data to complete the study dataset.

3.6 Data Analysis

Service utilization behaviour is a complex multidimensional phenomenon, with multiple factors including attitudes, values, knowledge and relationships influencing decisions around which services one chooses to access. Most studies of service utilization to date examine correlates of accessing a single service while, in reality, multiple services are often used concurrently. To provide a more holistic understanding of this complex phenomena, a person-centered approach focusing on patterns of services accessed concurrently was employed.

Retrospective, longitudinal data were used to create service use variables while predictor variables were drawn from clinical data captured in the RAI-HC. To address research question one, descriptive statistics (mean and standard deviation for continuous variables, frequencies and percentages for categorical variables) were used to summarize sample characteristics. Population characteristics and services utilized were described for the full sample and by level of cognitive impairment. Following this, latent class analysis was employed to identify unique service utilization patterns. Finally, a multinomial logistic regression model was fit to explore predictors of the service utilization patterns identified.

3.6.1 Sample Description

Types and amounts of services utilized were described for the full sample and by level of cognitive impairment. Cases were grouped into three levels of cognitive impairment based on the clinical stages of dementia (Vancouver Coastal Health, 2010). Group 1 includes those in the early stage of dementia, equivalent to a Cognitive Performance Scale (CPS) score of 0-2 or a Mini Mental Status Exam (MMSE) score of 19-30. Clinically, individuals in this group may have difficulty word finding, have some memory loss or disorientation and have mild difficulties with routine tasks, planning, organizing and making decisions. They may withdraw from activities
which were previously of interest and have some mild behavioural changes such as repeating themselves. Group 2 includes those in mid-stage dementia, equivalent to a CPS score of 3 to 4 or a MMSE score of 7-18. Individuals in this group have more noticeable cognitive changes such as disorientation, difficulty recognizing familiar objects or people and requiring supervision and cueing to complete tasks. Physically they may have difficulty with activities of daily living, a slower gait and difficulty with coordination. More disruptive behaviours such as wandering, hallucinations, sleep disturbances and mood swings can be present in this stage. Group 3 includes those in the later stages of dementia, equivalent to a CPS score of 5-6 or a MMSE score below 7. Individuals in this stage are severely impaired, with increasing dependency for communication, decision making and activities of daily living. Chi square tests were performed to determine whether service use differed across levels of cognitive impairment.

3.6.2 Identifying Patterns of Service Utilization with Latent Class Analysis

Latent class analysis (LCA) is a person-centered approach to modeling multidimensional concepts, such as patterns of behaviour. Person-centered approaches allow for modeling of multidimensional concepts comprehensively using several indicators to estimate complex phenomena. Latent class analysis assumes an underlying unobserved (latent) variable exists which explains the relationships between a set of observed indicator variables (Collins & Lanza, 2010). In LCA, the latent variable is categorical with a multinomial distribution of latent classes. LCA assumes that indicator variables within each latent class exhibit local independence (Collins & Lanza, 2010).

In this study, the latent variable being estimated is the service use behaviours of community-based seniors with ADRD, with different patterns of service use comprising the latent classes. In this application of LCA, the association among individuals’ observed service use behaviours is postulated to be due to the discrete latent class structure. LCA has been used previously to examine health and community-based service utilization in community dwelling older adults (Hastings et al., 2014; Hong, 2010) and specifically in a community-based dementia population (Beeber et al., 2008; Janssen et al., 2016).
3.6.2.1 The Latent Class Mathematical Model

The mathematical latent class (LC) model is clearly described in Collins and Lanza (2010). In their description of the general LC model there are $c = 1, \ldots, C$ classes and $i = 1, \ldots, I$ indicators. Indicator 1 has response categories $r_1 = 1, \ldots, R_1$; Indicator 2 has response categories $r_2 = 1, \ldots, R_2$; Indicator 3 has response categories $r_3 = 1, \ldots, R_3$ and so on. Each individual in the sample has a response pattern, $y = \{r_1, r_2, r_3\}$, which represents a cell of a contingency table made by cross tabulating the indicators in the model. Thus, the LC model can be expressed mathematically as the following equation:

$$P(Y = y) = \sum_{c=1}^{C} \gamma_c \prod_{i=1}^{I} \rho_{ir_1|c}$$

Where:

$\gamma_c$ (gamma) = class membership probability or the probability of membership in latent class $c$

$\rho_{ir_1|c}$ (rho) = item response probability or the probability of response $i$ to Indicator 1 conditional on membership in latent class $c$

The base latent class model estimates two parameters, gamma and rho. Gamma parameters are class membership probabilities which indicate the proportion of the sample in a particular class, or the relative size of the class (Collins & Lanza, 2010; Lanza, Bray & Collins, 2013). Rho parameters are item response probabilities which represent the probability of a specific response to an item, conditional on class membership (Collins & Lanza, 2010; Lanza et al., 2013). Rho parameters are probabilities, ranging from 0 to 1, with values of 0 and 1 indicating perfect relationships between the latent variable and the indicator (Collins & Lanza, 2010). The matrix of item–response probabilities produced in LCA is used to interpret and label each class based on the class characteristic profile of item responses (Collins & Lanza, 2010; Lanza et al., 2013).

In LCA, all model parameters are estimated by maximum likelihood using the EM (expectation-maximization) algorithm (Lanza et al., 2007). The EM algorithm alternates between the expectation step and the maximization step and compares the difference between the estimates produced (Lanza et al., 2013). Convergence is reached when the difference between the
estimates is smaller than a specified criterion (Collins & Lanza, 2010). One issue in latent class models is related to this process. Depending on the model’s likelihood function, complexity and the amount of information provided (in the form of sample size and indicators), there can be issues with model identifiability (Lanza et al., 2007). Berzofsky and Biemer (2012) describe a spectrum of identifiability in LCA modeling with four levels: 1) identifiable models, 2) local maxima models, 3) weakly identifiable models, and 4) non-identifiable models. Identifiable models are those models with only one maximum (Berzofsky & Biemer, 2012). Local maxima models are those models which may have many local maxima but only one global maximum (Berzofsky & Biemer, 2012). Weakly identifiable and non-identifiable models are problematic as they result in multiple solutions with the same maximum likelihood, which can lead to incorrect estimates and conclusions (Berzofsky & Biemer, 2012). To examine latent class model identification and increase confidence that the ML solution is identified, it is best practice to estimate parameters using multiple random start values and then examine of the distribution of the solutions (Lanza et al., 2007). If the solution with the smallest log-likelihood is reached most often, it can be confidently assumed to be the optimal solution (Lanza et al., 2007). In this study model, identification was examined for each competing model using 1000 random starts.

3.6.2.2 Model Building

In LCA, the observed variables included in the model are manifest indicators of the latent variable (Lanza et al., 2013). In LCA, no assumptions are made about the underlying distribution of these indicator variables other than that of local independence (Lanza et al., 2007). This assumption does not mean that indicators are independent in the overall sample, rather it assumes that the relationships between the indicators are accounted for by the latent class variable (Lanza et al., 2007). However, in Ontario, there are 14 Local Health Integration Networks (LHINs) which are responsible for planning, funding and integrating health care services on a local level. Therefore, observations within these clusters are unlikely to be independent as each LHIN would have unique service priorities and varying criteria for access to services. To account for these relationships, a latent class model was fit with a clustering variable to account for the unmeasured factors within the LHIN structures which may cause relationships among the item responses (Lanza et al., 2013). By including a clustering variable in LCA, the model assumes that the clusters (in this case the LHINs), rather than the individual observations, are independent.
of each other (Lanza et al., 2007; Lanza et al., 2013). Ignoring the impact of clustering in the model has been found to result in larger values of key information criteria and more complex model selection (Kaplan & Keller, 2011). Multilevel LCA models have been used previously to examine the impact of community membership on health behaviours (Rindskopf, 2006; Henry & Muthen, 2010).

In this study, 12 variables representing utilization of health services from across the health care continuum were considered for inclusion as indicators in the latent class model. Potential measures of home and community-based health service use included: nursing services, physician services, physiotherapy, and occupational therapy. Potential measures of home and community-based support service use included: informal support, personal support, homemaking, adult day services, meal services, and volunteer services. Potential measures of institution-based health service use included: emergency department use, and short stay LTCF admissions.

In latent class analysis, both the latent variable and indicator variables are categorical. Therefore, continuous service use data were categorized to reflect levels of service use (see Tables 3 to 5 in Section 3.4.2 for further details). In LCA, a balanced approach to retaining information captured in the original variables and data reduction strategies to allow for model identification are required. As data sparseness in the contingency table can result in difficulties in model estimation, it is important to be judicious when selecting measurement levels for indicator variables (Lanza, Bray & Collins, 2013). It is recommended that investigators start with binary indicators and then after attaining a good model fit, additional levels can be added to examine if they provide more granularity to the solution (S. Lanza, personal communication, Nov 11, 2016). Additionally, when fitting a latent class model, all new analyses should begin by fitting a baseline model with no grouping variable or covariates included (Lanza et al., 2007). This process allows the investigator to identify the optimal class structure prior to the inclusion of predictors of class membership. If covariates are included in the model, it is important to check the stability of the class definitions as the inclusion of covariates may result in changes to class membership.
3.6.2.3 Assessing Model Fit

The iterative process of model building in LCA involves continuous assessment of model fit statistics and model interpretability. Model assessment begins with a single class and models are fitted successively, adding an additional class to each successive model, until the most parsimonious model which accounts for the associations between variables is identified. To assess model fit and select a final model, both absolute model fit and relative model fit are considered. Absolute model fit refers to whether a specified LCA model provides an adequate representation of the data (Collins & Lanza, 2010). The likelihood ratio statistic, $G^2$, reflects the absolute fit of the model, or how well the latent class model fits the observed data. Lower values of $G^2$ represent a better model fit. Unfortunately, when models are complex and data sparseness is an issue (i.e. total sample size/size of the contingency table is less than 5), the distribution of the $G^2$ statistic is not well approximated by any known reference distribution (Collins & Lanza, 2010). To mitigate this problem, the Bootstrap Likelihood Ratio Test (BLRT) was developed. The BLRT produces an estimated (i.e. bootstrapped) distribution for the likelihood ratio test statistic which can then be used to test whether a model with one additional class is required to adequately describe the data (Nylund, Asparouhov & Muthen, 2007). In the test, null and alternative models are fit to the empirical dataset and the likelihood ratio statistic for the difference between the models is recorded. Many random samples are generated under the null model and the random samples are analyzed under the null and alternative models. For this test, a significant result lends support for the model with more classes.

Relative model fit refers to deciding which of two or more models represents an optimal balance of fit and parsimony (Collins & Lanza, 2010). To examine relative model fit, penalized fit statistics are used including the Akaike information criterion (AIC; Akaike, 1987), Bayesian information criterion (BIC; Schwartz, 1978), consistent AIC (CAIC; Bozdogan, 1987), and adjusted BIC (aBIC; Sclove, 1987). To take into account the number of parameters estimated and the sample size, these information criteria each impose a penalty on the $G^2$. In all these information criteria, the optimal number of classes is identified when the information criterion value is lowest (Collins & Lanza, 2010). However, because each of the four information criteria use slightly different calculations to penalize the $G^2$, they often do not identify the same model. The AIC and a-BIC have been found to err on the side of fit and overestimate the number of
latent classes, while the BIC and CAIC tend to err on the side of parsimony and underestimate the number of classes (Yang, 2006; Nylund, Asparouhov & Muthen, 2007). Additionally, the accuracy of the AIC decreases as sample size increases, while both CAIC and a-BIC perform better at higher sample sizes (Nylund, Asparouhov & Muthen, 2007). Therefore, these information criteria should be considered together to determine a range of plausible models and once this range is identified, the researcher can then use model interpretability criteria and content knowledge to select the final model (Collins & Lanza, 2010).

Three key aspects need to be considered when assessing model interpretability (Lanza et al., 2007): 1) latent class separation, 2) latent class homogeneity, and 3) latent class size. Latent class separation refers to the degree which latent classes can be clearly distinguished from each other based on the item-response probabilities (Lanza et al., 2007). If two classes do not have good separation, interpretation of the classes is essentially the same and the classes are redundant. Including the additional class would thus increase the complexity of the model without providing additional explanatory power. Latent class homogeneity refers to the degree to which the individuals within a class are similar to each other. High homogeneity is demonstrated when item-response probabilities which are close to 0 or 1 indicating clear patterns of service use by members of the class (Lanza et al., 2007). A value close to zero represents a high probability of not utilizing the service and a value of one represents a high probability of service use within the group. Finally, the size of the latent classes needs to be taken into consideration. No class should be negligible in size with a probability of membership being near zero (Lanza et al., 2007).

While including these rare classes does increase the fit of the model, it can be at the expense of parsimony. This is when content knowledge can be critical because these rare classes may be very important to the overall explanation of the phenomenon, and therefore, should be included for theoretical reasons (S. Lanza, personal communication, Nov 11, 2016).

3.6.2.4 Assessing Model Accuracy

Following the identification and selection of the optimal latent class model, Baye’s Theorem can be used to calculate each individual’s posterior probabilities of latent class membership, or the probability of membership in each latent class given their specific item response profile (Nagin, 2005; Lanza et al., 2007). These posterior probabilities can then be used to conduct subsequent analyses to examine relationships between latent class membership and other observed variables.
The most common technique used in the literature to do this is the traditional classify-analyze approach (Clogg, 1995). This approach involves three steps: 1) build a baseline latent class model, 2) classify cases based on their posterior probabilities, and 3) undertake subsequent analyses, such as multinomial logistic regression, treating the latent class as an observed categorical variable (Bray, Lanza & Tan, 2015).

The strength of accuracy of the posterior probabilities in predicting latent class membership is closely related to the concepts of latent class separation and homogeneity (Collins & Lanza, 2010). In models with good separation and homogeneity, posterior probabilities are near one for one class and near zero for the remaining classes, resulting in little classification uncertainty (Collins & Lanza, 2010). However, in models where there is less certainty in classification, error can be introduced when individuals are assigned to latent classes and subsequent analysis is conducted (Bray et al., 2015). This classification error has been demonstrated to result in attenuation of estimates in subsequent analyses of associations between the latent class variable and other variables (Bolck, Croon & Hagenaars, 2004; Vermunt, 2010).

To minimize the impact of classification error, several methods have been developed to either 1) incorporate both covariates and/or outcomes into the latent class model, often referred to as one-step approaches (Collins & Lanza, 2010, Bray et al., 2015) or 2) provide corrections for classification error, often referred to as the three-step approaches (Bolck et al., 2004; Vermunt, 2010; Asparouhov & Muthén, 2014). Currently, complex research questions, such as those with large numbers of covariates or large numbers of classes, cannot be addressed within the one-step approach (Vermunt, 2010; Bray et al., 2015). Additionally, improved three-step approaches have not been implemented in all statistical software and many of these approaches are extremely computationally heavy. Therefore, in this study, to examine the impact of patient and caregiver characteristics the traditional classify-analyze approach was employed.

Several methods are available to assign individuals to latent classes based on their posterior probabilities. The two most widely used classification rules are modal and proportional assignment (Vermunt, 2010). Modal assignment, also known as maximum-probability assignment, is an approach which assigns individuals to the latent class for which they have the highest posterior probability (Nagin, 2005; Goodman, 2007). Alternatively, proportional
assignment creates an expanded analysis dataset containing multiple records for each individual, one for each class, weighted by the probability of belonging to that class (Vermunt, 2010). While modal assignment does not consider the uncertainty in class assignment, when compared with other assignment approaches, modal assignment minimizes the number of incorrect assignments (Goodman, 2007). Therefore, modal assignment was utilized to assign individuals to latent classes in this study.

When assigning individuals to classes using posterior probabilities, it is important to understand the ability of the model to accurately assign individuals to the appropriate class (Collins & Lanza, 2010). Nagin (2005) proposed two diagnostics which can be used to assess the precision of class assignment: 1) average posterior probability of assignment, and 2) the odds of correct classification. The *average posterior probability of assignment* (AvePP) is calculated by averaging the posterior probabilities of those individuals assigned to a particular class (Nagin, 2005). In a model that perfectly predicts the latent class variable, the AvePP would be equal to one (Nagin, 2005). However, this is rarely the case. While there is no agreed upon value for AvePP, Nagin (2005) recommends a rule-of-thumb that AvePP should be at least 0.7 for all groups in a model. This rule however, does not consider the number of classes in a model. This is important to take into account in more complex models because classification error can increase simply as a function of the number of classes (Collins & Lanza, 2010). Furthermore, as each latent class is made up of multiple item response patterns, Collins and Lanza (2010) proposed that along with the average posterior probability, statistics regarding variation about the mean (i.e. standard deviation, range etc.) be reported to identify overall uncertainty in class assignment.

A second diagnostic is the *odds of correct classification* (OCC) (Nagin, 2005). The OCC compares the ability of the model to predict the correct class against chance (Nagin, 2005). The OCC is computed using the average posterior probability of assignment and the latent class membership probability (Nagin, 2005). The OCC is a ratio of the odds of correct classification into a given latent class based on modal assignment, over the odds of correct classification into that class based on random assignment using the latent class membership probability (Collins & Lanza, 2010). Therefore, an OCC of one would suggest that the model does no better at predicting group membership than chance. Nagin (2005) suggests that an OCC of five or greater
indicates a model with good assignment accuracy, with larger values of OCC indicating better accuracy.

3.6.3 Identifying Predictors of Latent Class Membership

Following assignment of cases into classes and the evaluation of the accuracy of that assignment, the third step of the traditional classify-analyze approach is to conduct subsequent analyses to estimate the relationships between the latent classes and other observed variables. In this study, to examine the impact of patient and caregiver characteristics on the service utilization patterns identified through latent class analysis, a multinomial logistic regression model was fit.

Multinomial logistic regression was chosen because it is a flexible analysis technique which allows for the inclusion of continuous, discrete or dichotomous predictors, has no assumptions about the distribution of predictor variables and allows for the prediction of a categorical dependent variable with more than two categories which do not have a meaningful order, such as service use patterns (Tabachnick & Fidell, 2013). While there are no assumptions about the distribution of the predictor variables, multinomial logistic regression models have two central assumptions: (1) low collinearity of the predictors and, (2) the independence of irrelevant alternatives (IIA).

To test for multicollinearity in the data, collinearity diagnostics were conducted. Collinearity diagnostics include examining bivariate correlations as well as tolerance levels and variance inflation factors for all predictor variables (Allison, 2012). Examination of bivariate correlations alone is not sufficient as there may be groups of variables which, when considered together, are identified as highly interdependent (Allison, 2012). In this case, low tolerance levels (below 0.40) and high variance inflation factors (above 2.5) can indicate an issue with multicollinearity (Allison, 2012). Using these values as cut-offs, collinearity was found to be an issue among two predisposing variables, marital status and caregiver relationship. Upon further examination of these variables, overlap was noted as the variable caregiver relationship had a response option of “spouse” and the variable marital status was a simple dichotomous measure indicating whether the individual was married. Therefore, marital status was dropped from the model.
Testing for the IIA assumption is more complex. The IIA assumption is that, all else being equal, an individual’s choice of outcome categories is not dependent on the other available alternatives (Long, 2013). In this study, this would mean that the probability of being in one class (or service utilization type), does not depend on the other classes (service use types) in the model. While statistical tests have been developed to test the IIA assumption such as the Hausman and McFadden test and the Small and Hsiao test, these tests have been demonstrated to generate inconsistent results based on complexities in dataset structures, making them inappropriate for applied research (Cheng & Long, 2007). Furthermore, Long (2013) states that while the “independence of irrelevant alternatives is the defining property of the [multinomial logistic regression model] that simplifies estimation and interpretation” it is “potentially unrealistic” (p. 6). Therefore, Long (2013) recommends that when employing a multinomial logistic regression model, it is vital to select alternatives that can reasonably be assumed to be discrete. As the outcomes being tested in the multinomial model in this study were derived from the latent class model which “identifies discrete, mutually exclusive classes based on responses to a set of observed categorical variables” (Lanza et al., 2007, p. 671), the classes can reasonably be assumed to be discrete.

3.6.3.1 Model Building

Following the assessment of multicollinearity, to construct the multinomial logistic regression model for this study, model building strategies drawn from Hosmer, Lemeshow and Sturvidant (2013) were employed to attain the most parsimonious model which accurately reflects the data. Parsimony in the model allows for increased stability and simpler interpretation of estimates (Hosmer et al., 2013). Initially, univariate analyses of each of the twenty-five-proposed independent variable were undertaken. For each categorical variable, contingency table analyses of the assigned latent class versus each categorical variable were conducted. Contingency tables were examined for sparseness in the data (less than 5 per cell) and chi square tests were conducted. For continuous variables, univariate logistic regression models were fit. All variables which had a $p$-value of 0.25 or less on these univariate tests were included in the preliminary model (Hosmer et al., 2013).

Next, the multivariate model was fit with all variables identified for inclusion in univariate testing. The $p$-value of the Wald statistic for each covariate was then examined to determine
which covariates are significant at the traditional (0.05) level of statistical significance (Hosmer et al., 2013). Non-significant variables were removed from the model and a more parsimonious model was fit. The values of the estimated coefficients were then compared between the reduced model and the larger model. If coefficients of the remaining variables changed by greater than 20% between the two models, the removed variables were added back into the model as this level of change suggests the variable provided needed adjustment in the model (Hosmer et al., 2013). Then, to complete the preliminary main effects model, each variable not selected in the first step (i.e. those with a \(p\)-value of greater than 0.25 in univariate analysis) were added one at a time to identify any variables which may make an important contribution to the model in the presence of other variables (Hosmer et al., 2013).

At this stage in model building, linearity in the logit for all continuous variables was tested using the Box-Tidwell approach. In this approach, an interaction between the continuous predictor being tested and its natural logarithm are added to the preliminary main effects model (Tabachnick & Fidell, 2013). The assumption of linearity in the logit is violated if the interaction term is significant (Tabachnick & Fidell, 2013). If the assumption is violated, the continuous variable must be categorized and included in the model using a series of dummy variables.

Finally, model fit was examined. While Hosmer et al. (2013) recommend the use of the Hosmer-Lemeshow Goodness-of-Fit statistic, the model did not meet criteria (the frequency of each “outcome” or class is not 25% of cases) to adequately power this test. Therefore, to assess model fit, the area under the Receiver Operating Characteristics (ROC) curve was utilized. As the ROC curve measures the model’s ability to accurately classify cases into two categories, those with the outcome and those without, an area under the ROC could not be generated for the full multinomial model (Hosmer et al., 2013). Therefore, a series of binary models were fit with to generate ROC curves for each outcome (class). Potential values for the area under the ROC curve range from 0.5 (indicating chance prediction) to 1.0 (indicating perfect prediction) (Tabachnik & Fidell, 2013). While there is no defined value for the area under the ROC which is considered optimal, Hosmer et al. (2013) outline the following rule-of-thumb for assessing model fit: 0.5 to 0.69 is poor, 0.7 to 0.79 is acceptable, 0.8 to 0.89 is excellent, and values greater than 0.9 are considered outstanding.
3.7 Ethical Considerations

Ethical approval has been obtained annually from the Health Sciences Research Ethics Board at the University of Toronto. Additionally, data access forms and confidentiality agreements were completed for the University of Waterloo before accessing ideasPNC data. Secondary data used in this study were obtained directly from the University of Waterloo, and were previously obtained from the Canadian Institutes of Health Information (CIHI) for the ideasPNC project. Throughout this study, safeguards were in place to reduce the level of risk involved with data access. All data were de-identified by CIHI with no personally identifiable information included as part of the dataset. Data were stored on secure servers physically located in a locked room at the University of Waterloo campus and accessed through a virtual private network. Only aggregate level analyses were exported and accessed through a research analyst at the University of Waterloo throughout study analyses.
Chapter 4

4 Results

In this chapter, study results are presented. All data analyses were carried out using Statistical Analysis Software (SAS) Version 9.4 ©. Latent class analysis was conducted utilizing PROC LCA, a SAS based procedure for latent class analysis developed and distributed by The Methodology Center at Penn State (PROC LCA & PROC LTA (version 1.3.2), 2015). PROC LCA is available as a free download at https://methodology.psu.edu/downloads/proclcalta.

4.1 Descriptive Findings and Tests of Difference

In this section, research question one, “Which home and community-based services do Ontario seniors with dementia and their caregivers utilize?” is addressed. First, a brief description of the overall sample demographic characteristics is provided. More in-depth examination of the sample characteristics by latent class is provided in section 4.2.3. Following the overall sample description, home and community-based service utilization for the full sample is presented. Then, to address research question two, “Do home and community-based care services utilized vary by stage of cognitive impairment?”, home and community-based service utilization is broken down and presented by stage of cognitive impairment. Tests of difference are presented to examine variation in services utilized by stage of cognitive impairment.

4.1.1 Sample Demographic Characteristics

Individuals in the study sample ranged in age from 65 to 107 years old, with an average age of 82.9 years. In the sample 63.9% (n=17,620) were female and 45.8% (n=12,643) were married. Twenty-seven percent (n=7,501) reported an elementary education or less, 59.4% (n=16,385) reported having a high school education or more and for 13.4% (n=3,706) of the sample no education information could be attained. In terms of living and caregiving arrangements, 62.0% (n=17,102) lived with their caregiver while the remaining 38.0% (n=10,490) lived alone. The primary caregiver for most of the sample (n=14,296, 51.8%) was a child or child-in-law, while 38.1% (n=10,512) reported their spouse as their primary caregiver and 10.1% (n=2,784) reported another relative, friend or neighbour as their primary caregiver. About 12% (n=3,402) of the sample lived in rural Ontario while the remaining 87.7% (n=24,190) lived in urban settings.
4.1.2 Home and Community-Based Services Utilized by Ontario Seniors with Dementia

There was a broad range of home and community-based services (HCBS) used by individuals in the study sample with varying levels of utilization. Services utilized by the majority of the population included informal care (n=27,144; 98.4%) and personal care (n=21,003; 76.1%). Other home and community-based services which were utilized frequently included homemaking (n=13,147; 47.7%), emergency department services (n=12,696; 46.0%), physician services (n=7,448; 27.0%), nursing services (n=6,827; 24.7%), and meal services (n=5,707; 20.7%). Finally, some home and community-based services were less frequently utilized (reported by less than a fifth of the study sample) including adult day services (n=3,035; 11.0%), physiotherapy (n=1,913; 6.9%), occupational therapy (n=1,623; 5.9%), short stay respite (n=1,041; 3.8%) and volunteer services (n=574; 2.1%).

Within the proportion of the sample utilizing each service, considerable variation was noted in frequency of use. For example, of those who utilized meal services, the frequency of use ranged from one to seven days per week, with an average number of days of service being 6.3 days per week. This demonstrates that for the most part, those who access the service, use it often. Table 7 summarizes the proportion of the population utilizing each service and the mean number of days or hours utilized each week by individuals utilizing the service. Mean service use (in hours or days) per week was not available for physician services.
### Table 7: Home and community-based service utilization for the full sample

<table>
<thead>
<tr>
<th>Service</th>
<th>Proportion utilizing service within observation window n (%)</th>
<th>Mean service use per week for patients utilizing service (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Informal Care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Utilized any informal care</td>
<td>27,144 (98.4%)</td>
<td>29.7 hours (28.9h)</td>
</tr>
<tr>
<td></td>
<td>15,057 (54.6%)</td>
<td>Range [1 - 168]</td>
</tr>
<tr>
<td>Utilized 21 hours or more of informal care</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Personal Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Utilized any personal support care</td>
<td>21,003 (76.1%)</td>
<td>4.5 days (2.4d)</td>
</tr>
<tr>
<td></td>
<td>9,493 (34.4%)</td>
<td>Range [1 - 7]</td>
</tr>
<tr>
<td>Utilized 6 days or more of personal care</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Homemaking</strong></td>
<td>13,147 (47.7%)</td>
<td>3.2 days (2.6d)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range [1 - 7]</td>
</tr>
<tr>
<td><strong>Meal Services</strong></td>
<td>5,707 (20.7%)</td>
<td>6.3 days (1.5d)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range [1 - 7]</td>
</tr>
<tr>
<td><strong>Adult Day Services</strong></td>
<td>3,035 (11%)</td>
<td>2.3 days (1.3d)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range [1 – 7]</td>
</tr>
<tr>
<td><strong>Volunteer Services</strong></td>
<td>574 (2.1%)</td>
<td>1.8 days (1.5d)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range [1 – 7]</td>
</tr>
<tr>
<td><strong>Nursing</strong></td>
<td>6,827 (24.7%)</td>
<td>4.5 days (2.8d)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range [1 – 7]</td>
</tr>
<tr>
<td><strong>Physician Services</strong></td>
<td>7,448 (27.0%)</td>
<td>Data not available</td>
</tr>
<tr>
<td><strong>Occupational Therapy</strong></td>
<td>1,623 (5.9%)</td>
<td>1.1 days (0.4d)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range [1 – 7]</td>
</tr>
<tr>
<td><strong>Physiotherapy</strong></td>
<td>1,913 (6.9%)</td>
<td>1.7 days (1.0d)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range [1 – 7]</td>
</tr>
</tbody>
</table>

*Note: h = hours, d = days, SD = standard deviation*

Table 8 summarizes the proportion of the sample utilizing emergency department and short stay respite services and the mean service use within the observation window.

### Table 8: Institution-based service utilization for the full sample

<table>
<thead>
<tr>
<th>Service</th>
<th>Proportion utilizing service within observation window n (%)</th>
<th>Mean service use within observation window for patients utilizing service (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short-Stay Respite Services</td>
<td>1,041 (3.8%)</td>
<td>1.8 admissions (2.5)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range [1 - 50]</td>
</tr>
<tr>
<td>Emergency Department Visit(s)</td>
<td>12,696 (46.0%)</td>
<td>2.0 visits (1.7)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Range [1 – 29]</td>
</tr>
</tbody>
</table>

*Note: SD = standard deviation*
4.1.3 Service Utilization by Level of Cognitive Impairment

To address the research question, “Do services utilized vary by stage of cognitive impairment?”, home and community-based service (HCBS) utilization is presented by level of cognitive impairment. Cases were assigned to three sub-groups based on the clinical stages of dementia and service utilization was compared across sub-groups. Group 1, “Mild Impairment”, includes those in the early stages of dementia with a Cognitive Performance Scale (CPS) score between 0 and 2 [equivalent to a Mini-Mental Status Examination (MMSE) score of 19-30]. This was the largest group in the sample, including 17,890 individuals. Group 2, “Moderate Impairment” includes those in mid-stage dementia with a CPS score of 3 to 4 (equivalent to a MMSE score of 7-18). This group was comprised of 6,843 individuals. Finally, group 3, “Severe Impairment”, includes those in the later stages of dementia, equivalent to a CPS score of 5-6 or a MMSE score below 7. As expected in a community-based population, this group was the smallest with 3,219 individuals. Dichotomous measures of HCBS utilization (as described in Section 4.4.1) were used to compare rates of use across dementia sub-groups. Findings are summarized in Table 9.

<table>
<thead>
<tr>
<th>Service</th>
<th>Mild Impairment</th>
<th>Moderate Impairment</th>
<th>Severe Impairment</th>
<th>Chi Square P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Informal Care (&gt; 20 hours per week)</strong></td>
<td>8262 (46.2%)</td>
<td>4305 (66.4%)</td>
<td>2490 (77.4%)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td><strong>Personal Support (&gt;5 days per week)</strong></td>
<td>5615 (31.4%)</td>
<td>2444 (37.7%)</td>
<td>1434 (44.6%)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td><strong>Homemaking</strong></td>
<td>8703 (48.7%)</td>
<td>3032 (46.8%)</td>
<td>1412 (43.9%)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td><strong>Meal Services</strong></td>
<td>3981 (22.3%)</td>
<td>1228 (18.9%)</td>
<td>498 (15.5%)</td>
<td>&lt;0.0001</td>
</tr>
</tbody>
</table>

**Bolded p values are significant at p<0.05**

Table 9: Home and community-based services utilized within observation by Cognitive Performance Scale score
<table>
<thead>
<tr>
<th>Service</th>
<th>Service Utilized Within Observation Window</th>
<th>Chi Square P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adult Day Services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild Impairment</td>
<td>1736 (9.7%)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Moderate Impairment</td>
<td>904 (13.9%)</td>
<td></td>
</tr>
<tr>
<td>Severe Impairment</td>
<td>395 (12.3%)</td>
<td></td>
</tr>
<tr>
<td><strong>Volunteer Services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild Impairment</td>
<td>343 (1.9%)</td>
<td>0.0106</td>
</tr>
<tr>
<td>Moderate Impairment</td>
<td>144 (2.2%)</td>
<td></td>
</tr>
<tr>
<td>Severe Impairment</td>
<td>87 (2.7%)</td>
<td></td>
</tr>
<tr>
<td><strong>Nursing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild Impairment</td>
<td>4401 (24.6%)</td>
<td>0.6678</td>
</tr>
<tr>
<td>Moderate Impairment</td>
<td>1611 (24.9%)</td>
<td></td>
</tr>
<tr>
<td>Severe Impairment</td>
<td>815 (25.3%)</td>
<td></td>
</tr>
<tr>
<td><strong>Physician Services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild Impairment</td>
<td>4963 (27.7%)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Moderate Impairment</td>
<td>1702 (26.3%)</td>
<td></td>
</tr>
<tr>
<td>Severe Impairment</td>
<td>783 (24.3%)</td>
<td></td>
</tr>
<tr>
<td><strong>Occupational Therapy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild Impairment</td>
<td>1064 (6.0%)</td>
<td>0.6872</td>
</tr>
<tr>
<td>Moderate Impairment</td>
<td>367 (5.7%)</td>
<td></td>
</tr>
<tr>
<td>Severe Impairment</td>
<td>192 (6.0%)</td>
<td></td>
</tr>
<tr>
<td><strong>Physiotherapy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild Impairment</td>
<td>1328 (7.4%)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Moderate Impairment</td>
<td>425 (6.6%)</td>
<td></td>
</tr>
<tr>
<td>Severe Impairment</td>
<td>160 (5.0%)</td>
<td></td>
</tr>
<tr>
<td><strong>Short-Stay Respite Admission(s)</strong></td>
<td></td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Mild Impairment</td>
<td>571 (3.2%)</td>
<td></td>
</tr>
<tr>
<td>Moderate Impairment</td>
<td>314 (4.8%)</td>
<td></td>
</tr>
<tr>
<td>Severe Impairment</td>
<td>156 (4.9%)</td>
<td></td>
</tr>
<tr>
<td><strong>Emergency Department Visit(s)</strong></td>
<td></td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Mild Impairment</td>
<td>8479 (47.4%)</td>
<td></td>
</tr>
<tr>
<td>Moderate Impairment</td>
<td>2859 (44.1%)</td>
<td></td>
</tr>
<tr>
<td>Severe Impairment</td>
<td>1358 (42.2%)</td>
<td></td>
</tr>
</tbody>
</table>

**Bolded** p values are significant at p<0.05

Utilization of all home and community-based services, apart from nursing and occupational therapy, varied by level of cognitive impairment. Utilization of informal care, personal support and volunteer services increased as the level of cognitive impairment increased. Conversely, home and community-based services which target important, frequently performed IADLs, including homemaking and meal services, showed decreasing utilization with increasing cognitive impairment. Additionally, physician services, physiotherapy services and emergency
department visits all showed decreasing utilization with increasing cognitive impairment. For both adult day services and short-stay respite admissions, utilization increased from mild to moderate cognitive impairment but either remained constant or declined in severe cognitive impairment.

### 4.2 Identifying Patterns of Service Utilization

In this section, to answer research question two, "What patterns of service utilization can be identified in community-based seniors with ADRD?", latent class model findings are presented. First, model building strategies and model selection are described. Then, for each identified latent class, the defining service utilization patterns of the group are presented and group characteristics are described.

#### 4.2.1 Fitting the Baseline Latent Class Model

When fitting a latent class (LC) model, all new analyses should begin with fitting a baseline model with no grouping variable or covariates included (Lanza et al., 2007). This allows for the investigator to identify the optimal model structure prior to identifying predictors of class membership. As polychotomous indicator variables require a larger number of parameters to be estimated, the LC model was initially fit with 12 binary indicators of home and community-based service use. Services included in the initial LC model were informal care, personal care, homemaking, meal services, volunteer services, adult day services, nursing, community-based physician services, occupational therapy, physiotherapy, short stay respite admissions, and emergency department visits. Additionally, a clustering variable was included in the model to account for the impact of service authorization procedures and funding priorities of each of the 14 Local Health Integration Networks (Kaplan & Keller, 2011; Lanza et al., 2015).

Models with one through eight latent classes were estimated and compared. Model identification for models with more than eight classes was not sufficient to allow for reliable estimation of parameters. In LCA, model identification is related to three inter-related characteristics of the data: 1) the absolute sample size, 2) data sparseness, and 3) the strength of the relationships between the indicators and the latent variable (Collins & Lanza, 2010; Wurpts & Geiser, 2014). While there is no consensus on the sample size required for LCA, literature suggests that to select the correct model, minimum sample size should be between 300 and 1000, depending on
model complexity (Yang, 2006, Wurpts & Geiser, 2014). Therefore, the absolute sample size of 27,592 in this study would be considered sufficiently large. However, as models become more complex, issues with data sparseness increase as sparseness is related to the size of the contingency table and the quality of the indicators (Collins & Lanza, 2010). In a model with 12 dichotomous indicators, the contingency table has $2^{12}$ or 4,096 cells, with each cell representing a potential unique service utilization pattern in the data. However, in the study sample only 1,081 of these patterns were observed, resulting in 73.6% of the cells in the contingency table remaining empty. Therefore, to improve model identification, the class structure of the largest model which could be estimated was examined to identify redundant items and those items which did not differentiate between the classes (Collins & Lanza, 2010).

Examination of the class structure for the eight-class model identified three indicators as candidates for removal: volunteer services, physician services and short stay respite. Utilization of both volunteer services and short stay respite were reported infrequently in the sample. Within the observation window, only 2.1% of the sample reported utilizing volunteer services with the probability of utilization varying from 0% to 9% across the classes. Similarly, utilization of short stay respite services was reported by only 3.8% of the sample, with slightly more variation in utilization (range: 0% to 17%). Furthermore, the class with the highest probability of using volunteer services (9%) also had the highest probabilities of utilizing adult day services (49%) and short stay respite (19%). Therefore, as this class could be better characterized by the utilization of these respite services, the volunteer services variable was removed from the model. Additionally, the two classes which had the highest probability of utilizing short stay respite services (11%, 17%) also had the highest probabilities of utilizing adult day services (37%, 50%). Therefore, to simplify the base model, a new variable, community-based respite services, was created by combining the adult day services and short stay respite variables. Finally, although community-based physician services were reported by 27% of the population, there was no class characterized by this service and little variation in utilization across the classes (range 23% to 48%). Those classes with the highest probabilities of utilization (44% and 48%) were high user groups which were characterized by much higher probabilities of utilization of informal care (85%), adult day service (50%) and emergency department services (65%) in the first group and personal support (85%), homemaking (95%), meal services (60%), nursing (70%)
and emergency department visits (81%) in the second group. Therefore, the physician services variable was removed from the model.

A simplified LCA model was fit with nine dichotomous indicators including: nursing, occupational therapy, physiotherapy, informal care, personal support, homemaking, meal services, respite services, and emergency department visits. The simplified 9-item measurement model is depicted in Figure 7. Again, a clustering variable was included in the model to account for the impact of the service authorization procedures and funding priorities of each Local Health Integration Network. In this simplified model with nine indicators, there are \(9^2\) cells in the contingency table, or 512 potential service utilization patterns. In the data, 398 unique patterns were observed, resulting in significantly less sparseness in the data. Latent class models with one through eight latent classes were estimated and compared using the information criteria. Model identification for models beyond eight classes was not sufficient to allow for reliable estimation of parameters. Goodness-of-fit statistics are reported in Table 10.
Table 10: Simplified 9 Indicator LCA Model Fit Statistics

<table>
<thead>
<tr>
<th>Classes</th>
<th>$G^2$</th>
<th>AIC</th>
<th>BIC</th>
<th>CAIC</th>
<th>a-BIC</th>
<th>df</th>
<th>Entropy</th>
<th>BLRT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (H0)</td>
<td>19243</td>
<td>19261</td>
<td>19335</td>
<td>19344</td>
<td>19306</td>
<td>502</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>2</td>
<td>4239</td>
<td>4277</td>
<td>4433</td>
<td>4452</td>
<td>4373</td>
<td>492</td>
<td>0.71</td>
<td>p=0.01</td>
</tr>
<tr>
<td>3</td>
<td>1875</td>
<td>1933</td>
<td>2172</td>
<td>2201</td>
<td>2079</td>
<td>482</td>
<td>0.69</td>
<td>p=0.01</td>
</tr>
<tr>
<td>4</td>
<td>1341</td>
<td>1419</td>
<td>1739</td>
<td>1779</td>
<td>1616</td>
<td>472</td>
<td>0.61</td>
<td>p=0.01</td>
</tr>
<tr>
<td>5</td>
<td>896</td>
<td>994</td>
<td>1397</td>
<td>1446</td>
<td>1241</td>
<td>462</td>
<td>0.54</td>
<td>p=0.01</td>
</tr>
<tr>
<td>6</td>
<td>712</td>
<td>830</td>
<td>1315</td>
<td>1374</td>
<td>1128</td>
<td>452</td>
<td>0.56</td>
<td>p=0.01</td>
</tr>
<tr>
<td>7</td>
<td>595</td>
<td>733</td>
<td>1300</td>
<td>1369</td>
<td>1081</td>
<td>442</td>
<td>0.57</td>
<td>p=0.01</td>
</tr>
<tr>
<td>8</td>
<td>542</td>
<td>700</td>
<td>1350</td>
<td>1429</td>
<td>1099</td>
<td>432</td>
<td>0.55</td>
<td>p=0.01</td>
</tr>
</tbody>
</table>

Several of the information criteria (BIC, CAIC and a-BIC) identified models with seven classes as optimal, although the AIC was not minimized in this model. The Bootstrap Likelihood Ratio Test, which has been reported to be the most reliable and accurate test for determining the number of classes in LCA (Nylund et al., 2007; Dziak et al., 2012) supports an eight-class model. However, due to the large sample size, consideration needs to be given to whether this statistically significant result is also practically and theoretically significant (Lantz, 2012). An examination of the parameter estimates revealed a clinically meaningful differentiation was made with the addition of this eighth class. The additional class appeared to differentiate between those with a high probability of receiving only high informal (99.7%) care versus those with a high probability of receiving informal care (86.9%) and respite services (29.2%). However, on closer examination of the posterior probabilities and class assignments, it was clear that differentiating between those receiving high informal care only and those receiving high informal care plus respite services resulted in a significant number of misclassifications. In the eight-class model, 70% of those classified as belonging to the “informal care plus respite” class...
did not receive respite services. This error in assignment may be related to the fact that respite services are not frequently used in the overall sample.

Therefore, the more parsimonious seven-class model was selected as the final latent class model for the study. All identified classes were non-trivial in size, ranging from 3.8% to 34.9% of the sample. While literature has suggested that classes with less than 5% prevalence can be difficult to replicate (Mora et al., 2009), given the study sample size and the strength of the conditional probabilities in the smallest class, this class was retained in the model. Figure 8 depicts the class profile for the seven-class model, showing the predicted probability of service use conditional on latent class assignment. This graphical representation of the model allows for visualization of the differences and similarities between the classes when identifying the defining characteristics for each class and assigning labels (Collins & Lanza, 2010).

![Figure 8. Latent Class Profiles: Predicted Probability of Service Use Conditioned on Class Assignment](image-url)
In the latent class profiles two clear groups can be identified, those with a high probability of utilizing home and community-based support services (personal support, homemaking and meal services) versus those with a high probability of extensive (greater than 21 hours) informal support. Additionally, for each of the health care services, differences in utilization between classes could be identified. Further inspection of the item response probabilities for each of the seven classes suggests that each class is distinguishable from the others. In Table 11, item response probabilities are reported for each latent class. Aligning with previous LCA literature examining health service utilization, item response probabilities were classified as: high (0.70-1.00), moderate (0.40-0.60) and low (less than 0.40) probability of service use (Beeber et al., 2008; Janssen et al., 2016). Each column of Table 11 represents a unique class. Labels were then assigned to classes based on patterns of service utilization.

Both rare services and rare classes are included in the model structure, as these smaller classes were important conceptually to understand the use of these less frequently utilized services. Rare services, defined in this study as those services utilized by less than 15% of the sample, are indicated in the table with an asterisk. For rare services, rather than using the above partitioning of high, moderate and low probability of service use, utilization within a class was compared to the overall utilization in the sample to determine which services are characteristic of the class (S. Lanza, personal communication, Nov 11, 2016). Each class identified in the model is described in detail below.
Table 11: Item-Response Probabilities for 7-Class Model: Probability of Endorsing Item Given Latent Class

<table>
<thead>
<tr>
<th>Item</th>
<th>Marginal Probabilities</th>
<th>Low Formal Support 12.6%</th>
<th>Emergency Department Users 14.8%</th>
<th>High Informal Care 34.9%</th>
<th>Community-Based Therapy 6.9%</th>
<th>Well HCBS Service Users 15.5%</th>
<th>Frail HCBS Service Users 11.6%</th>
<th>High Users 3.8%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal Care</td>
<td>0.5457</td>
<td>0.0151</td>
<td>0.8797</td>
<td>0.8521</td>
<td>0.8049</td>
<td>0.2980</td>
<td>0.0117</td>
<td>0.3524</td>
</tr>
<tr>
<td>Personal Care</td>
<td>0.3440</td>
<td>0.1638</td>
<td>0.3652</td>
<td>0.1049</td>
<td>0.4995</td>
<td>0.4986</td>
<td>0.7457</td>
<td>0.9150</td>
</tr>
<tr>
<td>Homemaking</td>
<td>0.4765</td>
<td>0.3021</td>
<td>0.3120</td>
<td>0.2690</td>
<td>0.3428</td>
<td>0.7967</td>
<td>0.9929</td>
<td>0.9604</td>
</tr>
<tr>
<td>Meal Services</td>
<td>0.2068</td>
<td>0.0742</td>
<td>0.0007</td>
<td>0.0315</td>
<td>0.0677</td>
<td>0.6258</td>
<td>0.5423</td>
<td>0.5807</td>
</tr>
<tr>
<td>Nursing</td>
<td>0.2474</td>
<td>0.1206</td>
<td>0.3538</td>
<td>0.0069</td>
<td>0.3840</td>
<td>0.2346</td>
<td>0.7449</td>
<td>0.7453</td>
</tr>
<tr>
<td>Physiotherapy*</td>
<td>0.0588</td>
<td>0.0218</td>
<td>0.0470</td>
<td>0.0203</td>
<td>0.4249</td>
<td>0.0209</td>
<td>0.0031</td>
<td>0.2389</td>
</tr>
<tr>
<td>Occupational Therapy*</td>
<td>0.0693</td>
<td>0.0206</td>
<td>0.0111</td>
<td>0.0127</td>
<td>0.3290</td>
<td>0.0455</td>
<td>0.1534</td>
<td>0.3439</td>
</tr>
<tr>
<td>Respite Services*</td>
<td>0.1361</td>
<td>0.0160</td>
<td>0.0868</td>
<td>0.2611</td>
<td>0.1427</td>
<td>0.1043</td>
<td>0.0111</td>
<td>0.0755</td>
</tr>
<tr>
<td>ED Services</td>
<td>0.4601</td>
<td>0.3783</td>
<td>0.5610</td>
<td>0.3487</td>
<td>0.8569</td>
<td>0.4279</td>
<td>0.4402</td>
<td>0.8317</td>
</tr>
</tbody>
</table>

ED = emergency department; HCBS = home and community-based support
Low probability of service use, Moderate probability of service use, High probability of service use; More than 2x probability of service use for rare events

Based on the seven-class model of home and community-based service utilization for seniors with Alzheimer’s disease and related dementias:

Members of Class 1, Low Support (12.6%), have a low probability of accessing any formal health services and have a low probability of receiving extensive informal care (21 hours or more per week).

Members of Class 2, Emergency Department Users (14.8%), have a low probability of accessing any formal health services other than the emergency department (0.56). Additionally, this group has a high probability (0.88) of receiving extensive informal care (21 hours or more per week).

Members of Class 3, High Informal Care (34.9%), are unlikely to utilize most formal home and community-based support services, but have a high (0.85) probability of relying heavily on informal care givers (21 hours or more per week). Members of this group have the highest likelihood of utilizing respite services (0.26) in the sample.
Members of Class 4, *Community-Based Therapy* (6.9%), are more likely to receive physiotherapy (0.42) and occupational therapy (0.33) than the overall sample. This group also has a high probability of receiving extensive informal care (21 hours or more per week) (0.80), visiting the emergency department (0.86) and a moderate probability of receiving high levels of personal support (6 or more days per week) (0.50).

Members of Class 5, *Well Home and Community-Based Support Service Users* (15.6%), are characterized by higher probabilities of service utilization aimed at supporting instrumental activities of daily living such as homemaking (0.80) and meal delivery (0.63). Members of this class also have a moderate probability of utilizing high levels of personal support (6 or more days per week) (0.50).

Members of Class 6, *Frail Home and Community-Based Support Service Users* (11.3%), have a high probability (0.75) of receiving nursing services in the community and a moderate probability of accessing the emergency department (0.44). Members of this class are characterized by high probabilities of receiving all in-home supportive services including high levels of personal support (6 or more days per week) (0.75), homemaking (0.99) and meal services (0.54) and have a very low probability (0.01) of receiving extensive informal care (21 hours or more per week). Individuals in this class differ from those in the *Well HCBS Service Users* class due to their use of health services in addition to supportive care services.

Class 7, *High Users* (3.8%), constitutes a small proportion of the sample with high likelihood of utilizing multiple formal services. Members of this class have a high probability of receiving homemaking (0.96), high levels of personal support (6 or more days per week) (0.91), and nursing (0.75) and a moderate probability of receiving meal services (0.58). There is also a high probability of visiting the emergency department (0.83) for members of this class. Additionally, this group is over four times as likely to receive physiotherapy (0.24) and about five times as likely to receive occupational therapy (0.34) than the overall sample.

### 4.2.2 Accuracy of Class Assignment

Following assignment of individual cases to latent classes using modal assignment, the following were calculated: the number of service utilization patterns contributing to the class, the number of individuals assigned to the class by modal assignment, the average posterior probability of
class membership (AvePP) and variation around the AvePP for the class as well as the Odds of Correct Classification (OCC) diagnostic. In the model, one class met the 0.7 cut-off for AvePP established by Nagin (2005). Three classes had AvePPs just below the cut-off (0.68, 0.69, 0.69) while two classes had AvePPs of 0.64 and only one class had an AvePP below 0.6. Taking into consideration the number of classes in the model (Collins & Lanza, 2010) and that OCC diagnostic criteria for high assignment accuracy (Nagin, 2005) were met by all seven classes, the model appears to fit the data well. A summary of the model’s accuracy of class assignment diagnostics is provided in Table 12.

Table 12: Accuracy of class assignment diagnostics

<table>
<thead>
<tr>
<th>Latent Class</th>
<th>Number of Unique Service Use Patterns in Class</th>
<th>Individuals Assigned to Class by Modal Assignment</th>
<th>Average Posterior Probability (SD) [Range]</th>
<th>Odds of Correct Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Support</td>
<td>21</td>
<td>4,941</td>
<td>0.58 (0.08) [0.27-0.73]</td>
<td>9.7</td>
</tr>
<tr>
<td>Emergency Department Users</td>
<td>25</td>
<td>2,576</td>
<td>0.64 (0.16) [0.32-0.88]</td>
<td>10.2</td>
</tr>
<tr>
<td>High Informal Care</td>
<td>39</td>
<td>10,690</td>
<td>0.76 (0.14) [0.36-0.95]</td>
<td>5.8</td>
</tr>
<tr>
<td>Community-Based Therapy</td>
<td>142</td>
<td>1,457</td>
<td>0.69 (0.18) [0.32-0.99]</td>
<td>30.4</td>
</tr>
<tr>
<td>Well HCBS Service Users</td>
<td>96</td>
<td>3,904</td>
<td>0.64 (0.16) [0.33-0.95]</td>
<td>9.6</td>
</tr>
<tr>
<td>Frail HCBS Service Users</td>
<td>22</td>
<td>3,358</td>
<td>0.68 (0.13) [0.25-0.86]</td>
<td>16.0</td>
</tr>
<tr>
<td>High Users</td>
<td>53</td>
<td>486</td>
<td>0.69 (0.16) [0.37-0.97]</td>
<td>56.2</td>
</tr>
</tbody>
</table>

Note: SD = standard deviation; HCBS = home and community-based support

Further examination of the service utilization patterns and individuals assigned to each class through modal assignment demonstrated that chosen class labels are accurate. All service utilization patterns in the Low Support class endorse a maximum of two services (either HCBS or professional services) utilized over the observation window. Additionally, no patterns in this class reported utilizing 21 hours or more of informal care per week. In the Emergency Department Users class, 72% of cases utilized the emergency department in the observation window. Ninety-six percent of users in the High Informal Care class utilized 21 hours or more of
informal care per week. Additionally, 27% of service users in this class utilized respite services (either adult day services or short stay respite) in the observation window. A full 100% of individuals in the Community-Based Therapy class utilized either occupational therapy (71%) or physiotherapy (48%) during the observation window. In both classes of HCBS Service Users (Well, Frail) individuals utilized homemaking (84%, 100%), meal delivery services (78%, 52%) and personal support services (62%, 70%). However, the major difference between the classes was in the utilization of nursing services (94%, 11%). Individuals assigned to the High User class utilized multiple services at high rates including in home supportive services such as homemaking (98%), personal support (96%) and meals (75%), as well as nursing services (83%) and the emergency department (88%).

4.2.3 Latent Class Group Profiles

After assignment of individual cases to latent classes, profiles of the latent classes were created by examining characteristics of service users in each group. Latent class group profiles are used to illustrate shared characteristics of class members and identify potential characteristics which may distinguish classes from one another (Nagin, 2005). To identify differences in characteristics across groups, the sample was analyzed using chi-square and one-way ANOVA tests. Tukey’s range test and standardized residuals were used, as appropriate, to determine where groups differ. Results of the chi square and ANOVA tests are presented according to the Behavioural Model and are summarized in Tables 13 to 16. To reduce the likelihood of Type I error in post-hoc testing, an alpha level of 0.01 was used for both Tukey’s range tests and when examining standardized residuals. Therefore, residuals greater than 2.58 were considered significant. Results of post hoc testing are discussed in the text below.

4.2.3.1 Predisposing Factors

Latent classes differed significantly on all predisposing factors including age (F=171.4; p<.0001), sex (χ²=731.5, p<.0001), highest level of education completed (χ²=261.2, p<.0001), marital status (χ²=2874.1, p<.0001) and caregiver relationship (χ²=3710.5, p<.0001). Table 13: Latent Class Group Profiles: Predisposing Factors by Latent Class summarizes the latent class profile for predisposing factors.
Table 13: Latent Class Group Profiles: Predisposing Factors by Latent Class

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Full Sample (n=27,592)</td>
</tr>
<tr>
<td>Age</td>
<td>82.9 (6.6)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Frequency (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Full Sample (n=27,592)</td>
</tr>
<tr>
<td>Female</td>
<td>63.9</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Elementary or less</td>
<td>27.2</td>
</tr>
<tr>
<td>High school</td>
<td>35.4</td>
</tr>
<tr>
<td>Post-secondary</td>
<td>24.0</td>
</tr>
<tr>
<td>Unknown</td>
<td>13.4</td>
</tr>
<tr>
<td>Married</td>
<td>45.8</td>
</tr>
<tr>
<td>Caregiver relationship</td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>51.8</td>
</tr>
<tr>
<td>Spouse</td>
<td>38.1</td>
</tr>
<tr>
<td>Other</td>
<td>10.1</td>
</tr>
</tbody>
</table>

Note: SD = Standard Deviation, ED = Emergency Department, HCBS = Home and Community-Based Support

On average, the High Informal Care group was the youngest class identified, while the Frail HCBS Service User class was oldest. Noteworthy, is that both the Well and Frail HCBS Service User classes were made up of predominantly female service users, and that these classes also had the fewest married individuals and the highest proportion of child caregivers. Taken together, these results suggest that older, likely widowed, females make up the majority of HCBS service users in Ontario. Additionally, the highest percentage of service users with post-secondary education were found in the High User class, supporting previous research linking higher education levels with increased service use (Gill et al., 1998).
4.2.3.2 Enabling Factors

Latent classes also differed significantly on all enabling factors including living arrangement ($\chi^2=9389.1$, $p<.0001$), rurality ($\chi^2=94.2$, $p<.0001$) and geographic location ($\chi^2=1712.6$, $p<.0001$). Table 14: Latent Class Group Profiles: Enabling Factors by Latent Class summarizes the latent class group profiles for enabling factors.

Table 14: Latent Class Group Profiles: Enabling Factors by Latent Class

<table>
<thead>
<tr>
<th></th>
<th>Frequency (%)</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Full Sample</td>
<td>Low Support</td>
<td>ED Users</td>
<td>High Informal Care</td>
<td>Community- Based Therapy</td>
<td>Well HCBS Service User</td>
<td>Frail HCBS Service User</td>
<td>High User</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(n=27,592)</td>
<td>(n=4,941)</td>
<td>(n=2,576)</td>
<td>(n=10,690)</td>
<td>(n=1,457)</td>
<td>(n=3,904)</td>
<td>(n=3,538)</td>
<td>(n=486)</td>
<td></td>
</tr>
<tr>
<td>Lives alone</td>
<td>38.0</td>
<td>55.5</td>
<td>14.8</td>
<td>11.2</td>
<td>19.0</td>
<td>68.9</td>
<td>82.8</td>
<td>57.0</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Rural</td>
<td>12.3</td>
<td>14.2</td>
<td>14.2</td>
<td>12.1</td>
<td>8.6</td>
<td>14.1</td>
<td>9.0</td>
<td>9.5</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Geographic location, %</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 1</td>
<td>6.2</td>
<td>5.4</td>
<td>6.0</td>
<td>5.7</td>
<td>11.0</td>
<td>7.0</td>
<td>3.3</td>
<td>5.1</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>▪ Health Region 2</td>
<td>8.3</td>
<td>8.3</td>
<td>9.5</td>
<td>8.4</td>
<td>8.8</td>
<td>6.6</td>
<td>6.3</td>
<td>8.3</td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 3</td>
<td>7.7</td>
<td>8.8</td>
<td>8.6</td>
<td>6.4</td>
<td>10.3</td>
<td>6.5</td>
<td>10.7</td>
<td>6.9</td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 4</td>
<td>16.2</td>
<td>15.3</td>
<td>18.1</td>
<td>16.5</td>
<td>14.4</td>
<td>15.6</td>
<td>24.9</td>
<td>16.4</td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 5</td>
<td>2.8</td>
<td>2.1</td>
<td>0.5</td>
<td>1.6</td>
<td>0.7</td>
<td>3.3</td>
<td>5.6</td>
<td>4.0</td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 6</td>
<td>5.0</td>
<td>4.4</td>
<td>9.3</td>
<td>4.8</td>
<td>3.6</td>
<td>6.3</td>
<td>8.1</td>
<td>4.7</td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 7</td>
<td>6.3</td>
<td>6.6</td>
<td>5.3</td>
<td>8.5</td>
<td>3.8</td>
<td>8.4</td>
<td>5.8</td>
<td>5.6</td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 8</td>
<td>8.7</td>
<td>6.2</td>
<td>5.0</td>
<td>9.6</td>
<td>5.4</td>
<td>9.9</td>
<td>9.6</td>
<td>11.0</td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 9</td>
<td>10.7</td>
<td>8.9</td>
<td>5.0</td>
<td>14.6</td>
<td>6.7</td>
<td>10.2</td>
<td>9.4</td>
<td>11.7</td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 10</td>
<td>4.3</td>
<td>5.9</td>
<td>4.2</td>
<td>3.3</td>
<td>4.5</td>
<td>4.3</td>
<td>2.8</td>
<td>4.1</td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 11</td>
<td>11.7</td>
<td>13.4</td>
<td>21.4</td>
<td>8.8</td>
<td>22.9</td>
<td>7.6</td>
<td>6.7</td>
<td>9.8</td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 12</td>
<td>3.9</td>
<td>4.2</td>
<td>2.6</td>
<td>4.0</td>
<td>3.0</td>
<td>14.2</td>
<td>2.2</td>
<td>4.1</td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 13</td>
<td>5.6</td>
<td>6.3</td>
<td>3.0</td>
<td>5.3</td>
<td>3.6</td>
<td>7.3</td>
<td>2.9</td>
<td>5.8</td>
<td></td>
</tr>
<tr>
<td>▪ Health Region 14</td>
<td>2.6</td>
<td>4.2</td>
<td>1.7</td>
<td>2.6</td>
<td>1.3</td>
<td>2.5</td>
<td>1.8</td>
<td>2.4</td>
<td></td>
</tr>
</tbody>
</table>

Note: SD = Standard Deviation, ED = Emergency Department, HCBS = Home and Community-Based Support

In classes with low formal service use (e.g. ED Users and High Informal Care), the majority of individuals lived with a caregiver, while in both the Well and Frail HCBS Users groups, most lived alone. This finding suggests that home and community-based supportive services may be substituting for the presence of a live-in informal caregiver. Also of note is the relationship of location of service delivery and latent class membership. Those latent classes with a high likelihood of professional service use (e.g. nursing, occupational therapy or physiotherapy), including Community-Based Therapy, Frail HCBS Service Users and High Users, have lower
frequencies of service users living in rural locations. Additionally, some geographical locations, such as Health Region 1, Health Region 4 and Health Region 11, make up higher percentages of the latent classes with professional services than expected. Together these findings suggest there may be issues with either availability of professional services or service authorization policies in certain Health Regions.

4.2.3.3 Need Factors

When examining need factors, latent classes were found to differ significantly on all measures of clinical complexity, past health service use and caregiver needs. Table 15: *Latent Class Group Profiles: Need Factors (Continuous) by Latent Class* and Table 16: *Latent Class Group Profiles: Need Factors (Categorical) by Latent Class* summarize the latent class group profiles for need factors.

### Table 15: Latent Class Group Profiles: Need Factors (Continuous) by Latent Class

<table>
<thead>
<tr>
<th>Variable</th>
<th>Full Sample (n=27,592)</th>
<th>Low Support (n=4,941)</th>
<th>ED Users (n=2,576)</th>
<th>High Informal Care (n=10,690)</th>
<th>Community-Based Therapy (n=1,457)</th>
<th>Well HCBS Service Users (n=3,904)</th>
<th>Frail HCBS Service Users (n=3,538)</th>
<th>High Users (n=486)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive status</td>
<td>2.5 (1.2)</td>
<td>2.1 (0.9)</td>
<td>2.9 (1.4)</td>
<td>2.8 (1.2)</td>
<td>2.5 (1.2)</td>
<td>2.4 (1.0)</td>
<td>2.4 (1.0)</td>
<td>2.5 (1.1)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Number of comorbidities</td>
<td>3.2 (2.1)</td>
<td>3.1 (2.0)</td>
<td>3.8 (2.3)</td>
<td>3.0 (2.0)</td>
<td>3.6 (2.2)</td>
<td>3.2 (2.0)</td>
<td>3.4 (2.0)</td>
<td>3.7 (2.2)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>BPSD</td>
<td>0.9 (1.4)</td>
<td>0.76 (1.2)</td>
<td>1.01 (1.5)</td>
<td>1.12 (1.5)</td>
<td>0.98 (1.4)</td>
<td>0.77 (1.2)</td>
<td>0.82 (1.2)</td>
<td>0.86 (1.3)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>IADL impairment</td>
<td>5.1 (1.2)</td>
<td>4.4 (1.5)</td>
<td>5.4 (1.0)</td>
<td>5.3 (1.0)</td>
<td>5.1 (1.2)</td>
<td>5.1 (1.2)</td>
<td>5.3 (1.1)</td>
<td>5.3 (1.0)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>ADL impairment</td>
<td>1.2 (1.5)</td>
<td>0.6 (1.1)</td>
<td>2.1 (1.9)</td>
<td>1.3 (1.4)</td>
<td>1.6 (1.6)</td>
<td>1.0 (1.3)</td>
<td>1.2 (1.4)</td>
<td>1.5 (1.5)</td>
<td>&lt;.0001</td>
</tr>
</tbody>
</table>

*Note: ADL = Activities of Daily Living, BPSD = Behavioural and Psychological Symptoms of Dementia, ED = Emergency Department, HCBS = Home and Community-Based Support, IADL = Instrumental Activities of Daily Living, SD = Standard Deviation*

Analysis of measures of clinical complexity revealed that latent classes differed on functional measures such as IADL impairment (F=443.8, p<.0001), ADL impairment (F=373.2, p<.0001) and ADL decline ($\chi^2=216.0$, p<0.0001); cognitive measures such as cognitive status (F=283.0, p<.0001), cognitive decline ($\chi^2=157.4$, p<.0001), behavioural and psychological symptoms of
dementia (F=59.0, p<.0001) and behaviour decline (χ²=113.3, p<.0001); as well as health status measures such as number of comorbidities (F=85.0, p<.0001), polypharmacy (χ²=549.1, p<.0001), psychotropic medication use (χ²=174.2, p<.0001), continence (χ²=834.2, p<.0001), daily pain (χ²=97.5, p<.0001) and recent falls (χ²=238.1, p<.0001).

Table 16: Latent Class Group Profiles: Need Factors (Categorical) by Latent Class

<table>
<thead>
<tr>
<th>Frequency (%)</th>
<th>Full Sample (n=27,592)</th>
<th>Low Support (n=4,941)</th>
<th>ED Users (n=2,576)</th>
<th>High Informal Care (n=10,690)</th>
<th>Community-Based Therapy (n=1,457)</th>
<th>Well HCBS Service Users (n=3,904)</th>
<th>Frail HCBS Service Users (n=3,538)</th>
<th>High Users (n=486)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recent cognitive decline</td>
<td>42.7</td>
<td>37.0</td>
<td>43.3</td>
<td>46.7</td>
<td>43.0</td>
<td>40.6</td>
<td>39.8</td>
<td>45.3</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Polypharmacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 5 medications</td>
<td>20.1</td>
<td>22.9</td>
<td>17.5</td>
<td>23.2</td>
<td>15.2</td>
<td>18.5</td>
<td>13.0</td>
<td>15.2</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>5 to 8 medications</td>
<td>36.6</td>
<td>36.9</td>
<td>33.0</td>
<td>39.7</td>
<td>37.5</td>
<td>35.0</td>
<td>31.3</td>
<td>31.9</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>&gt; 8 medications</td>
<td>43.3</td>
<td>40.2</td>
<td>49.5</td>
<td>37.0</td>
<td>47.3</td>
<td>46.4</td>
<td>55.7</td>
<td>52.9</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Psychotropic medication use</td>
<td>50.8</td>
<td>46.3</td>
<td>53.3</td>
<td>48.7</td>
<td>51.1</td>
<td>51.9</td>
<td>59.4</td>
<td>55.6</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>36.5</td>
<td>31.9</td>
<td>33.6</td>
<td>44.0</td>
<td>30.3</td>
<td>33.0</td>
<td>29.4</td>
<td>30.0</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Recent behaviour decline</td>
<td>12.7</td>
<td>10.5</td>
<td>12.8</td>
<td>15.3</td>
<td>12.2</td>
<td>10.3</td>
<td>11.3</td>
<td>10.3</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Recent ADL decline</td>
<td>43.3</td>
<td>36.6</td>
<td>47.8</td>
<td>44.3</td>
<td>53.3</td>
<td>41.6</td>
<td>42.2</td>
<td>56.8</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Continent</td>
<td>44.5</td>
<td>58.0</td>
<td>32.2</td>
<td>43.3</td>
<td>39.6</td>
<td>44.5</td>
<td>41.7</td>
<td>33.3</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Daily pain</td>
<td>32.3</td>
<td>33.8</td>
<td>36.7</td>
<td>30.3</td>
<td>40.0</td>
<td>30.4</td>
<td>31.2</td>
<td>35.6</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Recent falls</td>
<td>30.4</td>
<td>27.1</td>
<td>32.9</td>
<td>29.2</td>
<td>43.7</td>
<td>29.7</td>
<td>31.4</td>
<td>41.2</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Recent ED visit</td>
<td>14.6</td>
<td>13.7</td>
<td>18.7</td>
<td>13.1</td>
<td>20.5</td>
<td>14.4</td>
<td>14.8</td>
<td>20.4</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Recent hospitalization</td>
<td>16.6</td>
<td>16.1</td>
<td>25.6</td>
<td>13.2</td>
<td>28.6</td>
<td>14.8</td>
<td>16.9</td>
<td>28.4</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Caregiver distress</td>
<td>28.1</td>
<td>20.9</td>
<td>33.6</td>
<td>37.0</td>
<td>33.9</td>
<td>19.6</td>
<td>14.6</td>
<td>26.8</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Considering alternate living arrangement</td>
<td>30.7</td>
<td>31.4</td>
<td>22.2</td>
<td>26.8</td>
<td>22.0</td>
<td>37.2</td>
<td>43.2</td>
<td>40.1</td>
<td>&lt;.0001</td>
</tr>
</tbody>
</table>

Note: ADL = Activities of Daily Living, ED = Emergency Department, HCBS = Home and Community-Based Support

Latent classes also differed on past health service use measures such as recent emergency department use (χ²=111.4, p<.0001) and recent hospitalizations (χ²=425.5, p<.0001) and with respect to measures of caregiver needs including caregiver distress (χ²=1067.7, p<.0001), and whether the primary caregiver was considering alternate living arrangements (χ²=576.7, p<.0001).
4.3 Identifying Predictors of Latent Class Membership

In this section, findings related to research question three, “What impact do patient and caregiver characteristics have on patterns of service use for community-based seniors with ADRD?” are presented. Multinomial logistic regression modeling was used to address this research question. First, model building strategies and model selection are described. Then, an overview of the impact of patient and caregiver characteristics across classes is presented. Finally, for each class, the impact of patient and caregiver characteristics on class membership is explored in greater depth.

4.3.1 Multinomial Logistic Regression Model Building

Prior to building the multinomial logistic regression model, collinearity diagnostics were performed. Variables with a tolerance below 0.4 and a variance inflation factor above 2.5 were examined more closely (Allison, 2012). Collinearity was found to be an issue among two predisposing variables, marital status and caregiver relationship. Overlap was noted in the measurement of these two variables as the variable caregiver relationship had a response option of “spouse” and the variable marital status was a simple dichotomous measure indicating whether the individual was married. Therefore, marital status was dropped from the model.

Next, univariate analyses of all remaining 25 proposed predictor variables were conducted. As all variables had a $p$-value of 0.25 or less on univariate testing, all 25 were included in the preliminary multinomial model. For each categorical variable, dummy variables were created. This resulted in a total of 42 predictor variables for inclusion in the initial multinomial model. In this preliminary model, all predictors were significant at the traditional level of significance ($p<0.05$) except the variable Recent Decline in Behaviour. This variable was removed from the model and a new model with 41 predictors was fit and beta coefficients of the remaining variables were examined. Seven variables (four Geographic Location dummy variables, Recent Cognitive Decline, BPSD and Caregiver Distress) had changes in their beta coefficients of greater than 20 percent indicating that Recent Decline in Behaviour was providing needed adjustment in the model (Hosmer et al., 2013). Therefore, the variable was added back into the model.
All six continuous variables were then tested to verify the assumption was met related to of linearity in the logit. Using the Box-Tidwell approach, three variables (Age, ADL Assistance Required and Cognitive Status) were found to violate the assumption requiring these variables to be categorized. Age was categorized into young-old (65-74), middle-old (75-84) and old-old (over 85), aligning with age sub-group definitions utilized by the Canadian Institute of Health Information (CIHI, 2011). ADL Assistance Required was dichotomized with response options (0) no physical assistance required (ADLH = 2 or less) versus (1) any physical assistance required (ADLH = 3 or more), to account for increased caregiving demands brought on by the need for physical assistance. Cognitive status was also dichotomized with response options (0) intact to mild impairment and (1) moderate to severe impairment. Although the third health index variable, IADL Assistance Required, was not found to violate the linearity in the logit assumption, for ease of interpretation, this variable was also dichotomized. Response options for the new IADL Assistance Required variable included: (0) dependent in 2 IADLs or less (IADLH = 0 to 4) versus (1) dependent in 3 or more IADLs (IADLH = 5 to 6). The cut-off value of 5 on the IADL Hierarchy Scale was chosen to differentiate between those requiring assistance with physical IADLs (shopping, housework, meal preparation) versus those requiring assistance with both physical and cognitive IADLs (managing finances, managing medications). Care needs for IADLs has been found to be progressive, moving from primarily assistance with physical tasks to assistance with cognitive tasks (Morris et al., 2013).

The final model was fit with 43 predictor variables. All 43 variables were significant at the traditional level of significance ($p <0.05$). Full model results are available in Appendix B. To assess model fit, a series of binary models were fit comparing each latent class with all other patterns. Receiver Operating Characteristics (ROC) curves were generated for each binary model. All binary models demonstrated acceptable model fit (Hosmer et al., 2013). Model fit statistics are summarized in Table 17.
Table 17: Multinomial logistic regression model fit statistics

<table>
<thead>
<tr>
<th>Model Comparison</th>
<th>Area under the ROC curve</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Support vs. all other patterns</td>
<td>0.7406</td>
</tr>
<tr>
<td>ED Users vs. all other patterns</td>
<td>0.7371</td>
</tr>
<tr>
<td>High Informal Care vs. all other patterns</td>
<td>0.7866</td>
</tr>
<tr>
<td>Community-Based Therapy vs. all other patterns</td>
<td>0.7174</td>
</tr>
<tr>
<td>Well HCBS Service Users vs. all other patterns</td>
<td>0.7236</td>
</tr>
<tr>
<td>Frail HCBS Service Users vs. all other patterns</td>
<td>0.8337</td>
</tr>
<tr>
<td>High Users vs. all other patterns</td>
<td>0.7279</td>
</tr>
</tbody>
</table>

*Note: ED = Emergency Department; HCBS = Home and Community-Based Support; ROC = Receiver Operating Characteristic Curve*

4.3.2 Comparing the Impact of Patient and Caregiver Characteristics across Classes

Eight patient and caregiver characteristics were found to significantly influence membership in all six classes when compared with the Low Support class. Five factors increased the odds of class membership in a class (compared to the Low Support class) including: requiring assistance with 3 or more IADLs, requiring any physical assistance with ADLs, moderate to severe cognitive impairment, bladder incontinence and bowel incontinence. Additionally, when compared with living in Health Region 4, receiving care in Health Region 7 or Health Region 9, decreased the odds of being in any of the classes receiving formal care or high levels of informal care. The remaining variable, living alone, had mixed effects on class membership, increasing the odds of being in the Well HCBS, Frail HCBS or High User classes, and decreasing the odds of membership in the ED User, High Informal or Community-Based Therapy classes. Using Low Support as the reference class, odds ratios for each predictor of class membership are reported for the full multinomial logistic regression model in Table 18.
Table 18: Full multinomial logistic regression model results: Odds ratios

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Emergency Department</th>
<th>High Informal Care</th>
<th>CB Therapy</th>
<th>Well HCBS Support</th>
<th>Frail HCBS Support</th>
<th>High Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>65 to 84</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
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<td>75 to 84</td>
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<td>1.38</td>
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<td>0.69</td>
<td>1.63</td>
<td>2.11</td>
<td>1.65</td>
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<td>Sex:</td>
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<tr>
<td>Male</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
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<td>1.11</td>
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<tr>
<td>Elementary or less</td>
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<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
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<td>1.32</td>
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<td>1.04</td>
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<td>ref</td>
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<td>ref</td>
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<td>Child</td>
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<td>0.77</td>
<td>0.69</td>
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<tr>
<td>Health Region 1</td>
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<td>0.77</td>
<td>0.32</td>
<td>0.96</td>
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<td>0.50</td>
<td>1.01</td>
<td>1.43</td>
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<td>0.94</td>
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<td>1.27</td>
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<td>0.99</td>
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<tr>
<td>Health Region 4</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
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<td>1.71</td>
<td>1.22</td>
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<td>0.97</td>
<td>0.90</td>
<td>1.35</td>
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<tr>
<td>Health Region 7</td>
<td>0.65</td>
<td>0.58</td>
<td>0.42</td>
<td>0.66</td>
<td>0.41</td>
<td>0.35</td>
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<td>Health Region 8</td>
<td>0.69</td>
<td>0.90</td>
<td>0.50</td>
<td>0.69</td>
<td>0.66</td>
<td>0.37</td>
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<td>0.64</td>
<td>0.53</td>
<td>0.31</td>
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<td>Health Region 10</td>
<td>1.19</td>
<td>1.03</td>
<td>0.54</td>
<td>1.66</td>
<td>1.62</td>
<td>0.96</td>
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<td>Health Region 11</td>
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<td>1.37</td>
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<td>1.63</td>
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<td>1.07</td>
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<td>0.40</td>
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<td>0.45</td>
<td>1.89</td>
<td>0.80</td>
<td>0.78</td>
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</tbody>
</table>

**Bolded** odds ratios are significant at *p*<0.05, ref = reference category; *CB* = community-based; *HCBS* = home and community-based support support.
<table>
<thead>
<tr>
<th>Predictor</th>
<th>Emergency Department</th>
<th>High Informal Care</th>
<th>CB Therapy</th>
<th>Well HCBS Support</th>
<th>Frail HCBS Support</th>
<th>High Users</th>
</tr>
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<tbody>
<tr>
<td>Living arrangement:</td>
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<tr>
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<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
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<tr>
<td>Alone</td>
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<td>0.32</td>
<td>2.29</td>
<td>4.49</td>
<td>1.86</td>
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<tr>
<td>Urban</td>
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<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
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<td>Rural</td>
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<td>0.81</td>
<td>0.70</td>
<td>0.92</td>
<td>0.57</td>
<td>0.69</td>
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<td>IADL Assistance Required:</td>
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<tr>
<td>Requires assistance with 3 IADLs or less</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>Requires assistance with more than 3 IADLs</td>
<td>1.95</td>
<td>2.15</td>
<td>1.53</td>
<td>2.42</td>
<td>3.32</td>
<td>2.52</td>
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<tr>
<td>Independent to supervision only</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
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<td>Any physical assistance required</td>
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<td>1.67</td>
<td>2.17</td>
<td>1.61</td>
<td>1.88</td>
<td>2.20</td>
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<tr>
<td>Recent ADL Decline</td>
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<td></td>
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<td></td>
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<tr>
<td>No recent decline in ADL status</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>Decline in ADL status in past 90 days</td>
<td>0.92</td>
<td>0.96</td>
<td>1.19</td>
<td>0.98</td>
<td>0.92</td>
<td>1.32</td>
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<tr>
<td>Number of Comorbidities</td>
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<td>0.99</td>
<td>1.06</td>
<td>0.99</td>
<td>1.00</td>
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<tr>
<td>Intact to Mild</td>
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<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
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<tr>
<td>Moderate to Severe</td>
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<td>1.80</td>
<td>1.41</td>
<td>1.28</td>
<td>1.36</td>
<td>1.38</td>
</tr>
<tr>
<td>Recent Cognitive Decline</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No recent cognitive decline</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>Decline in decision-making or communication in past 90 days</td>
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<td>1.16</td>
<td>1.00</td>
<td>1.00</td>
<td>0.91</td>
<td>0.99</td>
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<td>Other dementia</td>
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<tr>
<td>Less than 5 medications</td>
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<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
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<tr>
<td>5 to 8 medications</td>
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<td>1.31</td>
<td>1.14</td>
<td>1.36</td>
<td>1.03</td>
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<tr>
<td>Greater than 8 medications</td>
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<td>0.94</td>
<td>1.22</td>
<td>1.27</td>
<td>1.82</td>
<td>1.12</td>
</tr>
</tbody>
</table>

**Bolded** odds ratios are significant at $p < 0.05$, ref = reference category; CB = community-based; HCBS = home and community-based support; IADL = instrumental activities of daily living; ADL = activities of daily living.
<table>
<thead>
<tr>
<th>Predictor</th>
<th>Emergency Department</th>
<th>High Informal Care</th>
<th>CB Therapy</th>
<th>Well HCBS Support</th>
<th>Frail HCBS Support</th>
<th>High Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychotropic Medication Use</td>
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<td></td>
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<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
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<td>Taking any psychotropic medications</td>
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<td>0.92</td>
<td>0.93</td>
<td>1.09</td>
<td>1.25</td>
<td>1.12</td>
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<td>BPSD</td>
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<tr>
<td>No reported BPSD</td>
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<td>ref</td>
<td>ref</td>
<td>ref</td>
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<tr>
<td>Any reported BPSD</td>
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<td>1.02</td>
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<td>ref</td>
<td>ref</td>
<td>ref</td>
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<td>0.76</td>
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<td>0.69</td>
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<td>Continence:</td>
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<td>ref</td>
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<td>Bladder incontinence</td>
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<td>1.60</td>
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<td>Bowel incontinence</td>
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<td>1.40</td>
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<td>1.66</td>
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<tr>
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<tr>
<td>1 or more falls in past 90 days</td>
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<td>1.50</td>
<td>1.05</td>
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<td>Presence of daily pain</td>
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<td><strong>0.83</strong></td>
<td><strong>0.84</strong></td>
<td>0.94</td>
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<td>Recent Emergency Department Use</td>
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<tr>
<td>No recent ED visits</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>1 or more ED visits in past 90 days</td>
<td><strong>1.24</strong></td>
<td>0.96</td>
<td><strong>1.25</strong></td>
<td>1.06</td>
<td>1.05</td>
<td>1.26</td>
</tr>
<tr>
<td>Recent Hospital Admission</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No recent hospital admissions</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>1 or more hospital admissions in past 90 days</td>
<td><strong>1.37</strong></td>
<td>0.75</td>
<td><strong>1.42</strong></td>
<td><strong>0.85</strong></td>
<td>0.99</td>
<td><strong>1.46</strong></td>
</tr>
<tr>
<td>Caregiver Distress</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No caregiver distress reported</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>Caregiver distress reported</td>
<td><strong>1.27</strong></td>
<td><strong>1.34</strong></td>
<td><strong>1.30</strong></td>
<td>0.95</td>
<td><strong>0.76</strong></td>
<td>1.20</td>
</tr>
<tr>
<td>Caregiver Commitment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Committed to current living arrangement</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
<td>ref</td>
</tr>
<tr>
<td>Considering alternate living arrangement</td>
<td><strong>0.68</strong></td>
<td><strong>0.88</strong></td>
<td><strong>0.63</strong></td>
<td><strong>1.15</strong></td>
<td><strong>1.32</strong></td>
<td>1.18</td>
</tr>
</tbody>
</table>

**Bolded** odds ratios are significant at \( p < 0.05 \), ref = reference category; \( CB \) = community-based; \( HCBS \) = home and community-based support; \( BPSD \) = behavioural and psychological symptoms of dementia; \( ED \) = emergency department.
4.3.3 Impact of Patient and Caregiver Characteristics on Class Membership

In this section, findings related to the impact of patient and caregiver characteristics are examined by service utilization pattern. Significant predictors of each pattern are reported and the impact of each predictor on class membership is discussed.

4.3.3.1 Emergency Department Users vs. Low Support

Those individuals in the Emergency Department (ED) User class have a low probability of accessing any community-based health services other than the emergency department and have a high probability of receiving high levels of informal care. Twenty-one patient and caregiver characteristics significantly impacted membership in the ED User class when compared with the Low Support class. These characteristics, organized by direction of impact (those increasing likelihood of class membership and those decreasing likelihood of class membership), are summarized in Tables 19 and 20 and described in detail below. Four of the five characteristics with the strongest impact on membership in this class were need factors which increased the likelihood of class membership. The fifth factor, living alone, decreased the likelihood of belonging to the ED User class.

Ten patient and caregiver characteristics increased the odds of membership in the ED User class versus the Low Support class. Those patients with greater functional and cognitive impairments were more likely to be members of the ED User class. For example, patients requiring physical assistance with ADLs had approximately 3 times greater odds of being in the ED User class than those who were independent or only required set-up help. Furthermore, patients with moderate to severe cognitive impairment were 1.93 times as likely to be members of the ED User class as those with mild to no cognitive impairment. Previous health service and medical conditions use also increased the odds of membership in this class. Those patients with any hospital admissions in the past 90 days had 1.37 greater odds of being in the ED user class as those with no admissions, while those who visited the ED in the past 90 days had 1.24 greater odds of being in the ED user class as those with no previous ED visits. Finally, for each additional comorbidity documented, the odds of being in the ED User class versus the
"Low Support" class increased by 11%. In Table 19, all 10 patient and caregiver characteristics found to be increase the probability of membership in the ED User class are summarized with odds ratios and 95% confidence intervals reported.

Table 19: Patient and caregiver characteristics increasing odds of membership in ED User class

<table>
<thead>
<tr>
<th>Patient and Caregiver Characteristics</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical assistance required with ADLs</td>
<td>2.99</td>
<td>2.62 - 3.41</td>
</tr>
<tr>
<td>Requires assistance with more than 3 IADLs</td>
<td>1.95</td>
<td>1.69 – 2.26</td>
</tr>
<tr>
<td>Moderate to severe cognitive impairment</td>
<td>1.94</td>
<td>1.70 – 2.20</td>
</tr>
<tr>
<td>Bowel incontinence</td>
<td>1.93</td>
<td>1.67 – 2.23</td>
</tr>
<tr>
<td>Geographic Location: Health Region 13</td>
<td>1.68</td>
<td>1.32 – 2.14</td>
</tr>
<tr>
<td>Recent hospitalizations</td>
<td>1.37</td>
<td>1.19 – 1.56</td>
</tr>
<tr>
<td>Caregiver distress</td>
<td>1.27</td>
<td>1.12 – 1.43</td>
</tr>
<tr>
<td>Bladder incontinence</td>
<td>1.26</td>
<td>1.11 – 1.44</td>
</tr>
<tr>
<td>Recent ED visits</td>
<td>1.24</td>
<td>1.07 – 1.42</td>
</tr>
<tr>
<td>Comorbidities</td>
<td>1.11</td>
<td>1.08 – 1.14</td>
</tr>
</tbody>
</table>

*Note: ADLs = activities of daily living; IADLs = instrumental activities of daily living; ED = emergency department*

Eleven patient and caregiver characteristics were identified as decreasing the odds of membership in the ED User class, with ten of the eleven characteristics being predisposing and enabling factors. The characteristic with the largest negative impact on class membership was living alone. Those seniors with dementia who were living alone were 0.25 times as likely to be in the ED User class compared with those living with a caregiver. In other words, those living with a caregiver were 4 times as likely to be in the ED User class as those living alone. In addition to who the patient lived with, where the patient lived also had an impact on membership in the ED User class. Four of eleven factors decreasing membership in the ED User class were related to the location of care delivery. Compared with those receiving care in Health Region 4, patients receiving care in Health Regions 7, 8, 9 and 11 were less likely to be members of the ED User class than the Low Support class. Table 20 summarizes the odds ratio and 95% confidence intervals for all factors which significantly decreased the likelihood of membership in the ED User class compared with the Low Support class.
### Table 20: Patient and caregiver characteristics decreasing odds of membership in *ED User* class

<table>
<thead>
<tr>
<th>Patient and Caregiver Factors</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living arrangement: Alone</td>
<td>0.25</td>
<td>0.21 – 0.29</td>
</tr>
<tr>
<td>Caregiver Relationship: Other</td>
<td>0.59</td>
<td>0.47 – 0.73</td>
</tr>
<tr>
<td>Geographic location: Health Region 9</td>
<td>0.63</td>
<td>0.52 – 0.77</td>
</tr>
<tr>
<td>Geographic location: Health Region 7</td>
<td>0.65</td>
<td>0.51 – 0.82</td>
</tr>
<tr>
<td>Caregiver considering alternate living arrangement</td>
<td>0.68</td>
<td>0.60 – 0.77</td>
</tr>
<tr>
<td>Geographic location: Health Region 8</td>
<td>0.69</td>
<td>0.56 – 0.86</td>
</tr>
<tr>
<td>Education: Unknown</td>
<td>0.69</td>
<td>0.58 – 0.83</td>
</tr>
<tr>
<td>Caregiver Relationship: Child caregiver</td>
<td>0.76</td>
<td>0.67 – 0.88</td>
</tr>
<tr>
<td>Geographic Location: Health Region 11</td>
<td>0.78</td>
<td>0.63 – 0.97</td>
</tr>
<tr>
<td>Education: Any post-secondary</td>
<td>0.86</td>
<td>0.74 – 0.99</td>
</tr>
<tr>
<td>Sex: Female</td>
<td>0.87</td>
<td>0.77 – 0.98</td>
</tr>
</tbody>
</table>

#### 4.3.3.2 High Informal Care vs. Low Support

Individuals in the *High Informal Care* class are unlikely to utilize formal home and community based support services, instead relying heavily on informal care givers. Members of this group may also be utilizing respite services. Twenty-five patient and caregiver characteristics were found to be significant predictors of membership in the *High Informal Care* class when compared with the *Low Support* class. These characteristics, organized by direction of impact (those increasing likelihood of class membership and those decreasing likelihood of class membership), are summarized in Tables 21 and 22 and described in detail below. The top five most influential characteristics comprised a combination of functional, cognitive and social needs. As would be expected, living arrangement had the largest impact on membership in this class.

Eleven patient and caregiver characteristics increased the odds of membership in the *High Informal Care* class versus the *Low Support* class. Care needs influencing membership in this class were more functional, cognitive and behavioural rather than medical in nature. Requiring assistance with more than 3 IADLs increased the odds of belonging to the *High Informal Care* class by 2.15 times over those requiring help with 3 IADLs or less. Similarly, requiring physical assistance with ADLs increased the odds of class membership by 1.67 times over those who are independent or require set up help.
with ADLs. Both bladder incontinence and bowel incontinence also increased the likelihood of class membership by approximately 1.2 times over those who reported being continent. Cognitively, those with moderate to severe cognitive impairment were 1.8 times as likely to be in the High Informal Care class as those with mild cognitive impairment or less. Additionally, having any reported behavioural and psychological symptoms of dementia increased the odds of membership in this class by 1.27 times over those with no reported behavioural symptoms. Table 21 summarizes all patient and caregiver characteristics (including odds ratio and 95% confidence interval) found to be significant predictors of the High Informal Care class.

Table 21: Patient and caregiver characteristics increasing odds of membership in High Informal Care class

<table>
<thead>
<tr>
<th>Patient and Caregiver Characteristics</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requires assistance with more than 3 IADLs</td>
<td>2.15</td>
<td>1.96-2.36</td>
</tr>
<tr>
<td>Moderate to severe cognitive impairment</td>
<td>1.80</td>
<td>1.63-1.98</td>
</tr>
<tr>
<td>Physical assistance required with ADLs</td>
<td>1.67</td>
<td>1.51-1.86</td>
</tr>
<tr>
<td>Geographic location: Health Region 5</td>
<td>1.65</td>
<td>1.25-2.19</td>
</tr>
<tr>
<td>Geographic location: Health Region 13</td>
<td>1.39</td>
<td>1.15-1.68</td>
</tr>
<tr>
<td>Caregiver distress</td>
<td>1.34</td>
<td>1.22-1.47</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>1.29</td>
<td>1.19-1.40</td>
</tr>
<tr>
<td>Any reported BPSD</td>
<td>1.27</td>
<td>1.17-1.38</td>
</tr>
<tr>
<td>Bladder incontinence</td>
<td>1.24</td>
<td>1.13-1.36</td>
</tr>
<tr>
<td>Bowel incontinence</td>
<td>1.23</td>
<td>1.10-1.38</td>
</tr>
<tr>
<td>Recent cognitive decline</td>
<td>1.16</td>
<td>1.07-1.27</td>
</tr>
</tbody>
</table>

Note: IADL = instrumental activities of daily living; ADLs = activities of daily living; BPSD = behavioural and psychological symptoms of dementia

Living arrangement had the largest impact on membership in this class, with those living with a caregiver being 6.5 times as likely to be in the High Informal Care class as those who live alone. Five out of the fourteen significant factors decreasing membership in the High Informal Care class were related to the location of care delivery. Those living in urban locations were 1.23 times as likely to belong to the High Informal Care class as those living in rural locations. Additionally, compared with patients receiving care in Health Region 4, patients receiving care in Health Regions 1, 2, 7 and 9 were less likely to be in the High Informal Care class. Other factors decreasing the odds of membership
in the *High Informal Care* class included having a caregiver other than a spouse or child, being in the middle-old or old-old age subgroups, or having been admitted to hospital in the past 90 days. All factors impacting the odds of membership in the *High Informal Care* class are summarized in Table 22.

**Table 22: Patient and caregiver characteristics decreasing odds of membership in *High Informal Care* class**

<table>
<thead>
<tr>
<th>Patient and Caregiver Characteristics</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lives alone</td>
<td>0.15</td>
<td>0.14-0.17</td>
</tr>
<tr>
<td>Other caregiver</td>
<td>0.50</td>
<td>0.43-0.59</td>
</tr>
<tr>
<td>Geographic location: Health Region 7</td>
<td>0.58</td>
<td>0.49-0.69</td>
</tr>
<tr>
<td>Geographic location: Health Region 9</td>
<td>0.68</td>
<td>0.59-0.79</td>
</tr>
<tr>
<td>Age: Greater than 85</td>
<td>0.71</td>
<td>0.62-0.81</td>
</tr>
<tr>
<td>Recent hospitalizations</td>
<td>0.75</td>
<td>0.67-0.83</td>
</tr>
<tr>
<td>Geographic location: Health Region 1</td>
<td>0.77</td>
<td>0.64-0.93</td>
</tr>
<tr>
<td>Education: Unknown</td>
<td>0.79</td>
<td>0.70-0.90</td>
</tr>
<tr>
<td>Age: 75 to 84</td>
<td>0.81</td>
<td>0.71-0.92</td>
</tr>
<tr>
<td>Rural</td>
<td>0.81</td>
<td>0.72-0.91</td>
</tr>
<tr>
<td>Geographic location: Health Region 2</td>
<td>0.84</td>
<td>0.72-0.99</td>
</tr>
<tr>
<td>Decline in behaviour</td>
<td>0.86</td>
<td>0.76-0.98</td>
</tr>
<tr>
<td>Female</td>
<td>0.88</td>
<td>0.80-0.96</td>
</tr>
<tr>
<td>Caregiver considering alternate living arrangement</td>
<td>0.88</td>
<td>0.80-0.96</td>
</tr>
</tbody>
</table>

**4.3.3.3 Community-Based Therapy vs. Low Support**

Members of the *Community-Based Therapy* class are more likely to receive physiotherapy and occupational therapy than the sample as a whole. This group also has a high likelihood of receiving extensive informal care, visiting the emergency department and a moderate probability of receiving personal care services. Thirty-two patient and caregiver characteristics significantly impacted membership in the *Community-Based Therapy* class when compared with the *Low Support* class. These characteristics, organized by direction of impact (those increasing likelihood of class membership and those decreasing likelihood of class membership), are summarized in Tables 23 and 24 and described in detail below. Factors with the greatest impact on membership in this class included living arrangement and geographic location of care.
Fourteen patient and caregiver characteristics increased the odds of membership in the *Community-Based Therapy* class versus the *Low Support* class. Functional characteristics impacting membership in the *Community-Based Therapy* included assistance with ADLs, assistance with IADLs, recent falls, incontinence and a recent decline in ADL ability. Patients requiring physical assistance to complete ADLs were approximately 2.2 times as likely to be in the *Community-Based Therapy* class as those who did not need help or only required supervision. Those requiring assistance with more than 3 IADLs were 1.5 times as likely to be in this class as those requiring assistance with 3 IADLs or less. Recent documented falls had a similar impact on class membership, increasing the likelihood of class membership by 1.5 times over those with no reported falls.

Increasing medical complexity also impacted membership in this class. Polypharmacy, recent emergency department visits and hospital admissions as well as the number of documented comorbidities all increased the likelihood of membership in the *Community-Based Therapy* class over the *Low Support* class. Patients discharged from hospital in the past 90 days were 1.4 times as likely to be in the *Community-Based Therapy* class as those with no recent hospital admissions. Additionally, patients taking between five and eight medications were 1.31 times as likely to be in this class as those taking less than five medications. Related to this, each additional documented comorbidity increased the likelihood of class membership by 6%.

**Table 23: Patient and caregiver characteristics increasing odds of membership in *Community-Based Therapy* class**
<table>
<thead>
<tr>
<th>Patient and Caregiver Characteristics</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical assistance required with ADLs</td>
<td>2.17</td>
<td>1.86-2.53</td>
</tr>
<tr>
<td>Geographic location: Health Region 5</td>
<td>1.71</td>
<td>1.20-2.45</td>
</tr>
<tr>
<td>Requires assistance with more than 3 IADLs</td>
<td>1.53</td>
<td>1.30-1.79</td>
</tr>
<tr>
<td>Recent falls</td>
<td>1.50</td>
<td>1.31-1.71</td>
</tr>
<tr>
<td>Recent hospitalizations</td>
<td>1.42</td>
<td>1.22-1.65</td>
</tr>
<tr>
<td>Moderate to severe cognitive impairment</td>
<td>1.41</td>
<td>1.21-1.64</td>
</tr>
<tr>
<td>Bowel incontinence</td>
<td>1.40</td>
<td>1.18-1.66</td>
</tr>
<tr>
<td>Five to eight medications</td>
<td>1.31</td>
<td>1.09-1.57</td>
</tr>
<tr>
<td>Caregiver distress</td>
<td>1.30</td>
<td>1.13-1.50</td>
</tr>
<tr>
<td>Recent ED visits</td>
<td>1.25</td>
<td>1.06-1.47</td>
</tr>
<tr>
<td>Any reported BPSD</td>
<td>1.24</td>
<td>1.08-1.42</td>
</tr>
<tr>
<td>Decline in ADL ability</td>
<td>1.19</td>
<td>1.03-1.36</td>
</tr>
<tr>
<td>Bladder incontinence</td>
<td>1.18</td>
<td>1.02-1.37</td>
</tr>
<tr>
<td>Comorbidities</td>
<td>1.06</td>
<td>1.03-1.10</td>
</tr>
</tbody>
</table>

Note: ADLs = activities of daily living; IADLs = instrumental activities of daily living; ED = emergency department; BPSD = behavioural and psychological symptoms of dementia

Cognitive and behavioural factors increasing the odds of membership in this class included level of cognitive impairment as well as behavioural and psychological symptoms of dementia. Those patients with moderate to severe cognitive impairment were 1.4 times as likely to be in the Community-Based Therapy class as those with mild impairment or less. All factors increasing odds of membership in the Community-Based Therapy class are summarized in Table 23, including odds ratios and 95% confidence intervals.

Eighteen characteristics were found to decrease odds of membership in the Community-Based Therapy class when compared with the Low Support class. Region of care had a significant impact on Community-Based Therapy class membership. Compared with those receiving care in Health Region 4, those receiving care in 10 Health Regions across Ontario were less likely to be members of this class. Several social characteristics also decreased likelihood of class membership including living arrangement, caregiver relationship and caregiver commitment to current living arrangement. Those living with a caregiver were approximately 3.2 times as likely to belong to this class as those living alone. Furthermore, when the primary caregiver was not a spouse, likelihood of
membership in *Community-Based Therapy* decreased. Those with spousal caregivers were 1.3 times as likely to be in the *Community-Based Therapy* class as those with child caregivers and 1.9 times as likely as those with caregivers with another relationship (friend, neighbour, other relative etc.). Finally, the commitment of the primary caregiver to the current living arrangement also impacted class membership. Those patients with caregivers committed to their current living arrangements were 1.6 times as likely to be members of the *Community-Based Therapy* class as those whose caregivers were considering alternate living arrangements. Table 24 reports the odds ratios and confidence intervals for all characteristics decreasing odds of membership in the *Community-Based Therapy* class versus the *Low Support* class.

**Table 24: Patient and caregiver characteristics decreasing odds of membership in *Community-Based Therapy* class**

<table>
<thead>
<tr>
<th>Patient and Caregiver Characteristics</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lives alone</td>
<td>0.32</td>
<td>0.27-0.38</td>
</tr>
<tr>
<td>Geographic Location: Health Region 1</td>
<td>0.32</td>
<td>0.23-0.46</td>
</tr>
<tr>
<td>Geographic Location: Health Region 12</td>
<td>0.35</td>
<td>0.23-0.53</td>
</tr>
<tr>
<td>Geographic Location: Health Region 7</td>
<td>0.42</td>
<td>0.32-0.55</td>
</tr>
<tr>
<td>Geographic Location: Health Region 9</td>
<td>0.43</td>
<td>0.34-0.54</td>
</tr>
<tr>
<td>Geographic Location: Health Region 14</td>
<td>0.45</td>
<td>0.28-0.70</td>
</tr>
<tr>
<td>Geographic Location: Health Region 13</td>
<td>0.46</td>
<td>0.32-0.65</td>
</tr>
<tr>
<td>Geographic Location: Health Region 11</td>
<td>0.46</td>
<td>0.36-0.60</td>
</tr>
<tr>
<td>Geographic Location: Health Region 2</td>
<td>0.50</td>
<td>0.38-0.65</td>
</tr>
<tr>
<td>Geographic Location: Health Region 8</td>
<td>0.50</td>
<td>0.39-0.65</td>
</tr>
<tr>
<td>Other caregiver</td>
<td>0.53</td>
<td>0.40-0.69</td>
</tr>
<tr>
<td>Geographic Location: Health Region 10</td>
<td>0.54</td>
<td>0.37-0.79</td>
</tr>
<tr>
<td>Caregiver considering alternate living arrangement</td>
<td>0.63</td>
<td>0.54-0.73</td>
</tr>
<tr>
<td>Age: Greater than 85</td>
<td>0.69</td>
<td>0.56-0.84</td>
</tr>
<tr>
<td>Rural</td>
<td>0.70</td>
<td>0.56-0.88</td>
</tr>
<tr>
<td>Decline in behaviour</td>
<td>0.76</td>
<td>0.62-0.94</td>
</tr>
<tr>
<td>Age: 75 to 84</td>
<td>0.76</td>
<td>0.63-0.92</td>
</tr>
<tr>
<td>Child caregiver</td>
<td>0.77</td>
<td>0.65-0.90</td>
</tr>
</tbody>
</table>
4.3.3.4 Well Home and Community-Based Support Service User vs. Low Support

Members of the Well Home and Community-Based Support (HCBS) Service User class are characterized by higher probabilities of using services which support instrumental activities of daily living. Members of this class also frequently utilized personal care services. Twenty-five characteristics influenced membership in the Well HCBS Service User class versus the Low Support class. These characteristics, organized by direction of impact (those increasing likelihood of class membership and those decreasing likelihood of class membership), are summarized in Tables 25 and 26 and described in detail below. Key characteristics influencing membership in this class included functional status measures (assistance with IADLs and ADLs), living arrangement and geographical location.

Patients requiring assistance with more than 3 IADLs were 2.4 times as likely to be in the Well HCBS Service User class as those requiring assistance with 3 IADLs or less. Those requiring assistance with more than 3 IADLs are more likely to require assistance with physical IADLs such as shopping, housework, and meal prep (Morris et al., 2013), tasks readily addressed by HCBS services. Living alone also had a strong impact on class membership. Those patients living alone were 2.3 times as likely to belong to the Well HCBS Service User class as those who lives with a caregiver. Other functional and health status measures increasing the likelihood of membership in this class included requiring physical assistance with ADLs, continence and polypharmacy. Those requiring physical assistance with ADLs were 1.6 times as likely to belong to this class as those who require set-up help or less. Compared with those who reported being continent, those reporting either bladder or bowel incontinence were approximately 1.3 times as likely to be in the Well HCBS Service User class. Table 25 provides the odds ratios and confidence intervals of all eighteen patient and caregiver characteristics which increased the odds of belonging to the Well HCBS Service User class versus the Low Support class.

Table 25: Patient and caregiver characteristics increasing odds of membership in Well HCBS Service User class
Patient and Caregiver Characteristics | Odds Ratio | 95% Confidence Interval
--- | --- | ---
Requires assistance with more than 3 IADLs | **2.42** | 2.18-2.70
Lives alone | **2.29** | 2.02-2.59
Geographic Location: Health Region 14 | **1.89** | 1.47-2.45
Geographic Location: Health Region 10 | **1.66** | 1.32-2.10
Age: Greater than 85 | **1.63** | 1.37-1.93
Physical assistance required with ADLs | **1.61** | 1.42-1.81
Education: Any post-secondary | **1.49** | 1.32-1.70
Geographic Location: Health Region 13 | **1.40** | 1.14-1.73
Geographic Location: Health Region 11 | **1.37** | 1.15-1.62
Education: High school | **1.32** | 1.18-1.48
Bowel incontinence | **1.29** | 1.14-1.47
Bladder incontinence | **1.28** | 1.12-1.42
Moderate to severe cognitive impairment | **1.28** | 1.13-1.43
More than 8 medications | **1.27** | 1.11-1.46
Geographic Location: Health Region 3 | **1.27** | 1.05-1.54
Age: 75 to 84 | **1.25** | 1.06-1.48
Caregiver considering alternate living arrangement | **1.15** | 1.04-1.27
Female | **1.11** | 1.01-1.23

Note: IADL = instrumental activities of daily living; ADL = activities of daily living

Seven characteristics decreased the odds of membership in the Well HCBS Service User class over the Low Support class. Location of care impacted class membership with those receiving care in Health Regions 7, 8 and 11 being less likely to belong to this class than those receiving care in Health Region 4. Additionally, patients whose primary caregiver was a spouse were 1.4 times as likely to belong to this class as those whose primary caregiver was a child. Finally, three characteristics indicating medical complexity or changes in health status decreased the odds of membership in the Well HCBS Service User class, including recent decline in behaviour, daily pain, and recent hospitalizations. Odds ratios and confidence intervals of all characteristics decreasing odds of membership in the Well HCBS Service User class are outlined in Table 26.
Table 26: Patient and caregiver characteristics decreasing odds of membership in Well HCBS Service User class

<table>
<thead>
<tr>
<th>Patient and Caregiver Characteristics</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geographic Location: Health Region 9</td>
<td>0.64</td>
<td>0.54-0.76</td>
</tr>
<tr>
<td>Geographic Location: Health Region 7</td>
<td>0.66</td>
<td>0.54-0.80</td>
</tr>
<tr>
<td>Geographic Location: Health Region 8</td>
<td>0.69</td>
<td>0.57-0.84</td>
</tr>
<tr>
<td>Child caregiver</td>
<td>0.69</td>
<td>0.60-0.80</td>
</tr>
<tr>
<td>Decline in behaviour</td>
<td>0.82</td>
<td>0.71-0.96</td>
</tr>
<tr>
<td>Daily pain</td>
<td>0.83</td>
<td>0.76-0.92</td>
</tr>
<tr>
<td>Recent hospitalizations</td>
<td>0.85</td>
<td>0.75-0.96</td>
</tr>
</tbody>
</table>

4.3.3.5 Frail Home and Community-Based Support Service Users vs. Low Support

In addition to having a high likelihood of receiving in-home supportive services (personal care, homemaking, and meal delivery services), members of the Frail Home and Community-Based Support (HCBS) Service Users class had a high probability of receiving nursing services in the community. Members of this class were also likely to access the emergency department. A total of 28 patient and caregiver characteristics were found to impact the odds of membership in the Frail HCBS Service Users class when compared with the Low Support class. These characteristics, organized by direction of impact (those increasing likelihood of class membership and those decreasing likelihood of class membership), are summarized in Tables 27 and 28 and described in detail below. Characteristics with the greatest impact on membership in the Frail HCBS Services User class included living arrangement, functional status, age, polypharmacy and location of care.

Twenty patient and caregiver characteristics increased the odds of membership in the Frail HCBS Service User class. Patients living alone were 4.5 times as likely as those living with caregivers to be members of the Frail HCBS Service User class. Additionally, reduced functional abilities in both IADLs and ADLs increased the likelihood of membership in this class. Those requiring assistance with more than 3 IADLs were 3.3 times as likely to be members of the Frail HCBS Service User class. Patients requiring physical assistance with ADLs were 1.9 times as likely to be members as those who required help with set-up or supervision only. As age increased, the odds of class
membership also increased. When compared to the young-old subgroup (65 to 74 years old), the old-old subgroup (85 years and older) were 2.1 times as likely to be members of the *Frail HCBS Service User* class, while the middle-old subgroup (75 to 84 years old) were 1.6 times as likely to be members. Other patient and caregiver characteristics increasing odds of class membership included location of care, education level, severity of cognitive impairment, incontinence, polypharmacy and psychotropic medication use. Odds ratios and confidence intervals of all characteristics increasing odds of membership in the *Frail HCBS Service User* class are reported in Table 27.

**Table 27: Patient and caregiver characteristics increasing odds of membership in the *Frail HCBS Service User* class**

<table>
<thead>
<tr>
<th>Patient and Caregiver Characteristics</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lives alone</td>
<td><strong>4.49</strong></td>
<td>3.88-5.20</td>
</tr>
<tr>
<td>Requires assistance with more than 3 IADLs</td>
<td><strong>3.32</strong></td>
<td>2.95-3.75</td>
</tr>
<tr>
<td>Geographic Location: Health Region 11</td>
<td><strong>2.53</strong></td>
<td>2.12-3.00</td>
</tr>
<tr>
<td>Geographic Location: Health Region 1</td>
<td><strong>2.17</strong></td>
<td>1.77-2.66</td>
</tr>
<tr>
<td>Age: Greater than 85</td>
<td><strong>2.11</strong></td>
<td>1.73-2.58</td>
</tr>
<tr>
<td>Physical assistance required with ADLs</td>
<td><strong>1.88</strong></td>
<td>1.66-2.13</td>
</tr>
<tr>
<td>More than 8 medications</td>
<td><strong>1.82</strong></td>
<td>1.57-2.12</td>
</tr>
<tr>
<td>Education: Any post-secondary</td>
<td><strong>1.81</strong></td>
<td>1.81-1.57</td>
</tr>
<tr>
<td>Geographic Location: Health Region 10</td>
<td><strong>1.62</strong></td>
<td>1.25-2.10</td>
</tr>
<tr>
<td>Age: 75 to 84</td>
<td><strong>1.58</strong></td>
<td>1.29-1.92</td>
</tr>
<tr>
<td>Geographic Location: Health Region 3</td>
<td><strong>1.54</strong></td>
<td>1.26-1.88</td>
</tr>
<tr>
<td>Education: High school</td>
<td><strong>1.46</strong></td>
<td>1.29-1.66</td>
</tr>
<tr>
<td>Geographic Location: Health Region 2</td>
<td><strong>1.43</strong></td>
<td>1.17-1.75</td>
</tr>
<tr>
<td>Moderate to severe cognitive impairment</td>
<td><strong>1.36</strong></td>
<td>1.20-1.54</td>
</tr>
<tr>
<td>Five to eight medications</td>
<td><strong>1.36</strong></td>
<td>1.18-1.57</td>
</tr>
<tr>
<td>Caregiver considering alternate living arrangements</td>
<td><strong>1.32</strong></td>
<td>1.19-1.47</td>
</tr>
<tr>
<td>Education: Unknown</td>
<td><strong>1.30</strong></td>
<td>1.11-1.52</td>
</tr>
<tr>
<td>Taking psychotropic medication(s)</td>
<td><strong>1.25</strong></td>
<td>1.13-1.38</td>
</tr>
<tr>
<td>Bladder incontinence</td>
<td><strong>1.23</strong></td>
<td>1.10-1.37</td>
</tr>
<tr>
<td>Bowel incontinence</td>
<td><strong>1.18</strong></td>
<td>1.03-1.36</td>
</tr>
</tbody>
</table>

*Note: IADL = instrumental activities of daily living; ADLs = activities of daily living*

More than half of the characteristics decreasing the odds of membership in the *Frail HCBS Service User* class were related to the region where care was provided. Compared
with those living in the Health Region 4, patients living in Health Regions 5, 7, 8, and 9 were less likely to be in the *Frail HCBS Service User* class. Additionally, those living in urban areas were 1.8 times as likely to be in this class as those living in rural areas. Other characteristics decreasing odds of membership in the *Frail HCBS Service User* class included caregiver distress, caregiver relationship and the presence of daily pain. Table 28 provides the odds ratios and confidence intervals for all characteristics decreasing odds of membership in the *Frail HCBS Service User* class.

**Table 28: Patient and caregiver characteristics decreasing odds of membership in the *Frail HCBS Service User* class**

<table>
<thead>
<tr>
<th>Patient and Caregiver Characteristics</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geographic Location: Health Region 7</td>
<td>0.41</td>
<td>0.32-0.52</td>
</tr>
<tr>
<td>Geographic Location: Health Region 5</td>
<td>0.49</td>
<td>0.30-0.79</td>
</tr>
<tr>
<td>Geographic Location: Health Region 9</td>
<td>0.53</td>
<td>0.44-0.65</td>
</tr>
<tr>
<td>Rural</td>
<td>0.57</td>
<td>0.48-0.66</td>
</tr>
<tr>
<td>Geographic Location: Health Region 8</td>
<td>0.66</td>
<td>0.53-0.83</td>
</tr>
<tr>
<td>Caregiver distress</td>
<td>0.76</td>
<td>0.67-0.87</td>
</tr>
<tr>
<td>Child caregiver</td>
<td>0.80</td>
<td>0.67-0.95</td>
</tr>
<tr>
<td>Daily pain</td>
<td>0.84</td>
<td>0.75-0.93</td>
</tr>
</tbody>
</table>

### 4.3.3.6 High User vs. Low Support

Members of the *High User* class have an elevated probability of utilizing multiple formal services including HCBS services (homemaking, personal care, meals services) and professional services (nursing, physiotherapy, occupational therapy). These individuals are also likely to visit the emergency department. Twenty-four patient and caregiver characteristics impact the likelihood of membership in the *High User* class when compared to the *Low Support* class. These characteristics, organized by direction of impact (those increasing likelihood of class membership and those decreasing likelihood of class membership), are summarized in Tables 29 and 30 and described in detail below. Location of care has the greatest impact on membership in this class with four of the top five characteristics impacting class membership being regions of care which decrease the likelihood of class membership. The remaining characteristic, receipt of any post-secondary education, increases likelihood of membership in this class. Other important
characteristics impacting membership in the *High User* class included functional status, living arrangement and caregiver relationship.

Fifteen patient and caregiver characteristics increased the odds of membership in the *High User* class. Details of these characteristics, including odds ratio and confidence intervals are included in Table 29. As the highest level of education attained by patients increased, so did the likelihood of membership in the *High User* class. Compared with patients who received an elementary school education, those seniors with any post-secondary education were 2.6 times as likely to be members of this class. Additionally, those with a high school education or whose education status was unknown were 1.5 times as likely to be members. Similar to the other classes with higher levels of support services, those living alone had a higher likelihood of class membership than those living with a caregiver.

Recent health status changes and greater functional needs also increased the odds of membership in the *High User* class. Patients requiring help with more than 3 IADLs were 2.5 times as likely to be members while those requiring physical assistance with ADLs were 2.2 times as likely to be members. Furthermore, a recent decline in one’s ability to complete ADLs increased the odds of class membership by 1.3 times. Characteristics representing more complex care needs such as moderate to severe cognitive impairment, recent hospitalizations, recent falls and additional comorbidities also increased the odds of membership in the *High User* class.

**Table 29: Patient and caregiver characteristics increasing odds of membership in *High User* class**

<table>
<thead>
<tr>
<th>Patient and Caregiver Characteristics</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education: Any post-secondary</td>
<td>2.60</td>
<td>1.96-3.45</td>
</tr>
<tr>
<td>Requires assistance with more than 3 IADLs</td>
<td>2.52</td>
<td>1.91-3.32</td>
</tr>
<tr>
<td>Physical assistance required with ADLs</td>
<td>2.20</td>
<td>1.75-2.77</td>
</tr>
<tr>
<td>Lives alone</td>
<td>1.86</td>
<td>1.42-2.44</td>
</tr>
<tr>
<td>Bowel incontinence</td>
<td>1.66</td>
<td>1.27-2.17</td>
</tr>
<tr>
<td>Age: Greater than 85</td>
<td>1.65</td>
<td>1.12-2.43</td>
</tr>
<tr>
<td>Geographic Location: Health Region 11</td>
<td>1.63</td>
<td>1.20-2.23</td>
</tr>
<tr>
<td>Bladder incontinence</td>
<td>1.60</td>
<td>1.27-2.03</td>
</tr>
</tbody>
</table>
Nine patient and caregiver characteristics decreased the odds of membership in the *High User* class when compared to the *Low Support* class. More than half of these characteristics were related to location of care. When compared with patients living in Health Region 4, seniors with dementia living in Health Regions 5, 7, 8, 9 and 12 were less likely to be members of the *High User* class. Furthermore, those living in urban areas were 1.45 times as likely to be members of this class as those living in rural areas. Caregiver relationship also impacted membership in this class. Those reporting their spouse as their primary caregiver were 1.8 times as likely as those reporting a child caregiver to be in the *High User* class and 1.9 times as likely as those reporting another caregiver (i.e. friend, neighbour, other relative). Odds ratios and confidence intervals for all patient and caregiver characteristics decreasing odds of membership in the High User class are summarized in Table 30.

**Table 30: Patient and caregiver characteristics decreasing odds of membership in *High User* class**

<table>
<thead>
<tr>
<th>Patient and Caregiver Characteristics</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Geographic Location: Health Region 5</td>
<td>0.20</td>
<td>0.05-0.83</td>
</tr>
<tr>
<td>Geographic Location: Health Region 9</td>
<td>0.31</td>
<td>0.20-0.49</td>
</tr>
<tr>
<td>Geographic Location: Health Region 7</td>
<td>0.35</td>
<td>0.22-0.57</td>
</tr>
<tr>
<td>Geographic Location: Health Region 8</td>
<td>0.37</td>
<td>0.23-0.59</td>
</tr>
<tr>
<td>Geographic Location: Health Region 12</td>
<td>0.40</td>
<td>0.20-0.82</td>
</tr>
<tr>
<td>Caregiver Relationship: Other</td>
<td>0.54</td>
<td>0.37-0.80</td>
</tr>
<tr>
<td>Caregiver Relationship: Child</td>
<td>0.57</td>
<td>0.42-0.77</td>
</tr>
<tr>
<td>Rural</td>
<td>0.69</td>
<td>0.49-0.97</td>
</tr>
<tr>
<td>Decline in behaviour</td>
<td>0.69</td>
<td>0.50-0.96</td>
</tr>
</tbody>
</table>
4.4 Summary of Results

Research Question 1: Which home and community-based services do Ontario seniors with dementia and their caregivers utilize?

A broad range of home and community-based services were utilized by seniors with Alzheimer’s disease and related dementias in this sample. The services most frequently utilized included those which provide support for activities of daily living and instrumental activities of daily living including informal care, personal care and homemaking services. Services addressing more medical and rehabilitation needs such as nursing, physician services, physiotherapy and occupational therapy were used less frequently. Utilization of services providing relief for caregivers such as adult day services, short stay respite and volunteer services were reported by a small proportion of the sample. Additionally, the amount of service utilized by patients within the sample varied widely. For individuals utilizing personal care, meal services and nursing care services, there was a high frequency of visits on average. Services delivered by allied health professionals had a low frequency of use, averaging 1-2 days per week.

Research Question 2: Do home and community-based care services utilized vary by stage of cognitive impairment?

Utilization of all home and community-based services, except nursing and occupational therapy, varied by level of cognitive impairment. However, the amount of variation in service utilization ranged. The most significant variation in rates of service utilization was observed for informal care and personal support. As the level of cognitive impairment increased, the percentage of individuals utilizing the service also increased. Other services following a similar trend included adult day services and short stay respite. However, these services were utilized by a much smaller proportion of the sample and no difference in utilization rates were noted between the moderate and severe impairment groups. Services where utilization decreased with increasing cognitive impairment included homemaking, meal services, physiotherapy and emergency department services.

Research Question 3: What patterns of service utilization can be identified in community-based seniors with ADRD?
Seven distinct patterns of home and community-based service utilization were identified in the sample of community-based seniors with Alzheimer’s disease and related dementias. Formal service utilization levels within these patterns ranged from dependence on informal caregivers and no or low formal support to high reliance on formal support providers. The seven patterns, in order of increasing utilization of formal support services included: Low Support, ED User, High Informal Care, Community-Based Therapy, Well Home and Community-Based Support Service User, Frail Home and Community-Based Service User and High User.

**Research Question 4: What impact do patient and caregiver characteristics have on patterns of service use for community-based seniors with ADRD?**

All forty-three patient and caregiver characteristics included in the multinomial model significantly predicted membership in at least one of the seven latent classes. Nine characteristics influenced membership in all classes when compared with the Low Support class. Characteristics increasing the likelihood of class membership in all classes (compared with the Low Support class) included functional status measures such as IADL assistance required, ADL assistance required, cognitive status and continence. Reporting either a child or another person as the primary informal caregiver, rather than a spouse, was associated with decreased likelihood of membership in all classes (when compared with the Low Support class). Two indicators of geographic region of care (Health Regions 7 and 9) also decreased the likelihood of membership in all classes (compared with the Low Support class). The final predictor, living arrangement, had mixed effects on the class membership, increasing the likelihood of membership in classes with home and community-based services while decreasing the likelihood of membership in the ED User, High Informal Care or Community-Based Therapy classes.

Patient and caregiver characteristics with the greatest impact on class membership included living arrangement, ADL assistance required and geographic location of care. These characteristics were in the top ten characteristics impacting membership in all classes (compared with the Low Support class). Other characteristics with a strong impact on membership in specific classes included IADL assistance required, cognitive status,
age, continence, polypharmacy, highest level of education, caregiver relationship and caregiver commitment.
Chapter 5

5 Discussion, Implications and Conclusions

In this study, a greater understanding of the services utilized by Ontario seniors with dementia and their caregivers was obtained. Specifically, results indicated which services are utilized by patients and their caregivers and identified unique patterns of service utilization. As well, results furthered our knowledge of the impact that level of cognitive impairment has on service utilization and ascertained which patient and caregiver characteristics are associated with different patterns of service use. In this chapter, study findings are compared with what is presently known in the literature and discussed within the context of the current structures of the Ontario home care system. Then, implications for practice, policy and education are outlined and recommendations for future research are presented. Finally, key limitations of the study are delineated and study conclusions are drawn.

5.1 Discussion

Five key observations, largely congruent with previous literature, can be made from study findings. First, many community-based seniors with dementia do not access formal supports, rather informal caregivers provide the majority of care in the community. Second, receipt of community-based support services is largely dependent on the availability of co-resident informal care providers. Those without a co-resident caregiver were most likely to receive services. Third, when a co-resident caregiver is present, the services utilized are influenced by the relationship of the caregiver to the patient, as well as the sex of the care recipient. Fourth, the types of services utilized are influenced by the patient’s level of cognitive impairment. Finally, the location where care is provided impacts what types of services are provided.

5.1.1 High Dependency on Informal Care

The most frequently identified service utilization pattern in this study was High Informal Support (n=10,690). This finding confirms results of previous studies which identify low formal service use as the most common pattern of service utilization in community-
dwelling seniors with dementia (Beeber et al., 2008; Gerves et al., 2014; Janssen et al., 2016; Robinson et al., 2005; Robinson et al., 2013; Smale & Dupuis, 2004; Zhu et al., 2008). In this sample, the High Informal Support pattern was largely populated by individuals with dementia with heavy care needs (moderate/severe cognitive impairment, dependent in most IADLs and requiring extensive assistance with ADLs) and with co-resident caregivers who were most frequently spouses. These findings support previous work demonstrating that spousal caregivers are less likely to accept help with caregiving or household responsibilities, despite high care needs (Phillipson et al., 2014; Robinson et al., 2005; Raivio et al., 2007; Robinson et al., 2005; Robinson et al., 2013; Toseland et al., 2002). Unfortunately, in this study, it was not possible to know whether spousal caregivers did not accept help, were not offered services or were not aware they could request additional help.

This high level of dependency on informal care in this sample is of concern as individuals in the High Informal Care class also had the highest reported rate of caregiver distress in the sample (37%). Few caregivers in this class reported considering alternate living arrangements (27%), suggesting no imminent decrease to the level of caregiver stress. In populations with dementia, high levels of caregiver stress have been linked to elder abuse including physical, psychological, financial and sexual abuse (Dong, Chen & Simon, 2014). However, research has demonstrated that utilization of home and community-based services has been found to have positive impacts for both patients and caregivers including reducing patient mortality, and decreasing rates of caregiver depression, health deterioration and social isolation (Bass, Noelker & Rechlin, 1996; Gaugler et al., 2003b; Kumamoto, Arai & Zarit, 2006; Kuzuya et al., 2006). Therefore, identifying the causes of low formal care utilization among the High Informal Support class and intervening to provide education, support and referrals to appropriate services in a timely manner is recommended to support informal caregivers.

5.1.2 Role of Co-Resident Caregivers

Receipt of community-based support services is largely dependent on the availability of informal care providers who can provide day-to-day assistance with patient’s daily functional needs. Similar to previous research, living arrangement was one of the
strongest predictors of service utilization across most identified patterns (Janssen et al., 2016, Michalowsky et al., 2016). In this study, those without a co-resident caregiver to assist with frequent tasks, such as meals and personal care, were most likely to receive supportive care services. However, co-residence does not always mean that caregivers are able to assist with day-to-day tasks. For example, Michalowsky et al. (2016) found that a caregiver’s employment status was significantly related to use of formal care services, with employed caregivers utilizing more services. When identifying the need for home and community-based support services consideration should be given to the co-resident caregiver’s ability and desire to manage the care needs of the individual with dementia. Assumptions based on co-residence may create an unmanageable caregiving situation resulting in increased potential for elder abuse (Hawranik, 2002).

Service utilization patterns with higher levels of home and community-based support service use such as Well Home and Community-Based Support (HCBS) Service Users, Frail HCBS Service Users and High Users had the highest rates of individuals living alone (68.9%, 82.8% and 57.0% respectively). These patterns also had the highest rates of caregivers considering alternate living arrangements (37.2%, 43.2% and 40.1% respectively). These findings support previous research which demonstrates that persons with dementia who live alone are more likely to receive community-based support services (Edwards & Morris, 2007; Eichler et al., 2016; Forbes et al., 2003; Gill et al., 1998; Janssen et al., 2016, Robinson et al., 2005; Toseland et al., 2002; Wattmo et al., 2013). Additionally, although not examined directly in this study, others have found that those utilizing community-based services, may be utilizing services as a step to institutionalization (Cho et al., 2009; Gaugler et al., 2003a).

It is important to note that more than half the individuals in the Low Support service utilization pattern also lived alone. While those in the Low Support group, on average, had lighter functional needs and less severe levels of cognitive impairment at the baseline assessment, these individuals would likely be at higher risk for unmet needs and adverse events as their dementia progresses due to lack of insight into their growing care needs (Edwards & Morris, 2007; Wattmo et al., 2014). For individuals with dementia who live alone, specialized support and outreach services may be required to regularly assess their
care needs and then identify and access appropriate services that address their individual needs (Chow et al., 2000; Eichler et al., 2016).

5.1.3 Impact of Sex and Caregiver Relationship on Service Utilization

When a co-resident caregiver is present, services utilized are influenced by the relationship of the caregiver as well as the sex of the care recipient. In this study, service utilization patterns with the highest rates of spousal caregivers included *ED Users, High Informal Care* and *Community-Based Therapy*. These three groups were all characterized by high levels of informal care. Individuals in service utilization patterns which accessed home and community based supportive services, including *Well HCBS Service Users, Frail HCBS Services Users*, had the highest rates of children (61.9%, 70.5%) as informal caregivers. These findings align with previous research highlighting the influence of competing demands on children, including work, marital responsibilities and their own children, resulting in the need to utilize more formal services (Cho et al., 2009; Moon, 2016; Wattmo et al., 2013).

Sex of the care recipient also had an impact on service utilization pattern. In this sample women were less likely to be in both service utilization patterns which had high levels of informal care (*High Informal Care, ED Users*) and more likely to be in service utilization patterns with high levels of home and community-based support (*Well HCBS Service Users, Frail HCBS Service Users*). These findings may be a result of two inter-related factors: 1) older women are more likely to be widowed and, therefore, may not have a spousal caregiver to provide high levels of informal care necessitating the use of HCBS services and 2) for those who do have a spousal caregiver, male caregivers have been found to be offered more support with traditionally “female” tasks, resulting in increased use of HCBS services. Previous research has shown that male caregivers are more likely to be offered services which fall along traditional gender roles such as domestic help, meal delivery services and home nursing (Forbes et al., 2008; Raivio et al., 2007; Cahill, 2000). While differential service utilization may not be problematic if caregivers and patient needs are identified and incorporated into service planning, building service plans on assumptions regarding whether caregivers require assistance based on gender roles can lead to unmet needs. Furthermore, as equitable care is one of the six key areas of
quality as outlined in Ontario’s *Excellent Care for All Act* (2010), further research is needed to identify whether services are being offered equitably and declined by patients and caregivers or whether biases exist in service planning due to sex and relationship of the caregiver to the care recipient.

### 5.1.4 Level of Cognitive Impairment and Service Utilization

Level of cognitive impairment impacted utilization of almost all home and community-based services examined in this study, except nursing and occupational therapy. In the current Ontario home care model, nursing and occupational therapy services are provided to address specific medical and safety needs often unrelated to level of cognitive impairment, such as falls, wounds and infections. Consequently, in the current service model, these services should not be expected to vary. However, there are many additional services nurses and occupational therapists could provide which would be of benefit for patients with dementia and their caregivers. Potentially beneficial roles for nursing in dementia care in the community include health assessment to identify treatable undiagnosed illness, medication review and management, patient and caregiver education as well as support for continence issues and end-of-life care in later stages of dementia (Gitlin *et al.*, 2010; Hodgson, Gitlin, Winter & Czekanski, 2011). Interventions which could be provided by occupational therapists to improve quality of life for patients and caregivers include interventions to improve memory, cognitive function and self-management of ADLs (Evans, 2008).

In this study, utilization of informal care, personal support and volunteer services increased as the level of cognitive impairment increased. This finding aligns with expectations and previous research, as in later stages of cognitive impairment, increasing difficulties with IADLs and ADLs necessitates increasing levels of supervision and physical assistance (Wimo *et al.*, 2013). Increasing levels of informal care and personal support can meet growing physical and supervision needs, while volunteer services provide caregivers with much needed respite. Unfortunately, HCBS which target frequently performed IADLs, including homemaking and meal delivery services, showed decreasing utilization with increasing cognitive impairment. Currently, in Ontario, these services are often utilized by those without a co-resident informal caregiver who can
assist with these frequent tasks. This finding illustrates the potential limits of these services in assisting individuals with dementia to remain living alone when safety comes into question (Wimo et al., 2013). At higher levels of cognitive impairment, safety issues related to cooking and fire safety, medication compliance, nutrition and falls may exceed the capacity of these services.

Furthermore, physician services, physiotherapy services and emergency department visits also showed decreasing utilization with increasing levels of cognitive impairment. It is possible that this pattern is related to both caregiver and provider biases regarding the potential for dementia patients to benefit from these services. Currently, in Canada, the primary focus of care provided both in acute and community settings remains curative, rather than restorative or supportive, in nature (Morton-Chang, Williams, Berta & Laporte, 2016). While there is increasing support for a more proactive community-based approach to dementia care which promotes living as independently as possible (Donner, 2015; NCCMH, 2007; Pitkälä et al., 2013a), individual provider biases regarding rehabilitation potential as well as policies and systems structured for a curative approach may impact referrals and authorization of these services (Armstrong et al., 2016; Cherry, 2012; Evans, 2008; Hall, Watkins, Lang, Endacott & Goodwin, 2017). Difficulties communicating symptoms to caregivers may also contribute to care being sought less often by patients and caregivers (Achterberg et al., 2013; Hodgson et al., 2011). This combination of reduced help seeking and fewer referrals to service may lead to unmet needs including undiagnosed, treatable medical conditions, suboptimal pain management, and declining self-care abilities (Bruggenjurgen et al., 2016; Gitlin et al., 2010; van der Roest et al., 2009). Moreover, untreated pain and underlying illnesses have also been linked to behavioural and psychological symptoms of dementia, which can contribute to increased caregiver burden (Achterberg et al., 2013; Hodgson et al., 2011).

Finally, for both adult day services and short-stay respite admissions, utilization increased from mild to moderate cognitive impairment but either remained constant or declined in severe cognitive impairment. These findings may be related to eligibility criteria for these services, with those with more severe impairment having unacceptable behavioural issues or care needs which are too high for the service providers to manage.
Alternatively, caregivers may feel the benefits of service utilization are not worth the effort required to get patients ready to attend these services or the disruption attendance causes in the patient’s daily routine (Cox, 1997; Markle-Reid & Browne, 2001; Morgan et al., 2002; Phillipson & Jones 2011b).

5.1.5 Service Inequity Based on Location of Care

In this study, the location where care was provided impacted the type(s) and patterns of services utilized. Membership in the Community-Based Therapy and High User service utilization patterns were most impacted by the location of care. This result supports previous work which demonstrated that where a patient resides in Ontario is a key determinant of receipt of rehabilitation services such as occupational therapy and physiotherapy (Armstrong et al., 2015). Furthermore, in this study, those living in rural locations were less likely to be members of Community-Based Therapy, Frail HCBS Services or High User service utilization patterns, all patterns with the receipt of at least one professional service (occupational therapy or physiotherapy, nursing, and nursing and occupational therapy or physiotherapy respectively). Previous research has demonstrated that Canadians living in rural areas access more support services while those living in urban areas had greater utilization of professional services (Forbes et al., 2006). Given the demonstrated value of both physical therapy and occupational therapy to improve functional outcomes, reduce costs and promote and maintain independence in seniors with dementia (Graff et al., 2006; Graff et al., 2008; Heyn et al., 2004; Hill et al., 2006; Pitkälä et al., 2013a; Pitkälä et al., 2013b; Suttanon et al., 2010; Suttanon et al., 2012), efforts to improve equity in access to professional services in non-urban locations should be made. Team-based approaches to care which include the utilization of physiotherapy and occupational therapy assistants or delegation of care to personal support workers with appropriate on-going monitoring of outcomes may be one potential cost-effective option to increase access to these services. Furthermore, telemedicine has the potential to link caregivers and individuals with dementia with professional services where health human resource challenges may have previously precluded access (Bossen, Kim, Wiliams, Steinhoff & Strieker, 2015).
5.1.6 Rates of Service Utilization

There were notable differences in rates of home and community-based support services utilization between this study and those found in the literature. In the present study, much higher proportions of the sample utilized personal care services (76.1%) than rates of personal care utilization found in the literature (Gill et al., 2011: 23.8%). However, lower rates of adult day services (Toseland et al., 1999: 15.5%; Smale & Dupuis, 2004: 44.1%; study: 11%), physiotherapy (Gill et al., 2011: 9.7%; study: 6.9%) and occupational therapy (Gill et al., 2011: 12.1%; study: 5.9%) were reported in this sample when compared with the general literature. These differences may be related to differences in the population sampled as well as the inclusion of both private pay and publicly funded services. The study conducted by Gill and colleagues (2011) utilized a population-based approach, examining claims data for all individuals with a dementia diagnosis or who received cholinesterase inhibitor therapy (a medication specifically indicated for dementia) in Ontario. Within the sample, only 28.7% had received a RAI-HC assessment, an indicator of involvement with formal home care. Therefore, of those individuals involved with formal home care services, approximately 83% received personal support. This finding closely aligns with the rate of utilization seen in this study.

Differences in study settings and the year in which the research was conducted are also likely to have contributed to differing rates of service utilization. Most studies reporting rates of service utilization identified in the literature were conducted in the mid to late 1990’s in the United States (Gill et al., 1998; Toseland et al., 1999). Therefore, significant differences in both the structure and funding of home and community care may have impacted availability, access and quality of services measured.

Finally, in this study, utilization of physiotherapy and occupational therapy are likely underestimated due to the short (one week) reporting window utilized in the RAI-HC for all community-based service utilization. Services accessed outside this window would not be accounted for. As both physiotherapy and occupational therapy in the home care system are time-limited services which often have extended periods between visits while the patient and family implement recommendations, some use may not be accurately captured depending on the proximity of the therapy visit to the RAI-HC assessment.
5.2 Implications for Practice, Policy and Education

Findings from this study have implications for a broad range of stakeholder groups including front-line nurses caring for individuals with dementia, care coordinators developing home and community-based service plans for seniors with dementia and their caregivers as well as health system decision and policy makers. While several factors influencing service utilization are not modifiable, such as age, sex and level of cognitive impairment, this study highlights the influence that patients’ social resources and IADL and ADL limitations have on service utilization. These findings reinforce recommendations for a proactive approach to supporting caregivers and supporting interventions which reduce the impact and progression of IADL and ADL limitations in community-dwelling seniors with dementia (Gustavsson et al., 2011; Markle-Reid et al., 2006; Markle-Reid, Browne & Gafni, 2013; NCCMH, 2007). Potential implications for practice, policy and nursing education are discussed below.

Low service utilization has been attributed to lack of knowledge of available services, low engagement with the care planning process, low satisfaction with received services and difficulty navigating the health care system (Brodaty et al., 2005; Dello Buono et al., 1999; Noyes et al., 2000; Peel & Harding, 2014; Raivio et al., 2007; van der Roest et al., 2009; Wolfs et al., 2010). Utilizing knowledge of factors influencing service utilization patterns generated in this study, direct service providers as well as care coordinators can engage patients and caregivers in discussions of appropriate community-based care options for individuals with dementia and their caregivers. Direct service providers, including nurses and other health professionals, spend a significant amount of time working with patients in their own living environments. As such, they acquire a unique perspective on daily challenges facing caregivers. This proximity to patients and families also places these professionals in a position to engage patients in identifying and discussing unmet care needs. Through the mutual identification of care recipient and caregiver needs and the development of a collaborative relationship with care coordinators, frontline nurses and other health professionals can assist patients and
families to access needed services (Brodaty et al., 2005; Wolfs et al., 2010). Nurses working in case management roles in home and community care organizations and in care coordination roles at Community Care Access Centres can then continue the conversation with patients and families and provide accurate and complete information about available services and assist with referrals to community-based services as needed. In some cases, this may include direct linkages to system navigation programs such as the Hospital Care Connector program through the Hamilton Seniors Isolation Impact Plan (Gilbrear Center for Studies in Aging, 2017) or the Intensive Geriatric Service Worker program in Waterloo Wellington region (Canadian Mental Health Association, 2016), which provide assistance for isolated seniors to navigate and access community-based services. Additionally, providing links to caregiver support groups and caregiver training programs through avenues such as the Alzheimer’s Society First Link® program as well as conducting outreach to groups least likely to utilize services may help to empower patients and caregivers to negotiate the system and access needed services (Ayalon & Huyck, 2001; Frank et al., 2011; Low et al., 2011).

Individualized care plans based on comprehensive assessment should be developed to promote and maintain independence of people with dementia (NCCMH, 2007; Sansoni et al., 2016). Utilizing knowledge of factors influencing patterns of service utilization along with outputs generated from the RAI-HC assessment such as the clinical assessment protocols, care coordinators can work with patients and families to identify services which meet care needs and patient-identified goals. Education and training of home and community care staff on how to appropriately evaluate needs of individuals with dementia and their caregivers is vital to ensure that appropriate services are discussed and offered. Including caregivers in service planning discussions is of great importance as often individuals with dementia downplay needs because they are reluctant to have unfamiliar formal care providers in their homes (Cherry, 2012; van der Roest et al., 2009). Furthermore, additional training and resources outlining dementia friendly services available within their jurisdiction would help to mitigate variation in services offered based on care coordinator knowledge (Armstrong et al., 2016).
The addition of therapies, such as occupational therapy and physiotherapy, to community-based care plans may be one path towards reducing the impact of IADL and ADL limitations and slowing or preventing further decline. This will require a shift from the current reactive, curative approach to service allocation to a more proactive, preventative approach. Currently, rehabilitative services are typically targeted to those with acute illnesses and injuries, rather than those with slowly deteriorating mobility (Armstrong et al., 2016). However, inclusion of occupational therapy in dementia care plans to develop self-care strategies, provide caregiver education, and to assess for environmental adaptations and appropriate equipment can improve health outcomes for persons with dementia and their caregivers (Graff et al.; 2006, Graff et al., 2007). Furthermore, physiotherapy can be utilized to maintain physical strength and balance, decrease risk of falls and to reduce the physical burden of transferring patients or assisting with ambulation (Pitkala et al., 2013a; Suttanon et al., 2012; Taylor, et al., 2017). These functional gains may result in improved quality of life and decreased acute care utilization for both patients and caregivers.

For these enhanced service plans to be carried out as intended, variation in access to home and community-based health care and support services across the province must be addressed. While clinical care pathways exist for several medical conditions which identify services to be considered in care plans, at this time in Ontario no such pathway exists for seniors with dementia. Although a rehabilitation clinical assessment protocol does exist as part of the decision support tools generated by the RAI-HC, further guidance on amount and timing of services are not provided. The development of provincial service allocation guidelines to accompany the rehabilitation algorithm, based on RAI-HC assessment data, could improve equity in access to professional services throughout the Province. To meet heightened service requirements in areas with health human resource shortages, the development of alternative delivery models for areas may be required. Transfer of home based exercise plans to personal support workers for ongoing support and utilization of occupational therapy assistants and physiotherapy assistants could extend the reach of registered health professionals (Jones & Frederick, 2003; Johnson, Myers, Scholey, Cyarto & Ecclestone, 2003; Tran et al., 2009).
To effectively support families and caregivers to continue to provide the majority of care for community-dwelling seniors with dementia, further integration of home care and community support services is needed (Sansoni et al., 2016). Current home care and community support system structures do not allow for care coordinators to directly coordinate and monitor community support services (Williams et al., 2009), placing much of the onus on informal caregivers. Improved integration of services would allow for the most appropriate services to be offered at the appropriate time. Structuring programs to allow care coordinators greater range in services which can be accessed to support patients with dementia, similar to the Veterans Independence Program, would allow care needs to dictate services provided (Veterans Affairs Canada, 2013).

Furthermore, the development of partnerships between the CCACs and community support agencies to develop innovative programs tailored to patient and caregiver needs should be a priority. Services such as enhanced adult day programs, which attend to transportation, dietary, personal care and recreation/stimulation needs may address caregiver concerns and increase uptake of services. Additionally, programs targeting specific groups that are likely to be non-users of service (i.e. spousal caregivers, minority ethnic groups, older women etc.) should be developed, tested and funded.

### 5.3 Implications for Future Research

Further studies are required to examine the impact of the identified patterns of service utilization on patient and caregiver outcomes such as utilization of acute care and residential long-term care. The identification of services which are more effective at supporting caregivers and patients when utilized concurrently and the optimal timing of specific service types in the dementia trajectory could be used to structure community-based care pathways for seniors with dementia. Additionally, studies examining patient and caregivers’ experiences of integration of and transitions between community-based service providers would be of great benefit in developing a more patient-centred system of integrated home and community care.

Given the strong relationship between functional status indicators and patterns with increased utilization of formal support services, further research should identify whether specific functional limitations are associated with increased use. Once identified,
interventions targeted at improving or slowing these limitations can be implemented and their efficacy at improving patient and caregiver independence can be evaluated. For example, if toileting and incontinence were found to have a strong influence on utilization of personal care services, intervention by a continence nurse to increase the caregiver’s ability to manage continence issues (e.g. creation of a bowel routine, obtaining funding for continence products or teaching caregivers to manage constipation with dietary changes) should be evaluated.

Research utilizing patient and caregiver engagement to understand caregivers’ decision-making processes around the use or non-use of discretionary services is required to better design services that meet patient and caregiver needs (Brett et al., 2014; Carman et al., 2013; Goeman, King & Koch, 2016; Moon, 2016). Developing a greater understanding of service delivery factors which influence decisions to access services, such as availability, scheduling, logistics and patient and caregiver preferences, will allow for more tailored and effective programs to be created and tested (Dello Buono et al., 1999; Phillipson & Jones, 2011a). Undertaking work to map out availability of services would allow for programs and funds to be directed to areas which are currently underserviced. Additionally, examining how caregiving needs of immigrant populations differ and how services can meet these needs will be of great importance with Ontario’s shifting demographics. While efforts have been made to address linguistic barriers to service utilization, facilitating culturally appropriate options may help to support caregiving in a culturally diverse context (Black et al., 2013; Chow et al., 2000; Goeman et al., 2016; Napoles, Chadiha, Eversley & Moreno-John, 2010; Xiao et al., 2015). Through improvements to both the package of services offered and the delivery of those services, personalized, yet standardized options for community-based dementia care can be developed.

5.4 Limitations

Several known limitations impacting the internal and external validity of study findings are discussed in this section. Due to the use of secondary data for these analyses, there are limitations related to the availability of data that match model concepts. As well, the cross-sectional nature of the data does not allow to examine changes over time. In
secondary data analyses, the scope and content of the study is limited by the quality and nature of data available (Shi, 2008). In this study, predictors of service utilization were limited to variables available in the RAI-HC. While the RAI-HC has undergone significant reliability and validity testing that has demonstrated excellent data quality (Carpenter et al., 2004; Landi, et al., 2000; Morris et al., 1997), several characteristics of interest in this study are not routinely measured by the instrument. This was particularly relevant in regard to caregiver characteristics which may be important in predicting patterns of service utilization. Variables for which caregiver data were not available included age, sex, education, ethnicity, income level, and knowledge of available services. Excluding these variables from multinomial logistic regression modeling may have led to biased regression coefficients due to omitted variable bias, if these variables did have a strong relationship with the care recipient’s pattern of service utilization. As there is no method to test for omitted variable bias other than the inclusion of the omitted variable or an available instrumental variable, the exclusion of these variables remains a limitation of the study (Hill, Griffiths & Lim, 2011). Additionally, although significant effort was made to identify previously validated scales and single items from the RAI-HC which approximate model variables of interest, the degree of match between concepts and available data is likely more precise for some concepts than others (Shi, 2008). Where possible, validated scales were utilized to minimize concerns related to construct validity.

As the RAI-HC is a clinical assessment conducted at a given point in time, the period prevalence nature of the data may have led to a history effect if a key event, such as the withdrawal of a caregiver or an acute event, occurred between the measurement of the predictor variables (baseline assessment) and the outcome variable (service utilization). To mitigate the impact of such an event on outcome measurement, all available data on service utilization from reassessments were included and the highest level of service utilization was included in the latent class model. However, if changes occurred over the study window to predictors, such as living arrangement or caregiver relationship, this variation was not accounted for in the multinomial model and, thus, remains a limitation to the study.
Community-based service utilization data were drawn from the RAI-HC and were not verified against provider or claims data. Emergency department visits were, however, drawn from claims data. Community support service levels would be most affected by any potential recall bias as care coordinators have access to funding information for professional services such as nursing and therapies but are more dependent on patient and caregiver recall for community services when completing the RAI-HC. Additionally, as discussed previously, the cross-sectional nature of the RAI-HC data, paired with the short (7 day) look-back window, may have resulted in under-estimation of service utilization for both occupational therapy and physiotherapy as these services are often time-limited and may have extended periods between visits while patients and families implement recommendations.

Due to the complexity of the model and the low rates of utilization of several home and community-based services, it was necessary to employ a classify-analyze approach to identify predictors of the latent classes rather than utilizing an inclusive, one-step latent class model. Utilization of a classify-analyze approach has been shown to lead to attenuation of the estimated associations between the latent class variable and the observed variables, with attenuation increasing as the strength of the true relationship increases (Bolck et al., 2004, Bray et al., 2015; Vermunt, 2010). However, the impact of this bias is decreased somewhat because of the large study sample (Bray et al., 2015). As a result of attenuation of estimates, findings pertaining to the strength of relationships between predictors and latent class membership from this study should be considered to be conservative estimates.

Finally, there are limitations related to generalizability of study findings. In this study, all participants received an assessment for home care services or long term care placement and had a documented diagnosis of Alzheimer’s disease or a related dementia in their initial assessment. Given low formal diagnosis rates for Alzheimer’s disease and related dementias, there are likely many other individuals receiving home care services which were excluded from these analyses. Additionally, many other seniors with dementia living in the community are outside the formal health care system (Edwards & Morris, 2007). These individuals may not have yet had an interaction with the formal home care
system either through a referral from hospital or community sources such as a primary care provider, community support agencies or family members. Taking this into account, the results from this study likely represent those individuals who are connected with the formal care system, have access to services and who, for the most part, have informal caregivers to support them. Additionally, as this study was conducted with data from one Canadian Province (Ontario), it may be difficult to generalize findings to other regions of Canada or internationally. As home care is not a service insured under the Canada Health Act (1985), the structure and availability of home care and community care services varies considerably across Canada. If attempting to apply these findings to systems elsewhere, care should be taken to evaluate the structures of the home and community care system to ensure systems share similar features.

5.5 Conclusion

In Ontario, publicly funded home care services typically address specific medical needs and provide assistance with personal care such as bathing, dressing and continence care while community support services focus on specific instrumental activities of daily living such as meal preparation and housekeeping. When accessed, these services may address many of the functional needs of individuals with dementia. However, support with needs related to cognitive limitations such as impaired memory, judgement, behavioural disturbances and personality changes including surveillance, diversion from dangerous activities and management of behaviours are still often left to families to manage (Forbes et al., 2008; Wattmo et al., 2013). The impact of this gap in support can be seen in the high levels of informal care provided for the majority of patients in this study. While recent Ontario policy and legislative changes including Patients First: A Roadmap to Strengthen Home and Community Care (2015) and the Patients First Act (2016), advocate a patient- and family-centred approach to community-based care, little attention has been paid to addressing these unmet needs. As demonstrated through service utilization patterns identified in this study, those utilizing services are not utilizing them in isolation. However, those with the highest levels of cognitive impairment and behavioural symptoms in the sample were more likely to be in service utilization patterns with little to no formal support. Further work is necessary to engage patients and families
in the care planning process. Only through understanding barriers to accessing services and offering relevant services to address unmet needs, can home and community-based services assist caregivers to effectively care for their loved ones in the community (Raivio et al., 2007, Black et al., 2013, van der Roest et al., 2009).
References

Background


Canadian Institute of Health Information. (2010). *Analysis in Brief: Caring for Seniors with Alzheimer’s Disease and Other Forms of Dementia*. Ottawa: Author. Available at: https://secure.cihi.ca/free_products/Dementia_AIB_2010_EN.pdf


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Literature Review


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Methods


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Results


**Discussion**


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Peel, E. & Harding, R. (2014). ‘It’s a huge maze, the system, it’s a terrible maze’: Dementia carers’ constructions of navigating health and social care services. *Dementia, 13*(5), 642-661. doi:10.1177/1471301213480514


community-dwelling older people with dementia. *International Psychogeriatrics*, 29(1), 81-91. doi:10.1017/S1041610216001629


Appendices
APPENDIX A: Search Strategy and Results

1. Ovid (Medline, PsycINFO, Embase) Search Strategy

<table>
<thead>
<tr>
<th>Concept</th>
<th>Search Terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>exp Dementia/ or dementia.mp. or exp Alzheimer Disease/ or ADRD.mp.</td>
</tr>
<tr>
<td>Intervention</td>
<td>exp *Home Care Services/ or (home adj care).mp. or exp Community Health Services/ or (community adj care).mp.</td>
</tr>
<tr>
<td>Comparison</td>
<td>No comparison used</td>
</tr>
<tr>
<td>Outcome</td>
<td>(utili<em>ation or barrier</em> or predictor*).mp.</td>
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</table>

2. CINHAL Search Strategy

<table>
<thead>
<tr>
<th>Concept</th>
<th>Search Terms</th>
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</thead>
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<td>Population</td>
<td>(MH &quot;Alzheimer's Disease&quot;) OR (MH &quot;Dementia&quot;) OR &quot;dementia&quot; OR (MH &quot;Frontotemporal Dementia&quot;) OR (MH &quot;Dementia, Vascular&quot;) OR (MH &quot;Dementia, Multi-Infarct&quot;) OR (MH &quot;Lewy Body Disease&quot;) OR (MH &quot;AIDS Dementia Complex&quot;) OR (MH &quot;Dementia, Senile&quot;)</td>
</tr>
<tr>
<td>Intervention</td>
<td>(MH &quot;Home Health Care&quot;) OR (MH &quot;Home Health Aides&quot;) OR &quot;community support&quot;</td>
</tr>
<tr>
<td>Comparison</td>
<td>No comparison used</td>
</tr>
<tr>
<td>Outcome</td>
<td>(MH &quot;Health Resource Utilization&quot;) OR &quot;utilization&quot;</td>
</tr>
</tbody>
</table>
APPENDIX A: Search Strategy and Results

Database search (n=1,034)
- Medline: n = 324
- PsycINFO: n = 125
- Embase: n = 516
- CINHAL: n = 69

Duplicates excluded  
  n = 316

Records after duplicates removed  
  n = 718

Excluded based on title and abstract  
  n = 581

Records screened in  
  n = 137

Included manuscripts from database search  
  n = 63

Additional manuscripts found through hand search  
  n = 17

Excluded  
  n = 74
  - n=31: Did not examine predictors of service utilization
  - n=3: No cognitive impairment
  - n=1: Population not 65 years or older
  - n=1: Examined caregiver outcomes
  - n=38: Conference abstract / full-text not available

Total studies included in literature review  
  n = 80
  Including quantitative, mixed methods and qualitative studies
## APPENDIX B: Multinomial Logistic Regression Model Results

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<th>Variable</th>
<th>P Value</th>
<th>Class</th>
<th>Odds Ratio</th>
<th>Confidence Interval</th>
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<td><strong>Age: 75 to 84</strong></td>
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<td>ED Users</td>
<td>0.93</td>
<td>0.78 1.10</td>
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<td></td>
<td>High Informal</td>
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<td></td>
<td>&lt;0.0001</td>
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<td>Well HCBS</td>
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<td>1.06 1.48</td>
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<td>Frail HCBS</td>
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<td>1.29 1.92</td>
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<td></td>
<td>High Users</td>
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<td></td>
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<td>0.62 0.81</td>
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<td>CB Therapy</td>
<td>0.69</td>
<td>0.56 0.84</td>
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<td>Well HCBS</td>
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<td>1.37 1.93</td>
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<td></td>
<td>Frail HCBS</td>
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<td></td>
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<td>0.80 0.96</td>
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<td>CB Therapy</td>
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<td>Frail HCBS</td>
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<td>1.00 1.25</td>
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<tr>
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<td></td>
<td>High Users</td>
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Note: **Odds ratios in bold** are significant at p<0.05
## APPENDIX B: Multinomial Logistic Regression Model Results

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Note: **Odds ratios in bold** are significant at p<0.05.
### APPENDIX B: Multinomial Logistic Regression Model Results

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Note: **Odds ratios in bold** are significant at p<0.05
## APPENDIX B: Multinomial Logistic Regression Model Results

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Note: Odds ratios in bold are significant at p<0.05; IADL = instrumental activities of daily living
## APPENDIX B: Multinomial Logistic Regression Model Results

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Note: **Odds ratios in bold** are significant at p<0.05; ADL = activities of daily living
### APPENDIX B: Multinomial Logistic Regression Model Results

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<tr>
<th>Variable</th>
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<th>Class</th>
<th>Odds Ratio</th>
<th>Confidence Interval</th>
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Note: **Odds ratios in bold** are significant at p<0.05
## APPENDIX B: Multinomial Logistic Regression Model Results

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<th>Class</th>
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<th>Confidence Interval</th>
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Note: **Odds ratios in bold** are significant at p<0.05
### APPENDIX B: Multinomial Logistic Regression Model Results

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<th>Variable</th>
<th>P Value</th>
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<th>Confidence Interval</th>
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Note: **Odds ratios in bold** are significant at p<0.05
### APPENDIX C: Significant Predictors of Class Membership in Order of Impact

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<th>Community-Based Therapy vs Low Support</th>
<th>Well HCBS vs Low Support</th>
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<td>Lives alone</td>
<td>Lives alone</td>
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<td>Lives alone</td>
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<td>Geographic Location: Health Region 9</td>
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<td>Requires assistance with more than 3 IADLs</td>
<td>Other caregiver</td>
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<td>Geographic Location: Health Region 7</td>
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<td>Bowel incontinence</td>
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<td>Geographic Location: Health Region 1</td>
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<td>Geographic Location: Health Region 13</td>
<td>Geographic Location: Health Region 5</td>
<td>Geographic Location: Health Region 13</td>
<td>Geographic Location: Health Region 5</td>
<td>Geographic Location: Health Region 12</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Geographic Location: Health Region 9</td>
<td>Geographic Location: Health Region 9</td>
<td>Physical assistance required with ADLs</td>
<td>Geographic Location: Health Region 7</td>
<td>Physical assistance required with ADLs</td>
<td>Requires assistance with ADLs</td>
</tr>
<tr>
<td>9</td>
<td>Geographic Location: Health Region 7</td>
<td>Age: Greater than 85</td>
<td>Geographic Location: Health Region 11</td>
<td>Education: Any post-secondary</td>
<td>Geographic Location: Health Region 9</td>
<td>Lives alone</td>
</tr>
</tbody>
</table>

Note: Predictors in italics are decrease odds of class membership (OR<1) while predictors in bold are increase odds of class membership (OR>1)
## APPENDIX C: Significant Predictors of Class Membership in Order of Impact

<table>
<thead>
<tr>
<th>Rank</th>
<th>ED Users vs. Low Support</th>
<th>High Informal Care vs Low Support</th>
<th>Community-Based Therapy vs Low Support</th>
<th>Well HCBS vs Low Support</th>
<th>Frail HCBS vs Low Support</th>
<th>High Users vs Low Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>Caregiver considering alternate living arrangement</td>
<td>Geographic Location: Health Region 13</td>
<td>Geographic Location: Health Region 2</td>
<td>Geographic Location: Health Region 8</td>
<td>More than 8 medications</td>
<td>Other caregiver</td>
</tr>
<tr>
<td>11</td>
<td>Geographic Location: Health Region 8</td>
<td>Caregiver distress</td>
<td>Geographic Location: Health Region 8</td>
<td>Child caregiver</td>
<td>Education: Any post-secondary</td>
<td>Child caregiver</td>
</tr>
<tr>
<td>12</td>
<td>Education: Unknown</td>
<td>Recent hospital admission</td>
<td>Other caregiver</td>
<td>Geographic Location: Health Region 13</td>
<td>Rural</td>
<td>Bowel incontinence</td>
</tr>
<tr>
<td>13</td>
<td>Recent hospital admission</td>
<td>Alzheimer’s disease</td>
<td>Geographic Location: Health Region 10</td>
<td>Geographic Location: Health Region 11</td>
<td>Geographic Location: Health Region 10</td>
<td>Age: Greater than 85</td>
</tr>
<tr>
<td>14</td>
<td>Child caregiver</td>
<td>Geographic Location: Health Region 1</td>
<td>Geographic Location: Health Region 5</td>
<td>Education: High school</td>
<td>Age: 75 to 84</td>
<td>Geographic Location: Health Region 11</td>
</tr>
<tr>
<td>15</td>
<td>Geographic Location: Health Region 11</td>
<td>Geographic Location: Health Region 6</td>
<td>Caregiver considering alternate living arrangement</td>
<td>Bowel incontinence</td>
<td>Geographic Location: Health Region 3</td>
<td>Bladder incontinence</td>
</tr>
<tr>
<td>16</td>
<td>Caregiver distress</td>
<td>Any reported BPSD</td>
<td>Dependent for 3 or more IADLs</td>
<td>Bladder incontinence</td>
<td>Geographic Location: Health Region 8</td>
<td>Education: High school</td>
</tr>
<tr>
<td>17</td>
<td>Bladder incontinence</td>
<td>Education: Unknown</td>
<td>Recent falls</td>
<td>Moderate to severe cognitive impairment</td>
<td>Education: High school</td>
<td>Education: Unknown</td>
</tr>
<tr>
<td>18</td>
<td>Recent ED visits</td>
<td>Bladder incontinence</td>
<td>Age: Greater than 85</td>
<td>More than 8 medications</td>
<td>Geographic Location: Health Region 2</td>
<td>Recent hospital admission</td>
</tr>
</tbody>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Education: Any post-secondary</td>
<td>Age: 75 to 84</td>
<td>Recent hospital admission</td>
<td>Geographic Location: Health Region 3</td>
<td>Moderate to severe cognitive impairment</td>
<td>Rural</td>
</tr>
<tr>
<td>20</td>
<td>Female</td>
<td>Rural</td>
<td>Rural</td>
<td>Age: 75 to 84</td>
<td>Five to eight medications</td>
<td>Decline in behaviour</td>
</tr>
<tr>
<td>21</td>
<td>Co-morbidities</td>
<td>Rural</td>
<td>Moderate to severe cognitive impairment</td>
<td>Decline in behaviour</td>
<td>Caregiver considering alternate living arrangement</td>
<td>Moderate to severe cognitive impairment</td>
</tr>
<tr>
<td>22</td>
<td>Bowel incontinence</td>
<td>Bowel incontinence</td>
<td>Daily pain</td>
<td>Caregiver distress</td>
<td>Decline in ADL ability</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Recent cognitive decline</td>
<td>Five to eight medications</td>
<td>Recent hospital admission</td>
<td>Education: Unknown</td>
<td>Recent falls</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Decline in behaviour</td>
<td>Decline in behaviour</td>
<td>Caregiver considering alternate living arrangement</td>
<td>Child caregiver</td>
<td>Co-morbidities</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Female</td>
<td>Age: 75 to 84</td>
<td>Five to eight medications</td>
<td>Taking psychotropic medication(s)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Caregiver considering alternate living arrangement</td>
<td>Child caregiver</td>
<td>Female</td>
<td>Bladder incontinence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>Caregiver distress</td>
<td></td>
<td>Daily pain</td>
<td></td>
<td></td>
<td></td>
</tr>
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<tbody>
<tr>
<td>28</td>
<td>Recent ED visits</td>
<td></td>
<td></td>
<td>Bowel incontinence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>Any reported BPSD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>Decline in ADL ability</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>Bladder incontinence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>Co-morbidities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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