# Predictors of Palliative Home Care Costs in Ontario, Canada

by

Clare Yuet Kan Cheng

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# Examining Committee Membership

The following served on the Examining Committee for this thesis. The decision of the Examining Committee is by majority vote.

| | |
|---|---|
| External Examiner | Dr. Robin Urquhart<br>Associate Professor, Department of Community Health and Epidemiology<br>Dalhousie University |
| Supervisor | Dr. John Hirdes<br>Professor, School of Public Health and Health Systems<br>University of Waterloo |
| Internal Members | Dr. Jeff Poss<br>Adjunct Associate Professor, School of Public Health and Health Systems<br>University of Waterloo |
| | Dr. Dawn Guthrie<br>Professor, Department of Kinesiology and Physical Education; Department of Health Sciences<br>Wilfrid Laurier University |
| Internal-external Member | Dr. Susan Cadell<br>Professor, School of Social Work<br>Renison College University, University of Waterloo |

# Author’s Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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# Abstract

**Background:** The demand for palliative care in Canada is expected to grow in coming years due to a confluence of factors that include population aging, a more gradual dying process, emphasis on the early provision of palliative care, as well as the expansion of the scope of palliative care beyond cancer. In particular, there is emphasis on the provision of palliative care in home settings as individuals prefer to remain at home for as long as possible, and for health systems, the potential reduction in end of life care costs. The proportion of Canadian decedents who received palliative home care services prior to death is low, however, and may reflect an inadequate supply of palliative home care services resulting from the dearth of information required to support health system planning activities. Specifically, the need to understand the characteristics, service utilization patterns and costs of palliative home care clients has been emphasized in reports on palliative care in Canada.

**Objectives:** This dissertation sought to address information gaps on palliative home care in Ontario, Canada by: 1) characterizing palliative home care clients and examining their service utilization patterns; 2) estimating formal service-related palliative home care costs, informal care costs, and combined formal and informal care costs; 3) identifying predictors of formal, informal and combined care costs, with particular emphasis on the Palliative Performance Scale (PPS).

**Methods:** A sample of palliative home care clients was drawn from home care clients in Ontario assessed using the interRAI Palliative Care (PC) between 2011 and 2017 (n=68,731). For each client, their first interRAI PC assessment was selected and linked to home care referral information and service billing/payment records of up to 181 days post-assessment contained in Health Shared Services Ontario's Client Health Related Information System. Descriptive statistics were used to characterize these clients and describe their patterns of palliative home care service utilization. A subsample of clients on service for five or more weeks post-assessment and with a PPS score was then drawn from the original sample (n=39,072). Mean weekly costs of formal palliative home care services over the first five weeks of service post-assessment were estimated for this sample, as were informal care costs and combined formal and informal care costs. Predictors of these costs were then identified using linear and logistic regression models. Candidate variables considered as predictors of cost were organized based on Andersen and Newman’s framework on health service utilization, and informed by existing literature and by one-on-one interviews with individuals familiar with the management or provision of palliative care in Ontario. These variables were obtained from clients’ assessment records that included PPS scores and interRAI PC scales and items.

**Results:** A large majority of palliative home care clients had a cancer diagnosis (85.0%) and over half had an expected prognosis of less than six months (60.7%), with half dying during the follow-up period. Almost all (93.4%) clients had at least some loss of function based on the Instrumental Activities of Daily Living-Activities of Daily Living (IADL-ADL) Functional Hierarchy Scale, and moderate to high health instability based on the Changes in health, End-stage Disease Signs and Symptoms (CHESS) Scale. Services were initiated within days of assessment and utilization of services was particularly great in the first week post-assessment. Essentially all clients received case management and nursing services, while the most frequently used services were for nursing and personal support. For clients who were discharged during the follow-up period, increasing service use could be observed with closer proximity to discharge.

The estimated mean weekly formal palliative home care cost over the first five weeks of service was $352.91 (2020 Canadian dollar [CAD]). Linear regression using generalized linear models found the PPS to be significant in predicting formal care costs and explained 29.4% of variation in costs. By comparison, interRAI scales and items corresponding to components of the PPS explained 31.2% of cost variation. Expanded models containing interRAI PC scales and items both related and unrelated to components of the PPS had an explained variance of 37.7%, and addition of the PPS to this model led to a small increase in the explanation of cost variation (39.7%). Logistic regression models used to assess the probability of being a ‘high’ cost palliative home care cost client performed well (c-statistic between 0.81 and 0.94) and identified similar characteristics to those identified as predictors of cost in linear regression. Across models, characteristics that were consistently significant in predicting formal care costs included clients' region of residence (Local Health Integration Network [LHIN]), having a live-in caregiver, being designated as an end of life home care client, having an informal caregiver who reported being unable to continue in care activities, having family and friends who felt overwhelmed by the client's illness, poorer functioning (PPS and IADL-ADL Functional Hierarchy Scale), greater health instability (CHESS), altered mode of nutritional intake, the presence of dyspnea, presence of fatigue, greater pain, need for and use of intravenous (IV) medications, and bladder and bowel incontinence.

Estimates of weekly informal care costs were between $565.24 and $693.55, and ranged between $918.15 and $1,046.45 for combined mean weekly formal and informal care costs for the first five weeks of service post-assessment (all 2020 CAD). As a share of the total combined care costs, between 61.6% and 66.3% of care costs were for informal care. The generalized linear model of informal care costs and interRAI PC scales and items explained 41.4% of variation in costs. Addition of the PPS to this model increased variance explanation to 42.1%. A large number of characteristics were identified as significant predictors of informal care costs, although clients' marital status, LHIN of residence, poorer function (IADL-ADL Functional Hierarchy Scale), greater fatigue, presence of expressions of unrealistic fears, and greater bowel incontinence had particularly large effect sizes. The association between formal care costs and informal care costs was also examined and the two types of costs were found to be complementary. In regard to the combined mean weekly formal and informal care costs, variance explanation using interRAI PC scales and items was 51.7%, and increased to 53.3% with the addition of the PPS. A large number of characteristics were also found to be predictive of combined care costs. Characteristics with particularly large effect sizes included LHIN of residence, function, need for altered mode of nutritional intake, dyspnea, fatigue, and daily use of intravenous medications.

**Conclusions:** This dissertation provides a detailed description of palliative home care clients in Ontario, and their home care service utilization patterns and associated costs. The PPS appears to be a reasonable predictor of formal, informal and combined palliative home care costs. A number of other client characteristics were also identified as being predictive of these costs with substantial overlap in the characteristics identified for each type of cost. The majority of these characteristics can be categorized as illness (need) factors within Andersen and Newman's framework on health service utilization indicating that cost variations are influenced primarily by clients' clinical and/or functional needs. Caregiver characteristics, including indicators of distress, were also predictive of formal, informal and combined costs indicating the importance of caregiver capacity to provide care in the care of palliative home care clients. One application of findings from this dissertation may be to inform on future development of a case-mix system for palliative home care as variance explanation of palliative home care costs observed in this dissertation were high, suggesting that the classification of palliative home care clients into groups with relatively similar clinical characteristics and levels of resource utilization is possible.

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# List of Abbreviations

**2SLS** Two-stage least squares
**ADL** Activities of daily living
**AHCR** Ambulatory Home Care Record
**AN-SNAP** Australian National Sub-Acute and Non-Acute Patient
**CAD** Canadian dollar
**CHESS** Changes in Health, End-Stage Disease, Signs, and Symptoms
**CHRIS** Client Health Related Information System
**CI** Confidence interval
**CINAHL** Cumulative Index to Nursing and Allied Health Literature
**CL** Confidence limit
**ED** Emergency department
**HSSOntario** Health Shared Services Ontario
**IADL** Instrumental activities of daily living
**interRAI HC** interRAI Home Care
**interRAI PC** interRAI Palliative Care
**IQR** Interquartile range
**IV** Intravenous
**LHIN** Local Health Integration Network
**MAPLe** Method for Assigning Priority Levels
**OHIP** Ontario Health Insurance Plan
**OLS** Ordinary least squares
**ORE** Office of Research Ethics
**PCPSS** Palliative Care Problem Severity Score
**PCU** Palliative care unit
**PPS** Palliative Performance Scale
**PSW** Personal support worker
**RUG-ADL** Resource Utilization Groups Activities of Daily Living
**RUG-III** Resource Utilization Groups Version III
**SD** Standard deviation
**SRC** Service recipient code
**VIF** Variance inflation factor
**WHO** World Health Organization

# Chapter 1

# Introduction

## 1.1 Background

More Canadians are now dying than in the past due to both population growth and aging (Arnup, 2013; Canada & Health Canada, 2018; Statistics Canada, 2017). While death was generally a sudden event caused by infections, accidents and childbirth in the past (Murray et al., 2005), most deaths are now due to chronic conditions such as heart disease, stroke, cancer, chronic respiratory diseases, and dementia (World Health Organization & Public Health Agency of Canada, 2005). Even with the global SARS-CoV-2 pandemic that made COVID-19 the third leading cause of death in 2020, it remains true that the majority of deaths are due to chronic conditions (Ahmad & Anderson, 2021; Statistics Canada, 2020a, 2020b). Deaths from chronic conditions are preceded by a period of decline that can lead to pain, declines in function and poor quality of life over months to years until death (Gott & Ingleton, 2011). While older age does not necessarily equate to poorer health, chronic conditions are much more common in older populations (Statistics Canada, 2015). With a growing population of elderly Canadians, the prevalence of chronic, life-limiting conditions that are associated with more gradual dying processes has increased (Public Health Agency of Canada, 2017; Statistics Canada, 2017). This shift in how Canadians are dying has made palliative care a priority with its emphasis on quality of life, reduction in suffering, and supporting a peaceful death with dignity (Canada & Health Canada, 2018).

The palliative care movement began in Canada in the 1970s with the first palliative care units being opened in Winnipeg and Montréal during that time (Fainsinger, 2000). Although organizations for palliative care continued to open in some provinces in the 1980s, it was not until the 1995 senate committee report *Of Life and Death* that palliative care drew national attention with its recommendations for the prioritization of care for individuals at the end of life and their families (MacDonald, 2012). The 1990s also saw the introduction of initiatives like interdisciplinary care teams, specialist palliative consult services, residential hospices, home-based palliative care and tertiary palliative care units (DeMiglio & Williams, 2012; Fassbender et al., 2005). More recently, emphasis has been placed by health systems on the provision of palliative care in the community, and more specifically at home (Sun et al., 2017). In part, this emphasis may be due to its potential to reduce health care costs at the end of life. Some studies have found home-based palliative care to be less costly than inpatient palliative care (Hollander, 2009; Stajduhar et al., 2008; Walker et al., 2011), and to be associated with lower health care costs at the end of life more generally (Seow et al., 2019). Increased interest in home-based palliative care is also likely to reflect the preferences of many patients and their families for a home death (Canadian Hospice Palliative Care Association, 2013b; Stajduhar, 2003). Indeed, there is evidence that individuals who receive palliative care at home are likelier to remain and die at home (Canadian Institute for Health Information, 2018; Tanuseputro et al., 2018).

In Canada, one key component of home-based palliative care is home care, which refers to publicly-funded services provided in individuals' private homes that allow them to remain in the community. For the purposes of this dissertation, home-based palliative care refers to any palliative care provided in a home setting, while palliative home care refers to palliative care that is provided under the publicly-funded home care system to home care clients with identified palliative care needs. Even with greater emphasis on the provision of palliative care in home settings, it appears that only a minority (15%) of Canadians who died received palliative home care in their final year of life (Canadian Institute for Health Information, 2018). One reason for this finding may be the inadequate supply of palliative home care resources that have resulted from poor resource planning. Information on resourcing (i.e., the types of services being provided and the appropriate mix of resources), utilization patterns, and cost are all required in order to develop the understanding of the palliative care system needed for resource planning (Office of the Auditor General of Ontario, 2014). Presently, this understanding is limited by the dearth of information on the palliative care system in Canada (Canadian Institute for Health Information, 2018; Office of the Auditor General of Ontario, 2014, 2016), and is further complicated by the complexity and variability of care needs across the palliative care population (Aldridge & Bradley, 2017; Carter et al., 1999).

One way to address these challenges in understanding the health service needs and utilization of those requiring palliative home care is through case-mix classification systems. These systems categorize individuals into groups that are both clinically relevant and have relative resource homogeneity (Fries et al., 1994; Hornbrook, 1982). While there is considerable interest in the classification of persons receiving palliative care services or with palliative needs, it has traditionally been thought that the palliative care population was too heterogeneous and therefore unsuitable for classification. Nevertheless, a case-mix system for palliative care exists in Australia that classifies individuals receiving palliative care in both inpatient and outpatient settings (Eagar, Green, & Gordon, 2004; Eagar, Green, & Smith, 2004). Early work in France has also demonstrated that persons receiving palliative care can be categorized into clinically relevant groups with similar levels of resource intensity (Tibi-Lévy & d'Hérouville, 2004), while classification systems are in development both in Germany (Becker et al., 2018), and in England (Guo et al., 2018). In Canada, a home care case-mix system exists (Björkgren et al., 2000; Poss et al., 2008), but does not fully address the unique characteristics of clients with palliative care needs. Preliminary steps for the development of case-mix systems involve understanding the characteristics and service utilization patterns of a given care population, as well as identifying factors predictive of service utilization, and by extension, cost (Hopfe et al., 2016). Thus, this dissertation aims to understand home care clients with identified palliative needs (subsequently referred to as palliative home care clients) and identify predictors of their home care costs in Ontario, Canada's most populous province.

### 1.1.1 **Terminology**

#### 1.1.1.1 Palliative care

Palliative care is defined by the World Health Organization (WHO) as "an approach that improves the quality of life of patients […] and their families who are facing problems associated with life-threatening illness." (World Health Organization, 2017). Quality of life is improved by preventing and relieving physical, psychosocial and spiritual problems through early identification, assessment and treatment (World Health Organization, 2017). Specifically, palliative care provides relief from distressing symptoms like pain, supports individuals in living independently for as long as possible, and provides affirmation of life through a team-based, interdisciplinary approach (World Health Organization, 2017). Palliative care "intends neither to hasten or postpone death," although enhancements to quality of life can be provided alongside life-prolonging treatments early in the course of illness (World Health Organization, 2017). For families, palliative care can provide help with coping both during the illness and as part of bereavement (World Health Organization, 2017).

One common conceptualization of palliative care has been typified in the Canadian Hospice Palliative Care Association's model, which focuses on treatment early in the course of illness with some palliative care support provided to relieve suffering and improve quality of life (Canadian Hospice Palliative Care Association, 2013a). As the illness progresses and goals of care shift, the share of palliative care relative to treatment and therapies increases (Canadian Hospice Palliative Care Association, 2013a). Palliative care continues beyond death with bereavement for family and/or friends (Canadian Hospice Palliative Care Association, 2013a). More recently, a model of palliative care has been proposed that places greater emphasis on the possibility of survivorship for those receiving palliative care (Hawley, 2014). Referred to as the "bow-tie" model, it is meant to foster greater acceptability of palliative care, especially early in a course of illness, with the inclusion of survivorship as a possible outcome (Hawley, 2014).

#### 1.1.1.2 Hospice

Hospice care and supportive care are terms similar to palliative care that have been used in the literature. The term palliative care was introduced as an alternative to hospice care, which was stigmatized due to its association with death and dying (Phillips, 2019). Today, the term hospice care is used predominantly to describe community-based programs providing interdisciplinary care to individuals expected to survive less than six months, and their families (Hui et al., 2013). The care provided includes symptom management as well as bereavement care, and is considered to be a form of palliative care (Hui et al., 2013). This term is used primarily in the United States with its definition likely influenced by the parameters of the Medicare Hospice Benefit (Connor, 2009). In Canada, hospice has been used to refer to a setting of care where 24-hour care is provided in a home-like setting (Canada, 2018; Canadian Institute for Health Information, 2018). The definition of supportive care is also similar and has been described as "essentially equivalent" to palliative care, although there is greater heterogeneity in its definition than palliative care (Hui et al., 2013).

#### 1.1.1.3 End of life and terminally ill

End of life is another term that is used commonly in the palliative care literature. This term emphasizes prognosis and a time of irreversible decline prior to death (Lunney, 2001). Although the term has been used to describe prognoses ranging from days to years, it is most commonly understood as a period of months or less (Hui et al., 2014). Similarly, the term terminally ill has also been used to describe a prognostic period of months or less for those with a progressive, life-limiting condition (Hui et al., 2014). Unlike end of life, however, the focus is on the condition of the individual rather than a specific time frame (Hui et al., 2014). One example of its use is to describe the period after curative treatments have been stopped (McCusker, 1984). Implied in both terms are the impaired function and increased symptom burden observed during these periods (National Institutes of Health, 2004). End of life care and terminal care are thus used to describe the care provided during these periods of worsening symptomatology in the last months of life.

#### 1.1.1.4 Palliative care phase

Palliative care phase refers to a specific tool that was developed in Australia to communicate clinical status, and for care planning, quality improvement, and funding purposes. It describes a number of phases that exist prior to death for clients receiving palliative care, and includes stable, unstable, deteriorating, terminal and bereavement phases (Masso et al., 2015). Importantly, these phases are not necessarily linear as individuals can move in both directions (Masso et al., 2015). These phases are considered to be “distinct, clinically meaningful, phases of care” and interrater reliability has been found to be moderate (kappa=0.67) (Masso et al., 2015). For the stable, unstable and deteriorating phases, assignment is determined by the presence or absence of problem-related variables, variables related to activities of daily living (ADLs), and variables related to degree of carer support (Masso et al., 2015). Phase type has previously been reported to be the best predictor of palliative care service utilization, and it is included as part of the Australian case-mix system for palliative care (Eagar et al., 1997).

#### 1.1.1.5 Trajectories of death

The concept for dying trajectories was first introduced by Glaser and Strauss (1968) to describe patterns in duration and shape of the dying process. Four patterns were described and include a sudden plunge, a slow but steady decline, a fluctuating course followed by a plunge, and a slow decline that plateaus before an abrupt decline towards death (Glaser & Strauss, 1968). More recently, these trajectories have been referred to as sudden death, frailty, organ failure and terminal illness trajectories, respectively (Lunney et al., 2002). In particular, the terminal illness, organ failure and frailty trajectories are considered to represent the dying process for chronic conditions (Lunney et al., 2002). Understanding these trajectories is important for both care planning at the individual level, and resource planning at the policy level (Cohen-Mansfield et al., 2017; Glaser & Strauss, 1968). For the terminal illness trajectory, which is commonly associated with cancer, individuals may continue to function reasonably well even after development of the health condition until a rapid decline occurs (Lunney et al., 2002). One study looking at individuals dying from cancer, as compared to those dying of other conditions, found better functioning between one year and three months prior to death, at which point functional status declined markedly (Lunney et al., 2003). In the organ failure trajectory, which aptly describes those with a life-limiting organ system condition, functioning decreases gradually with periodic exacerbations in illness that make prognosis difficult to estimate (Lunney et al., 2002). Examples of this trajectory include chronic obstructive pulmonary disease or heart failure. Finally, the frailty trajectory is characterized by a slow, steady decline, with death resulting from complications of advanced frailty, such as old age (Lunney et al., 2002). Dementia is commonly associated with this illness trajectory.

### 1.1.2 Palliative care in Ontario

In Ontario, palliative care is defined as an approach to care that provides “comfort and dignity for patients and families who are living with a life-threatening illness,” and “helps people with the physical, psychological, social, spiritual and practical issues as well as coping with loss and grief during the illness and bereavement” (Health Quality Ontario, 2016). In addition to helping with coping, palliative care also helps individuals and their families with the preparation and management of the end of life process, preventing issues as they occur, and the promotion of meaningful and valuable experiences (Health Quality Ontario, 2016). Palliative care can be provided across a number of different care settings including a person’s home, long-term care facilities, in hospice, or in inpatient hospital settings (Health Quality Ontario, 2016). While it is recognized that the majority of individuals who die may have benefitted from palliative care, it appears that many Ontarians who die do not receive palliative care. Of those who died in 2017-2018, only 61.4% received palliative care in their final year of life (Health Quality Ontario, 2019).

#### 1.1.2.1 Inpatient hospital settings

Inpatient palliative care can be provided on palliative care units (PCUs) in acute care hospitals. While there does not exist a core set of services available across all PCUs in Ontario, the majority of these units provide care from palliative care physicians, nurses, occupational therapists, physiotherapists, spiritual care advisors, social workers, pharmacists and speech language pathologists (Towns et al., 2012). The majority of PCUs provide supportive care programs that include individual counseling and recreational therapy, care to patients requiring medical treatments like tracheostomies, are able to deal with patients with antibiotic resistant infections, provide palliative radiation treatment, as well as have physicians who can provide methadone for pain management (Towns et al., 2012). Palliative care can also be provided in regular beds located on medical wards that include general or subspecialty units like oncology. On some medical wards, a small number of beds may be designated specifically for the provision of palliative care. In contrast to PCUs, palliative care provided on medical wards tends to be provided by providers without specialized training in palliative care, and are less likely to have supportive care programs (Towns et al., 2012). Care on these general units is also likelier to include more aggressive treatments like intravenous chemotherapy or antibiotics (Towns et al., 2012). While some medical wards also have access to palliative care consultation services, these services are primarily located at hospitals with PCUs (Towns et al., 2012).

#### 1.1.2.2 Residential hospice

Residential hospices provide a home-like environment for individuals with life-limiting conditions who are unable to remain at home, but do not require care from an acute care setting. Care is provided by interprofessional teams specializing in the provision of palliative care and includes nurses, physicians, pharmacists, physiotherapists, social workers, and personal support workers (PSWs) (Hospice Palliative Care Ontario, 2015). Medical services that are commonly provided in this setting include care for a colostomy/ileostomy, oxygen, wound care, and care for central lines (Towns et al., 2012). Operational funding for residential hospices in Ontario is provided partly by the Ministry of Health and Long-Term Care (now separated into the Ministry of Health, and the Ministry of Long-Term Care) through the funding of nurse and PSW salaries (Hospice Palliative Care Ontario, 2015). In some cases, publicly-funded home care services provided by nurses and PSWs may also be provided in the residential hospice setting (Hirdes & Kehyayan, 2014; Hospice Palliative Care Ontario, 2015). The remainder of operational funding covering the costs of medical supplies, equipment, furniture, patient food, linens, psychosocial care, spiritual care, bereavement support, maintenance, housekeeping and administration are raised through fundraising activities and by private donations (Hospice Palliative Care Ontario, 2015). Volunteers also play a prominent role in residential hospices that can include administrative support, maintenance, food preparation and fundraising support (Hospice Palliative Care Ontario, 2015; Towns et al., 2012). A 2018 survey found 40 hospice organizations with a total of 72 sites in Ontario, but are not found in all regions of the province (Canadian Institute for Health Information, 2018).

#### 1.1.2.3 Long-term care

Long-term care facilities provide care to individuals with difficulty managing in their daily life, require 24-hour nursing and personal support services, and require supervision to ensure safety and well-being. They must also have care needs that exceed what can be provided through other community-based care services. While not all long-term care residents are at the end of life, this setting is a common place of death for those with chronic conditions (Brazil et al., 2006). For those at the end of life, palliative care may be provided in the long-term care setting where end of life care is considered to be a central component of care. Individuals receiving palliative care in this setting may not be formally identified as palliative care residents, however, which is reflected in the low proportion (6%) of residents being identified as having received palliative care in their final year of life (Canadian Institute for Health Information, 2018; Health Quality Ontario, 2016).

#### 1.1.2.4 Home care

Home care in Ontario refers to the government-funded care that is arranged by Home and Community Support Services (as of April 2021), previously known as Local Health Integration Networks (LHINs)  (Government of Ontario, 2021a). Until November 2019, 14 LHINs existed to represent 14 regions in the province, and which have since been clustered into five regions under Ontario Health (Government of Ontario, 2019b). The purpose of home care is to help individuals remain in the community and live as independently as possible. In Ontario, home care largely serves the needs of older adults aged 65 and over with the population of home care clients being comprised of 60% older adults, 20% adults between 18 and 64, 15% children under 18, and 5% palliative clients (Office of the Auditor General of Ontario, 2015).

Receiving home care services, including those for palliative care, begins with a referral that can be made by hospitals, family physicians, family members and/or clients (Office of the Auditor General of Ontario, 2015). To be eligible for home care, individuals must be insured by the Ontario Health Insurance Plan (OHIP) (Hirdes & Kehyayan, 2014). Further eligibility is then based on an assessment of individuals' needs and health status made through a home visit by a case manager (Government of Ontario, 2019a). Once individuals are deemed eligible for home care, a care plan outlining the types and volumes of services to be provided is created in order to address the needs of the referred individual (Government of Ontario, 2019a). Care that can be provided as part of care plans includes nursing, respiratory therapy, nutrition, physiotherapy, occupational therapy, speech language pathology, social work and personal support (Johnson et al., 2009). In addition, home care clients can be provided with access to medical supplies and equipment, as well as transportation to other health services (Government of Ontario, 2019a).

For palliative home care clients, they may be designated as an end of life client as part of the assessment process. According to a report by the Office of the Auditor General of Ontario (2014), the determination for this designation is guided by scales like the Palliative Performance Scale (PPS) or other tools depending on the LHIN, an expected prognosis of between three and six months, and/or that the referred individual is no longer receiving treatment for curative purposes. In many cases, clients designated as end of life are managed by specialized case managers dealing with caseloads consisting of end of life clients only. The primary difference between those designated as end of life home care clients and other palliative home care clients, however, is the intensity of service for which clients are eligible. Specifically, general long-stay home care clients are permitted a lower volume of service each week, even if they have identified palliative care needs (Office of the Auditor General of Ontario, 2014). In contrast, those designated as end of life are permitted to have higher volumes of service and may, in some cases, have no restrictions on these service volumes (Government of Ontario, 2020; Office of the Auditor General of Ontario, 2014). There exist home care clients with identified palliative needs who may not receive such a designation, which can be due to client preference (i.e., wishing to remain with a case manager who does not specialize in end of life case management, or lack of acceptance of terminal prognosis) or ineligibility for the designation. As such, while all end of life clients in Ontario may be considered palliative home care clients, the reverse is not necessarily true.

### 1.1.3 Andersen and Newman framework

The Andersen and Newman framework for health care utilization is a common theoretical model that has been used to conceptualize the use of health services by individuals, and takes societal, health system and individual factors into account (Andersen & Newman, 2005; Cai et al., 2017; Chai et al., 2013, 2014; Cheng et al., 2020; Masucci et al., 2013; Sun et al., 2017). In particular, it places emphasis on individual characteristics, which are further separated into predisposing, enabling and illness/need factors (Andersen & Newman, 2005). Predisposing factors are individual characteristics that “exist prior to the onset of specific episodes of illness” and can influence an individual’s propensity to use health services “even though the characteristics are not directly responsible for health service use” (Andersen & Newman, 2005). Categories that exist as predisposing factors include demographic characteristics such as age or gender, social structure characteristics like education or occupation, as well as beliefs that include attitudes towards health services or disease knowledge (Andersen & Newman, 2005). In contrast, enabling factors “make health service resources available to the individual” by impeding or facilitating individual’s access to health services, irrespective of need or propensity to use these services. (Andersen & Newman, 2005). They can be further categorized into family resources like income or insurance coverage, and community characteristics such as residence in an urban/rural area or levels of health human resources available (Andersen & Newman, 2005). Finally, illness factors, commonly referred to as need factors, describe an individual’s defined level of illness both subjectively and objectively (Andersen, 1995). Subjectively, individuals’ use of health services is influenced by their perceived need for care, while their objective level of need for care is determined by health care providers (Andersen & Newman, 2005). Examples of both subjective and objective need factors can include symptoms and diagnoses.

### 1.1.4 Cost analyses

Cost analyses are a form of economic evaluation and are one important way of looking at health service utilization. They are descriptive in nature, and provide information that can be used to support funding and resource allocation decisions (Bloom et al., 2001; Lowson et al., 1981), ensure accountability, conduct outcomes evaluation (Wodchis et al., 2013), and contribute to full economic analyses that look at effectiveness and value (Drummond et al., 1997). Conducting cost analyses requires clear study objectives in order to select a viewpoint, which in turn affects subsequent methodology on the measurement of service/resource utilization (Drummond & Jefferson, 1996; Weinstein et al., 1996). Viewpoints include the public payer perspective, which considers only costs incurred by the public health care system, while the societal perspective includes all costs incurred, most notably out of pocket expenditures (e.g. medications, travel expenses) and time costs associated with care provided by family and/or friend caregivers. Irrespective of the viewpoint used, the collection of utilization data is a key component to cost analyses, with collection of information on service utilization from medical records being recommended for observational studies (Drummond & Jefferson, 1996). Costs are then estimated by applying unit costs to services and/or resources used (Drummond et al., 1997).

One challenge specific to palliative care is the inconsistencies in accounting practices used across the sector. These inconsistencies are likely due to the origins of palliative care and residential hospices in the charitable sector where submission of routine cost and utilization data were not required (Carter et al., 1999; Groeneveld et al., 2017; Hill & Oliver, 1988; Tierney et al., 1994). As palliative care has transitioned increasingly into the formal health care system, and funded through hospital, long-term care and home care budgets (Williams et al., 2010), there may now be greater consistency to accounting practices. Nevertheless, services that are funded as palliative care are still not well-defined and can therefore lead to substantial differences in the types of costs included as part of cost analyses (Carter et al., 1999; Johnston, 2016).

### 1.1.5 Case-mix

Case-mix systems aim to explain health care utilization (Costa, Poss, et al., 2015; Turcotte et al., 2019). They are developed for policy purposes such as planning expected service demand; administration, including support for prospective payment systems; as well as research (Hornbrook, 1982). There are two types of case-mix systems. The first is an index system, which attaches weights to individuals' characteristics that are then summed in order to produce a value that represents their resource use (Fries, 1990). The second type is a cluster system that groups individuals based on their characteristics into clinically homogenous clusters (Fries, 1990). There are some advantages to cluster-based systems as they are better able to accommodate interactions between characteristics, are more intuitive, and are more widely acceptable (Fries, 1990). Most case-mix systems in use today are based on clustering, and classify patients into groups with similar clinical characteristics and resource utilization.

Case-mix is based mainly on patients' primary diagnosis in hospital-based acute care settings (Fetter et al., 1980). Outside of these settings, however, the classification of individuals based on diagnosis alone is thought to be inappropriate (Björkgren et al., 2000; Eagar, Green, & Smith, 2004). In particular, determinants of service needs in subacute and nonacute settings are complex, and involve many dimensions of functional (dis)ability in addition to medical conditions (Björkgren et al., 2000; Eagar, Green, & Smith, 2004). For palliative care, classification on diagnosis alone may also be inappropriate due to uncertainty over patients' expected survival (Tibi-Lévy & d'Hérouville, 2004). As such, case-mix development for palliative care requires an understanding of additional factors associated with service use.

#### 1.1.5.1 Australian National Sub-Acute and Non-Acute Patient (AN-SNAP) System

At present, the only case-mix system exclusively for palliative care exists in Australia as part of the AN-SNAP system. It was developed in 1996 through the broader AN-SNAP study, which was commissioned by the national government, and sought to develop a classification system to inform on the funding of care in subacute and nonacute care settings (Gordon et al., 2009). Specific to the development of the palliative care classification, episodes of inpatient or ambulatory palliative care were included as part of the study sample (Eagar, Green, & Gordon, 2004). Clinical data collected from this sample were comprised of basic clinical measures; palliative care phase (Masso et al., 2015); activities of daily living based on Resource Utilization Groups (RUG-ADL) that consider bed mobility, toileting, transfers and eating (Fries et al., 1994); and the Palliative Care Problem Severity Score (PCPSS) that is a clinician-assessed score based on pain, other symptoms, psychological/spiritual issues and family/caregiver issues (Eagar, Green, & Gordon, 2004; Masso et al., 2016). Other data collected from the episodes of care included service utilization, financial, and demographic data (Eagar, Green, & Gordon, 2004). Using these data, a cost analysis was first undertaken in order to derive a costed dataset. The analysis involved calculating mean per diem costs for the episodes of care, which were comprised of overhead and direct care costs that were then separated into core and noncore costs (Eagar, Green, & Gordon, 2004). Core costs were considered to be those from nursing and allied health services, while noncore costs included physician, imaging, pathology, pharmacy and capital costs, as well as volunteer time (Eagar, Green, & Gordon, 2004). The costed dataset, in conjunction with the other episode data were then used in regression tree analyses in order to separately classify inpatient and ambulatory episodes of care.

The result of these analyses contributed to the development of the palliative care component of the first version of AN-SNAP that had 134 classes, of which 33 were specific to palliative care (L. Lee et al., 1998). Of the 33 palliative care classes, 11 were for inpatient care, while 22 were for ambulatory care (L. Lee et al., 1998). For the 11 inpatient classes, palliative care phase was used as the first split. While the bereavement phase had its own class, the other palliative care phases were further split on RUG-ADL measures used in interRAI assessments (Fries et al., 1994; Morris et al., 1999), and in the case of the deteriorating phase, was then further split on age (Eagar, Green, & Gordon, 2004). For ambulatory palliative care, the first split was based on whether the phase type was bereavement. In episodes that were for bereavement, age was then used to further group episodes into two classes. Episodes where bereavement was not the phase type were further grouped into those for which care provided was primarily for therapies only, and those in which care was primarily for other forms of care (i.e., medical, nursing, multidisciplinary) (Eagar, Green, & Gordon, 2004). For classes that were not for therapies only, additional splits were made based on a combination of palliative care phase and provider type, followed by further splits on the combination of RUG-ADL, PCPSS, and length of episode (Eagar, Green, & Gordon, 2004). Overall, this system explained 17.1% of variation in costs for ambulatory patients, and 20.9% of overnight patients (Eagar, Green, & Smith, 2004). By comparison, a review of the performance of the Resource Utilization Groups Version III (RUG-III) classification system, used in long-term and post-acute care settings internationally, has been found to explain up to 65% of variance in wage-weighted staff time (Turcotte et al., 2019). The RUG-III for home care (RUG-III/HC) has also been found to explain 37.3% of combined formal and informal care costs (Poss et al., 2008). Nevertheless, the AN-SNAP system has been used for funding in some States/Territories of Australia, including New South Wales and South Australia (Green & Gordon, 2007).

Since the introduction of the AN-SNAP system, the classification system has been updated and is currently in its fourth iteration. In version four of the AN-SNAP system, palliative care now has 30 classes, and is split primarily on whether or not a patient is admitted to hospital (Green et al., 2015). This classification includes 18 admitted, and 12 non-admitted classes (Green et al., 2015). Within the admitted classes, 16 are for inpatient classes, of which four are for pediatric clients and two are for same-day classes (one of which is for pediatric clients) (Green et al., 2015). These classes are separated on palliative care phase, RUG-ADL, age, and palliative care phase at the beginning of an episode (Green et al., 2015). For the 12 ambulatory classes, four are for pediatric classes, with classes being defined using the same variables as the admitted classes, in addition to the PCPSS (Green et al., 2015).

#### 1.1.5.2 Other palliative care classification and case-mix development

In France, two studies have attempted to typologize palliative care patients in inpatient PCUs, albeit as part of proofs of concept rather than attempts to develop case-mix systems (Tibi-Lévy et al., 2006; Tibi-Lévy & d'Hérouville, 2004). In one study, the authors were able to categorize individuals in PCUs into five groups with similar costs (both direct and indirect) based on age, disease type, nature and number of symptoms, prognosis, and degree of care required using multiple correspondence analysis (Tibi-Lévy & d'Hérouville, 2004). In the second study, authors attempted to demonstrate the inappropriateness of funding PCUs through fixed payments by identifying key patient characteristics that could be used to segment PCU patients into cost groups in different types of hospitals (Tibi-Lévy et al., 2006). In hospitals providing medical, surgical and obstetrical care, degree of functional dependency, diagnosis (cancer versus other conditions), and patient age were the most significant characteristics in predicting cost group (Tibi-Lévy et al., 2006). By comparison, in extended care and rehabilitation hospitals, age was identified as the first segmentation criterion, followed by degree of dependency, and then presence of difficulties with elimination (Tibi-Lévy et al., 2006).

Other classification projects directed specifically at the development of case-mix systems have also been undertaken in England (Guo et al., 2018) and in Germany (Becker et al., 2018). In Germany, this classification work has been limited to specialist palliative care provided in hospital, where analyses of cost and predictors of cost have been done. Predictors of cost that were identified include phase of illness, Karnofsky Performance Scale score, and discharge type (Becker et al., 2018). In England, it appears that classification work aims to include inpatient, hospice and community settings based on a published study protocol (Guo et al., 2018). The study protocol proposes two stages that include the determination of potential classes through the identification of predictors of cost, and classification and regression trees in the first stage, followed by a second stage that aims to validate the classification developed as part of the first stage (Guo et al., 2018). For work undertaken in both Germany and England, it does not yet appear that case-mix classification systems resulting from these projects have been fully developed and/or made available.

## 1.2 Rationale and objectives

It is clear that palliative care has a growing role in Canadian health care. Particular emphasis has been placed on home-based palliative care as a potential way to reduce health care costs, as well as to allow individuals to remain in the community for as long as possible at the end of life. Palliative home care is one important component of home-based palliative care, providing a number of services including nursing and personal support to those with palliative needs. Yet despite its importance, understanding of palliative home care clients and their service utilization required for resource planning in Ontario is poor. Case-mix classification systems present one way of better understanding this complex and highly variable population. Existing information on palliative home care is neither sufficient to assess the plausibility of such a system, nor develop such a system, however.

To address this dearth of information, this dissertation first explores existing home- and community-based palliative care cost literature in Chapter 2. The characteristics and service utilization patterns of palliative home care clients in Ontario are then described in Chapter 3. Chapter 4 summarizes interviews with palliative care experts in Ontario to identify characteristics that are potential predictors of palliative care service need and service utilization. Costs of palliative home care are estimated, and predictors of these costs are identified in Chapters 5 and 6. Chapter 5 focuses on the prediction of formal palliative home care costs, with particular emphasis on the Palliative Performance Scale, a commonly used assessment tool. Chapter 6 focuses on informal, and combined formal and informal palliative home care costs. Finally, findings from this dissertation are summarized and discussed in Chapter 7.

# Chapter 2

# Literature Review

## 2.1 Objectives

The purpose of this review is to identify existing studies on the service utilization and costs of home-based palliative care programs. Specifically, the objectives of this review are to:

1. assess how the utilization and costs of home-based palliative care programs have been captured, including cost components, data sources and study design;
2. determine what is currently known about home-based palliative care service utilization patterns; and
3. examine predictors of home-based palliative care service utilization that have been previously identified.

Objective one of this review is detailed in this chapter, while objective two is summarized in Chapter 3 of this dissertation, and objective three is summarized in Chapters 5 and 6.

## 2.2 Methods

This review of literature was conducted in July 2020 and was guided by Arksey and O'Malley's (2005) methodological framework. Key concepts related to community, resource utilization and palliative care were used to search Medline, EMBASE, the Cumulative Index for Nursing and Allied Health Literature (CINAHL) and Scopus for articles that estimated the utilization of costs of community-based palliative-specific programs. Title searches were used for palliative and related terms that included "palliative," "hospice," "end of life," "dying" and "terminal" as palliative-specific programs were of primary interest for this review. These terms were used in conjunction with title, abstract and keyword searches for resource utilization and related terms including "resource use," "resource utilization," "service use," "service utilization," "health care utilization," "health care cost," "case-mix," "unpaid," "informal," and "societal". Finally, title, abstract and keyword searches were used for the terms "home" and "community."

Title and abstract reviews were conducted on the unique articles identified. As an in-depth understanding of the methods used to identify utilization and estimate costs were key components of this review, conference proceedings and abstracts, posters, commentaries, letters and editorials were excluded. This review was also restricted to articles focused on an adult population and published in English. Once the title and abstract review had been completed, a full-text review of the selected articles was conducted to ensure that inclusion criteria were met. Articles that did not report on methods and results related to resource use were excluded from review.

## 2.3 Results

The results of the searches were as follows: 327 articles in EMBASE and Medline, 203 in CINAHL and 311 in Scopus. The most common reason for exclusion during the title and abstract review was that the study did not include the costs and/or service utilization of a home/community-based palliative care program. In total, 31 articles were selected for full-text review. After the full text review, an additional three articles were excluded due to the absence of information on the measurement of resource use in two articles, and because home-based palliative care was not considered in one article. In total, 28 articles were selected for inclusion into this review representing 27 studies. Information on the study objectives and sample characteristics can be found in Tables A.1 and A.2 of Appendix A, respectively. Results focus on methods used to cost home- and community-based palliative care; however, methods used to cost care in other settings were also included for studies that met the inclusion criteria of this review.

### 2.3.1 Study design

Longitudinal study designs were used across all studies selected for review. Study follow-up periods typically ranged between six and 12 months, with death marking the end of follow-up. A prospective approach was commonly used, and for these studies, the mean follow-up period sometimes deviated from the period determined as part of the study design due to differences in expected survival and actual time to death. In some studies, the mean follow-up post-enrollment in the study was substantially shorter than determined as part of the study design (Dumont et al., 2010; Johnson et al., 2009), although the reverse was also observed with participants surviving beyond the predetermined study period (Dumont et al., 2010, 2015). In other prospective studies, this issue was avoided as no particular follow-up period was defined, instead aiming to capture costs from enrollment into the palliative care program until death (Cai et al., 2017; Chai et al., 2013), or over an episode of care defined as the duration of a phase of illness (Eagar, Green, & Gordon, 2004). The use of the post-enrollment period as the follow-up was also found in one retrospective study (Bogasky et al., 2014), although the retrospective identification of use in the final year was more common (Allan et al., 2005; Brick et al., 2017; Fassbender et al., 2005).

### 2.3.2 Cost components

Information on the settings and cost components selected for inclusion in the reviewed articles can be found in Table A.3 of Appendix A. Few studies described the process for determining relevant components for costing. Four studies reported using a Delphi approach that surveyed individuals who had recently provided care to a family member who had died of cancer to inform on cost components that should be considered (Dumont et al., 2009, 2010, 2014, 2015), and one study determined relevant cost components through a group of expert advisors (Eagar, Green, & Gordon, 2004; Eagar, Green, & Smith, 2004). Components selected for inclusion varied depending on the care setting.

Components of home-based palliative care were generally organized by service providers, although four studies considered the cost of home palliative services as a single component without differentiating service providers (Bogasky et al., 2014; Look Hong et al., 2020; McCaffrey et al., 2013; Shnoor et al., 2007). For most other studies, services provided by nurses, physicians and personal support workers (PSWs) were consistently included (Cai et al., 2017; Chai et al., 2013, 2014; Coyle et al., 1999; Dumont et al., 2009, 2010, 2015; Fassbender et al., 2005; Howell et al., 2011; Johnson A.P. et al., 2009; Klinger et al., 2013; Kralik & Anderson, 2008; Sun et al., 2017; Yu et al., 2015). In two studies, nurses were further differentiated as specialist nurses, consultant nurses, clinical nurses or advanced practice nurses (Klinger et al., 2013; Kralik & Anderson, 2008). Other health professionals that were considered included occupational therapists, physiotherapists, social workers and speech language pathologists (Chai et al., 2013, 2014; Dumont et al., 2009, 2010, 2015; Howell et al., 2011; Johnson et al., 2009; Klinger et al., 2013). Irrespective of the home service providers included, there was no further disaggregation to differentiate the types of services being provided by each provider in patients' homes. A number of studies did consider costs associated with equipment and supplies, and included beds, pain pumps and assistive devices (Brick et al., 2017; Dumont et al., 2009, 2010, 2015; Guerriere et al., 2016; Howell et al., 2011; Johnson et al., 2009), and a few studies included travel and administrative costs (Dumont et al., 2009, 2010, 2015; Haltia et al., 2018). For studies that adopted a societal approach, costs of care provided by family members or friends were also considered, as were out-of-pocket and third-party payer costs that included prescription medications, and medical equipment (Brick et al., 2017; Cai et al., 2017; Chai et al., 2013, 2014; Dumont et al., 2009, 2010, 2015; Sun et al., 2017; Yu et al., 2015). While some studies examined costs beyond home and community settings, there were no differences in the cost components selected as part of home- or community-based palliative care costs in these studies, as compared to those focusing only on home or community settings.

Where multiple care settings were considered as part of the study, hospital-based costs were frequently considered and categorized into inpatient and outpatient services. Inpatient care was included based on hospital admissions without further disaggregation of costs (Chai et al., 2013, 2014; Dumont et al., 2009, 2010, 2015; Guerriere et al., 2010; Haltia et al., 2018; Look Hong et al., 2020; McCaffrey et al., 2013; Yu et al., 2015). For outpatient palliative care provided in hospital settings, cost components were primarily service-based, and included diagnostic and lab tests, and treatments such as chemotherapy or radiotherapy (Chai et al., 2013, 2014; Coyle et al., 1999; Doyle et al., 1997; Eagar, Green, & Gordon, 2004; Eagar, Green, & Smith, 2004; Guest et al., 2006; Look Hong et al., 2020; Yu et al., 2015). Costs of drugs and clinic visits were also frequently included as components for outpatient palliative care (Chai et al., 2013, 2014; Eagar, Green, & Gordon, 2004; Eagar, Green, & Smith, 2004; Guerriere et al., 2010; Haltia et al., 2018; Kralik & Anderson, 2008; Look Hong et al., 2020; Mosoiu et al., 2014). Studies that focused on palliative care programs spanning across care sectors generally also included visits to the emergency department (ED) without further disaggregation (Chai et al., 2013, 2014; Dumont et al., 2009, 2010, 2015; Guerriere et al., 2010; Look Hong et al., 2020; Yu et al., 2015). Outpatient care provided outside of hospital settings consisted of visits to health care providers. Visits to physicians were consistently included in studies where outpatient care was considered, with physician services being further differentiated as visits to family physicians and to specialists in some studies (Chai et al., 2013, 2014; Dumont et al., 2009, 2010, 2015). Some studies also included non-physician services as cost components, although there was no differentiation on service provider type  (Chai et al., 2013, 2014; Dumont et al., 2009, 2010, 2015; Guerriere et al., 2010).

### 2.3.3 Measurement of service use and estimation of cost

Information on costs incurred were obtained through various approaches, and many studies used a combination of approaches to comprehensively capture costs incurred within the components identified. A summary of the data sources for service utilization and cost information used in the reviewed studies can be found in Table 2.1. Although the use of medical records is considered the best approach for collecting information on costs incurred (Drummond & Jefferson, 1996), the review of patient charts and home care records was used in only one study (Klinger et al., 2013). This study on a home-based palliative care program relied primarily on home care records to identify the use of home care services (Klinger et al., 2013). Home care records were supplemented with information from the review of charts from family physicians and from a local hospital to identify the use of other physician services, the ED and admissions to hospital (Klinger et al., 2013).

**Table 2.1: Data sources of reviewed articles**

| Article | Use Data | Cost Data |
|---|---|---|
| Allan et al., 2005 | British Columbia Linked Health Database | N/A |
| Bogasky et al., 2014 | Episode database of Medicare hospice users created by Office of the Assistant Secretary for Planning and Evaluation. | Daily wage-weighted visit units were calculated whereby one-fourth of the 2009 hourly wage rate for each visit discipline was multiplied by the corresponding number of visit units reported on hospice claims. |
| Brick et al., 2017 | 215 retrospective interviews were conducted with key informants (those closest to the deceased) between three- and 10-months post-death. | Various administrative data sources were used to assign unit costs. Informal care was valued using replacement cost of care. |
| Cai et al., 2017 | Ambulatory and Home Care Record; CBS-EOLC to measure caregiver burden | N/A |
| Chai et al., 2013 | Prospective, self-reported by caregivers through bi-weekly phone interview using AHCR (See Guerriere and Coyte 2011) | Labour cost estimates from 2006 census inflated to 2011 values for lost time; FFS rate schedules for physician and laboratory service unit costs; resource expenditure rates used by home care agencies used for publicly financed home care services; medication costs from the public drug insurance formulary rate; OOP costs reported by families; hospitalizations costed using RIW |
| Chai et al., 2014 | As above (Chai et al., 2013) | As above (Chai et al., 2013) |
| Chan et al., 2001 | Prospectively collected through monthly interviews by nurses. | Inpatient: per diem cost on cancer ward<br>Outpatient: cost per visit for clinic visits; formulary cost to hospital for drugs plus cost of pharmacists' services; diagnostic/lab tests were based on workload units for each type<br>Indirect costs/informal care: interview |
| Coyle et al., 1999 | Care providers gave information on resource input that included number of inpatient stays, outpatient visits, day care visits, hospice inpatient stays, whether patient received treatment, tests or procedures. | Determined based on national averages because of little reliable calculation of costs across districts. |

| Article | Use Data | Cost Data |
|---|---|---|
| Dumont et al., 2009 | Prospectively collected using questionnaire every 2 weeks to capture use (to be completed primarily by caregiver), and whether the costs were covered by family, not for profit, health system or other payer. | Alberta unit costs were used for formal care services and were adjusted using Alberta CPI to 2005-2006 prices; OOP costs were based on self-reports; travel costs were based on rates from the Canada Revenue Agency from 2005 adjusted to 2006 values; informal care costs were based on the value of household work in 1992, adjusted to 2005-2006 values. |
| Dumont et al., 2010 | As above (Dumont et al., 2009) | As above (Dumont et al., 2009) |
| Dumont et al., 2014 | As above (Dumont et al., 2009, 2010) | Similar to Dumont et al., 2009, 2010 except prices were adjusted to 2010 values. |
| Dumont et al, 2015 | As above (Dumont et al., 2014) | As above (Dumont et al., 2014) |
| Eagar, Green and Smith, 2004; Eagar, Green and Gordon, 2004 | Staff time were recorded by clinicians when doing the following activities: patient-attributable time, teaching, research, health promotion, travel, quality improvement, general clinical time, administration. | Financial data from facilities/community services and included all costs including salaries and wages, medical/surgical supplies, goods and services for direct (e.g. patient care) and indirect costs (e.g. administration/hotel costs) |
| Fassbender et al., 2005 | Use estimated using administrative data. | Inpatient costs: RIW multiplied by cost per weighted case, which includes operatizing costs and allocations of fixed overheads, administration, education and research dollars<br>Professional care: In nursing home and hospices per diem and actual costs were assigned; in home actual costs were used<br>Nursing home: accommodation fee plus average cost of care were used<br>Residential hospices: average reported cost used<br>Home care and medications: actual costs (from data on charges) used<br>Adjusted for inflation from 1996 to 1999 |

| Article | Use Data | Cost Data |
|---|---|---|
| Guerriere et al. 2010 | Prospective, self-reported by caregivers through bi-weekly phone interview using AHCR (See Guerriere and Coyte 2011) | OHIP fee schedules, payment rates for HC agencies, hospital stays from figures from Joint Policy and Planning Committee of Toronto, Cost of ED from Coyte et al., 2001; Medications from Ontario Drug Benefit program; OOP as incurred, time losses assigned monetary value using human capital approach - costs aggregated over entire period and expressed as rate per 30 days of observation. |
| Guest et al., 2006 | DIN-link database, contains longitudinal information on patients in GPs using Meditel software. | DIN-link |
| Haltia et al., 2017 | Health care service utilization collected from records of the Helsinki and Uusimaa Hospital District; visits to private practitioners collected from National Social Insurance Institution of Finland registries; informal service use data were from questionnaire mailed to patients. | Costs came from information from National Social Insurance Institution of Finland, hospital districts, administrative databases of cities (Helsinki, Espoo and Vantaa); informal care costed using a proxy good method that attached the mean pre-tax salary of a practical nurse in 2010 at €13.63. |
| Howell et al., 2011 | Administrative home care service data, OHIP billing data. | Estimated based on total billing charges. |
| Johnson et al., 2009 | Utilization were drawn from home care data, OHIP billings, ODB Program billings. | Associated fees were also drawn from service data and presented in 2007 dollars. For physician services provided under alternative funding plans, costs were imputed from fee for service charges. |
| Klinger et al., 2013 | Resource data came from the records of Enhanced Palliative Care Team, CCAC, and family physicians/family health teams. ED visits and hospitalizations came from community hospital records. | Costs determined based on CCAC, Enhanced Palliative Care Team and OHIP fee schedules<br>ED visits based on US Medical Expenditure Panel Survey |
| Kralik and Anderson, 2008 | Home-based PC service records. | N/A |
| Look Hong et al., 2020 | OHIP, Discharge Abstract Database, National Ambulatory Care Reporting System, Home Care | Costs generated from three methodologies at the Institute for Clinical and Evaluative Sciences: |

| Article | Use Data | Cost Data |
|---|---|---|
| | Database, Registered Persons' Database, Continuing Care Reporting System | disaggregated health system costs, cancer-specific costing methodologies for cancer-related medications, and radiation (see Austin, 2011; Mittmann et al., 2019; Pink & Bolley, 1994) |
| Masucci et al., 2013 | Prospective, self-reported by caregivers through bi-weekly phone interview using AHCR (See Guerriere and Coyte 2011) for five main service categories that included home-based physician visits, nurse visits, personal support visits, ambulatory physician visits, other ambulatory and home-based visits. | N/A |
| McCaffrey et al., 2013 | Patient data were collected prospectively (method for collection unstated). | Inpatient costs from case-mix weights of the Australian Refined Diagnosis Related Groups as recommended by the Australian Medical Services Advisory Committee; specialist palliative care and costs from the Palliative Care Extended Packages at Home costs based on local salary hourly rates, agency staff costs and equipment costs; National Hospital Cost Data Collection used for outpatient costs. |
| Nesrallah et al., 2018 | OHIP, Discharge Abstract Database, National Ambulatory Care Reporting System, Home Care Database, Continuing Care Reporting System, RAI-CA, RAI-HC | N/A |
| Shnoor et al., 2007 | District quality control unit provided the data on use of services. | Ministry of Health's price list for ambulatory care, medications and some private services; inpatient costs based on the fixed cost per hospital day paid by third-party payer; for home health services, salaries, administrative costs, overhead and costs of training were also included, as well as the cost of running home hospice units, but the source of these costs are unclear. |
| Sun et al., 2017 | Prospective, self-reported by caregivers through bi-weekly phone interview using AHCR (see Guerriere | N/A |

| Article | Use Data | Cost Data |
|---|---|---|
|  | and Coyte 2011) for home-based physician visits, nurse visits, and personal support visits. |  |
| Yu et al., 2015 | Prospective, self-reported by caregivers through bi-weekly phone interview using AHCR (see Guerriere and Coyte 2011). | OHIP for physician and laboratory services; ODB fee schedule for medications; CCAC costs for home-based public services; unpaid care time valued using Human Capital Approach for time lost from employment, and replacement cost using the hourly wage of a homemaker for caregiver time lost to leisure and household work; hospitalization costs from CIHI's RIW; OOP costs were self-reported. |

AHCR = Ambulatory Home Care Record; CBS-EOLC = Caregiver Burden Scale in End-of-Life Care; CCAC = Community Care Access Centre; CIHI = Canadian Institute for Health Information; CPI = consumer price index; DIN = Doctors Independent Network; ED = emergency department; FFS = fee-for-service; GP = general practitioner; LTC = long-term care; N/A = not applicable; ODB = Ontario Drug Benefit; OHIP = Ontario Health Insurance Plan; OOP = out of pocket; RAI-CA = Resident Assessment Instrument – Contact Assessment; RAI-HC = Resident Assessment Instrument – Home Care; RIW = resource intensity weight

Administrative data were used to capture a wide range of costs incurred in home care programs, long-term care, acute care, emergency departments, publicly funded drug programs, and from physician billings (Allan et al., 2005; Bogasky et al., 2014; Fassbender et al., 2005; Guest et al., 2006; Haltia et al., 2018; Howell et al., 2011; Johnson et al., 2009; Look Hong et al., 2020). These data were collected by health authorities and ministries, and so only costs incurred by the public health care system were captured. Studies that explored the costs of cross-sector palliative care programs relied on linkages across administrative databases (Allan et al., 2005; Bogasky et al., 2014; Fassbender et al., 2005; Howell et al., 2011; Johnson et al., 2009).

Remaining studies relied primarily on patient and family interviews, and were prospective in nature. A large number of studies conducted these interviews using the Ambulatory Home Care Record (AHCR) framework and tool, which measures public costs in ambulatory, inpatient and home settings, as well as private costs from third-party insurers, out-of-pocket costs, and time lost to caregiving and from work (Guerriere & Coyte, 2011). For studies that used the AHCR, an in-person interview with patients and their caregivers was first conducted, and was then followed up with biweekly phone interviews on a prospective basis with caregivers to collect information on services or resources used in the prior two weeks, including caregivers' time dedicated to caregiving (Cai et al., 2017; Chai et al., 2013, 2014; Guerriere et al., 2010; Sun et al., 2017; Yu et al., 2015). A similar data collection approach was used by Dumont et al. in four studies that collected information on the utilization of services in two week increments through interviews with participants that were comprised of patients and their primary caregivers (Dumont et al., 2009, 2010, 2014, 2015). The form used to collect this information was developed using a Delphi process to determine relevant cost components that should be included as part of the form (Dumont et al., 2009, 2010, 2014, 2015). These components included resources and services used in hospital, long-term care, in an outpatient setting, and at home (Dumont et al., 2009, 2010, 2014, 2015). Interviews with participants also collected information on time spent caregiving in excess to time spent on household activities prior to palliative care recipients' illness (Dumont et al., 2009, 2010, 2014, 2015).

A number of studies used information on the costs of home-based services, including costs not directly related to patient care, that were determined based on average payment rates to home care agencies. These rates were obtained from regional health authorities that were responsible for payment of these services (Chai et al., 2013, 2014; Dumont et al., 2009, 2010, 2015; Guerriere et al., 2010; Howell et al., 2011; Johnson et al., 2009; Klinger et al., 2013; Yu et al., 2015). Costs of home visits by physicians for palliative care were derived from fee service schedules (Chai et al., 2014). The costs of hospital admissions were estimated using patient-level estimates of hospitalization costs that were derived from the multiplication of resource intensity weights assigned to records of acute care with the average cost of a hospital stay in the jurisdiction (Chai et al., 2013, 2014; Fassbender et al., 2005; Yu et al., 2015). Other studies that included inpatient costs relied on the average cost of hospitalization (Guerriere et al., 2010; Guest et al., 2006).

Across studies, informal care costs were valued using one of two methods. The first approach valued informal care time as the replacement cost of unpaid work that was estimated by Statistics Canada (Chandler, 1994), and then adjusted for inflation (Dumont et al., 2009, 2010, 2014, 2015). For the second approach, informal care was valued using a combination of time lost to paid and unpaid labour, in addition to leisure, from the Canadian census matched on caregiver age and gender (Cai et al., 2017; Chai et al., 2013, 2014; Guerriere et al., 2010; Sun et al., 2017; Yu et al., 2015). These census estimates were further adjusted for inflation, nominal earnings, employer-paid benefits, vacation days, and holidays (Cai et al., 2017; Chai et al., 2013, 2014; Chan et al., 2001; Guerriere et al., 2010; Sun et al., 2017; Yu et al., 2015).

Finally, in regard to the units of measurement selected, the majority of studies reported costs at the person level. Studies that reported costs over the entire sample population generally sought to inform on funding and resource allocation decisions, or for the evaluation of a pilot palliative care program (Howell et al., 2011; Johnson et al., 2009; Klinger et al., 2013). The time unit used to express costs is also relevant. Some studies expressed costs as the total for an entire period from study or program enrollment until death (Chan et al., 2001; Johnson et al., 2009), although most used a defined period of time like a certain number of months prior to death (Brick et al., 2017; Chai et al., 2013, 2014; Coyle et al., 1999; Guerriere et al., 2010). In the studies that were aimed at classifying persons receiving palliative care, per diem costs were calculated using the aggregate episode costs divided the duration of the episode (Eagar, Green, & Gordon, 2004; Tibi-Lévy et al., 2006; Tibi-Lévy & d'Hérouville, 2004).

## 2.4 Discussion

The purpose of this portion of the review was to consider how the costs of palliative care programs are currently being estimated, including cost components, data sources and study design. Overall, there was substantial variation across the reviewed articles reflecting the wide-ranging objectives of the reviewed studies. These objectives included informing on system-level funding, resource allocation decisions by care providers, contributing to case-mix development, as well as evaluating pilot programs. There were no studies that examined palliative home care specifically, although a number of studies included home care services as part of a broader array of palliative care services provided at home. In addition, there were no studies that addressed the plausibility of a case-mix system for this care setting. Nevertheless, these studies raised some important methodological considerations relevant to this dissertation.

In regard to the analytic perspectives, perspectives that were adopted in the studies reviewed were either societal or public payer. For studies that adopted a societal perspective, the primary objectives of the studies tended to be to understand the financial implications of palliative care on families. Studies that adopted a public payer perspective were primarily for the evaluation of existing or newly developed palliative care programs, or to inform on public funding of palliative care. Interestingly, the study with the objective of developing a case-mix system (Eagar, Green, & Gordon, 2004; Eagar, Green, & Smith, 2004) adopted a public payer perspective. The use of this perspective is reasonable given that the focus of this study was primarily on inpatient care settings where the large majority of costs are incurred by the public health care system. For this dissertation, however, both viewpoints need to be considered given its focus on palliative home care, a setting in which families provide a substantial amount of care that would otherwise require formal care services (Dumont et al., 2009; Gott et al., 2015).

Different methods for defining and valuing caregiver time were used in the reviewed studies, although not all are necessarily appropriate for the purposes of this dissertation. Considering only caregiver time in excess of usual time spent on household tasks as found in the studies by Dumont et al. (2009, 2010, 2014, 2015) ignores that even caregiver time not spent in excess would still require the substitution of formal services if they were not provided by informal caregivers. The alternate approach identified in this review, which accounts for all dedicated caregiving time, may be appropriate for the purposes of this dissertation. With regard to the valuation of caregiving time, both approaches identified in the reviewed studies may not be entirely relevant in capturing the costs associated with palliative home care client needs that would otherwise have to be addressed through formal care services. Home care case-mix studies outside of the palliative care literature have previously attached values to caregiving based on a rate relative to PSW costs (Björkgren et al., 2000; Cheng et al., 2020; Poss et al., 2008), and may be more appropriate for the purposes of this dissertation.

For cost components, it was unsurprising to see that the components included were primarily influenced by the analytic perspective adopted. For studies from Ontario, palliative home care components were organized by provider type and consistently included services provided by nurses and PSWs, but did not necessarily include the full array of provider types available through Ontario’s publicly funded home care system. The inclusion of only nursing and personal support costs may be reasonable since the bulk of home care costs can be attributable to services provided by nurses and PSWs (Cai et al., 2017), although it would be preferable to include other publicly-funded home care services in order to capture as much client variance as possible. Interestingly, one component that did not appear in the Ontario-based studies was case management costs. In cost analyses of a long-stay home care client population, this exclusion may be reasonable since case management costs can be expected to be relatively similar and stable across clients (Cheng et al., 2020). For palliative home care clients, however, care needs can change frequently, consequently requiring a greater intensity of case management. As such, case management should be included in estimates of cost for palliative home care.

Study follow-up period and units of measurement are also important considerations for this dissertation. Length of follow-up varied across studies, but no studies were instructive on the length of follow-up appropriate for cost analyses required in this dissertation given the potential case-mix development implications. Specifically, costs are known to be greater during transition points (Gibson et al., 2013) and so selecting time periods that are too short may not allow costs to stabilize post-transition. A time period that is too long is also problematic, however, as those receiving palliative care can decline rapidly. For unit of measurement, studies that classified individuals receiving palliative care used per diem costs, and is likely to be appropriate for the objectives of this dissertation.

A final consideration based on the studies reviewed were the data sources selected for identifying service utilization and estimating cost. Although a number of studies in this review relied on utilization information collected through interviews with the families of patients, this approach is likely inappropriate for analyses that are required as part of this dissertation. Recall bias is certainly a concern for data collected through caregiver interviews, but the greatest limitation of using this data collection method is its impracticality for large samples that are required to inform on resource planning and case-mix development (Tibi-Lévy & d'Hérouville, 2004). Instead, administrative data are considered to be more appropriate in examining health service utilization and cost since the primary function of these data is for billing and/or payment of health services (Allan et al., 2005). Use of these data also allows for large samples to be drawn efficiently, and can potentially provide an unbiased measure of health service utilization at the population-level (Allan et al., 2005; Urquhart et al., 2015). Indeed, a number of studies originating from Canada relied upon this type of data (Fassbender et al., 2005; Howell et al., 2011; Johnson et al., 2009; Klinger et al., 2013; Nesrallah et al., 2018), demonstrating the feasibility of these data for subsequent analyses in this dissertation. There are, of course, some limitations to administrative data that should be noted as well, including challenges in defining and identifying individuals who are, and services that are "palliative" (Allan et al., 2005). More generally, administrative health databases can also be limited to certain segments of the population (i.e., seniors) due to service eligibility criteria, or to certain types of services (Klinger et al., 2013; Tanuseputro et al., 2015).

### 2.4.1 Limitations

This review included only literature on palliative care that contained some component of home- or community-based care. While this inclusion criterion was appropriate based on the focus on palliative home care in this dissertation, only a small number of studies were identified that met this criterion. Of these studies, few examined predictors of home-based palliative care service utilization or costs, and the number of studies that focused on, or included informal care were particularly small. Supplementation to studies identified in this review with grey literature and research that is nonspecific to palliative care but examine service utilization and costs at the end of life or of dying (Tanuseputro et al., 2015), and of home care (Björkgren et al., 2000; Cheng et al., 2020; Health Council of Canada, 2012; Y. Lee & Penning, 2019; Poss et al., 2008) can help to further inform on subsequent analyses in this dissertation.

## 2.5 Conclusions

This review identified only a small number of studies that examined home- and community-based palliative home care service utilization and costs, providing further support to the need for research being undertaken as part of this dissertation. Overall, the methods used in the studies included as part of this review appeared to be appropriate in addressing their study objectives. Some considerations for subsequent analyses in this dissertation include the use of both a payer and societal perspective, inclusion of cost components for all palliative home care service types, identification of an appropriate period for aggregating costs, as well as use of administrative data that are comprehensive in capturing palliative home care service utilization. Additional literature nonspecific to home and community settings, or to palliative care will need to be considered to inform on analyses on predictors of palliative home care costs in this dissertation.

# Chapter 3

# Characteristics and Service Utilization Patterns of Palliative Home Care Clients

## 3.1 Introduction

Most Canadians prefer to remain at home at the end of life, with at least one survey finding that that the majority would prefer a home death (Canadian Hospice Palliative Care Association, 2013b; Stajduhar et al., 2008). However, the ability to remain at home through the end of life is largely dependent on the ability to access care services at home. By providing access to medical equipment, nursing and personal support services, as well as services from other health professionals, home care plays an important role for those living with a life-limiting condition to make a remaining at home possible (Guerriere et al., 2015). These services help by providing care at home that would otherwise be provided in acute care hospitals or long-term care homes, as well as supporting caregivers who provide the majority of care to these individuals.

There is evidence that those receiving palliative home care have better outcomes than those receiving standard home care at the end of life. One report found that those receiving palliative home care were more likely to have a home death as compared to those receiving other forms of home care (Canadian Institute for Health Information, 2018). From a cost perspective, it has also been noted that those enrolled in community-based palliative care programs that include home care have lower costs due to fewer hospitalizations prior to death (Haltia et al., 2018; Seow et al., 2019; Yu et al., 2015). Higher formal palliative home care cost has also been found to decrease the likelihood of emergency department visits and hospitalizations (Salam-White et al., 2014), which are costly. Yet a report from Ontario found that of those who resided in the community and died in 2017-2018, only 25.3% received palliative home care in their final month of life (Health Quality Ontario, 2019). Expanding access to palliative home care requires an understanding of the characteristics and service utilization patterns of those receiving these services.

No studies to date have examined costs in palliative home care specifically, although there have been some studies examining the costs and utilization patterns of those receiving home-based palliative care services. Based on these studies, it would appear that individuals with palliative needs only began to receive home-based palliative care services in the final six months of life. One study from Finland found that on average, those with a cancer diagnosis remained on home-based palliative care service for 179 days prior to death (Haltia et al., 2018). This length of service was lower in Ontario where a study of those with a cancer diagnosis found that individuals received home-based palliative care in only the final four months of life (Yu et al., 2015). This duration may be different for those with noncancer diagnoses, as one study found that those in Ontario with noncancer diagnoses received home-based palliative care for a longer duration than those with a cancer diagnosis (Klinger et al., 2013), while another study of individuals with renal disease found that home-based palliative care was initiated only in the final month of life for 80.2% of individuals (Nesrallah et al., 2018). Aside from diagnosis-related differences, regional differences have also been observed. A study of home-based palliative care in Ireland found significant differences in the level of service utilization across three areas (Brick et al., 2017), while in Canada, the utilization of palliative home care services were found to be lower in rural areas than in urban areas (Dumont et al., 2015).

In looking across the care trajectory, studies also found that service utilization and costs tended to be low early in the trajectory, and increased with proximity to death (Chai et al., 2013; Dumont et al., 2010; Hollander, 2009; Sun et al., 2017). While much of the increase in utilization and cost were attributable to the rise in admissions to hospital (Coyle et al., 1999; Sun et al., 2017), the increase in home care costs was also high with one study finding that these costs increased from $188 to $1,032 over the final five months of life (Dumont et al., 2010). This increase was less dramatic in another study of costs that was nonspecific to the home setting, but still found that costs increased over the final year of life at 21.6% for privately financed costs, 12.7% for publicly funded costs and 10.8% for informal care costs

(Chai et al., 2013). These increases may not necessarily be linear, however. One American study observed that utilization was greater in the period immediately following the initiation of palliative services (Bogasky et al., 2014). In Canada, the greatest increase in costs was found in the final three months of life (Dumont et al., 2010), while a study from Ontario described the increase in costs over the last year of life as “exponential” (Chai et al., 2013). Increases in service utilization differed across service types as well, with use of physician services fluctuating across the trajectory but highest in the final month of life, while services provided by nurses and personal support workers (PSWs) increased across the trajectory until the final month of life when their use decreased (Sun et al., 2017).

Change in Canadian palliative home care service utilization patterns over time has also been investigated. One study found a decline in visits to physicians and utilization of home nursing services between fiscal years 1992-1993 and 1998-1999 (Allan et al., 2005). Another study looked at palliative programs in Alberta, Canada and found that while 45% of decedents with a cancer diagnosis were referred to these programs in 1993, this proportion had increased to 81% by 2000 (Fassbender et al., 2005). These increases varied across services, however, as one study found substantial increases in the propensity for home-based physician visits and personal support services between 2005 and 2015, with physician home visits increasing 40% and PSW services increasing fourfold (Sun et al., 2017). In contrast, the propensity for home nursing services decreased 60% over this same time period (Sun et al., 2017). Regarding the intensity of services, Sun et al. (2017) found that the intensity of physician home visits increased 40% between 2005 and 2015, and decreased by 20% for nursing services. The change in intensity of PSW visits was found to be variable between 2005 and 2015, with a decrease in intensity between 2010 and 2012 as compared to 2005 and 2007, followed by a large increase between 2013 and 2015 (Sun et al., 2017).

Studies that adopted a societal viewpoint also examined informal care. Characteristics of the informal caregivers were not described in all studies, although those that did found that they were more likely to be female, and either a spouse or child to the individual receiving palliative care services (Cai et al., 2017; Chai et al., 2013, 2014; Guerriere et al., 2010; Sun et al., 2017; Yu et al., 2015). Many of these caregivers were also unemployed, retired, or on leave from work (Cai et al., 2017; Chai et al., 2013, 2014; Guerriere et al., 2010; Sun et al., 2017; Yu et al., 2015). Across studies, the intensity of informal care provided to individuals receiving palliative care was expressed as costs (rather than hours), and were found to be substantial (Brick et al., 2017; Cai et al., 2017; Chai et al., 2013, 2014; Dumont et al., 2009, 2014, 2015; Guerriere et al., 2010; Sun et al., 2017; Yu et al., 2015). There were wide variations in the costs of informal care due to differences in the valuation of informal care time, which was discussed in Chapter 2. Two studies examined changes in informal care costs over the end of life trajectory. One study from Ontario found that these costs increased with proximity to death, although there were some fluctuations early in the trajectory (Chai et al., 2014). A different study from various regions in Canada found that while costs increased between five and three months prior to death, they declined in the final two months of life (Dumont et al., 2010).

## 3.2 Rationale and objectives

Understanding the palliative home care system is required in order to inform on resource planning and allocation decisions. This understanding requires information on the characteristics of individuals receiving these services, as well as their service utilization patterns. While there have been studies looking at the costs and utilization of home-based palliative care service in Ontario and beyond, these studies have been limited in sample size, to specific diagnostic groups, and often to a single palliative care program. Together, these studies provide only a patchwork of information of limited utility for resource planning purposes. The distinction between palliative home care and home-based palliative care is also important to informing on planning and allocation decisions in Ontario given that home care budgets are separate from the budgets of other care settings. The purpose of this study was therefore to characterize palliative home care clients in Ontario and describe their utilization of palliative home care services. Specifically, the objectives of this study were to address the following questions:

1. What are the characteristics of individuals using palliative home care services?

2. What palliative home care services are clients using, and how are they using these services? Specifically,
    a) How long do clients remain on palliative home care and what are their reasons for discharge from service?
    b) What proportion of home care clients receive each palliative home care service type?
    c) What volume of services are being used by clients?
    d) How does service use change over the course of care?
3. What informal help are clients receiving?

## 3.3 Methods

This study used a retrospective cohort approach with a follow-up period of up to 181 days post-assessment (for up to a total 182-day study period, representing 6 months) and was conducted using secondary administrative and clinical health data. A 182-day study period was selected to correspond with the prognostic categorization for palliative home care clients found in the interRAI Palliative Care (interRAI PC) instrument. Ethics approval for this study was provided by the Office of Research Ethics (ORE) at the University of Waterloo (ORE #41489), as well as the Research Ethics Board at Wilfrid Laurier University (File #6486).

### 3.3.1 Data

An analytic dataset was created for this study by linking palliative home care assessment data from the interRAI PC to referral information and service utilization records collected by the Local Health Integration Networks (LHINs) through the Client Health Related Information System (CHRIS). CHRIS is managed by Health Shared Services Ontario (HSSOntario) (now a part of Ontario Health) and is used by LHINs to manage referrals, clinical assessments, procurement and billing of home care services, procurement and billing of equipment and supplies for clients, as well as applications and placement for long-term care. The use of these data for the management of home care clients and their services means that these data can be expected to be both reliable and complete. Data from CHRIS were obtained through a sharing agreement between HSSOntario and the University of Waterloo, allowing for the transfer of anonymized, client-level data from HSSOntario to the University of Waterloo. Data of this type have been used in previous home care case-mix research done in Ontario (Cheng et al., 2020; Poss et al., 2008).

#### 3.3.1.1 interRAI Palliative Care (PC)

For those receiving palliative home care in Ontario, the interRAI PC is used by trained case managers to assess individual needs in order to develop care plans. This instrument was developed by interRAI, an international collaborative of clinicians and researchers working to promote clinical practice and health policy using high quality data through the development and implementation of health assessment instruments across health settings (L. C. Gray et al., 2009). The interRAI PC instrument contains sections that collect demographic information, as well as information on health conditions, nutritional status, skin conditions, cognition, communication, mood, psychosocial well-being, functional status, continence, medications, treatments and procedures and directives (Steel et al., 2003). Information on support provided by caregivers can also be found in the interRAI PC (Steel et al., 2003). Many of the items contained within these sections are common to interRAI instruments in use in other health settings such as acute care, mental health, long-term care and home care (L. C. Gray et al., 2009), and many of these items have been found to be valid and reliable across the suite of instruments, including the interRAI PC (Hirdes, Ljunggren, et al., 2008; Steel et al., 2003). Data from this instrument have been used for palliative care research related to caregiver distress (Freeman et al., 2016), depressive symptoms (Fisher et al., 2014), pressure ulcers (Brink et al., 2006), do not resuscitate orders (Brink et al., 2008), determinants of home death (Brink & Smith, 2008), prognostic awareness (Fisher, Seow, Cohen, et al., 2015), nutrition (Stevens et al., 2021), as well as for the development of clinical assessment protocols (Freeman et al., 2014).

#### 3.3.1.2 Referral data

Referral data are comprised of all client referrals made to LHINs. Information found as part of these data include age, gender, forward sortation area (first three characters of the postal code), LHIN of residence, referral date, source of referral, admission status of referred client, service recipient code (SRC), date of admission, date of discharge, and reason for discharge.

#### 3.3.1.3 Service utilization data

Service utilization data include records of the services provided to home care clients in Ontario. These records include information on the type of service/provider providing the service, the date of service provision, as well as information on the unit(s) of service provided (i.e., number of visits or hours depending on the service). These data are considered to be accurate as providers are incentivized to be paid for all services that they have provided, while LHINs are incentivized to pay only for services that were provided to its clients. At the time of this study, the most recent service utilization data available for analyses were up to March 31, 2018.

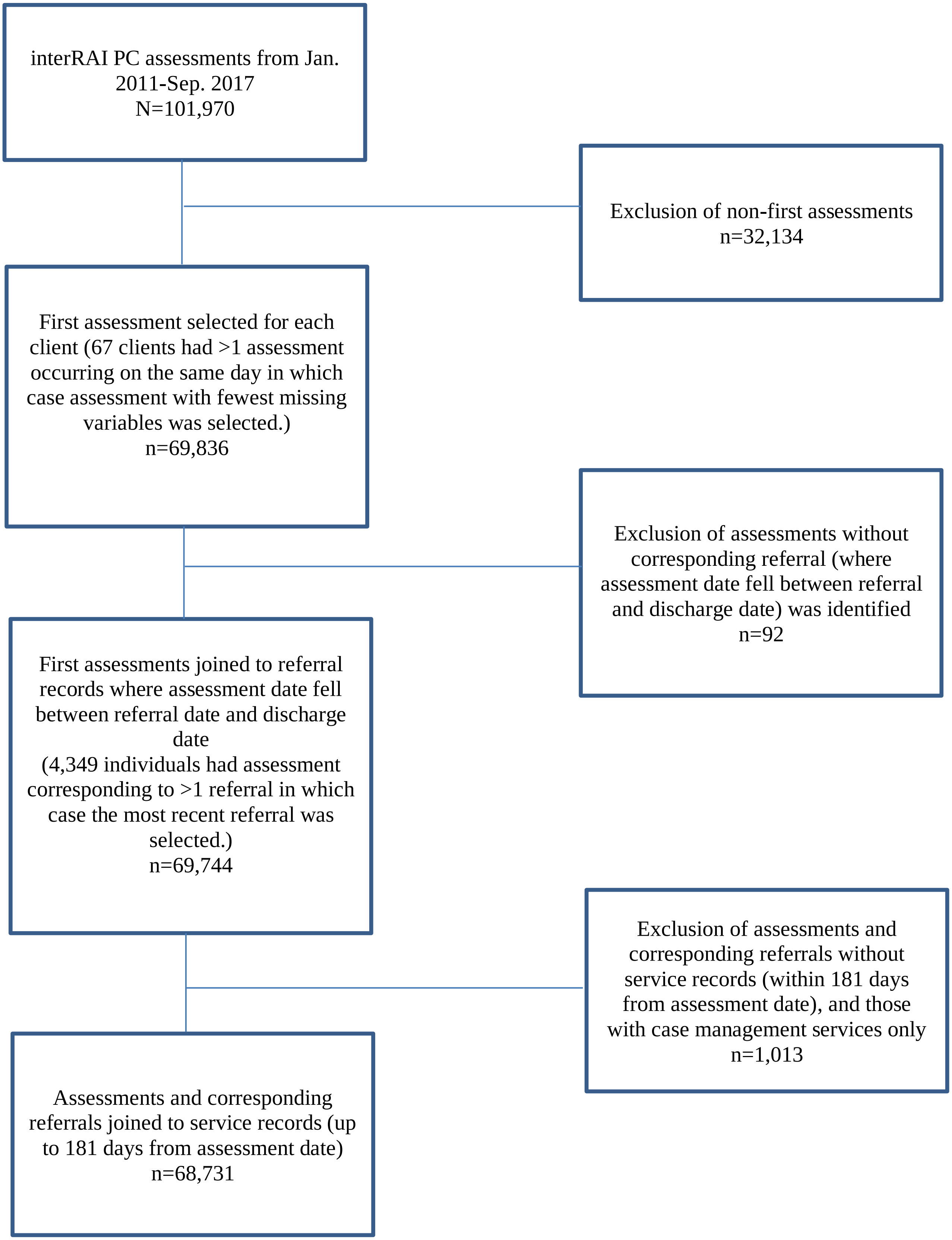
### 3.3.2 **Sample**

The study sample was created by identifying all interRAI PC assessments for individuals residing in a private home/apartment/rented room conducted between January 2011 and September 2017. These dates were selected to represent the earliest and most recent dates for which interRAI PC assessments were available for analyses when considering the 181-day follow-up period required for this study. In total, 101,970 assessments were identified. The first interRAI PC assessment for each individual was then selected resulting in the exclusion of 32,134 assessments. Data quality checks identified that for 67 clients, more than one interRAI PC assessment occurring on the same day existed. For these 67 clients, further data quality checks identified the assessment record with the fewest missing variables and retained that record for inclusion into the study sample.

Corresponding referral information was then obtained by joining assessment data with referral data using a deidentified, unique client identifier, and where the date of assessment fell between the referral and discharge dates. In the case of 5,103 assessments, more than one referral was identified that fit these criteria, in which case the most recent referral was selected. Priority was given to referral records with end of life care as the reason for referral (as denoted by a SRC 95 at admission), followed by those with acute (SRC 91), rehabilitation (SRC 92), maintenance (SRC 93) or long-term supportive (SRC 94) as reasons for referral. These criteria led to the further exclusion of 92 assessments for which a corresponding referral could not be found.

Assessments and their corresponding referrals were then joined to all service records for services occurring up to 181 days from assessment date using the client identifier. A further 1,013 assessments were excluded as they did not have corresponding service records, or had only a record of case management during the 182-day study period. Those with only a record of case management during the follow-up period were also excluded as they were thought to be unrepresentative of palliative home care clients more generally. The result was a study sample containing 68,731 assessments with corresponding referral and service utilization information, representing the same number of palliative home care clients. A visual representation of this study sample creation can be found in Figure 3.1.

**Figure 3.1: Study sample flowchart**



interRAI PC assessments from Jan. 2011-Sep. 2017
N=101,970

Exclusion of non-first assessments
n=32,134

First assessment selected for each client (67 clients had >1 assessment occurring on the same day in which case assessment with fewest missing variables was selected.)
n=69,836

Exclusion of assessments without corresponding referral (where assessment date fell between referral and discharge date) was identified
n=92

First assessments joined to referral records where assessment date fell between referral date and discharge date
(4,349 individuals had assessment corresponding to >1 referral in which case the most recent referral was selected.)
n=69,744

Exclusion of assessments and corresponding referrals without service records (within 181 days from assessment date), and those with case management services only
n=1,013

Assessments and corresponding referrals joined to service records (up to 181 days from assessment date)
n=68,731

### 3.3.3 **Measures**

#### 3.3.3.1 Person-level characteristics

Information on the characteristics of interest in this study were obtained from the first interRAI PC assessment selected for the study sample, as well as from the corresponding referral data. Basic demographic information included age, gender, marital status and LHIN of residence. Of interest were also the clinical characteristics of clients related to presence of a cancer diagnosis and prognosis. Other clinical characteristics of interest measured using scales in the interRAI PC are described below. Although not available for the full sample, the Palliative Performance Scale (PPS) was also examined as a clinical characteristic of interest where available.

##### 3.3.3.1.1 Changes in Health, End-stage Disease, Signs, and Symptoms (CHESS)

Used to measure health instability, the CHESS scale is scored from zero, indicating no health instability, to five, which indicates high health instability. Items from the interRAI PC used to assign a CHESS score include estimated survival, decision making, activity of daily living (ADL) status, vomiting, peripheral edema, dyspnea, weight loss, insufficient fluid, dehydration, ≤1 meals on at least 2 of last 3 days and fluid output exceeds input. The scale is highly predictive of mortality (Hirdes et al., 2003, 2014a; Hjaltadóttir et al., 2011; Tjam et al., 2012), in addition to other adverse events such as hospital admission (Sinn et al., 2020), or long-term care placement amongst home care clients (Sinn et al., 2018). It has also been found to be associated with the receipt of medical treatments like intravenous (IV) medication and oxygen therapy, as well as pain (Hirdes et al., 2003).

##### 3.3.3.1.2 Cognitive Performance Scale (CPS)

The CPS is a valid and reliable measure of individuals' level of cognitive impairment (Jones et al., 2010; Landi et al., 2000; Morris et al., 1994, 2000). It is correlated strongly with the Mini Mental State Exam (Landi et al., 2000; Morris et al., 1994), as well as to Montreal Cognitive Assessment scores (Jones et al., 2010). This scale was originally developed for use in a long-term care population but its use has extended to other settings including acute care, inpatient psychiatry and home care (Morris et al., 2016). The scale is scored from zero to six, with zero indicating intact cognition and six indicating very severe cognitive impairment. Items considered as part of this scale include ability to make self understood, whether the individual is fully dependent in eating, short term memory, and cognitive skills for daily decision making (Morris et al., 1994, 2016).

#### 3.3.3.1.3 Depression Rating Scale (DRS)

The DRS is used to screen for possible depression in clients, and has been found to be a reliable measure for screening for depression in a home care setting (Morris et al., 2000), as well as in those receiving palliative care (Fisher, Seow, Brazil, et al., 2015). The scale ranges from zero (no evidence of depression) to 14, with a score at or above three being predictive of clinical depression (Burrows, 2000). This scale is comprised of items from the mood section of the interRAI PC instrument including negative statements from the assessed, persistent anger with self or others, expressions of unrealistic fears, repetitive health complaints, repetitive anxious complaints/concerns that are non-health related, as well as crying/tearfulness (Burrows, 2000). Items from this scale have previously been validated against the Hamilton Depression Rating Scale and the Cornell Scale for depression (Burrows, 2000). The DRS has previously been used in studies on the prevalence of depression and antidepressant use in home and institutional settings (Dalby et al., 2008; Szczerbińska et al., 2012).

#### 3.3.3.1.4 Instrumental Activities of Daily Living-Activities of Daily Living (IADL-ADL) Functional Hierarchy Scale

The IADL-ADL Functional Hierarchy Scale integrates measures of IADL with measures of ADL into a single scale that ranges from zero (independent) to 11 (ADL dependent) (Morris et al., 2013). The validity and reliability of separate measures of ADL and IADL for home care have previously been demonstrated (Landi et al., 2000; Morris et al., 2000), although use of the integrated scale was selected for this dissertation as it allows the hierarchical pattern in the progression of functional loss to be captured

(Morris et al., 2013). In the interRAI PC, the scale is comprised of ADL items that include hygiene, locomotion, toileting and eating, as well as IADL items that include meal preparation, ordinary housework, and managing medications. Categories for the IADL-ADL Functional Hierarchy Scale include independent (0), IADL early (1, 2), IADL mid (3, 4), IADLs dependent (5), IADLs-ADLs transition (6, 7), ADL early (8), ADL mid-late (9, 10), and ADL dependent (11).

###### 3.3.3.1.5 Pain Scale

The Pain Scale is measured using pain frequency and intensity, and ranges from zero (no pain) to four (excruciating, daily pain). It has been validated against the Visual Analogue Scale (VAS) and found to be predictive of VAS scores (Fries et al., 2001). The Pain Scale has previously been used to examine the prevalence of pain and its management in home (Freeman et al., 2014; Maxwell et al., 2008; Morris et al., 2000) and institutional settings (Proctor & Hirdes, 2001; Zyczkowska et al., 2007). Its use as a potential quality indicator for home care clients with an expected prognosis of less than six months or with high health instability has also been previously examined (Harman et al., 2019).

###### 3.3.3.1.6 Palliative Performance Scale (PPS)

Based on the Karnofsky Performance Status Scale, the PPS primarily measures physical status and is scored from 0% (dead) to 100% (full health and ambulation) (Anderson et al., 1996). Factors considered as part of this scale include ambulation, activity levels and evidence of disease, ability to perform self-care activities, nutritional intake, and level of consciousness (Anderson et al., 1996). The PPS is not collected as part of the interRAI PC but instead recorded in the CHRIS system separately as part of the clinical assessment for 80.6% of palliative home care clients in the sample.

###### 3.3.3.1.7 Caregiver Risk Evaluation (CaRE) Algorithm

The CaRE Algorithm is used to measure the risk of caregiver burden (Guthrie et al., 2020). In the interRAI PC, it is scaled using items from the social support section and includes the following items: primary caregiver expresses feelings of distress, anger or depression; primary caregiver lives with client;

primary caregiver’s relationship with client, hours of informal care in the prior three days from assessment; the CPS, and the DRS. The scale is rated from one to four, representing low, moderate, high and very high risk.

#### 3.3.3.2 Episode characteristics

Characteristics of interest for the episodes of care considered in this study included length of stay on palliative home care (up to 182 days), as well as discharge disposition at the end of the follow-up period. Length of stay was captured using the date of assessment from the interRAI PC data and discharge date from the referral data. Discharge disposition was obtained from the referral data. Those with a discharge date exceeding the 182-day study period, or a missing discharge date (presumed to still be on home care service) were considered ‘undischarged’.

#### 3.3.3.3 Service utilization

Information on clients’ use of palliative home care services was obtained from the CHRIS payment/billing records, which include visits for case management, nursing, respiratory therapy, nutrition, physiotherapy, occupational therapy, speech language pathology, social work, and psychology, as well as the number of hours of personal support provided by PSWs. Specific measures of interest included the proportion of palliative home care clients receiving services from each of the different service types (propensity), frequency of services used (intensity), and common service mixes (types of services being provided in combination with one another). Service utilization patterns were also of interest and included the number of days between assessment and first service, the number of days between final service and discharge, mean service utilization by week of care, and mean service utilization by time to discharge.

Interruptions in service were also examined as part of this study. Conceptually, service interruptions were meant to capture missed palliative home care services over a prolonged period of time whereby the utilization of care in other sectors of the health system could be expected (i.e., due to hospitalization), rather than gaps that occur due to system-related or administrative factors (i.e., delays in initiating services or closing client files at discharge), or gaps that are consistent with the level of service intensity required based on client needs (i.e., biweekly nursing check-ins). Due to the deidentified nature of the data used for this study, linkage to data holdings containing records of hospitalization could not be made. As such, service interruptions were examined using three different approaches and are as follows:

- Method one: Gaps in service of at least seven consecutive days without service. This method assumes that all palliative home care clients have care needs that require a frequency of service of at least one service per week.
- Method two: Gaps in service of at least seven consecutive days without service occurring after the first service gap of less than seven days (excluding first case management service). Assumptions for this method are that not all palliative care clients require weekly service immediately following assessment, but that once services begin to occur with gaps of less than seven days between service, they will continue to be provided on a weekly basis, at minimum. The first case management service was excluded as it is likely to represent the assessment visit.
- Method three: Gaps in service of at least seven consecutive days without service occurring after the initiation of weekly personal support services (defined as the date after which a second PSW service is provided within seven days). This method assumes that not all palliative home care clients require frequent service immediately following assessment, and that personal support services are provided at regular intervals once initiated, while other services may continue to be sporadically provided. Those who do not require frequent service immediately following assessment are expected to be more functionally independent, have lower health instability, and longer prognoses. In contrast, it is expected that those receiving PSW services have greater levels of dependence, greater health instability, and shorter prognoses.

#### 3.3.3.4 Informal care

Care provided by clients’ families and/or friends is also considered in interRAI assessments, including the interRAI PC, in the social supports section. A number of previous studies have used information on social supports from the interRAI suite of instruments on topics that include profiling caregivers in a home setting (Mitchell et al., 2015), caregiver distress (Chang & Hirdes, 2015; Guthrie et al., 2020; Hirdes et al., 2012; Mitchell et al., 2015; Pauley et al., 2018), development of a scale to inform on allocation of home care resources (Hirdes, Poss, et al., 2008), as well as long-term care admission (Betini et al., 2017). Items of interest in this study included the proportion of clients with an informal caregiver, whether the caregiver resided with the client, the relationship between the primary caregiver and the client, and the hours of informal care received by the client in the prior three days.

### 3.3.4 Analyses

All analyses were calculated using SAS Version 9.4 (*SAS System*, 2013). Analytic techniques used to describe sample and episode characteristics, and patterns of service utilization included frequencies, means, standard deviations (SDs) and 95% confidence limits (CLs), and medians and interquartile ranges (IQRs). Comparisons between groups were tested using chi-square tests.

## 3.4 Results

### 3.4.1 Characteristics of the study sample

The mean age of the study sample was 71.2 years (SD=13.2), and the median age was 72.0 years (IQR=63.0-81.0 years). Over two-thirds (70.6%) of the study sample was aged 65 and over, with an even split between male and female clients. The majority (62.6%) of clients were either married or identified a partner or significant other. The largest segments of the sample resided within the boundaries of the Hamilton Niagara Haldimand Brant LHIN (16.3%), followed by Central LHIN (15.3%). One-tenth of the sample had a prognosis of less than six weeks of life, and half expected to live between six weeks and six months. With respect to the functional characteristics of the sample, it appeared that the majority of clients had mild to moderate levels of impairment with 68.8% of the sample scoring between 50% and 70% on the PPS, and 57.7% scoring between one (early IADL loss) and seven (transitioning IADL to ADL loss) on the IADL-ADL Functional Hierarchy Scale. Two-thirds of clients demonstrated substantial health instability and medical complexity as indicated by a CHESS score of three or greater. Pain was also common with approximately three-quarters of clients experiencing at least some pain. The possible presence of depression was present in 12.2% of clients, and about a third of clients showed at least some cognitive impairment. Over half of clients had a caregiver with a low to moderate risk of experiencing burden. A summary of sample characteristics can be found in Table 3.1.

**Table 3.1: Characteristics of palliative home care clients in Ontario at first interRAI PC assessment, 2011 to 2017 (n=68,731)**

| Characteristic | Sample<br>n=68,731<br>% (n) |
|---|---|
| Age | |
| 18 to 44 | 3.1 (2,097) |
| 45 to 64 | 26.4 (18,144) |
| 65 to 74 | 26.8 (18,425) |
| 75 to 84 | 27.6 (18,935) |
| ≥85 | 16.2 (11,130) |
| Gender | |
| Female | 49.8 (34,229) |
| Male | 50.2 (34,502) |
| Marital status | |
| Never married | 5.6 (3,832) |
| Married | 59.4 (40,853) |
| Partner/significant other | 3.2 (2,177) |
| Widowed | 22.8 (15,638) |
| Separated | 2.4 (1,620) |
| Divorced | 6.7 (4,611) |
| LHIN | |
| Central East | 10.8 (7,424) |
| Central | 15.3 (10,482) |
| Champlain | 13.9 (9,577) |
| Central West | 2.9 (1,988) |
| Erie St. Clair | 5.6 (3,869) |
| Hamilton Niagara Haldimand Brant | 16.3 (11,204) |
| Mississauga Halton | 4.8 (3,295) |
| North East | 6.9 (4,767) |
| North Simcoe Muskoka | 3.1 (2,109) |
| North West | 1.7 (1,198) |
| South East | 2.3 (1,584) |
| South West | 4.9 (3,383) |
| Toronto Central | 2.7 (1,867) |
| Waterloo Wellington | 8.7 (5,984) |
| IADL-ADL Functional Hierarchy* | |
| 0 (independent) | 6.6 (4,321) |
| 1-2 (IADLs early) | 17.8 (11,736) |
| 3-4 (IADLs mid) | 22.2 (14,652) |
| 5 (IADLs dependent) | 10.0 (6,594) |
| 6-7 (IADLs-ADLs transition) | 13.3 (8,769) |
| 8 (ADL early) | 10.7 (7,034) |
| 9-10 (ADL mid-late) | 15.8 (10,398) |

| **Characteristic** | **Sample<br>n=68,731<br>% (n)** |
|---|---|
| 11 (ADL dependent) | 3.7 (2,469) |
| CHESS* | |
| 0 | 4.1 (2,672) |
| 1-2 | 29.4 (19,310) |
| ≥3 | 66.6 (43,789) |
| PPS* | |
| 0 | 0.1 (59) |
| 10-40 | 26.2 (14,539) |
| 50-70 | 68.8 (38,115) |
| 80-100 | 4.9 (2,700) |
| CPS* | |
| 0 | 59.2 (38,907) |
| 1-2 | 32.5 (21,349) |
| 3-4 | 4.6 (3,008) |
| 5-6 | 3.7 (2,431) |
| DRS* | |
| 0 | 65.4 (42,953) |
| 1-2 | 22.5 (14,770) |
| ≥3 | 12.2 (7,990) |
| Estimated survival | |
| Days | 2.0 (1,342) |
| <6 weeks | 8.2 (5,634) |
| ≥6 weeks but <6 months | 50.5 (34,730) |
| ≥6 months | 39.3 (27,025) |
| Pain scale* | |
| 0 | 25.9 (17,784) |
| 1-2 | 54.2 (37,181) |
| 3-4 | 20.0 (13,697) |
| Cancer | |
| No | 15.0 (10,280) |
| Yes | 85.0 (58,451) |
| CaRE* | |
| 1 | 12.8 (8,329) |
| 2 | 46.6 (30,448) |
| 3 | 34.3 (22,391) |
| 4 | 6.3 (4,129) |

*Sum of n does not equal to 68,731 due to missing data.

ADL = activities of daily living; CaRE = Caregiver Risk Evaluation; CHESS = Changes in Health, End-stage disease, Signs, and Symptoms; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

### 3.4.2 Episode characteristics

Episode characteristics for the sample can be found in Table 3.2, and episode characteristics stratified by prognosis can be found in Table 3.3. Based on the episodes of care, 72.2% the study sample was on service for six or more weeks. Clients with a prognosis of days and clients with a prognosis of less than six weeks generally had a length of stay on service that was concordant with their prognosis. For clients with longer prognoses, a substantial proportion had a length of stay on service that was shorter than prognosticated. While the majority of episodes ended with death, clients with shorter prognoses were much more likely to have an episode that ended with death.

**Table 3.2: Episode characteristics of palliative home care clients in Ontario, 2011 to 2017 (n=68,731)**

| **Characteristic** | **Sample n=68,731 % (n)** |
|---|---|
| Fiscal year of assessment* | |
| 2011-2012 | 5.8 (3,971) |
| 2012-2013 | 16.5 (11,313) |
| 2013-2014 | 15.4 (10,586) |
| 2014-2015 | 16.6 (11,436) |
| 2015-2016 | 19.2 (13,165) |
| 2016-2017 | 17.7 (12,174) |
| 2017-2018 | 8.9 (6,085) |
| Length of stay | |
| 1-2 weeks | 10.7 (7,331) |
| 3-5 weeks | 17.1 (11,773) |
| 6 to 26 weeks | 42.5 (29,210) |
| >26 weeks | 29.7 (20,417) |
| Episode discharge disposition | |
| Service plan/placement complete | 3.6 (2,450) |
| Death | 51.3 (35,231) |
| Transfer to other LHIN | 0.8 (577) |
| LTC admission | 0.6 (388) |
| Hospitalization >14 days | 10.7 (7,351) |
| Client preference | 0.6 (416) |
| Other community service | 0.1 (97) |
| Vacation >30 days | 0.2 (116) |
| Other discharge | 2.5 (1,688) |
| Undischarged | 29.7 (20,417) |

*Sum of n does not equal to 68,731 due to small cell size suppression to prevent residual disclosure.

LHIN = Local Health Integration Network; LTC = long-term care

**Table 3.3: Episode characteristics of palliative home care clients in Ontario, by prognosis, 2011 to 2017 (n=68,731)**

| Characteristic | Prognosis of days n=1,342 %(n) | Prognosis of <6 weeks n=5,634 %(n) | Prognosis of ≥6 weeks <6 months n=34,730 %(n) | Prognosis of ≥6 months n=27,025 %(n) | $x^2$ (df) | p-value |
|---|---|---|---|---|---|---|
| Length of stay | | | | | 19,834.5 (9) | <0.0001 |
| 1-2 weeks | 80.3 (1,078) | 40.8 (2,300) | 9.4 (3,247) | 2.6 (706) | | |
| 3-5 weeks | 11.2 (150) | 30.2 (1,700) | 21.2 (7,353) | 9.5 (2,570) | | |
| 6 to 26 weeks | 6.3 (84) | 24.2 (1,361) | 46.9 (16,300) | 42.4 (11,465) | | |
| >26 weeks | 2.2 (30) | 4.9 (273) | 22.6 (7,830) | 45.5 (12,284) | | |
| Episode discharge disposition | | | | | 9,546.2 (27) | <0.0001 |
| Service plan/placement complete | 1.0 (14) | 1.5 (86) | 2.0 (686) | 6.2 (1,664) | | |
| Death | 90.8 (1,218) | 83.2 (4,685) | 59.1 (20,517) | 32.6 (8,811) | | |
| Transfer to other LHIN | 0.1 (1) | 0.4 (20) | 0.9 (301) | 0.9 (255) | | |
| LTC admission | 0.2 (2) | 0.3 (19) | 0.6 (205) | 0.6 (162) | | |
| Hospitalization >14 days | 1.9 (26) | 5.8 (324) | 11.7 (4,066) | 10.9 (2,935) | | |
| Client preference | 0.0 (0) | 0.2 (12) | 0.3 (118) | 1.1 (286) | | |
| Other community service | 0.1 (1) | 0.1 (4) | 0.2 (61) | 0.1 (31) | | |
| Vacation >30 days | 0.0 (0) | 0.0 (1) | 0.1 (48) | 0.3 (67) | | |
| Other discharge | 3.7 (50) | 3.7 (210) | 2.6 (898) | 2.0 (530) | | |
| Undischarged | 2.2 (30) | 4.9 (273) | 22.6 (7,830) | 45.5 (12,284) | | |

LHIN = Local Health Integration Network; LTC = long-term care

Clients’ duration on palliative home care service post-assessment can be found in Table 3.4. Overall, the mean days on palliative home care service by clients was 97.1 days (SD=68.1) with a median of 83.0 days (IQR=31-182 days). For those who were discharged during the follow-up period, which represented 70.3% of the sample, the mean number of days on service was 61.2 days (SD=47.6) with a median of 48.0 days (IQR=22.0-92.0 days). Variations in days on service existed across the LHINs, and a slight trend towards fewer days on service could be observed across the fiscal years included as part of this study. For those who were discharged, those who died had the shortest number of days on service, while clients who preferred to be discharged had the longest number of days on service.

**Table 3.4: Number of days on service of palliative home care clients in Ontario by LHIN, and by fiscal year, 2011 to 2017 (n=68,731 full sample; 48,314 discharged during follow-up)**

| | **Full sample n=68,731** | | **Sample discharged during follow-up period n=48,314** | |
|---|---|---|---|---|
| | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** |
| LHIN | | | | |
| Central East | 86.7 (85.2-88.2) | 65.0 (26.0-173.0) | 56.8 (55.6-58.0) | 42.0 (20.0-84.0) |
| Central | 108.2 (106.9-109.5) | 107.0 (41.0-182.0) | 67.2 (66.1-68.4) | 56.0 (27.0-100.0) |
| Champlain | 100.4 (99.1-101.8) | 91.0 (35.0-182.0) | 63.7 (62.6-64.9) | 50.0 (24.0-96.0) |
| Central West | 91.8 (88.8-94.8) | 71.5 (28.0-182.0) | 58.5 (56.0-60.9) | 44.0 (21.0-85.0) |
| Erie St. Clair | 94.8 (92.6-97.0) | 79.0 (29.0-182.0) | 58.7 (56.9-60.5) | 43.0 (20.0-87.0) |
| Hamilton Niagara Haldimand Brant | 92.9 (91.6-94.2) | 74.0 (29.0-182.0) | 58.7 (57.7-59.7) | 45.0 (21.0-87.0) |
| Mississauga Halton | 91.8 (89.5-94.1) | 72.0 (27.0-182.0) | 58.6 (56.7-60.5) | 43.0 (21.0-88.0) |
| North East | 97.3 (95.4-99.2) | 83.0 (34.0-182.0) | 63.7 (62.0-65.3) | 51.0 (23.0-93.0) |
| North Simcoe Muskoka | 91.9 (89.0-94.9) | 74.0 (28.0-182.0) | 59.4 (57.0-61.8) | 44.0 (21.0-89.0) |
| North West | 91.1 (87.3-94.9) | 74.0 (29.0-182.0) | 59.2 (56.2-62.2) | 47.0 (21.0-86.0) |
| South East | 61.9 (58.8-65.0) | 34.0 (14.0-92.0) | 40.8 (38.6-42.9) | 26.0 (11.0-56.0) |
| South West | 101.6 (99.2-103.9) | 92.0 (32.0-182.0) | 59.8 (57.8-61.8) | 45.0 (20.0-90.0) |
| Toronto Central | 99.1 (96.1-102.0) | 86.0 (39.0-182.0) | 66.6 (64.2-69.1) | 55.0 (29.0-97.0) |
| Waterloo Wellington | 107.8 (106.1-109.5) | 107.0 (41.0-182.0) | 67.0 (65.5-68.6) | 55.0 (26.0-101.0) |
| Fiscal year of assessment | | | | |
| 2011-2012 | 101.7 (99.6-103.8) | 93.0 (35.0-182.0) | 63.7 (61.9-65.5) | 50.0 (24.0-96.0) |
| 2012-2013 | 101.4 (100.2-102.7) | 92.0 (35.0-182.0) | 62.8 (61.8-63.9) | 50.0 (23.0-95.0) |
| 2013-2014 | 95.5 (94.2-96.8) | 79.0 (35.0-182.0) | 60.4 (59.3-61.4) | 48.0 (22.0-90.0) |
| 2014-2015 | 95.3 (94.1-96.5) | 79.0 (31.0-182.0) | 60.7 (59.7-61.8) | 46.0 (21.0-91.0) |
| 2015-2016 | 95.4 (94.2-96.6) | 79.0 (30.0-182.0) | 60.5 (59.5-61.5) | 46.0 (22.0-91.0) |
| 2016-2017 | 96.6 (95.3-07.8) | 82.0 (30.0-182.0) | 60.5 (59.5-61.5) | 46.0 (22.0-91.0) |
| 2017-2018 | 96.6 (94.8-98.3) | 81.0 (32.0-182.0) | 61.7 (60.3-63.1) | 49.0 (22.0-91.0) |

|  | Full sample n=68,731 |  | Sample discharged during follow-up period n=48,314 |  |
|---|---|---|---|---|
|  | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** |
| Episode discharge disposition |  |  |  |  |
| Service plan/placement complete | - | - | 86.4 (84.4-88.4) | 80.5 (43.0-129.0) |
| Death | - | - | 57.0 (56.5-57.5) | 42.0 (19.0-85.0) |
| Transfer to other LHIN | - | - | 66.9 (63.0-70.9) | 55.0 (25.0-102.0) |
| LTC admission | - | - | 79.3 (74.1-84.4) | 69.5 (35.5-122.5) |
| Hospitalization >14 days | - | - | 69.2 (68.1-70.2) | 56.0 (31.0-99.0) |
| Client preference | - | - | 96.7 (91.7-101.6) | 94.5 (52.0-141.5) |
| Other community service | - | - | 68.5 (57.9-79.1) | 56.0 (23.0-99.0) |
| Vacation >30 days | - | - | 89.2 (81.2-97.2) | 85.0 (53.0-125.0) |
| Other discharge | - | - | 58.8 (56.7-61.0) | 45.0 (22.0-86.0) |

LHIN = Local Health Integration Network; LTC = long-term care

### 3.4.3 Characteristics and patterns of service utilization

#### 3.4.3.1.1 Utilization of service types

The propensity for using each service type during the episodes of care can be found in Table 3.5. The most commonly used services by palliative home care clients during their episode of care were case management and nursing, with almost all clients receiving these services. Half of clients received occupational therapy and 61.5% received services provided by PSWs. (A comparison of key characteristics between those receiving and not receiving PSW services can be found in Table B.1 of Appendix B.) No clients received psychology services, and very few received respiratory therapy services (0.2%).

Also found in Table 3.5 is the intensity of service utilization by clients using that service. Personal support was the most frequently used service, followed by nursing. Service intensity was substantially lower for all other services, with case management having the third highest utilization, and speech language pathology having the lowest intensity of use.

**Table 3.5: Type and intensity* of service use of palliative home care clients in Ontario, by service type, 2011 to 2017 (n=68,731)**

| Service type | % (n) | Mean ± SD | Median (IQR) |
|---|---|---|---|
| Personal support** | 61.5 (42,292) | 87.9 ± 153.7 | 32.0 (9.0-96.0) |
| Nursing | 98.4 (67,651) | 30.5 ± 34.6 | 20.0 (9.0-39.0) |
| Case management | 98.2 (67,466) | 5.6 ±5.7 | 4.0 (2.0-7.0) |
| Physiotherapy | 18.5 (12,740) | 3.5 ±3.5 | 3.0 (1.0-4.0) |
| Social work | 8.2 (5,605) | 3.1 ± 2.6 | 2.0 (1.0-4.0) |
| Nutrition | 8.7 (5,955) | 2.6 ± 2.2 | 2.0 (1.0-3.0) |
| Occupational therapy | 50.6 (34,756) | 2.4 ± 1.7 | 2.0 (1.0-3.0) |
| Respiratory therapy | 0.2 (143) | 2.3 ± 2.0 | 2.0 (1.0-3.0) |
| Speech language pathology | 3.2 (2,209) | 2.2 ± 1.8 | 2.0 (1.0-3.0) |
| Psychology | 0.0 (0) | - | - |

*Intensity of use measures only those receiving the services.
**The unit of service utilization is by hours. All other services are reported in visits.

A comparison of the propensity for and intensity of nursing and PSW service use, by fiscal year and by LHIN can be found in Table 3.6. A similar proportion of clients were found to use nursing services both across LHINs and fiscal years. The propensity for PSW service utilization was similar over time, but wider variations were observed across LHINs. The intensity of nursing and PSW service utilization varied substantially across LHINs. Across fiscal years, the intensity of nursing service utilization remained stable, but the intensity of PSW service utilization declined.

**Table 3.6: Propensity and intensity of nursing and PSW service utilization by palliative home care clients in Ontario, by LHIN and by fiscal year, 2011 to 2017 (n=68,731)**

| | Nurse visits | | | PSW hours | | |
|---|---|---|---|---|---|---|
| | **% (n)** | **Mean (95% CL)** | **Median (IQR)** | **% (n)** | **Mean (95% CL)** | **Median (IQR)** |
| LHIN | | | | | | |
| Central East | 98.2 (7,291) | 27.0 (26.3-27.8) | 18.0 (8.0-35.0) | 76.5 (5,676) | 98.2 (94.3-102.2) | 38.5 (11.5-113.0) |
| Central | 95.7 (10,030) | 28.8 (28.1-29.5) | 19.0 (8.0-36.0) | 59.2 (6,210) | 81.4 (78.3-84.5) | 39.0 (11.5-94.0) |
| Champlain | 99.0 (9,483) | 25.5 (25.0-26.1) | 17.0 (8.0-33.0) | 52.2 (5,003) | 84.6 (80.6-88.6) | 30.0 (8.0-89.0) |
| Central West | 98.7 (1,962) | 31.4 (29.9-32.8) | 22.0 (9.0-42.0) | 73.3 (1,457) | 115.3 (105.9-124.6) | 45.0 (14.0-148.0) |
| Erie St. Clair | 99.4 (3,845) | 32.2 (31.2-33.2) | 23.0 (11.0-43.0) | 57.6 (2,230) | 65.1 (60.2-70.0) | 22.0 (7.0-68.0) |
| Hamilton Niagara Haldimand Brant | 99.4 (11,138) | 35.4 (34.6-36.1) | 23.0 (10.0-47.0) | 61.4 (6,876) | 71.8 (68.7-74.8) | 24.5 (8.0-76.0) |
| Mississauga Halton | 99.5 (3,278) | 35.6 (34.6-36.1) | 25.0 (11.0-47.0) | 74.7 (2,462) | 117.0 (110.0-124.0) | 45.0 (14.0-134.0) |
| North East | 98.1 (4,674) | 30.7 (29.7-31.6) | 20.0 (9.0-40.0) | 56.0 (2,670) | 70.6 (65.1-76.1) | 22.5 (6.3-72.0) |
| North Simcoe Muskoka | 99.1 (2,090) | 26.9 (25.5-28.3) | 18.0 (8.0-35.0) | 60.3 (1,271) | 76.8 (69.0-84.6) | 27.0 (7.0-79.5) |
| North West | 97.9 (1,173) | 43.6 (40.4-46.9) | 26.0 (10.0-57.0) | 57.9 (694) | 70.0 (61.5-78.5) | 26.3 (8.0-80.0) |
| South East | 98.5 (1,560) | 26.1 (24.5-27.6) | 16.0 (7.0-33.0) | 74.9 (1,186) | 84.8 (74.4-95.3) | 26.0 (8.0-81.5) |
| South West | 98.8 (3,343) | 31.5 (30.4-32.6) | 21.0 (10.0-41.0) | 58.9 (1,991) | 123.7 (112.5-134.9) | 40.0 (10.0-129.3) |
| Toronto Central | 98.3 (1,836) | 27.4 (25.8-29.0) | 17.0 (7.0-33.0) | 68.8 (1,285) | 106.4 (98.6-114.2) | 45.0 (14.0-140.0) |
| Waterloo Wellington | 99.4 (5,948) | 32.4 (31.6-33.2) | 23.0 (11.0-43.0) | 54.8 (3,281) | 96.7 (90.7-102.6) | 33.0 (9.0-102.3) |
| Fiscal year | | | | | | |
| 2011-2012 | 98.3 (3,902) | 33.0 (31.8-34.1) | 22.0 (10.0-43.0) | 61.8 (2,455) | 101.8 (95.1-108.4) | 39.5 (12.0-112.0) |
| 2012-2013 | 98.1 (11,095) | 30.8 (30.1-31.4) | 20.0 (9.0-40.0) | 60.5 (6,842) | 91.4 (87.8-94.9) | 34.0 (10.0-102.3) |
| 2013-2014 | 98.5 (10,422) | 30.2 (29.6-30.9) | 20.0 (9.0-39.0) | 62.7 (6,634) | 86.2 (82.4-89.9) | 31.5 (9.0-95.0) |
| 2014-2015 | 98.6 (11,274) | 30.9 (30.2-31.6) | 20.0 (8.0-40.0) | 62.5 (7,152) | 86.8 (83.4-90.1) | 32.0 (9.0-94.0) |
| 2015-2016 | 98.6 (12,979) | 29.8 (29.2-30.4) | 20.0 (9.0-39.0) | 62.7 (8,250) | 86.5 (83.2-89.9) | 32.0 (8.5-94.0) |
| 2016-2017 | 98.5 (11,991) | 30.2 (29.6-30.8) | 20.0 (9.0-39.0) | 60.3 (7,341) | 86.4 (82.8-89.9) | 31.8 (9.0-93.0) |
| 2017-2018 | 98.4 (5,987) | 30.1 (29.2-30.9) | 20.0 (9.0-39.0) | 59.4 (3,617) | 83.4 (78.4-88.4) | 29.0 (8.0-89.0) |

LHIN = Local Health Integration Network

### 3.4.3.2 Initiation of services

The number of days from assessment to first service can be found in Table 3.7. Overall, most clients received palliative home care services shortly after being assessed using the interRAI PC. Even when excluding the first case management service (which likely represents the visit in which the interRAI PC was completed), the mean number of days from assessment to first service was short at 2.0 days (SD=6.7), and based on the median, at least half of clients received service other than case management on the day of assessment. Overall, case management and nursing services appear to be the earliest initiated services. For at least half of clients receiving PSW services, it would also appear that these services were initiated one day post-assessment, despite the mean initiation of services occurring in the third week of service. Other services that were initiated later on within episodes of care included respiratory therapy, nutrition, physiotherapy, occupational therapy, speech language pathology and social work. While these patterns appear to persist across prognostic categories, clients with shorter prognoses generally received service sooner after assessment than those with longer prognoses (Table 3.8).

**Table 3.7: Number of days from assessment to first service for palliative home care clients in Ontario, by service type, 2011 to 2017 (n=68,731)**

| Service type | Mean ± SD | Median (IQR) |
|---|---|---|
| Personal support | 16.3 ± 34.7 | 1.0 (0.0-10.0) |
| Nursing | 3.1 ± 9.4 | 1.0 (0.0-3.0) |
| Case management | 2.5 ± 13.3 | 0.0 (0.0-0.0) |
| Physiotherapy | 28.0 ± 40.0 | 9.0 (3.0-35.0) |
| Social work | 27.5 ± 38.0 | 11.0 (5.0-31.0) |
| Nutrition | 24.8 ± 35.9 | 10.0 (4.0-28.0) |
| Occupational therapy | 22.5 ± 35.9 | 7.0 (2.0-24.0) |
| Respiratory therapy | 33.0 ± 42.7 | 13.0 (6.0-46.0) |
| Speech language pathology | 33.4 ± 42.7 | 14.0 (5.0-46.0) |
| Any | 0.3 ± 1.7 | 0.0 (0.0-0.0) |
| Any, excluding case management | 2.0 ± 6.7 | 0.0 (0.0-2.0) |

**Table 3.8*:* Number of days from assessment to first service for palliative home care clients in Ontario, by service type and prognosis, 2011 to 2017 (n=68,731)**

| | Prognosis of days | | Prognosis of <6 weeks | | Prognosis of ≥6 weeks, <6 months | |
|---|---|---|---|---|---|---|
| **Service type** | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** |
| Personal support | 0.6 (0.4-0.9) | 0.0 (0.0-0.0) | 3.9 (3.5-4.3) | 0.0 (0.0-2.0) | 15.5 (15.1-15.9) | 1.0 (0.0-11.0) |
| Nursing | 0.2 (0.1-0.3) | 0.0 (0.0-0.0) | 0.8 (0.7-0.8) | 0.0 (0.0-1.0) | 2.5 (2.4-2.6) | 1.0 (0.0-2.0) |
| Case management | 0.6 (0.3-0.8) | 0.0 (0.0-0.0) | 1.0 (0.8-1.1) | 0.0 (0.0-0.0) | 2.4 (2.3-2.6) | 0.0 (0.0-0.0) |
| Physiotherapy | 13.2 (7.5-18.8) | 3.0 (0.0-15.0) | 17.2 (13.8-19.6) | 6.0 (2.0-18.0) | 25.5 (24.6-26.4) | 8.0 (3.0-30.0) |
| Social work | 9.2 (3.1-15.3) | 2.0 (1.0-8.0) | 12.9 (10.5-15.3) | 6.0 (2.0-12.0) | 24.8 (23.5-26.1) | 10.0 (5.0-28.0) |
| Nutrition | 4.3 (1.0-7.7) | 2.0 (0.0-8.0) | 12.3 (9.5-15.0) | 4.0 (1.0-11.0) | 22.2 (21.0-23.3) | 9.0 (4.0-25.0) |
| Occupational therapy | 4.8 (3.0-6.6) | 1.0 (0.0-3.0) | 7.4 (6.8-8.0) | 2.0 (1.0-7.0) | 20.3 (19.8-20.7) | 7.0 (2.0-21.0) |
| Respiratory therapy | - | - | 9.0 (1.0-19.0) | 9.0 (1.0-16.0) | 28.7 (20.4-37.1) | 9.5 (4.0-38.0) |
| Speech language pathology | 6.4 (0.4-12.4) | 1.0 (0.0-8.0) | 20.4 (15.2-25.5) | 8.0 (2.0-20.5) | 30.2 (27.8-32.5) | 12.0 (4.0-38.0) |
| Any | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.1 (0.0-0.1) | 0.0 (0.0-0.0) | 0.2 (0.2-0.2) | 0.0 (0.0-0.0) |
| Any, excluding case management | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) | 0.4 (0.3-0.4) | 0.0 (0.0-0.0) | 1.6 (1.5-1.7) | 0.0 (0.0-1.0) |

**Table 3.8: Number of days from assessment to first service for palliative home care clients in Ontario, by service type and prognosis, 2011 to 2017 (n=68,731), continued**

| | **Prognosis of ≥6 months** | |
|---|---|---|
| **Service type** | **Mean (95% CL)** | **Median** |
| Personal support | 22.9 (22.2-23.6) | 2.0 (0.0-23.0) |
| Nursing | 4.5 (4.3-4.6) | 1.0 (0.0-4.0) |
| Case management | 3.0 (2.9-3.2) | 0.0 (0.0-0.0) |
| Physiotherapy | 32.0 (30.8-33.1) | 11.0 (4.0-43.0) |
| Social work | 33.2 (31.5-34.9) | 14.0 (6.0-42.0) |
| Nutrition | 28.9 (27.4-30.4) | 11.0 (5.0-34.0) |
| Occupational therapy | 30.1 (29.3-30.8) | 10.0 (3.0-39.0) |
| Respiratory therapy | 42.4 (28.9-55.9) | 23.5 (9.0-55.5) |
| Speech language pathology | 39.7 (36.7-42.7) | 20.0 (6.0-57.0) |
| Any | 0.4 (0.4-0.4) | 0.0 (0.0-0.0) |
| Any, excluding case management | 2.9 (2.8-3.0) | 1.0 (0.0-3.0) |

#### 3.4.3.3 Days between services

Table 3.9 shows the mean and median number of days between services across the different service types once service was initiated. Across all services, the mean number of days between services was 2.7 (SD=4.4), with large variations across the different service types. Nursing and personal support were the two most frequently used services. By comparison, case management, respiratory therapy, nutrition, occupational therapy, speech language pathology and social work services were provided at less frequent intervals. By prognosis, the number of days between services increased with longer prognoses, and was evident across service types (Table 3.10). For personal support services, however, the difference between the four prognostic groups was small, indicating frequent utilization of services by PSWs once PSW services were initiated (Table 3.10).

**Table 3.9: Mean number of days between services provided* for palliative home care clients in Ontario, by service type, 2011 to 2017 (n=74 to 68,731)**

| Service type | n** | Mean ± SD | Median (IQR) |
|---|---|---|---|
| Personal support | 39,729 | 2.1 ± 3.2 | 1.2 (0.7-2.5) |
| Nursing | 65,740 | 4.4 ± 5.9 | 2.7 (1.3-5.5) |
| Case management | 56,094 | 22.2 ± 29.4 | 12.0 (5.0-26.5) |
| Physiotherapy | 9,387 | 13.8 ± 12.4 | 10.5 (7.0-16.0) |
| Social work | 3,844 | 19.2 ± 15.5 | 15.0 (9.0-24.0) |
| Nutrition | 3,731 | 21.5 ± 16.3 | 17.8 (11.3-27.5) |
| Occupational therapy | 22,068 | 19.4 ± 21.3 | 12.7 (6.9-24.0) |
| Respiratory therapy | 74 | 23.5 ± 26.6 | 13.0 (7.0-34.0) |
| Speech language pathology | 1,202 | 20.1 ± 19.2 | 14.5 (8.6-25.5) |
| Any | 68,671 | 2.7 ± 4.4 | 1.3 (0.6-3.0) |

* Number of days between service describes the mean and median of clients' mean numbers of days between service for those receiving ≥2 services from that service type within the follow-up period only.
**n includes only clients using >1 of the service type.

**Table 3.10: Mean number of days between service* for palliative home care clients in Ontario, by service type and prognosis, 2011 to 2017 (n=68,731)**

| | **Prognosis of days** | | **Prognosis of <6 weeks** | | **Prognosis of ≥6 weeks, <6 months** | |
|---|---|---|---|---|---|---|
| **Service type** | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** |
| Personal support | 0.7 (0.7-0.8) | 0.5 (0.3-1.0) | 1.2 (1.1-1.2) | 0.9 (0.5-1.2) | 2.0 (2.0-2.1) | 1.2 (0.7-2.5) |
| Nursing | 0.9 (0.8-0.9) | 0.6 (0.4-1.0) | 1.5 (1.5-1.6) | 1.0 (0.7-1.7) | 3.7 (3.6-3.7) | 2.4 (1.2-2.5) |
| Case management | 4.1 (3.2-5.0) | 1.2 (0.4-3.0) | 7.7 (7.3-8.1) | 3.5 (1.5-8.4) | 19.2 (18.9-19.5) | 10.3 (4.7-22.3) |
| Physiotherapy | 8.9 (6.6-11.3) | 7.0 (6.0-10.5) | 10.9 (10.0-11.9) | 7.8 (6.0-14.0) | 13.2 (12.9-13.5) | 10.0 (7.0-15.3) |
| Social work | 9.3 (4.6-14.0) | 9.0 (1.0-13.3) | 15.6 (12.9-18.4) | 10.5 (6.0-18.7) | 18.4 (17.7-19.1) | 14.1 (8.3-23.0) |
| Nutrition | 8.2 (1.2-17.6) | 9.5 (4.5-12.0) | 20.2 (15.9-24.5) | 14.5 (7.8-25.8) | 20.3 (19.5-21.0) | 16.5 (10.2-26.0) |
| Occupational therapy | 8.5 (6.3-10.7) | 4.0 (1.0-9.0) | 12.3 (11.4-13.1) | 7.0 (4.0-14.0) | 18.5 (18.2-18.9) | 12.0 (6.5-23.0) |
| Respiratory therapy | - | - | 7.5 (-75.1-90.1) | 7.5 (1.0-14.0) | 21.9 (16.8-27.0) | 14.0 (7.3-37.5) |
| Speech language pathology | 13.6 (1.6-25.7) | 10.9 (7.0-20.0) | 13.3 (9.5-17.0) | 12.0 (5.0-17.3) | 18.0 (16.7-19.3) | 14.0 (7.3-23.0) |
| Any | 0.4 (0.4-0.5) | 0.3 (0.2-0.4) | 0.8 (0.8-0.8) | 0.5 (0.3-0.8) | 2.1 (2.0-2.1) | 1.1 (0.6-2.3) |

* Number of days between service describes the mean and median of clients' mean numbers of days between service for those receiving ≥2 services from that service type within the follow-up period only.

**Table 3.10: Mean number of days between service* for palliative home care clients in Ontario, by service type and prognosis, 2011 to 2017 (n=68,731), continued**

| | **Prognosis of ≥6 months** | |
|---|---|---|
| **Service type** | **Mean (95% CL)** | **Median (IQR)** |
| Personal support | 2.5± 3.5 | 1.5 (0.9-3.3) |
| Nursing | 6.1 (6.0-6.2) | 4.0 (2.2-7.1) |
| Case management | 29.8 (29.4-30.3) | 17.7 (8.5-36.7) |
| Physiotherapy | 14.6 (14.2-15.0) | 11.0 (7.0-17.0) |
| Social work | 20.5 (19.8-21.2) | 17.0 (10.5-25.5) |
| Nutrition | 22.7 (22.0-23.4) | 19.5 (12.7-28.0) |
| Occupational therapy | 21.9 (21.4-22.4) | 14.3 (7.0-28.0) |
| Respiratory therapy | 28.1 (10.7-45.5) | 10.5 (4.0-32.8) |
| Speech language pathology | 22.9 (21.0-24.7) | 16.5 (10.5-28.0) |
| Any | 3.9 (3.9-4.0) | 2.1 (1.0-4.8) |

#### 3.4.3.4 Service mixes

The top 10 most common service mixes can be found in Table 3.11. Case management and nursing services were present in all of the top 10 service mixes, with personal support present in six of the top 10 service mixes, and occupational therapy present in five of the top 10 service mixes. Case management, nursing and personal support services were commonly found together, as well as in conjunction with occupational therapy services.

**Table 3.11: Top 10 most common service mixes for palliative home care clients in Ontario, 2011 to 2017 (n=68,731)**

| **Rank** | **Service mix** | **Sample n=68,731 %(n)** |
|---|---|---|
| 1 | Case management, nursing, personal support, occupational therapy | 22.5 (15,436) |
| 2 | Case management, nursing | 19.4 (13,334) |
| 3 | Case management, nursing, personal support | 16.4 (11,235) |
| 4 | Case management, nursing, occupational therapy | 8.4 (5,748) |
| 5 | Case management, nursing, personal support, occupational therapy, physiotherapy | 6.4 (4,379) |
| 6 | Case management, nursing, personal support, physiotherapy | 3.3 (2,255) |
| 7 | Case management, nursing, personal support, occupational therapy, social work | 2.1 (1,424) |
| 8 | Case management, nursing, physiotherapy | 1.9 (1,318) |
| 9 | Case management, nursing, personal support, occupational therapy, nutrition | 1.8 (1,263) |
| 10 | Case management, nursing, occupational therapy, physiotherapy | 1.6 (1,108) |

Cumulative proportion of sample shown in table is 83.7% (57,500).

#### 3.4.3.5 Discharge from service

Across all episodes, the mean number of days from final service to discharge was 6.9 days (SD=14.3), with a median of 2.0 days (IQR=0.0-7.0 days). The variation across discharge dispositions was wide-ranging from 3.6 days for those transferred to another LHIN to 20.6 days for those on vacation for greater than 30 days (Table 3.12).

**Table 3.12: Number of days from final service to discharge for palliative home care clients in Ontario, by discharge disposition, 2011 to 2017 (n=68,731)**

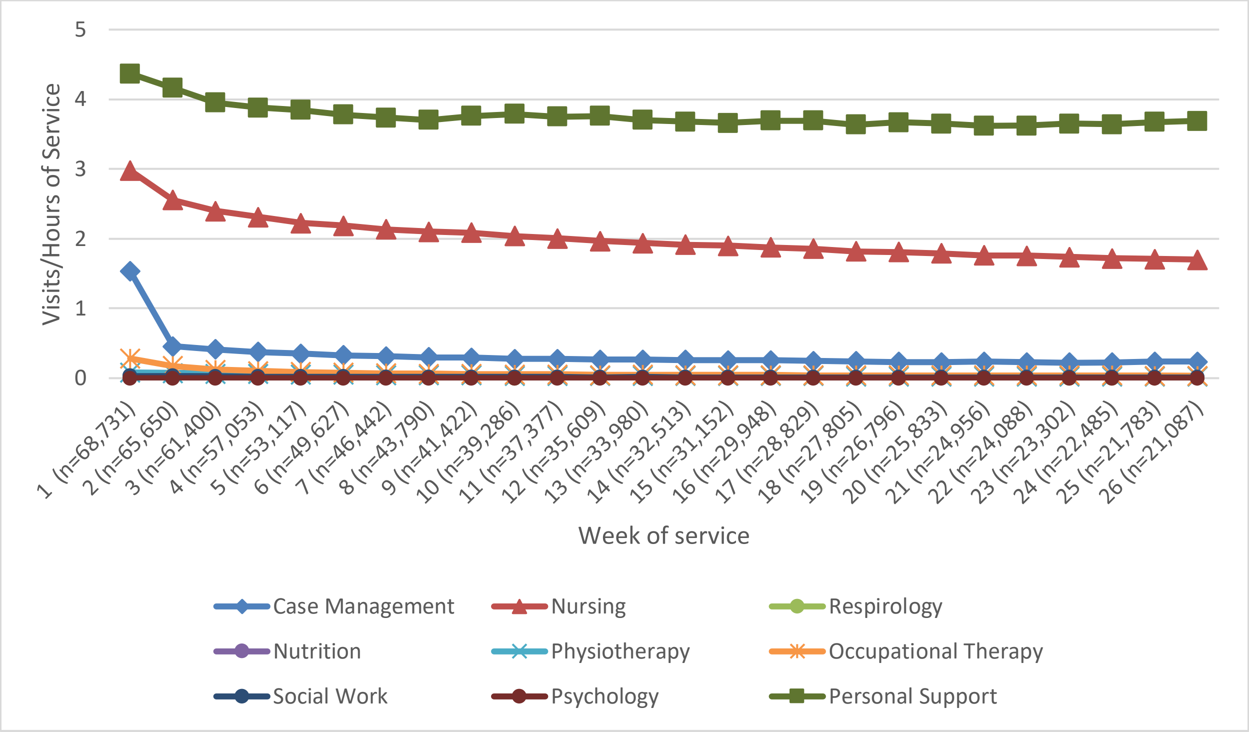
| Discharge disposition | Mean ± SD | Median (IQR) |
|---|---|---|
| Service plan/placement complete | 11.3 ± 19.6 | 4.0 (0.0-13.0) |
| Death | 5.3 ± 10.4 | 2.0 (0.0-6.0) |
| Transfer to other LHIN | 3.6 ± 12.7 | 0.0 (0.0-2.0) |
| LTC admission | 3.8 ± 9.3 | 1.0 (0.0-3.0) |
| Hospitalization >14 days | 12.3 ± 10.6 | 14.0 (3.0-18.0) |
| Client preference | 13.4 ± 23.7 | 3.0 (0.0-15.0) |
| Other community service | 3.8 ± 6.8 | 1.0 (0.0-5.0) |
| Vacation >30 days | 20.6 ± 21.7 | 7.5 (2.0-36.5) |
| Other discharge | 8.2 ± 17.2 | 2.0 (0.0-9.0) |
| Undischarged* | 7.0 ± 18.7 | 2.0 (0.0-5.0) |

*Values for those undischarged at the end of the follow-up period represent the number of days from the final service during the follow-up period to the end of the follow-up period.

### 3.4.3.6 Patterns in service utilization across the episode

Across service types, mean service utilization appeared to indicate a slight decrease in service utilization over the course of the episode (Figure 3.2). The decline in service utilization after the first week of service was especially pronounced for case management services, but was evident across the service types.

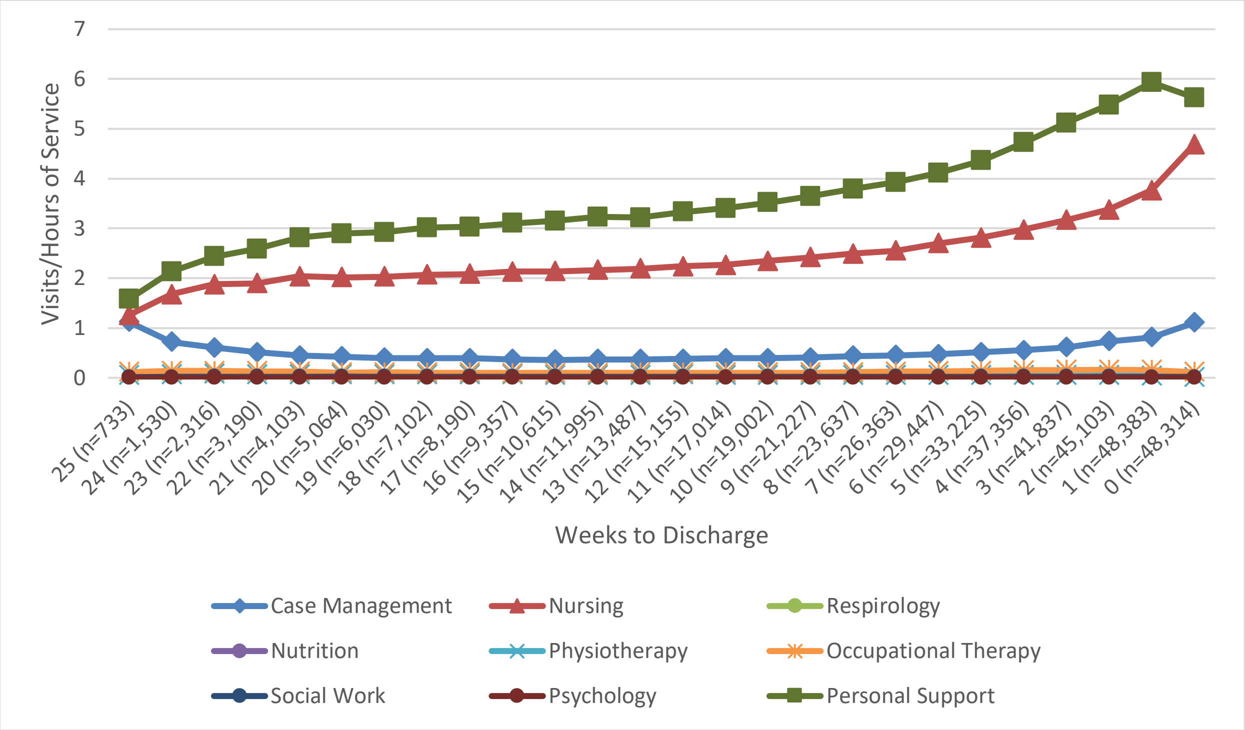
**Figure 3.2: Mean service utilization of palliative home care clients in Ontario, by week of care and service type, 2011 to 2017 (n=68,731)**



For those discharged during the follow-up period, the inverse service utilization by weeks to discharge was also examined (Figure 3.3). For most service types, service utilization increased with proximity to discharge (Figure 3.3). The pattern of greater service utilization with proximity to discharge was somewhat different for case management and personal support services, however. Case management services were highest during the first week of care (Figure 3.2), but also in the weeks closest to discharge

(Figure 3.3). For PSW services, utilization in the final week of service was also lower than in the second to final week of service (Figure 3.3).

**Figure 3.3: Mean service utilization for palliative home care clients in Ontario by weeks to discharge and service type, 2011 to 2017 (n=48,314)**



### 3.4.3.7 Service mix by week of care

Table 3.13 shows the top five most common service mixes by week of care. The most common service mixes in the first week all included case management, and four of the five included nursing services. Service mixes as well as the proportions of clients receiving those service mixes were fairly consistent after the first week of care until week 18 of care when there were minor variations in the fourth and fifth most common service mixes.

**Table 3.13: Top five service mixes for palliative home care clients in Ontario, by week of care, 2011 to 2017 (n=68,731)**

| | Rank | | | | |
|---|---|---|---|---|---|
| **Week** | **1** | **2** | **3** | **4** | **5** |
| 1 | Case management, nursing<br>32.3% (22,180) | Case management, nursing, personal support<br>20.7% (14,219) | Case management, nursing, personal support, occupational therapy<br>10.9% (7,487) | Case management, nursing, occupational therapy<br>7.0% (4,805) | Case management<br>6.3% (4,334) |
| 2 | Nursing<br>26.7% (17,538) | Nursing, personal support<br>16.8% (11,000) | No service<br>11.7% (7,678) | Case management, nursing, personal support<br>7.3% (4,783) | Case management, nursing<br>7.2% (4,755) |
| 3 | Nursing<br>28.0% (17,168) | Nursing, personal support<br>17.9% (11,004) | No service<br>14.8% (9,098) | Case management, nursing, personal support<br>7.1% (4,336) | Case management, nursing<br>6.7% (4,093) |
| 4 | Nursing<br>29.2% (16,652) | Nursing, personal support<br>18.6% (10,621) | No service<br>15.9% (9,076) | Case management, nursing, personal support<br>6.8% (3,859) | Case management, nursing<br>6.3% (3,596) |
| 5 | Nursing<br>29.7% (15,769) | Nursing, personal support<br>19.3% (10,266) | No service<br>16.9% (8,982) | Case management, nursing, personal support<br>6.5% (3,460) | Case management, nursing<br>6.2% (3,268) |
| 6 | Nursing<br>30.5% (15,125) | Nursing, personal support<br>19.9% (9,868) | No service<br>17.3% (8,605) | Case management, nursing, personal support<br>6.1% (3,037) | Case management, nursing<br>6.0% (2,983) |
| 7 | Nursing<br>31.5% (14,612) | Nursing, personal support<br>20.5% (9,528) | No service<br>17.5% (8,137) | Case management, nursing, personal support<br>5.9% (2,724) | Case management, nursing<br>5.6% (2,617) |
| 8 | Nursing<br>31.3% (13,696) | Nursing, personal support<br>20.9% (9,133) | No service<br>18.3% (7,990) | Case management, nursing, personal support<br>5.8% (2,538) | Case management, nursing<br>5.6% (2,454) |
| 9 | Nursing<br>31.8% (13,163) | Nursing, personal support | No service<br>18.3% (7,573) | Case management, nursing, personal support | Case management, nursing |

| | Rank | | | | |
|---|---|---|---|---|---|
| **Week** | **1** | **2** | **3** | **4** | **5** |
| | | 21.3% (8,826) | | 5.8% (2,397) | 5.3% (2,177) |
| 10 | Nursing<br>31.7% (12,437) | Nursing, personal support<br>21.5% (8,438) | No service<br>18.9% (7,405) | Case management, nursing, personal support<br>5.7% (2,219) | Case management, nursing<br>5.2% (2,058) |
| 11 | Nursing<br>32.1% (11,981) | Nursing, personal support<br>21.7% (8,105) | No service<br>18.9% (7,058) | Case management, nursing, personal support<br>5.5% (2,059) | Case management, nursing<br>5.0% (1,872) |
| 12 | Nursing<br>32.3% (11,488) | Nursing, personal support<br>21.9% (7,811) | No service<br>19.2% (6,840) | Case management, nursing, personal support<br>5.5% (1,950) | Case management, nursing<br>5.2% (1,841) |
| 13 | Nursing<br>32.0% (10,887) | Nursing, personal support<br>21.8% (7,407) | No service<br>19.2% (6,511) | Case management, nursing, personal support<br>5.4% (1,829) | Case management, nursing<br>5.1% (1,732) |
| 14 | Nursing<br>31.7% (10,292) | Nursing, personal support<br>22.1% (7,200) | No service<br>19.8% (6,441) | Case management, nursing, personal support<br>5.3% (1,727) | Case management, nursing<br>5.3% (1,706) |
| 15 | Nursing<br>32.3% (10,066) | Nursing, personal support<br>22.0% (6,843) | No service<br>19.3% (6,007) | Case management, nursing, personal support<br>5.3% (1,652) | Case management, nursing<br>5.1% (1,589) |
| 16 | Nursing<br>32.3% (9,664) | Nursing, personal support<br>21.9% (6,551) | No service<br>19.6% (5,857) | Case management, nursing, personal support<br>5.2% (1,570) | Case management, nursing<br>5.2% (1,544) |
| 17 | Nursing<br>32.3% (9,309) | Nursing, personal support<br>22.1% (6,384) | No service<br>19.7% (5,685) | Case management, nursing, personal support<br>5.1% (1,467) | Case management, nursing<br>5.0% (1,451) |
| 18 | Nursing<br>32.0% (8,887) | Nursing, personal support<br>22.0% (6,108) | No service<br>20.5% (5,689) | Case management, nursing, personal support<br>5.0% (1,397) | Personal support<br>5.0% (1,393) |

|  | Rank |  |  |  |  |
|---|---|---|---|---|---|
| **Week** | **1** | **2** | **3** | **4** | **5** |
| 19 | Nursing<br>31.9% (8,559) | Nursing, personal support<br>22.3% (5,965) | No service<br>20.7% (5,546) | Personal support<br>5.0% (1,337) | Case management, nursing, personal support<br>4.9% (1,323) |
| 20 | Nursing<br>32.0% (8,262) | Nursing, personal support<br>22.4% (5,798) | No service<br>20.7% (5,336) | Personal support<br>5.2% (1,346) | Case management, nursing<br>4.6% (1,187) |
| 21 | Nursing<br>31.8% (7,938) | Nursing, personal support<br>22.3% (5,558) | No service<br>21.0% (5,233) | Personal support<br>5.3% (1,322) | Case management, nursing, personal support<br>4.9% (1,228) |
| 22 | Nursing<br>31.5% (1,585) | Nursing, personal support<br>22.2% (5,351) | No service<br>21.1% (5,081) | Personal support<br>5.5% (1,331) | Case management, nursing, personal support<br>4.9% (1,185) |
| 23 | Nursing<br>31.2% (7,269) | Nursing, personal support<br>22.5% (5,233) | No service<br>21.2% (4,940) | Personal support<br>5.5% (1,274) | Case management, nursing<br>4.8% (1,120) |
| 24 | Nursing<br>31.5% (7,071) | Nursing, personal support<br>22.3% (5,003) | No service<br>21.0% (4,724) | Personal support<br>5.8% (1,304) | Case management, nursing<br>4.7% (1,053) |
| 25 | Nursing<br>30.6% (6,654) | Nursing, personal support<br>22.3% (4,857) | No service<br>21.3% (4,630) | Personal support<br>5.9% (1,289) | Case management, nursing<br>5.0% (1,090) |
| 26 | Nursing<br>30.4% (6,405) | Nursing, personal support<br>22.3% (4,698) | No service<br>21.2% (4,464) | Personal support<br>5.9% (1,247) | Case management, nursing<br>5.3% (1,108) |

### 3.4.3.8 Service interruptions

Table 3.14 shows the results of the three different methodologies for identifying service interruptions examined as part of this study. For the third method, the assumption that PSW services tend to be provided at regular intervals once initiated was tested by identifying the proportion of clients with gaps in service of over seven days after the initiation of weekly PSW services, and was found to be 16.6%. The expectation that those receiving PSW services would have greater functional dependence, greater health instability, and shorter prognoses was also tested by comparing those with and without PSW service, and was confirmed (Table B.1 of Appendix B). The first two methods identified a similar proportion of clients with service interruptions (39.9% for method one and 36.8% for method two) while a substantially lower proportion was identified using the third method at 10.6%. The first two methods also identified a similar number of interruptions per client for clients identified as having service interruptions (mean=3.1 and 2.9; median=2.0 and 2.0), while the third method identified 1.6 interruptions per client with service interruptions. The mean and median durations of the interruptions were similar across all three methodologies examined. Differences in the clinical characteristics of clients identified as having service interruptions using the three methods can be found in Tables B.2 to B.4 of Appendix B.

**Table 3.14: Service interruption characteristics for palliative home care clients in Ontario, by operational definition, 2011 to 2017 (n=68,731)**

| Measure | Gaps ≥7 days | Gaps ≥7 days after first service gap <7 days | Gaps ≥7 days after initiation of weekly personal support services |
|---|---|---|---|
| Number of service interruptions | | | |
| 0 | 60.1% (41,282) | 63.2% (43,452) | 90.4% (62,142) |
| 1 | 15.6% (10,716) | 15.3% (10,532) | 6.7% (4,605) |
| 2-3 | 11.4% (7,846) | 10.6% (7,314) | 2.3% (1,555) |
| 4-9 | 11.8% (8,089) | 10.1% (6,923) | 0.6% (422) |
| ≥10 | 1.2% (798) | 0.7% (510) | 0.0% (7) |
| Mean (SD) number of interruptions (for those with interruptions) | 3.1 (2.5) | 2.9 (2.4) | 1.6 (1.2) |

| Measure | Gaps ≥7 days | Gaps ≥7 days after first service gap <7 days | Gaps ≥7 days after initiation of weekly personal support services |
|---|---|---|---|
| Median (IQR) number of interruptions (for those with interruptions) | 2.0 (1.0-4.0) | 2.0 (1.0-4.0) | 1.0 (1.0-2.0) |
| Mean (SD) duration of service interruption (days) | 15.1 (10.3) | 14.4 (9.4) | 14.4 (10.1) |
| Median (IQR) duration of service interruption (days) | 13.0 (9.0-15.0) | 13.0 (9.0-15.0) | 12.0 (9.0-15.0) |

### 3.4.4 Informal care

Essentially all (99.6%) palliative home care clients had an informal caregiver. The mean number of informal hours provided in the three days prior to assessment was 16.0 hours (SD=15.8) with a median of 12.0 hours (IQR=6.0-20.0 hours). The majority (78.9%) of clients reported having two caregivers. Those with two or more informal caregivers reported a greater number of informal care hours provided in past three days with a mean of 16.1 hours (SD=15.5) and a median of 12.0 hours (IQR=6.0-20.0 hours), compared with clients with only one caregiver who had a mean of 13.5 hours (SD=13.9) and a median of 9.0 hours (IQR=5.0-16.0 hours). The majority of clients with a caregiver resided with at least one of their caregivers (79.6%). The most common primary informal caregiver was a spouse, partner or significant other (56.4%), while the most common secondary caregiver was a child or child-in-law (55.5%).

## 3.5 Discussion

This study examined the characteristics and home care service utilization patterns of palliative home care clients across Ontario. Analyses of sample characteristics, propensity and intensity of service utilization, and select utilization patterns replicated the work of previous studies of a regional home-based palliative care program in Ontario, albeit using a much larger sample of palliative home care clients across the province (Cai et al., 2017; Chai et al., 2013, 2014; Guerriere et al., 2010; Sun et al., 2017; Yu et al., 2015). Other study analyses presented in this chapter, such as service mixes and service interruptions, represent the first attempts to examine these aspects of palliative home care service utilization.

Overall, the sample of palliative home care clients in this study were younger and more evenly split between males and females than the general home care population in Ontario (Canadian Institute for Health Information, 2019). These sample characteristics are likely to reflect the high proportion of clients with a cancer diagnosis in the sample (85.0%), which is substantially greater than in general home care clients (13.3 to 13.8% in 2017-2018) (Canadian Institute for Health Information, 2019). The proportion of clients with a cancer diagnosis is also consistent with what has been reported in other studies of palliative home care clients in Ontario that were not restricted to those with a cancer diagnosis (Fassbender et al., 2005; Klinger et al., 2013). Almost the entire sample of clients had some level of functional limitation based on both the IADL-ADL Functional Hierarchy Scale and the PPS, and over half of clients in this study had a prognosis of less than six months.

As with previous studies, this study found that nursing services were the most commonly used palliative home care service (Cai et al., 2017; Johnson et al., 2009). Although it does not appear that case managers have previously been included in studies examining the service utilization of palliative home care clients, the rate of case management service use was essentially as high as for home nursing. This finding is unsurprising given the coordination role that case managers play in the care of home care clients in Ontario, and is also reflected in the consistent presence of case managers in the top 10 service mixes in this study. PSWs were also involved in the care of a large proportion of palliative home care clients at rates that were similar to what have previously been reported in other studies of Ontario home-based palliative care programs (Cai et al., 2017; Klinger et al., 2013). Nursing and personal support services were received by the majority of palliative care clients, and they were received with high frequency when those services were provided. Indeed, while personal support services were used by a smaller proportion of clients than nursing or case management services, the intensity of PSW service use was far greater than for any other service. Interestingly, a smaller proportion of palliative home care clients in this study received personal support services compared with what has previously been reported in a general, long-stay population at 61.5% and 83.8%, respectively (Sinn et al., 2017), and could reflect the greater clinical complexity of palliative home care clients and their need for more skilled services like nursing. More generally across the service types, the large gap between the mean and median number of services used suggest that service utilization is heavily influenced by a small number of very high users.

Considering patterns of nursing and personal support service utilization across Ontario's 14 LHINs, it did not appear that fewer mean or median days on service necessarily corresponded to a lower intensity of service for either service type. While the rate of any nursing service use was similar across the regions, there was wide variation in the intensity of service utilization. For PSW services, the rate of any service use varied widely. Interestingly, LHINs with the higher intensities of PSW service use also had higher rates of any PSW service use. Similarly, those with the lowest intensities of PSW service use had lower propensities for service use. As with the Dumont et al. (2015) study comparing urban and rural regions, LHINs that might be assumed to have a substantial share of rural areas (i.e., North East, North Simcoe Muskoka and North West) appear to have lower propensities and intensities of PSW services, although such a distinction was not evident for nursing services. Like other studies comparing differences in utilization and cost across regions (Brick et al., 2017; Dumont et al., 2015), LHIN-based variations may potentially be explained by differences in models of palliative care, and/or resource availability and accessibility.

Changes in nursing and personal support service utilization between fiscal years 2011-2012 to 2017-2018 were also examined as part of this study. The propensity of service was largely unchanged for both types of services. In regard to the intensity of service, a decline in the number of service hours provided by PSWs could be observed over the span of fiscal years included in this study. This decline in PSW service hours appears to correspond with a decline in days on service over the same period. In both cases, there was a particularly large decline between the fiscal years 2012-2013 and 2013-2014, although it is unclear what may have resulted in this change. For nursing services, the number of visits remained relatively stable over time. These findings are not necessarily consistent with Sun et al.'s (2017) findings, although comparisons are difficult to make as their study was limited to a small sample from a single palliative care program in Toronto Central.

This study is believed to be the first to explore the time required for the initiation of services after assessment. In general, services were quick to be initiated for palliative home care clients, even when excluding case management services provided on the day of assessment. Based on the mean days to first service, both nursing and case management services were initiated within the first week of assessment, while the median days to first service would suggest that personal support services were also provided to clients within the first week of service for at least half of palliative home care clients receiving PSW services. Across all service categories, the higher mean than median days to first service indicates that there were a small number of clients with a very long time to first service within the study sample. The time to initiation of service was also lower for those with shorter expected survival, reflecting the importance of prognosis in determining service provision.

Looking across the palliative home care trajectory, it initially appears that service utilization declined as clients remained on service. This pattern is particularly pronounced during the first three weeks of services, and as suggested in a previous study (Bogasky et al., 2014), is likely to represent one-off services provided to address client needs identified during assessment. More generally, the pattern of declining service over the course of the episode is also likely to represent the relatively lower service utilization for clients with longer survival, and thus a greater number of weeks on service.

Higher service utilization was also observed with approaching discharge. This finding is generally consistent with earlier findings of increasing service utilization or costs over time, as well as findings of increased service utilization with proximity to death (Chai et al., 2013; Coyle et al., 1999; Dumont et al., 2009; Haltia et al., 2018; Sun et al., 2017). For case management, in particular, its increased intensity in the final week prior to discharge likely indicates the need for services like discharge planning or reassessment. For services provided by PSWs, however, there does appear to be a slight decrease in service intensity during the final week prior to discharge. This finding may represent the need for more specialized care like visits from nurses or physicians during this period, and is also consistent with the observation made by Sun et al. (2017) that the intensity of PSW services is not necessarily linear across the trajectory. Taken together, it would appear that the pattern of palliative home care service utilization is U-shaped in Ontario.

This study also attempted to identify potential interruptions in palliative home care service using three methods. The first method identified a large proportion of clients with gaps in service of seven days or more that was similar to the proportion of those with inpatient hospitalizations (42%) previously reported by Dumont et al. (2009). Unlike their study, however, this method identified a sizable proportion of clients who had greater than one service interruption, including a small but not insubstantial number having 10 or more interruptions. Given the prominence of weeks of service without any service utilization found in this study, it may be reasonable to assume that some of the gaps in service of seven days or longer represent a lower intensity of service use due to lower need rather than due to missed services from hospitalization. The characteristics of those identified with service interruptions using this first method further bolsters this argument as these individuals had lower levels of functional impairment (identified both by the IADL-ADL functional hierarchy and the PPS), health instability, and longer prognoses, all of which suggest healthier clients with lower need for inpatient care.

Similar to the first method, method two identified a large proportion of clients as having gaps in service of seven or more days after the first service gap of less than seven days. Even with the addition of the second condition (gaps occurring after first service of less than seven days), it appears that this method may also be capturing gaps of seven days or greater due to infrequent service rather than missed services. In particular, this method likely captures the first gap of seven days or less between one-off services provided post-assessment given the U-shaped care trajectory identified in this study, as well as the greater variation in service mixes observed during the first week of service. As with the first method, characteristics of those identified as having service interruptions had lower levels of functional impairment and health instability, and also had longer prognoses.

The third method for identifying service interruptions identified a comparatively small proportion of clients as having gaps in service of seven days or more after the initiation of weekly personal support services. While this proportion appears to be much lower than the proportion of individuals with inpatient hospitalizations identified by Dumont et al. (2009), the mean number of service interruptions captured per client was similar at 1.6 (SD=1.2), as compared to Dumont et al.'s 1.5 (SD=1.1) inpatient hospitalizations. Characteristics of clients with and without service interruptions using this third definition were also more similar, although still significantly different from one another. Overall, this third method appears to be the best approach for identifying prolonged care gaps that deviate from planned or expected levels of service utilization without the ability to link to inpatient data. However, the mean duration of service interruptions identified using this method would suggest that it is useful only in capturing prolonged gaps in service. Based on Dumont et al.'s (2009) study, this limitation may not be greatly problematic as they found that the mean length of hospitalization for those with any hospitalization was 12.0 days (SD=11.3). Determining the level of service interruptions are particularly important when considering service utilization in a resource planning context, where expected levels of service utilization are as important as actual service utilization.

Finally, this study identified that essentially all palliative home care clients received informal care, and that this care was provided primarily by spouses and children. The number of care hours provided to individuals in the study sample was high, a finding that corresponds with earlier studies that used a societal perspective and found the costs of informal care to be substantial (Brick et al., 2017; Cai et al., 2017; Chai et al., 2013, 2014; Dumont et al., 2009, 2014, 2015; Guerriere et al., 2010; Sun et al., 2017; Yu et al., 2015). The considerable time informal caregivers spent providing care to palliative home care clients indicates the high level of care needs of palliative home care clients, even in the presence of formal home care services.

### 3.5.1 Limitations

A number of study limitations must be noted. First, the sample used for this study may not be inclusive of all palliative home care clients in Ontario, Canada. While the majority of clients with identified palliative home care needs are assessed using the interRAI PC, some LHINs have chosen to discontinue the use of this assessment instrument in more recent years. Nevertheless, all LHINs are represented in the data. Another limitation has to do with the administrative data used as part of this study. Specifically, discharge dates recorded in CHRIS represent the date for which a client file is closed, and may not represent the date on which a client may be expected to stop receiving services. In all cases, it is likely that the discharge date lengthens the episodes of care, and can be observed in the findings on the number of days between final service and discharge. The rationale for delays in administratively discharging clients likely varies based on the reason for discharge. In the case of hospitalizations greater than 14 days, the expected duration of hospitalization may not be known and so clients may not be discharged until the client has been hospitalized for at least 14 days. For discharges based on client preference, clients may be left undischarged for some time to allow clients the opportunity to return to palliative home care service for at least some time after ceasing service. Finally, the inability to link the data used as part of this study to other data sources means that it was not possible to determine what other services care clients were receiving. Thus, gaps in service resulting in missed services due to use of services elsewhere in the health system (i.e., hospitalization) cannot be ascertained. While this study proposes a methodology for identifying prolonged absences from service, it is not sensitive to capturing shorter hospitalizations that contribute to no or only few missed services. Finally, only informal care time from the three days prior to assessment could be reported, and so patterns of informal care over the follow-up period could not be examined.

## 3.6 Conclusions

This study sought to address a number of questions on the characteristics of palliative home care clients, and on the service utilization patterns of these individuals. Palliative home care clients were found to primarily be individuals with a cancer diagnosis, and individuals with a prognosis of less than six months. The most commonly used formal services were case management and nursing, while personal support services and nursing had the greatest intensity of service use. Informal care was also identified as an important component of care for palliative home care clients. Service utilization was generally initiated soon after assessment and varied over time with greater utilization in the initial week after service, and increased with proximity to discharge. Lastly, most palliative home care clients did not appear to have prolonged interruptions from palliative home care services.

# Chapter 4

# Perspectives of Palliative Care Experts in Ontario on Client Characteristics Indicative of Palliative Care Service Need

## 4.1 Introduction

Individuals' need characteristics, or illness level, have been referred to by Andersen and Newman (2005) as "the most immediate cause of health service use" requiring the perception of need by individuals and their families, as well as determination of need through clinical assessment. Such characteristics can include specific diagnoses, severity of illness and/or a set of symptoms, and are used to determine levels of service provision across health sectors. In case-mix systems, need characteristics are the preferred basis for classifying individuals into groups with relatively homogenous clinical characteristics and resource utilization (Hornbrook, 1982). Identifying characteristics that indicate need is therefore imperative to understanding service utilization of palliative care services in Ontario.

## 4.2 Rationale and objectives

Care providers have an important role in determining the level of service provision to individuals requiring palliative care, and so the purpose of this study was to obtain the perspectives of individuals familiar with the management or provision of palliative care in Ontario about which client characteristics are most indicative of palliative care service need. Specifically, palliative care service need in this study refers to the service needs of individuals identified as palliative care clients/patients. The intention was to create an advisory group that could inform on efforts to identify potential predictors of palliative home care costs in subsequent studies in this dissertation (Chapters 5 and 6). The focus here was on obtaining pragmatic advice from informed stakeholders that would guide the quantitative analyses, rather than a comprehensive theoretical explication of all qualitative aspects of palliative care service use.

## 4.3 Methods

This study involved one-on-one interviews of individuals with knowledge and experience in the management or provision of palliative care in Ontario. Ethics clearance for this study was provided by the University of Waterloo's Office of Research Ethics (ORE #41489) and Wilfrid Laurier University's Research Ethics Board (File #6486).

### 4.3.1 Recruitment and sample

A convenience sample was drawn from palliative care providers or managers already known to the student investigator (myself), thesis supervisor (Dr. John Hirdes), or members of the thesis committee (Dr. Dawn Guthrie and Dr. Jeff Poss). Priority was given to the recruitment of individuals familiar with palliative home care in Ontario. A target sample size of six to eight individuals was selected as it was thought to be adequate in capturing sufficient views on indicators of palliative care service need, while limiting the burden to health care managers and providers. Sample size was constrained because this study was conducted at the peak of the second wave of the COVID-19 pandemic in Ontario. Many health care managers and providers that could have served as key informants were unavailable due to competing time demands.

In total, eight individuals were initially contacted via email to participate in this study, with one follow-up email sent to those who had not responded to the initial email. This approach led to the recruitment of four individuals. Recruitment was supplemented using snowball sampling in order to reach the target sample size. Participants that were recruited via the initial email were asked to share the recruitment email with potential participants so that interested potential participants could communicate with the research team. This step led to the recruitment of two additional participants.

### 4.3.2 Data collection

Data for this study were collected through semi-structured, one-on-one interviews of 30 to 60 minutes conducted using Microsoft Teams (for five participants) or by telephone (for one participant), between November 2020 and January 2021. Prior to the interviews, participants were asked to review a study information sheet and return a signed copy of the consent form authorizing the interview and the audio/video recording of the interview. At the beginning of each interview, verbal consent for the interview and the recording of the interview were sought. Participants were also advised that use of video was optional. Questions asked as part of the interview were guided by an interview guide developed for this study (Appendix C). To address the objective on the identification of characteristics indicative of palliative care service need, questions in this interview centered on client characteristics associated with high and low care needs. After completion of the interview, the recording was transcribed and shared with the participant for member checking, after which the interview recording was deleted. In the case of one participant, a recording of the interview could not be made due to software issues, and so detailed notes of the interview were made, and these notes were shared with the participant for member checking instead.

### 4.3.3 Analysis

Participants' backgrounds in the management and/or provision of palliative care were extracted from interview notes and transcripts in order to describe the sample. Analysis was guided by a content analysis approach (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). Interview transcripts and notes were reviewed, and passages related to indicators of palliative care service need were manually marked, and then coded on a subsequent review of the transcripts and notes. As the interview transcripts and notes were reviewed, it became evident that additional themes relevant to the broader objectives of this dissertation were present. As such, the transcripts were reviewed once again, and then marked and coded to reflect participants' observations on the allocation, provision and utilization of palliative care services in Ontario. Once all interview transcripts and notes were coded, codes were then classified into broader categories.

## 4.4 Results

### 4.4.1 Study participant characteristics

In total, this study consisted of six participants. Five of the six (83.3%) participants had a clinical background, including one nurse (16.7%), two social workers (33.3%), and two physicians (33.3%). Due to the prioritization of individuals with a background in or knowledge of palliative home care, the majority (66.7%) of study participants were working or had previously worked in one of Ontario's agencies responsible for the delivery of home care in Ontario (i.e., a Local Health Integration Network [LHIN] and/or a Community Care Access Centre [CCAC]), including half who had previously been case managers with palliative home care clients.

### 4.4.2 Characteristics associated with service need in palliative care clients

Broadly, participants in this study identified a number of characteristics that they believed were associated with palliative care service need. While participants in this study were asked about characteristics associated with high and low need separately in order to identify characteristics that may be associated with only high or only low need, participant responses suggested that such a differentiation did not necessarily exist. In general, the presence and/or greater severity of a characteristic was associated with higher need, and the inverse (absence or lesser severity) of the same characteristic was associated with lower need. These characteristics and the frequency at which these characteristics emerged from interviews can be found in Table 4.1.

**Table 4.1: Characteristics identified as being indicative of palliative care service need by individuals with knowledge and experience in the management or provision of palliative care in Ontario (n=6)**

| Characteristic | % Endorsed (n) |
|---|---|
| Symptoms | 83.3 (5) |
| Pain | 66.7 (4) |
| Dyspnea | 50.0 (3) |
| Confusion and delirium | 33.3 (2) |
| Incontinence | 33.3 (2) |
| Exhaustion/fatigue | 33.3 (2) |

| Characteristic | % Endorsed (n) |
|---|---|
| Psychosocial well-being (i.e., anxiety, depression, existential distress) | 33.3 (2) |
| Gastrointestinal issues | 16.7 (1) |
| Cognition | 16.7 (1) |
| Weakness | 16.7 (1) |
| Nausea | 16.7 (1) |
| Vomiting | 16.7 (1) |
| Itchiness | 16.7 (1) |
| Symptoms associated with active dying (including peripheral perfusion/mottling, losing consciousness, difficulty speaking) | 16.7 (1) |
| Health conditions/diagnoses | 66.7 (4) |
| Cancer | 66.7 (4) |
| Mitochondrial disorders | 16.7 (1) |
| Moderate to severe developmental delays | 16.7 (1) |
| Pneumonia | 16.7 (1) |
| Urinary tract infections (frequent) | 16.7 (1) |
| Treatments/Procedures | 50.0 (3) |
| Ventilator (including tracheotomy) | 50.0 (3) |
| Intravenous (IV) medication | 33.3 (2) |
| Gastrotomy tube feeds | 16.7 (1) |
| Function | 50.0 (3) |
| Activities of Daily Living (ADLs) | 50.0 (3) |
| Palliative Performance Scale (PPS) | 16.7 (1) |
| Prognosis/stage of illness trajectory | 66.7 (4) |
| Health instability | 16.7 (1) |

One category of characteristics that almost all participants identified as being associated with service need was client symptoms. While no participants identified the same set of symptoms, pain and dyspnea were identified by at least half of participants as being two of the major symptoms associated with greater client need. Some remaining symptoms were also identified by participants, although less commonly, and were oftentimes identified in relation to specific diagnoses. Examples include the presence of itchiness, nausea and fatigue in those with renal failure, while confusion, delirium and agitation were symptoms associated with liver disease. More generally, participants noted that while a higher number of symptoms reflected greater need, the level of control over symptoms, the severity of symptoms, complexity of the overall symptom profile and level of health (in)stability also contributed to clients' levels of need. Closely tied to clients' symptoms was their use of treatments and procedures, another category identified by participants as being indicative of greater client need. Treatments and procedures identified included the use of a ventilator, gastrotomy tube feeds, and IV medication.

Another category of need identified by participants was clients' primary diagnosis. Cancer, in particular, was identified by the majority of participants as an indicator of need. However, rather than identifying cancer as an indicator of increased or decreased need or service utilization, participants instead elaborated on the greater predictability of need for those with cancer. As one physician participant stated, "if you have cancer […] the system is built for you. You're easy to prognosticate. Needs tend to go up when the system is ready to kick in for you." In contrast to cancer, participants indicated that palliative care service needs were more difficult to determine for those with conditions following an organ failure trajectory (e.g., congestive heart failure or chronic obstructive pulmonary disease) due to the nonlinear trajectory marked by frequent exacerbations and recoveries. One participant suggested that clients with conditions following an organ failure trajectory may appear to have lower levels of utilization, but that it would be unclear whether it was the result of the absence of need, or the inability of the system to respond to sudden deteriorations.

Indeed, clients' health conditions were tied closely with prognosis, another characteristic identified by participants as an indicator of need. Prognosis was described both in terms of expected time to death, and as a point on the illness trajectory. With regard to time to death, participants identified the final three to four months of life as a period of greater need for those receiving palliative care. However, they noted that this pattern was primarily descriptive of cancer trajectories, which account for the large majority of palliative care clients/patients, and not necessarily the minority of patients/clients with differing trajectories. From an illness trajectory perspective, participants also suggested that the difficulty in prognosticating clients with noncancer conditions could lead to the misidentification of need, particularly during clients' final decline. As one non-clinician participant stated, "if they have cancer you kind of know the trajectories that they're following, you kind of know how to take care of them."

Clients’ level of function was another characteristic that corresponded with need so that those who were more functionally dependent had greater needs. Measures of function identified by participants included ADLs and the PPS. With regard to ADLs, specific activities identified by participants included walking and locomotion, as well as bed mobility. Here too, two participants noted the relevance of clients’ illness trajectories by describing the longer, more gradual functional decline in those on an organ failure trajectory, and the difficulties in identifying the needs for these individuals. One physician participant highlighted this difference between cancer and noncancer trajectories by stating:

> *Noncancer patients don’t change quickly so there’s no big inflection point so that there’s no dramatic change for us to pick up on. Plus, they don’t go from being independent to being dependent. They’re already dependent so they get slightly more dependent and people don’t tend to notice that, whereas in cancer world if you go from independent to dependent, which is quite a substantial change and it’s easy to spot.*

### 4.4.3 Other findings

While the focus of this study was to identify characteristics that are indicative of palliative care service need, some additional themes emerged from across interviews. One such theme had to do with client need and level of service utilization. Participants spoke to the adequacy of the health care system and five of six participants believed that the needs of palliative care patients/clients were generally met by the system. The one participant who did not endorse this view had a background in the paediatric system and instead expressed that it is the “expectation that family meets those [care] needs” and that “all parents feel they need more care” for their child. Within the adult system, participants noted the one major limitation to the ability to meet service needs of individuals with life-limiting conditions was the organization of the system around those with cancer. Participants indicated that while this limitation led to the overrepresentation of those with cancer in palliative care settings, it did not necessarily result in higher or lower costs for those with other health conditions. Instead, participants described patterns of utilization whereby those with organ failure conditions received general home care services over a longer period of time, while those with cancer were more likely to receive palliative home care after an inflection point. Nevertheless, participants with backgrounds in palliative home care felt that the system was generally responsive to, and met the needs of both clients with and without cancer diagnoses, although clients' families could potentially require more mental health support. One participant with a social work background expressed that

> *for the most part, [clients'] needs were met. Um, probably physical needs were definitely met, I think. Probably the things that were more challenging were um, meeting the mental health needs of the family because some families just that the you know, it just happened really quickly and they just weren't ready.*

The perspective that the needs of individuals receiving palliative care were generally met led participants to frequently refer to client need and service utilization interchangeably. In doing so, participants discussed a number of additional client characteristics they associated with palliative care service utilization, and which can be categorized into predisposing and enabling factors based on Andersen and Newman's (2005) health care utilization framework. These characteristics that emerged from participant interviews can be found in Table 4.2.

**Table 4.2: Predisposing and enabling characteristics identified as being related to service utilization by individuals with knowledge and experience in the management or provision of palliative care in Ontario (n=6)**

| Characteristic type | Characteristic | % Endorsed (n) |
|---|---|---|
| Predisposing | Cultural background (which informs on attitudes towards death and dying, and the role of family in taking care of the ill) | 50.0% (3) |
| | Client/family knowledge and understanding of impending death | 50.0% (3) |
| Enabling | Level of caregiver support provided to client (which is influenced by caregiver characteristics) | 83.3% (5) |
| | Caregiver needs (i.e., distress, unable to provide more care) | 50.0% (3) |
| | Region of residence | 66.7% (4) |
| | Home care client type | 50.0% (3) |
| | Case manager | 33.3% (2) |

#### 4.4.3.1 Predisposing characteristics

Half of participants identified predisposing characteristics that were related to service utilization which were expressed through clients and their families' preferences for care. Specifically, participants stated that clients and their families' cultural backgrounds shaped care preferences through beliefs on the role of family in taking care of the ill, and through attitudes on death and dying. In regard to the role of family, one physician participant described the thought process for family caregivers belonging to some cultures as "if I let somebody else [take care of] my loved one while [they're] sick, I'll get judged by my family for not doing my job," which could in turn lead to the rejection of formal services, or to the potentially inappropriate reliance on hospital-based inpatient care. Attitudes on death and dying were also discussed by participants with one nurse participant stating that

> *North American society, culturally, we're probably not at a place where we're comfortable talking about death and dying, and that actually did play out a lot, and so the support looked quite different, and was much more devastating in the ability to support the loved ones and or the person who is passing, who is in the dying process and accepting that.*

Attitude towards death was also discussed within the context of location of death such that "there is a cultural belief that you know, it's bad luck to have a loved one die in the home and so in planning the care, you do start looking and talking about hospice placement."

A second predisposing characteristic that emerged from the interviews was clients and their families' knowledge and understanding of a client's health status. For some clients and their families, participants suggested that this factor could be related at least somewhat to attitudes on death and dying, which could lead to families withholding information from clients and vice versa, or to denial of the client's health status. However, it did not appear there was a specific direction through which service utilization was affected by this predisposing characteristic. For example, clients and/or their families' denial of a client's health status could lead to greater service utilization through the pursuit of more (curative) treatment, but could also lead to lower service utilization through the rejection of additional services offered to these clients (because they do not believe they need these services).

#### 4.4.3.2 Enabling characteristics

With respect to enabling factors, almost all participants identified family/caregiver support to clients as a factor that influenced service utilization levels. Specifically, participants stated that those with stronger caregiver networks tended to have lower levels of formal service utilization. Some participants further elaborated by identifying characteristics of families/caregivers that were associated with the ability to provide greater informal support. These caregiver characteristics included age, relationship to client, competing responsibilities, burnout and/or distress, ability to advocate for formal services, as well as support for the caregiver. These caregiver characteristics were not necessarily independent of one another. One example provided by a participant suggested that younger caregivers were generally the children of clients and that these caregivers were more likely to have competing responsibilities such as children of their own, and full-time employment. Related to that point, clients' service utilization was also affected by the needs of their caregivers. As one participant stated, "to prevent caregiver burnout, it would be providing the respite hours to let the caregivers to get out and do things for their own sanity, which would then contribute to the overall wellbeing of the patient." Participants implied that there was a relationship between caregiver distress and respite service utilization so that greater distress was met with greater provision of service.

Another enabling characteristic identified by participants was a client's region of residence, which affected access to palliative care through the availability of service providers. Specifically, participants indicated that the availability of palliative care service providers was higher in urban areas, and lower in rural areas. Particular emphasis was placed on the lower availability of service providers in northern regions/LHINs. One participant with a social work background who had previous experience with the case management of palliative home care clients in both northern and more central regions offered the following comparison (region names have been concealed to protect the identity of the participant):

> *[A more central region] has a huge budget, they never really had waitlists so their utilization tends to be higher. Um, you know whereas you get other organizations like little [northern region], which doesn't really get a big budget, um, so they either waitlist people and they don't serve them, or they tend to underutilize, try to give a lot to everybody instead of what people need to the few.*

Two participants also noted that specific to the home care setting, clients' region of residence could influence care due to differences in eligibility criteria for being designated as an end of life client, differences in models of care, and the availability of specific services provided through pilot programs. Specific to client type, participants indicated that there were possible variations in the eligibility criteria for this designation across the LHINs, including the expected prognosis which could range between three and six months. Finally, one participant identified clients' case managers as a fourth enabling factor, given their role in determining the volume of care provided to home care clients. In particular, this participant mentioned that a case manager's knowledge of, experience with, and attitudes towards both palliative care, and death and dying could influence their determination of service provision level, including whether a client was designated as end of life.

#### 4.4.3.3 Informal care

The discussion of need and enabling characteristics identified by participants also pointed to the importance of informal help in palliative care. Participants noted unequivocally that without informal care, palliative clients would be unable to remain in the community. The need to provide support services to caregivers in order to prevent distress and/or burnout was therefore emphasized by half of participants. One participant noted that in many cases, clients would not turn to formal services until their caregivers felt unable to provide any more support. Within the paediatric setting, one participant stated that the expectation was for at least one parent to provide full-time care to the child receiving palliative care, and that those receiving home care tended to belong to a complex population with assistive technology needs and/or those experiencing a rapid decline.

#### 4.4.3.4 Service allocation decision making

A final theme that emerged from interviews with participants familiar with the palliative home care system was the absence of formal mechanisms for determining clients' palliative home care service needs. The absence of these mechanisms was contrasted with the more general long-stay home care population where a number of scales and/or algorithms are used. Measures and indicators named by participants included clinical assessment protocols (CAPs) that are built into the assessment process, the Method for Assigning Priority Level (MAPLe) score (Hirdes, Poss, et al., 2008), the Personal Support Algorithm (Sinn et al., 2017), the Changes in Health, End-stage Disease, Signs, and Symptoms (CHESS) scale (Hirdes et al., 2003), and Detection of Indicators and Vulnerabilities for Emergency Room Trips (DIVERT) scale (Costa, Hirdes, et al., 2015). In the case of CAPs and CHESS scores, participants acknowledged that these measures existed for the interRAI PC (Freeman et al., 2014) but were not used by case managers to determine service need. With regard to CAPs, one former case manager explained that service allocation decisions were not informed by CAPs because "the CAPs have been around for a long time and never developed in our software." Further, participants mentioned that although decision support teams exist within LHINs, indicators of client need and/or predictors of service utilization had not previously been examined. Thus, participants with experience in the palliative home care system emphasized the need for research to better understand palliative home care client care needs and service utilization.

## 4.5 Discussion

The primary objective for this study was to obtain guidance to identify characteristics indicative of need for palliative care service to inform on subsequent analyses on predictors of palliative home care costs. To this end, a number of characteristics were identified, falling into categories that include client symptoms, health conditions, level of function, treatments and procedures, level of health instability and prognosis. These categories suggest that need for palliative care is multidimensional in nature, which necessitates a comprehensive assessment as a starting point. The characteristics identified by participants in this study were also highly specific, and alongside more comprehensive palliative home care client assessments, may help to identify a more specific set of factors predictive of palliative home care costs than has previously been identified. Despite not being the focus of questions asked as part of the interviews, participants also spoke of predisposing and enabling characteristics that can affect palliative care service utilization. These characteristics may also be considered as potential predictors of palliative home care cost in subsequent studies in this dissertation, and include clients and their families' cultural backgrounds (which influence attitudes towards death and dying, and the role of family in taking care of the ill), caregiver capacity to provide care (informed by caregiver characteristics), caregiver burden or distress, region of residence, and having cancer.

The discussion of cancer in this study was particularly interesting as participants described a characteristic that appeared to function as an enabling characteristic rather than a need characteristic. Specifically, participants described the palliative care system as being structured around a cancer trajectory so those with cancer had access to a system that would be better suited to their needs. This observation is consistent with earlier research by Klinger et al. (2013) who found individuals with noncancer trajectories tended to be costlier, and hypothesized that this finding was due to the unpredictability of their care needs.

Finally, participants in this study generally discussed indicators of palliative care service need interchangeably with characteristics they felt were associated with service utilization. Indeed, almost all participants in this study stated that they believed that the palliative care system was adequate in meeting the needs of palliative care clients/patients. However, it was unclear whether participants believed that the system was adequate at identifying individuals who could benefit from palliative care, and thus become palliative care clients/patients. Some participants' discussions on challenges identifying need in those with noncancer diagnoses would suggest that at least for this population of individuals, there may be room for improvement.

### 4.5.1 Limitations

Despite meeting the target sample size, the primary limitation to this study was the small number of participants. It is possible that a greater number of participants could have identified additional potential indicators of palliative care service need. However, recruitment of additional participants was difficult in the context of a global pandemic, especially given the need for participants with health care backgrounds. Further, the objective of this study was not to produce an exhaustive list of characteristics that may indicate palliative care service need, but rather to supplement existing literature to inform on subsequent analyses in this dissertation.

## 4.6 Conclusions

The purpose of this study was to identify indicators of palliative care service need from the perspective of palliative care experts in Ontario. In addition to identifying a broad range of potential indicators of palliative care service need, a number of predisposing and enabling characteristics were also identified that are considered in subsequent studies described in this dissertation. The need for research to better understand palliative home care, including the identification of predictors of palliative home care costs, was also endorsed by participants familiar with the home care system.

# Chapter 5

# Predicting Formal Palliative Home Care Costs using the Palliative Performance Scale and Related Factors

## 5.1 Introduction

Understanding the service needs of palliative home care clients is increasingly important as the number of Canadians with life-limiting conditions is expected to increase, and emphasis on the role of palliative care within the health system continues to grow. In particular, the potential for palliative home care to allow those with life-limiting conditions to remain and die at home (Masucci et al., 2010), as well as the potential cost savings associated (Penning et al., 2017; Scitovsky, 2005; Seow et al., 2019) has resulted in great interest in this type of care. Due to the complexity and variability of the palliative home care population, the ability to classify this population of clients into groups with comparable resource needs would be particularly beneficial to ensuring their ability to receive a high quality of care that is responsive to their level of care needs (Becker et al., 2018).

At this time, only a single palliative care case-mix classification system has been developed. It is not specific to the home care setting, but instead includes persons receiving subacute and nonacute care in both inpatient and outpatient settings. Situated within the Australian Sub-Acute and Non-Acute Patient (AN-SNAP) system, Australia’s subacute and nonacute classification system, 21 of the 124 classes of the most recent version of this system are specific to adult palliative care clients, with 13 classes for those in inpatient settings, and eight for those in outpatient settings (Green et al., 2015). Across both settings, classes are determined based on phase of illness, functional dependence, age, and initial phase type at the start of the episode (Green et al., 2015). For outpatient settings, symptom severity (Palliative Care Problem Severity Score [PCPSS]) is used to further classify individuals (Green et al., 2015).

Although case-mix systems for palliative care are still under development in England and in Germany, preliminary studies have identified potential client characteristics that may be used to classify palliative clients into case-mix groupings (Becker et al., 2018; Guo et al., 2018). In England, the objective is to classify individuals in inpatient, hospice, and community settings. The study protocol for this development work reports that potential classification items under consideration include demographic information (i.e., age, gender, marital status), clinical information on diagnoses, episode start and end date, discharge disposition for those discharged from an episode of care, phase of illness, functional status measured using the Australian Karnofsky Performance Scale, dependency measured by the Barthel Index, problem severity using the PCPSS, and family/caregiver needs (Guo et al., 2018). Information collected from patients and their caregivers is also being considered, and includes caregiver demographic information, distress, views on care data from the Short-Form Health Survey, as well as patient experiences (Guo et al., 2018). Finally, model of care is also under consideration (Guo et al., 2018).

In Germany, existing work has focused on identifying predictors of cost for inpatient care on palliative care units (PCUs), and as consultation services on other hospital units. For those on PCUs, change in palliative care phase within an episode was found to be associated with higher costs, as was being discharged to hospice as compared with other care settings (Becker et al., 2018). As a consultation service, a change in palliative care phase within an episode was also predictive of higher care costs, in addition to being male, and discharge home (Becker et al., 2018). A single unit increase in the Karnofsky Performance Scale score at the end of an episode was associated with lower costs for palliative care provided as a consult service (Becker et al., 2018).

While neither the AN-SNAP system nor studies on the preliminary stages of case-mix development have focused on palliative care provided in the home setting, a number of studies have identified factors that are predictive of formal home-based palliative care service utilization or cost in Ontario. No studies examined palliative home care exclusively, but the studies did include palliative home care services as part of broader home-based palliative care services. The majority of these studies were guided by Andersen and Newman’s (2005) framework on health services utilization, and findings are organized as such here. For predisposing characteristics, age, marital status and gender were identified as being predictive of home-based palliative care service use (Cai et al., 2017; Howell et al., 2011; Masucci et al., 2013; Sun et al., 2017), and cost (Chai et al., 2013). More specifically, older age was associated with greater propensity and intensity of personal support service use (Cai et al., 2017; Howell et al., 2011; Masucci et al., 2013; Sun et al., 2017), while being associated with lower propensity and intensity of physician visits and nursing services (Cai et al., 2017; Masucci et al., 2013). Another study, which examined the share of costs attributable to the public health care system, found older age to be associated with lower shares of costs attributable to the public system (Chai et al., 2013). Gender was also identified as a determinant of formal home-based palliative care utilization, with two studies finding that being male was significantly associated with lower propensity of services provided by personal support workers (PSWs), and lower intensity of PSW, nursing and physician visits (Cai et al., 2017; Sun et al., 2017). This association was not necessarily consistent, however, with one study finding that being male was positively, but nonsignificantly associated with the share of costs attributable to publicly financed costs (Chai et al., 2013). Similarly, another study of home care expenditures for those enrolled in a pilot palliative home care program also found that being male was nonsignificant in its association with costs (Howell et al., 2011). For marital status, being single was associated with a greater share of costs attributable to the public system (Chai et al., 2013). Other studies considering specific home-based palliative care services found that being unmarried was associated with a lower propensity for nursing services, and a greater propensity for personal support services (Cai et al., 2017; Sun et al., 2017).

With regard to enabling characteristics, factors that were found to be predictive of service utilization or costs included living alone, caregiver characteristics, and socioeconomic status, although findings were not necessarily consistent across studies (Cai et al., 2017; Chai et al., 2013; Howell et al., 2011; Masucci et al., 2013; Sun et al., 2017). One study found that those living alone were approximately half as likely to receive any home-based nursing and personal support services (Cai et al., 2017). For service intensity, another study found that living alone was associated with lower nursing service intensity (Sun et al., 2017). Caregiver characteristics were also identified as predictors of formal palliative home care service utilization. Having a male caregiver, or having a caregiver that was a spouse were both found to be associated with a lower propensity of receiving home-based nursing or personal support services

(Cai et al., 2017). Older caregiver age, and caregivers who were employed (as compared to retired) were also found to be predictive of lower service intensity for physician home visits (Sun et al., 2017). Socioeconomic factors were also identified as predictors of home-based palliative care service utilization. Lower socioeconomic status, measured using the Carstairs deprivation score, was found to be associated with a greater propensity and intensity of nursing and personal support services (Cai et al., 2017; Masucci et al., 2013). However, another study using the same measure found that having higher socioeconomic status was associated with a greater share of publicly financed health care costs (Chai et al., 2013). Measured using household income, yet another study found socioeconomic status to be nonsignificant in predicting palliative home care expenditures (Howell et al., 2011).

Regarding need characteristics, increased home-based palliative care service utilization was associated with a greater number of comorbidities, advanced disease, declines in functioning, greater symptom severity, and proximity to death (Cai et al., 2017; Chai et al., 2013, 2014; Chan et al., 2001; Eagar, Green, & Gordon, 2004; Guerriere et al., 2010; Sun et al., 2017). Poor functioning measured with the Palliative Performance Scale (PPS) was found to be associated with a greater propensity and intensity of home-based physician, nurse and PSW visits (Masucci et al., 2013). This finding is not consistent across studies, however. One study found that greater PPS scores (higher functioning) were not significantly associated with the propensity for PSW service use, but were significantly associated with a higher intensity of nurse, PSW, and physician home visits (Sun et al., 2017). Somewhat similarly, another study found greater PPS scores to be associated with a greater propensity and intensity of physician and PSW home visits, but a lower propensity and intensity of home visits by nurses (Cai et al., 2017). In a study of the proportion of palliative care costs attributable to the public health care system, higher PPS scores were associated with a smaller share of public system costs (Chai et al., 2013).

Other need characteristics were examined in only a small number of studies. Greater symptomatology, measured using the Edmonton Symptom Assessment Scale (ESAS), was found to be associated with a smaller public share of costs (Chai et al., 2013). A second study was more specific in the symptoms that it examined, and found that the presence of eating problems was associated with greater home-based palliative care costs, while gastrointestinal symptoms were associated with lower care costs (Howell et al., 2011). Relatedly, greater comorbidity has been found to be significantly predictive of both the propensity and intensity of PSW home visits, but not physician or nurse home visits (Cai et al., 2017). Proximity to death has also been found to be associated with the propensity and intensity of physician, nurse and PSW home visits (Sun et al., 2017). For the propensity of home-based palliative care service, longer time to death has been found to be associated with lower propensities of physician, nursing and PSW visits, although for nursing and PSW visits, the propensity of service was greatest in the period between 30 days and six months rather than the final 30 days of life (Sun et al., 2017). The intensity of service was consistent across physician, nurse, and PSW services so that being closer to death was associated with greater service intensity (Sun et al., 2017). Finally, one study examined the association between radiation and chemotherapy treatments, and found that receiving no therapy and receiving radiation therapy were associated with having a lower share of costs attributable to the public health care system (Chai et al., 2013).

## 5.2 Rationale and objectives

Understanding the palliative home care system in Ontario requires information on how the system is currently being used. Part of this information includes factors that predict formal palliative home care costs. The existing case-mix system in Australia and development work in Germany and England suggest that the concept of palliative care phase is a key characteristic that may be used to classify palliative care clients, albeit primarily in inpatient care settings (Becker et al., 2018; Green et al., 2015; Guo et al., 2018). However, information on palliative care phase is not collected in Ontario. The PPS, which considers ambulation, activity and evidence of disease, self-care and intake level (Anderson et al., 1996), may be the closest approximation to palliative care phase available in Ontario given the consideration of problem-related variables and ADL function used as part of the assignment of palliative care phase (Masso et al., 2015). The first objective of this study was therefore to determine the effectiveness of the PPS in predicting formal palliative home care costs in Ontario. As the PPS is not consistently used to assess palliative home care clients in Ontario, a second objective of this study was to identify palliative home care assessment items and scales available as part of the interRAI Palliative Care (PC), that correspond with components of the PPS in order to determine whether these items can be used to predict palliative care costs in place of PPS scores. The final objective of this study was to identify other characteristics available in the interRAI PC that are predictive of formal palliative home care costs, and to compare the performance of the PPS with the performance of these interRAI PC scales and items in predicting care costs.

## 5.3 Methods

This study was a retrospective study of secondary health data collected through the interRAI PC assessment instrument linked to administrative data including home care client referral and service utilization information collected as part of Health Shared Services Ontario's (HSSOntario) Client Health Related Information System (CHRIS). Detailed descriptions of these data sources may be found in the methods section of Chapter 3. This study received ethics clearance from the University of Waterloo's Office of Research Ethics (ORE #41489) and Wilfrid Laurier University's Research Ethics Board (File #6486).

### 5.3.1 Sample

This study relied on subsamples of the 68,731 palliative home care clients identified in the first study of this dissertation (Chapter 3). For the analysis of predictors of PPS score, the subsample drawn consisted of individuals with a PPS score. For analyses related to costs, the subsample was restricted to individuals with a PPS score, and who were on palliative home care service for at least five weeks based on the number of days between interRAI PC assessment date and the discharge date found in clients' referral data. The sample was restricted to those on service for at least five weeks in order to ensure that a stable estimate of cost, which is required for case-mix development, could be established. For those discharged from palliative home care due to death in hospital, hospitalization greater than 14 days, or vacation greater than 30 days, an adjusted discharge date of the final date of service was used instead. This adjustment was made based on findings from the study described in Chapter 3 that suggest delays in discharges exist for administrative reasons, and in which clients would not be expected to receive palliative home care services during that time.

### 5.3.2 Dependent variables

Two dependent variables were considered as part of this study. The first dependent variable was the PPS, represented as a continuous variable. The second dependent variable was the mean weekly formal cost of palliative home care services provided during the first five weeks of service, which was examined with both continuous and categorical operationalizations.

#### 5.3.2.1 PPS

The PPS is scored from 0% to 100% and is used to measure physical status. In assigning a score, the PPS considers individuals' ambulation, activity and evidence of disease, self-care, intake and conscious level (Anderson et al., 1996). Clients' PPS scores were obtained from assessment records. As the PPS is not collected as part of the interRAI PC, and assessment using this scale is not mandatory, PPS scores were available for only 80.6% of the sample.

#### 5.3.2.2 Mean weekly cost

The measure of cost considered as part of this study was the mean weekly cost of formal palliative home care services provided over the first five weeks of service post-assessment. The aggregation of costs over this defined period was employed in order to ensure that a stable estimate of clients' mean weekly costs could be obtained given week-to-week variations in service use, as well as the higher levels of service utilization that are generally observed at service initiation (as found in the study described in Chapter 3 and discussed in other earlier studies (Bogasky et al., 2014; Coyle et al., 1999)). This approach has been used in previous studies of palliative care cost (Coyle et al., 1999), as well as in the case-mix literature (Björkgren et al., 2000; Poss et al., 2008). Specifically, a period of five weeks was deemed appropriate as shorter time periods would have resulted in an overestimate of costs due to an insufficient period for costs to stabilize after the initial week of service post-assessment. Longer periods would have excluded an even greater proportion of palliative home care clients. Due to rapid declines that can be expected in palliative care clients, information captured as part of the interRAI PC as it relates to cost could also be expected to become less relevant as time periods increase.

The cost of palliative home care over the first five weeks of service was estimated from a public payer perspective by applying unit costs (hourly or by visit, depending on the service) to the quantity of service used by clients. Information on the quantity of service used was obtained from the billing/payment data available as part of the CHRIS. Service types considered as part of this study included case management, nursing (clinics, shifts and visits), respiratory therapy, nutrition, physiotherapy, occupational therapy, speech language pathology, social work, psychology and personal support. Unit costs were obtained from Ontario Health (personal communication, August 11, 2020) for this study and represent the mean payment amount made to individual providers across Ontario for each service category in Canadian dollars (CAD) up to January 2020 for most services. As case managers are considered to be salaried LHIN staff and are therefore are not considered billed visits in CHRIS, the payment rate was assumed to be the cost of a nursing visit as most case managers in Ontario are nurses. Payment rates for each service type included as part of this study may be found in Table 5.1. The cost of each service type over the first five weeks of service were then aggregated for each client and then divided by five in order to obtain the mean weekly formal palliative home care service cost.

**Table 5.1: Palliative home care service payment rates, 2020 CAD**

| Service type | Payment rate |
|---|---|
| Case management | $62.63 |
| Nursing clinics | $40.57 |
| Nursing shift | $52.13 |
| Nursing visits | $62.63 |
| Respiratory therapy | $138.68 |
| Nutrition | $129.62 |
| Physiotherapy | $99.50 |
| Occupational therapy | $127.63 |

| Service type | Payment rate |
|---|---|
| Speech language pathology | $140.54 |
| Social work | $155.99 |
| Psychology | $91.28* |
| Personal support | $35.86 |

*Rate is for fiscal year 2017-2018.

In treating cost as a continuous variable, a log-transformation was applied to clients' mean weekly costs in order normalize its distribution due to the right-skewed nature of cost data. The log-transformation of costs has been used previously (Masucci et al., 2013) and is consistent with existing costing methodology (Diehr et al., 1999).

In considering cost as a dichotomous variable, clients were assigned to either a 'high' or 'low' cost group. These groupings were conceptualized in a number of ways that included the following:

- Clients with the highest 90% weekly mean costs were placed in a 'high' cost group and the remaining 10% were placed in a 'low' cost group;
- Clients with the highest 10% weekly mean costs were placed in a 'high' cost group with the remaining 90% in a 'low' cost group;
- Clients with the highest 20% weekly mean costs were considered 'high' cost while those with the lowest 20% of costs were considered 'low' cost.

Cost was also considered as an ordinal variable. Clients with the highest 10% weekly mean cost were assigned to a 'high' cost group, the middle 80% were assigned to a 'mid' cost group, and the lowest 10% assigned to a 'low' cost group.

### 5.3.3 Independent variables

#### 5.3.3.1 PPS models

Independent variables considered for inclusion in predicting PPS scores was guided by the five components considered in the assignment of PPS score. (The PPS and its scoring criteria can be found in Table D.1, Appendix D.) These components and the corresponding interRAI PC items considered as independent variables in the prediction of PPS scores can be found in Table 5.2. The Instrumental Activities of Daily Living (IADL) Activities of Daily Living (ADL) Functional Hierarchy scale was used to represent three PPS components due to its breadth in measuring function (Morris et al., 2013), corresponding to the PPS's ambulation, self-care and activity components. In the interRAI PC, this scale is comprised of items that include meal preparation, housework, medication management, hygiene, toilet use, locomotion and eating.

**Table 5.2: interRAI PC items/scales corresponding to components of the PPS for the prediction of PPS scores**

| PPS component | interRAI PC item/scale (continuous unless stated otherwise) |
|---|---|
| Ambulation | IADL-ADL Functional Hierarchy Scale |
| Activity and evidence of disease | CHESS<br>IADL-ADL Functional Hierarchy Scale |
| Self-care | IADL-ADL Functional Hierarchy Scale |
| Intake | Ate ≤1 meal on at least 2 of last 3 days[1]<br>Fluid intake <1,000 cc per day[1]<br>Mode of nutritional intake[2] |
| Conscious level | CPS<br>Fluctuating state of consciousness[1]<br>Acute change in mental status from person's usual functioning[1] |

ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptoms; CPS = Cognitive Performance Scale; IADL = instrumental activities of daily living

[1] Dichotomous 'No,' 'Yes'

[2] Categories are 'Normal,' 'Modified independent,' 'Requires diet modification to swallow solid food,' 'Requires modification to swallow liquids,' 'Can swallow only puréed solids,' 'Combined oral and parenteral or tube feeding,' 'Nasogastric tube feeding only'

#### 5.3.3.2 Cost models

In the models of cost related to the PPS, the PPS and the interRAI PC scales and items listed in Table 5.2 were considered as independent variables. In considering broader predictors of cost, a number of additional independent variables were considered. The selection of these independent variables was guided by the Andersen and Newman's (2005) framework on health service use, and informed by factors previously identified in the literature, as well as by participants in the study described in Chapter 4. A list of these variables can be found in Table 5.3.

**Table 5.3: Contender interRAI PC scales and items for the prediction of palliative home care costs**

| Characteristic type | interRAI PC item/scale (continuous variables unless stated otherwise) |
|---|---|
| Predisposing | Age |
| | Gender[1] |
| | Marital status[2] |
| | Verbalizes awareness of terminal prognosis of less than 6 months to live[3] |
| | Accepting of situation[3] |
| Enabling | LHIN of residence[4] |
| | Informal helper(s) |
| | Living arrangement[5] |
| | Live-in caregiver[3] |
| | Primary caregiver relationship to client[6] |
| | End of life home care client type[3] |
| | Informal helper(s) unable to continue in caring activities[3] |
| | CaRE |
| | Family or close friends report feeling overwhelmed by person's illness[3] |
| Need | Prognosis[7] |
| | IADL-ADL Functional Hierarchy Scale |
| | CHESS scale |
| | CPS |
| | Fluid intake <1,000 cc per day[3] |
| | Ate ≤1 meal on at least 2 of last 3 days[3] |
| | Mode of nutritional intake[8] |
| | Dyspnea[9] |
| | Fatigue[10] |
| | Nausea[3] |
| | Vomiting[3] |
| | Acid reflux[3] |
| | Bloating[3] |
| | Constipation[3] |
| | Diarrhea[3] |
| | Fecal impaction[3] |
| | Pain Scale |
| | IV medication[11] |
| | Ventilator or respirator[11] |
| | Cancer[3] |
| | DRS |
| | Expressions, including nonverbal, of what appear to be unrealistic fears[3] |
| | Repetitive health complaints[3] |
| | Repetitive anxious complaints/concerns (non-health related)[3] |
| | Bladder continence[12] |
| | Bowel continence[12] |
| | Fluctuating state of consciousness[3] |
| | Acute change in mental status[3] |

ADL = activities of daily living; CaRE = Caregiver Risk Evaluation; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; LHIN = Local Health Integration Network; IADL = instrumental activities of daily living; IV = intravenous

[1] Categories are 'Male,' 'Female'

[2] Categories are 'Never married,' 'Married,' 'Partner/Significant other,' 'Widowed,' 'Separated,' 'Divorced'

[3] Dichotomous 'No,' 'Yes'

[4] Categories are the 14 LHINs in Ontario

[5] Categories are 'Alone,' 'With others'

[6] Categorical 'Child or child-in-law,' 'Spouse/Partner/Significant other,' 'Other family,' 'Friend/Neighbour,' 'None'

[7] Categories are 'Death imminent (within days),' 'Less than 6 weeks,' '6 weeks or longer, but less than 6 months,' '6 months or longer'

[8] Categories are 'Normal,' 'Modified independent,' 'Requires diet modification to swallow solid food,' 'Requires modification to swallow liquids,' 'Can swallow only puréed solids,' 'Combined oral and parenteral or tube feeding,' 'Nasogastric tube feeding only'

[9] Categories are 'Absence of symptom,' 'Absent at rest, but present when performed moderate activities,' 'Absent at rest, but present when performed normal day-to-day activities,' 'Present at rest'

[10] Categories are 'None,' 'Minimal,' 'Moderate,' 'Severe,' 'Unable to commence any normal day-to-day activities'

[11] Categories are 'Not ordered AND did not occur,' 'Ordered, not implemented,' '1-2 of last 3 days,' 'Daily in last 3 days,' 'Did not occur, declined offered treatment'

[12] Categories are 'Continent,' 'Complete control with any catheter or ostomy over last 3 days,' 'Infrequently incontinent,' 'Occasionally incontinent,' 'Frequently incontinent,' 'Incontinent,' 'Did not occur'

### 5.3.4 **Analyses**

All analyses for this study were conducted using SAS version 9.4 (*SAS System*, 2013). The subsample of palliative home care clients with a PPS score were described through a number of key characteristics and compared to those clients without a PPS score. Chi-square tests were conducted in order to identify any biases that may exist within the sample. The association between PPS and interRAI PC scales and items were then investigated using generalized linear models. Manual backwards elimination was used to retain only those variables significantly associated with PPS scores at the 95% significance level (p=0.05). The level of explained variance ($R^2$) was used to assess the combined performance of the variables retained in the final model predicting PPS score.

For analyses related to care costs, descriptive analyses were also conducted for the subsample of palliative home care clients with a PPS score, and on service for five or more weeks. In order to identify any biases in this subsample, client characteristics were compared between those included and excluded from this subsample through Chi-square tests. The mean weekly quantity of service utilization over the first five weeks of service were calculated for each of the service types in following with guidelines for conducting economic analyses (Drummond & Jefferson, 1996). Mean weekly formal costs over the first five weeks of service, estimated as described in the section on dependent variables, were then calculated for the sample and reported in 2020 CAD.

A bivariate generalized linear model was fit to assess the utility of the PPS in predicting log mean weekly costs in a subsample of clients both on service for five weeks or greater, and with a PPS score. This analysis was followed by multivariate analyses, which were conducted to identify predictors of the log mean weekly cost based on the interRAI PC scales and items found to be predictive of PPS scores in the first analysis. The performance of the PPS was then compared to the performance of interRAI PC scales and items (found to be associated with PPS scores) in predicting the log mean weekly formal care costs using the explained variance. A combined model containing both the PPS and interRAI PC scales and items (associated with PPS) as dependent variables was then fit to determine the contributory effect of the PPS to the model containing interRAI PC scales and items only. Due to the potential collinearity between PPS scores and interRAI PC scales and items related to the PPS, the variance inflation factor (VIF) was assessed.

Bivariate analyses were then conducted between the log mean weekly cost and the candidate interRAI PC variables listed in Table 5.3. Variables significant in bivariate analyses were entered into three multivariate models, each one representing one of the categories of Andersen and Newman’s (2005) framework on determinants of health service utilization in order to gauge the level of explained variance for each category. Models were finalized using manual backward elimination of variables nonsignificant at the 95% level. Variables found to be significant in bivariate models were then also included into multivariate generalized linear models containing all contender variables across predisposing, enabling and need characteristics. Using manual backwards elimination, variables that were nonsignificant were removed from the model until all remaining variables were significant at the 95% level. Attempts were made to reintroduce removed variables into this model individually to maximize the number of significant predictors of cost in the final model and to counter-balance potential order of entry/deletion effects. Once the model was finalized, VIF values were produced and assessed for potential collinearity. This process was undertaken twice, first without the inclusion of the PPS, then with the inclusion of the PPS, in order to assess the contributory effect of the PPS in the variance explanation of the log mean weekly care cost. To identify gender-based differences in predictors of formal care costs, a gender-stratified approach was taken to separately fit the finalized model consisting of interRAI PC scales and items, and the PPS for males and for females.

Logistic regression models were then fit in order to identify predictors of high cost (as compared to low cost) using the same covariates examined in the multivariate generalized linear models. Once again, backwards elimination was used to remove nonsignificant variables at the 95% level. These steps were repeated for each of the three dichotomous measures of cost described earlier in the dependent variables section. Effects of significant variables in the final models were assessed using odds ratios and 95% confidence intervals (CIs). Performance of the models were assessed based on the c-statistic. Similar steps were taken in identifying predictors of cost measured as an ordinal variable with the ‘high,’ ‘mid’ and ‘low’ categories using ordinal logistic regression.

## 5.4 Results

### 5.4.1 Predicting PPS scores using interRAI PC scales and items

Overall, a subsample of 55,413 palliative home care clients was identified with a PPS score. Select characteristics of the subsample (with a PPS score) used for the prediction of PPS scores can be found in Table 5.4, and are compared to those excluded from the subsample (without a PPS score). Overall, there were a number of significant differences between those included and excluded from the subsample. These differences included age group, gender, IADL-ADL Functional Hierarchy Scale score, CHESS, mode of nutritional intake, fluctuating state of consciousness, acute change in mental status, and CPS score. While significant, the absolute differences across subcategories of these characteristics were small.

**Table 5.4: Characteristics of palliative home care clients in Ontario with and without a PPS score, 2011 to 2017 (n=68,731)**

| **Characteristic** | **Without PPS score n=13,318 % (n)** | **With PPS score n=55,413 % (n)** | **$X^2$ (df)** | **Cramer's V** | **p-value** |
|---|---|---|---|---|---|
| Age group | | | 54.5 (4) | 0.03 | <0.0001 |
| 18 to 44 | 2.9 (380) | 3.1 (1,717) | | | |
| 45 to 64 | 26.2 (3,484) | 26.5 (14,660) | | | |
| 65 to 74 | 26.3 (3,496) | 26.9 (14,929) | | | |
| 75 to 84 | 26.5 (3,527) | 27.8 (15,408) | | | |
| ≥85 | 18.3 (2,431) | 15.7 (8,699) | | | |
| Gender | | | 4.5 (1) | 0.008 | <0.0001 |
| Female | 50.6 (6,743) | 49.6 (27,486) | | | |
| Male | 49.4 (6,575) | 50.4 (27,927) | | | |
| IADL-ADL Functional Hierarchy Scale* | | | 267.4 (7) | 0.06 | <0.0001 |
| 0 | 8.4 (1,032) | 6.1 (3,289) | | | |
| 1-2 | 17.8 (2,181) | 17.8 (9,555) | | | |
| 3-4 | 19.8 (2,430) | 22.8 (12,222) | | | |
| 5 | 9.6 (1,175) | 10.1 (5,419) | | | |
| 6-7 | 13.1 (1,610) | 13.3 (7,159) | | | |
| 8 | 10.2 (1,254) | 10.8 (5,780) | | | |
| 9-10 | 15.6 (1,910) | 15.8 (8,488) | | | |
| 11 | 5.6 (690) | 3.3 (1,779) | | | |
| CHESS* | | | 153.5 (2) | 0.05 | <0.0001 |
| 0 | 5.4 (665) | 3.8 (2,007) | | | |
| 1-2 | 32.2 (3,939) | 28.7 (15,371) | | | |
| ≥3 | 62.3 (7,615) | 67.6 (36,174) | | | |
| Ate ≤1 meal on at least 2 of last 3 days* | | | 0.7 (1) | 0.003 | 0.41 |
| No | 75.6 (10,061) | 75.2 (41,674) | | | |
| Yes | 24.5 (3,256) | 24.8 (13,739) | | | |
| Fluid intake <1,000 cc per day* | | | 0.3 (1) | 0.002 | 0.57 |
| No | 85.4 (11,370) | 85.6 (47,417) | | | |
| Yes | 14.6 (1,947) | 14.4 (7,996) | | | |
| Mode of nutritional intake* | | | 130.0 (9) | 0.04 | <0.0001 |
| Normal | 71.6 (9,540) | 74.8 (41,461) | | | |
| Modified independent | 13.6 (1,807) | 12.3 (6,826) | | | |
| Requires diet modification to swallow solid food | 7.7 (1,022) | 7.3 (4,022) | | | |

| **Characteristic** | **Without PPS score n=13,318 % (n)** | **With PPS score n=55,413 % (n)** | **$X^2$ (df)** | **Cramer's V** | **p-value** |
|---|---|---|---|---|---|
| Requires modification to swallow liquids | 1.6 (212) | 1.2 (636) | | | |
| Can swallow only puréed foods | 1.9 (249) | 1.2 (687) | | | |
| Combined oral and parenteral or tube feeding | 0.6 (79) | 0.6 (338) | | | |
| Nasogastric tube feeding only | 0.1 (18) | 0.1 (69) | | | |
| Abdominal feeding tube | 1.3 (169) | 1.5 (833) | | | |
| Parenteral feeding only | 0.3 (43) | 0.2 (125) | | | |
| Activity did not occur | 1.3 (178) | 0.8 (416) | | | |
| Fluctuating state of consciousness* | | | 14.8 (1) | 0.01 | 0.0001 |
| No | 92.8 (12,224) | 93.8 (51,652) | | | |
| Yes | 7.2 (943) | 6.3 (3,441) | | | |
| Acute change in mental status from person's usual functioning* | | | 10.8 (1) | 0.01 | 0.001 |
| No | 90.3 (11,895) | 91.3 (50,271) | | | |
| Yes | 9.7 (1,272) | 8.8 (4,822) | | | |
| CPS* | | | 55.7 (3) | 0.03 | <0.0001 |
| 0 | 58.5 (7,142) | 59.4 (31,765) | | | |
| 1-2 | 31.6 (3,864) | 32.7 (17,485) | | | |
| 3-4 | 5.2 (636) | 4.4 (2,372) | | | |
| 5-6 | 4.7 (570) | 3.5 (1,861) | | | |

ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; IADL = instrumental activities of daily living
*Sum of n does not equal to column total due to missing data.

In the multivariate model of the PPS, all interRAI PC scales and items considered for the prediction of the PPS were found to be highly significant except for acute change in mental status, which was found to be nonsignificant in predicting PPS score. The finalized model excluding change in mental status is shown in Table 5.5. The direction of the associations between the PPS and the interRAI PC scales and items were generally negative so that the presence of symptoms, or the greater loss of functioning or cognitive performance were associated with a lower PPS score. The exception to this pattern was found for select modes of nutritional intake involving tube feeding and parenteral feeding only whereby the association with the PPS score was positive. This model was able to explain 60.3% of variation in PPS scores.

**Table 5.5: Multivariate model of PPS scores of palliative home care clients in Ontario using interRAI scales and items, 2011 to 2017 (n=53,483)**

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Intercept | 74.00 (0.10) | <0.0001 |
| IADL-ADL Functional Hierarchy Scale | -2.60 (0.01) | <0.0001 |
| Ate ≤1 meal on at least 2 of last 3 days (ref=no) | -1.85 (0.10) | <0.0001 |
| Fluid intake <1,000 cc per day (ref=no) | -0.81 (0.12) | <0.0001 |
| Mode of nutritional intake (ref=normal) | | |
| Modified independent | -1.25 (0.12) | <0.0001 |
| Requires diet modification to swallow solid food | -1.39 (0.15) | <0.0001 |
| Requires modification to swallow liquids | -2.08 (0.37) | <0.0001 |
| Can swallow only puréed foods | -2.63 (0.36) | <0.0001 |
| Combined oral and parenteral or tube feeding | 2.58 (0.47) | <0.0001 |
| Nasogastric tube feeding only | 4.11 (1.04) | <0.0001 |
| Abdominal feeding tube | 1.52 (0.30) | <0.0001 |
| Parenteral feeding only | 1.66 (0.77) | 0.03 |
| Activity did not occur | -7.05 (0.68) | <0.0001 |
| Fluctuating state of consciousness (ref=no) | -2.00 (0.18) | <0.0001 |
| CHESS | -1.97 (0.03) | <0.0001 |
| CPS | -0.44 (0.04) | <0.0001 |

Degrees of freedom = 15; F statistic = 5,410.2; p-value <0.0001; $R^2$ = 60.3%
ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; IADL = instrumental activities of daily living

### 5.4.2 Service utilization and costs

In total, 39,072 palliative home care clients on service for five or more weeks and with a PPS score were identified and included into the subsample used for the analyses related to formal care costs in this study. Characteristics of those included in this subsample as compared to those excluded from the subsample can be found in Table 5.6. Those included into the subsample were significantly different from those excluded across all key characteristics. While highly significant, the differences in the distribution across the subcategories for age group and gender were small. Larger differences could be observed for the remaining characteristics indicating lower levels of functional impairment and health instability in those included into the subsample.

**Table 5.6: Characteristics of palliative home care clients in Ontario, by inclusion into study subsample, 2011 to 2017 (n=68,731)**

| **Characteristic** | **Excluded from subsample n=29,659 % (n)** | **Included in subsample n=39,072 % (n)** | **$X^2$ (df)** | **Cramer's V** | **p-value** |
|---|---|---|---|---|---|
| Age group | | | 221.8 (4) | 0.06 | <0.0001 |
| 18 to 44 | 2.6% (770) | 3.4% (1,327) | | | |
| 45 to 64 | 24.8% (7,358) | 27.6% (10,786) | | | |
| 65 to 74 | 26.5% (7,872) | 27.0% (10,553) | | | |
| 75 to 84 | 27.8% (8,252) | 27.3% (10,683) | | | |
| ≥85 | 18.2% (5,407) | 14.7% (5.723) | | | |
| Gender | | | 50.1 (1) | 0.03 | <0.0001 |
| Female | 48.3% (14,311) | 51.0% (19,918) | | | |
| Male | 51.8% (15,348) | 49.0% (19,154) | | | |
| IADL-ADL Functional Hierarchy Scale* | | | 3,928.2 (7) | 0.24 | <0.0001 |
| 0 | 4.8% (1,315) | 7.8% (3,006) | | | |
| 1-2 | 12.3% (3,363) | 21.7% (8,373) | | | |
| 3-4 | 17.5% (4,802) | 25.6% (9,850) | | | |
| 5 | 9.6% (2,637) | 10.3% (3,957) | | | |
| 6-7 | 14.3% (3,912) | 12.6% (4,857) | | | |
| 8 | 12.7% (3,498) | 9.2% (3,536) | | | |
| 9-10 | 22.7% (6,228) | 10.8% (4,170) | | | |
| 11 | 6.2% (1,704) | 2.0% (765) | | | |
| CHESS* | | | 1,665.8 (2) | 0.16 | <0.0001 |
| 0 | 2.9% (788) | 4.9% (1,884) | | | |
| 1-2 | 21.6% (5,898) | 34.9% (13,412) | | | |
| ≥3 | 75.5% (20,595) | 60.3% (23,194) | | | |
| PPS* | | | 6637.0 (3) | 0.35 | <0.0001 |
| 0 | 0.2% (26) | 0.1% (33) | | | |
| 10-40 | 49.3% (8,054) | 16.6% (6,485) | | | |
| 50-70 | 49.5% (8,083) | 76.9% (30,032) | | | |
| 80-100 | 1.1% (178) | 6.5% (2,522) | | | |
| Prognosis | | | 5958.4 (3) | 0.29 | <0.0001 |
| Death imminent (within days) | 4.2% (1,253) | 0.2% (89) | | | |
| <6 weeks | 14.6% (4,340) | 3.3% (1,294) | | | |
| ≥6 weeks, <6 months | 53.6% (15,901) | 48.2% (18,829) | | | |
| 6 months or longer | 27.5% (8,165) | 48.3% (18,860) | | | |

ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; IADL = instrumental activities of daily living; PPS = Palliative Performance Scale

*Sum of n does not equal to column total due to missing data.

The mean volume of service utilization by service type can be found in Table 5.7, followed by corresponding estimates of cost in Table 5.8. Overall, costs were greater in the first week on service, and decreased in the second week for most service types. This pattern was especially apparent for case management, but was not observed for personal support services. Also apparent from the estimates of cost found in Table 5.8 was that nurse visits generally had the highest costs, except in the fifth week of service where personal support costs exceeded the costs of nurse visits.

**Table 5.7: Service utilization of palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score, by service type and week of service post-assessment, 2011 to 2017 (n=39,072)**

| | **Week 1** | | **Week 2** | | **Week 3** | |
|---|---|---|---|---|---|---|
| **Service type** | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** |
| Personal support* | 3.2 (3.1-3.3) | 0.0 (0.0-3.0) | 3.5 (3.4-3.6) | 0.0 (0.0-3.0) | 3.6 (3.5-3.7) | 0.0 (0.0-3.0) |
| Nursing clinic | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) |
| Nursing shift* | 0.1 (0.1-0.2) | 0.0 (0.0-0.0) | 0.1 (0.1-0.2) | 0.0 (0.0-0.0) | 0.2 (0.1-0.2) | 0.0 (0.0-0.0) |
| Nursing visits | 2.4 (2.4-2.4) | 2.0 (1.0-3.0) | 2.2 (2.2-2.3) | 1.0 (1.0-3.0) | 2.2 (2.2-2.3) | 1.0 (1.0-3.0) |
| Case management | 1.4 (1.4-1.4) | 1.0 (1.0-2.0) | 0.3 (0.3-0.4) | 0.0 (0.0-0.0) | 0.3 (0.3-0.3) | 0.0 (0.0-0.0) |
| Physiotherapy | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) |
| Social work | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) |
| Nutrition | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) |
| Occupational therapy | 0.2 (0.2-0.2) | 0.0 (0.0-0.0) | 0.2 (0.2-0.2) | 0.0 (0.0-0.0) | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) |
| Respiratory therapy | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) |
| Speech language pathology | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) |

*The unit of service utilization is by hours. All other services are reported in visits.

**Table 5.7: Service utilization of palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score, by service type and week of service post-assessment, 2011 to 2017 (n=39,072), continued**

| | **Week 4** | | **Week 5** | | **Weekly mean over first five weeks of service** | |
|---|---|---|---|---|---|---|
| **Service type** | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** |
| Personal support* | 3.8 (3.7-3.9) | 0.0 (0.0-3.0) | 3.9 (3.8-4.0) | 0.0 (0.0-3.5) | 3.6 (3.5-3.7) | 0.0 (0.0-3.6) |
| Nursing clinic | 0.1 (0.0-0.1) | 0.0 (0.0-0.0) | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) |
| Nursing shift* | 0.2 (0.2-0.2) | 0.0 (0.0-0.0) | 0.3 (0.2-0.3) | 0.0 (0.0-0.0) | 0.2 (0.2-0.2) | 0.0 (0.0-0.0) |
| Nursing visits | 2.3 (2.2-2.3) | 1.0 (1.0-3.0) | 2.2 (2.2-2.3) | 1.0 (1.0-3.0) | 2.3 (2.3-2.3) | 1.6 (1.0-3.0) |
| Case management | 0.3 (0.3-0.3) | 0.0 (0.0-0.0) | 0.4 (0.3-0.4) | 0.0 (0.0-0.0) | 0.5 (0.5-0.6) | 0.4 (0.2-0.6) |
| Physiotherapy | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) |
| Social work | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) |
| Nutrition | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) |
| Occupational therapy | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) | 0.1 (0.1-0.1) | 0.0 (0.0-0.0) | 0.1 (0.1-0.1) | 0.0 (0.0-0.2) |
| Respiratory therapy | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) |
| Speech language pathology | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) | 0.0 (0.0-0.0) |

*The unit of service utilization is by hours. All other services are reported in visits.

**Table 5.8: Formal cost of palliative home care services by palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score, by service type and week of service, 2011 to 2017 (n=39,072)**

| | Week 1 | | Week 2 | | Week 3 | |
|---|---|---|---|---|---|---|
| **Service type** | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** |
| Personal support | $115.22 (112.33-118.11) | $0.00 (0.00-107.58) | $124.48 (121.43-127.54) | $0.00 (0.00-107.58) | $129.25 ± 318.03 | $0.00 (0.00-107.58) |
| Nursing clinic | $2.35 (2.21-2.49) | $0.00 (0.00-0.00) | $2.17 (2.03-2.31) | $0.00 (0.00-0.00) | $2.09 (1.96-2.23) | $0.00 (0.00-0.00) |
| Nursing shift | $7.32 (5.96-8.68) | $0.00 (0.00-0.00) | $7.64 (6.29-8.99) | $0.00 (0.00-0.00) | $8.01 (6.64-9.38) | $0.00 (0.00-0.00) |
| Nursing visits | $149.47 (147.91-151.03) | $125.26 (62.63-187.89) | $140.74 (139.23-142.24) | $62.63 (62.63-187.89) | $140.86 (139.34-142.38) | $62.63 (62.63-187.89) |
| Case management | $86.76 (86.06-87.46) | $62.63 (62.63-126.26) | $21.45 (20.90-22.00) | $0.00 (0.00-0.00) | $20.88 (20.31-21.45) | $0.00 (0.00-0.00) |
| Physiotherapy | $8.77 (8.45-9.08) | $0.00 (0.00-0.00) | $8.57 (8.25-8.88) | $0.00 (0.00-0.00) | $7.73 (7.43-8.02) | $0.00 (0.00-0.00) |
| Social work | $4.62 (4.33-4.91) | $0.00 (0.00-0.00) | $5.07 (4.77-5.37) | $0.00 (0.00-0.00) | $4.21 (3.94-4.48) | $0.00 (0.00-0.00) |
| Nutrition | $4.72 (4.47-4.98) | $0.00 (0.00-0.00) | $3.86 (3.63-4.10) | $0.00 (0.00-0.00) | $3.32 (3.10-3.53) | $0.00 (0.00-0.00) |
| Occupational therapy | $30.62 (30.00-31.25) | $0.00 (0.00-0.00) | $21.49 (20.96-22.02) | $0.00 (0.00-0.00) | $15.42 (14.97-15.87) | $0.00 (0.00-0.00) |
| Respiratory therapy | $0.09 (0.05-0.13) | $0.00 (0.00-0.00) | $0.11 (0.07-0.16) | $0.00 (0.00-0.00) | $0.05 (0.02-0.08) | $0.00 (0.00-0.00) |
| Speech language pathology | $1.59 (1.43-1.75) | $0.00 (0.00-0.00) | $1.11 (0.98-1.24) | $0.00 (0.00-0.00) | $1.01 (0.88-1.14) | $0.00 (0.00-0.00) |
| Total | $411.53 (407.20-514.87) | 277.79 (125.26-518.69) | $336.70 (332.36-341.04) | $190.26 (62.63-438.41) | $332.83 (328.41-337.25) | $187.89 (62.63-438.41) |

**Table 5.8: Formal cost of palliative home care services by palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score, by service type and week of service, 2011 to 2017 (n=39,072), continued**

| | **Week 4** | | **Week 5** | | **Weekly mean over first five weeks of service** | |
|---|---|---|---|---|---|---|
| **Service type** | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** | **Mean (95% CL)** | **Median (IQR)** |
| Personal support | $134.98 (131-67-138.30) | $0.00 (0.00-107.58) | $141.18 (137.76-144.60) | $0.00 (0.00-125.51) | $129.02 (126.08-131.97) | $0.00 (0.00-127.30) |
| Nursing clinic | $2.08 (1.95-2.22) | $0.00 (0.00-0.00) | $2.20 (2.05-2.34) | $0.00 (0.00-0.00) | $2.18 (2.07-2.28) | $0.00 (0.00-0.00) |
| Nursing shift | $10.96 (9.31-12.62) | $0.00 (0.00-0.00) | $14.64 (12.78-16.49) | $0.00 (0.00-0.00) | $9.71 (8.40-11.03) | $0.00 (0.00-0.00) |
| Nursing visits | $140.93 (139.39-142.47) | $62.63 (62.63-187.89) | $140.71 (139.14-142.28) | $62.63 (62.63-187.89) | $142.54 (141.21-143.88) | $100.21 (62.63-187.89) |
| Case management | $20.43 (19.88-20.98) | $0.00 (0.00-0.00) | $21.94 (21.36-22.52) | $0.00 (0.00-0.00) | $34.29 (363.93-34.65) | $25.05 ($12.53-37.58) |
| Physiotherapy | $6.86 (6.58-7.13) | $0.00 (0.00-0.00) | $6.01 (5.75-6.27) | $0.00 (0.00-0.00) | $7.59 (7.38-7.79) | $0.00 (0.00-0.00) |
| Social work | $3.96 (3.69-4.22) | $0.00 (0.00-0.00) | $3.64 (3.38-3.89) | $0.00 (0.00-0.00) | $4.30 (4.12-4.48) | $0.00 (0.00-0.00) |
| Nutrition | $2.96 (2.76-3.16) | $0.00 (0.00-0.00) | $2.58 (2.39-2.76) | $0.00 (0.00-0.00) | $3.49 (3.35-3.62) | $0.00 (0.00-0.00) |
| Occupational therapy | $13.69 (13.25-14.12) | $0.00 (0.00-0.00) | $11.89 (11.48-12.31) | $0.00 (0.00-0.00) | $18.62 (18.34-18.90) | $0.00 (0.00-25.53) |
| Respiratory therapy | $0.05 (0.02-0.07) | $0.00 (0.00-0.00) | $0.08 (0.04-0.11) | $0.00 (0.00-0.00) | $0.08 ± (0.06-0.10) | $0.00 (0.00-0.00) |
| Speech language pathology | $0.87 (0.76-0.99) | $0.00 (0.00-0.00) | $0.84 (0.72-0.96) | $0.00 (0.00-0.00) | $1.09 (1.01-1.17) | $0.00 (0.00-0.00) |
| Total | $337.76 (333.04-342.49) | $187.89 (62.63-438.41) | $345.70 (340.70-350.70) | $187.89 (62.63-438.41) | $352.91 ± 415.20 | $221.27 (112.73-450.10) |

### 5.4.3 Predicting formal palliative home care costs

#### 5.4.3.1 Predicting cost using the PPS and interRAI PC scales and items related to the PPS

Generalized linear models of cost found that both the models of formal cost using the PPS and the interRAI PC scales and items related to the PPS were significantly predictive of cost. These models can be found in Tables 5.9 and 5.10, respectively. Variance explanation was similar, but higher for the interRAI PC scales and items model at 31.2%, as compared to the PPS model at 29.4%. For PPS scores, the association with cost was negative so that poorer functional status was associated with higher cost. In the model containing interRAI PC scales and items, higher IADL-ADL Functional Hierarchy Scale score, the presence of symptoms related to nutrition and cognition, modes of nutritional intake other than normal, higher CHESS score and higher CPS scores were all associated with greater palliative home care costs.

**Table 5.9: Bivariate model of log mean weekly formal cost of palliative home care clients in Ontario using the PPS, 2011 to 2017 (n=39,054)**

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Intercept | 7.75 (0.02) | <0.0001 |
| PPS | -0.04 (0.00) | <0.0001 |

Degrees of freedom = 1; F statistic = 16253.9; p-value <0.0001; $R^2$ = 29.4%
PPS = Palliative Performance Scale

**Table 5.10: Multivariate model of log mean weekly formal care cost in the first five weeks of service post-assessment of palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score using interRAI PC scales and items related to the PPS, 2011 to 2017 (n=38,461)**

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Intercept | 4.36 (0.01) | <0.0001 |
| IADL-ADL Functional Hierarchy Scale | 0.14 (0.002) | <0.0001 |
| Ate ≤1 meal on at least 2 of last 3 days (ref=no) | 0.6 (0.01) | <0.0001 |
| Fluid intake <1,000 cc per day (ref=no) | 0.05 (0.02) | <0.0001 |
| Mode of nutritional intake (ref=normal) | | |
| Modified independent | 0.05 (0.01) | 0.0009 |
| Requires diet modification to swallow solid food | 0.12 (0.02) | <0.0001 |
| Requires modification to swallow liquids | 0.17 (0.05) | 0.0005 |

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Can swallow only puréed foods | 0.25 (0.05) | <0.0001 |
| Combined oral and parenteral or tube feeding | 0.25 (0.05) | <0.0001 |
| Nasogastric tube feeding only | 0.15 (0.11) | 0.18 |
| Abdominal feeding tube | 0.35 (0.03) | <0.0001 |
| Parenteral feeding only | 0.67 (0.09) | <0.0001 |
| Activity did not occur | 0.26 (0.14) | 0.06 |
| Fluctuating state of consciousness (ref=no) | 0.08 (0.02) | 0.001 |
| CHESS | 0.12 (0.004) | <0.0001 |
| CPS | 0.03 (0.00) | <0.0001 |

Degrees of freedom = 15; F statistic = 1164.3; p-value <0.0001; $R^2$ = 31.2%
ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; IADL = instrumental activities of daily living

Table 5.11 shows the results of the model combining PPS scores with interRAI PC scales and items related to the PPS. The level of explained variance for this combined model was 34.9%, and the VIF for all dependent variables included in the model were <2.3, well below the minimum threshold (of four) at which multicollinearity may be problematic (O’Brien, 2007). The directions of these associations were consistent with earlier models of cost (shown in Tables 5.9 and 5.10 previously).

**Table 5.11: Multivariate model of log weekly formal cost in the first five weeks of service post-assessment of palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score using the PPS and interRAI PC scales and items related to the PPS, 2011 to 2017 (n=38,461)**

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Intercept | 5.97 (0.0.4) | <0.0001 |
| IADL-ADL Functional Hierarchy Scale | 0.09 (0.002) | <0.0001 |
| Ate ≤1 meal on at least 2 of last 3 days (ref=no) | 0.03 (0.01) | 0.01 |
| Fluid intake <1,000 cc per day (ref=no) | 0.04 (0.02) | 0.01 |
| Mode of nutritional intake (ref=normal) | | |
| Modified independent | 0.02 (0.01) | 0.11 |
| Requires diet modification to swallow solid food | 0.09 (0.02) | <0.0001 |
| Requires modification to swallow liquids | 0.14 (0.05) | 0.003 |
| Can swallow only puréed foods | 0.19 (0.04) | <0.0001 |
| Combined oral and parenteral or tube feeding | 0.29 (0.05) | <0.0001 |
| Nasogastric tube feeding only | 0.23 (0.11) | 0.03 |
| Abdominal feeding tube | 0.36 (0.03) | <0.0001 |
| Parenteral feeding only | 0.71 (0.09) | <0.0001 |
| Activity did not occur | 0.13 (0.14) | 0.35 |

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Fluctuating state of consciousness (ref=no) | 0.06 (0.02) | 0.02 |
| CHESS | 0.08 (0.004) | <0.0001 |
| CPS | 0.02 (0.00) | <0.0001 |
| PPS | -0.02 (0.00) | <0.0001 |

Degrees of freedom = 16; F statistic = 1287.8; p-value <0.0001; $R^2$ = 34.9%
ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; IADL = instrumental activities of daily living; PPS = Palliative Performance Scale

### 5.4.3.2 Predicting costs using the PPS and interRAI PC scales and items

Except for acid reflux, all candidate variables selected for testing in bivariate regression were significantly associated with the log formal palliative home care costs at the 95% significance level. Explained variances for these models can be found in Table 5.12 below and were particularly high (>10.0%) for the IADL-ADL Functional Hierarchy Scale score, and CHESS score. The level of explained variance in bivariate regression was also high (>5.0%) for a number of other need characteristics including prognosis, CPS score, fatigue, bladder incontinence and bowel incontinence.

**Table 5.12: Explained variance of candidate variables in bivariate regression of log mean weekly formal cost in the first five weeks of service post-assessment of palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score, 2011 to 2017 (n=39,054)**

| Characteristic type | interRAI PC item/scale | Explained variance |
|---|---|---|
| Predisposing | Age | 1.7%*** |
| | Gender | 0.1%*** |
| | Marital status | 0.9%*** |
| | Verbalizes awareness of terminal prognosis of less than 6 months to live | 0.4%*** |
| | Accepting of situation | 0.5%*** |
| Enabling | LHIN of residence | 3.8%*** |
| | Informal helper(s) | 0.3%*** |
| | Living arrangement | 0.0%** |
| | Live-in caregiver | 0.0%* |
| | Primary caregiver relationship to client | 0.7%*** |
| | End of life home care client type | 3.2%*** |
| | Informal helper(s) unable to continue in caring activities | 1.0%*** |
| | CaRE | 3.8%*** |

| Characteristic type | interRAI PC item/scale | Explained variance |
|---|---|---|
| Need | Family or close friends report feeling overwhelmed by person’s illness | 3.3%*** |
| | Prognosis | 6.9%*** |
| | IADL-ADL Functional Hierarchy Scale | 28.1%*** |
| | CHESS | 11.7%*** |
| | CPS | 8.3%*** |
| | Fluid intake <1,000 cc per day | 2.1%*** |
| | Ate ≤1 meal on at least 2 of last 3 days | 2.2%*** |
| | Mode of nutritional intake | 4.8%*** |
| | Dyspnea | 1.8%*** |
| | Fatigue | 8.5%*** |
| | Nausea | 0.0%* |
| | Vomiting | 0.2%*** |
| | Acid reflux | 0.0% |
| | Bloating | 0.1%*** |
| | Constipation | 0.3%*** |
| | Diarrhea | 0.0%** |
| | Fecal impaction | 0.2%*** |
| | Pain Scale | 0.9%*** |
| | IV medication | 0.9%*** |
| | Ventilator or respirator | 0.5%*** |
| | Cancer | 3.2%*** |
| | DRS | 0.9%*** |
| | Expressions, including nonverbal, of what appear to be unrealistic fears | 0.5%*** |
| | Repetitive health complaints | 0.1%*** |
| | Repetitive anxious complaints/concerns (non-health related) | 0.3%*** |
| | Bladder incontinence | 9.2%*** |
| | Bowel incontinence | 9.1%*** |
| | Fluctuating state of consciousness | 2.5%*** |
| | Acute change in mental status from person’s usual functioning | 2.3%*** |

***p-value <0.0001; **p-value <0.01; *p-value <0.05
ADL = activities of daily living; CaRE = Caregiver Risk Evaluation; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

In the multivariate model of predisposing characteristics, all variables were significant, and the model for those variables had a modest explained variance of 3.2%. All variables entered into the multivariate model of enabling characteristics were also significant, with the explained variance for this model of 12.7%. The multivariate model of need characteristics from the interRAI PC had an explained variance of 34.0% after the removal of CPS score, fluid intake < 1,000 cc per day, DRS score, nausea, bloating, constipation, non-health-related repetitive anxious complaints, fluctuating state of consciousness, and acute change in mental status due to their non-significance. Addition of the PPS into this model resulted in the removal of having eaten ≤1 meal on at least 2 of last 3 days and diarrhea, but nevertheless had a somewhat increased explained variance of 36.6%.

Results of the multivariate generalized linear model of only interRAI PC scales and items (found in Table D.2, Appendix D) had a level of explained variance of 37.7%. Candidate variables removed from this model included age, marital status, accepting of situation, CPS score, fluid intake < 1,000 cc per day, nausea, bloating, constipation, fecal impaction, DRS score, all items related to anxiety, fluctuating state of consciousness, and acute change in mental status from person's usual functioning.

The final combined model of the log mean weekly formal care cost with interRAI PC scales and items, as well as the PPS is shown in Table 5.13. The inclusion of the PPS in this model resulted in the nonsignificance of ate ≤ 1 meal on at least 2 of last 3 days and diarrhea, as well as the reintroduction of expressions of unrealistic fears for a final model that explained 39.7% of cost variance. The VIFs in both models were below four and so multicollinearity was not considered to be a concern (O'Brien, 2007).

For predisposing characteristics in this model, being female and being aware of terminal prognosis were associated with greater care cost. For enabling characteristics, the directions of the associations varied across characteristics. In the case of LHIN of residence, most LHINs were associated with lower cost than Hamilton Niagara Haldimand Brant, with particularly large differences in Central, Champlain and North Simcoe Muskoka. For other enabling characteristics, the presence of caregivers, residing alone, and having a primary caregiver that was not a spouse were all associated with greater cost, while having a live-in caregiver was associated with lower cost. Indicators of caregiver distress and burden were also associated with greater formal cost. In regard to need characteristics, higher IADL-ADL Functional Hierarchy Scale score, lower PPS score, higher CHESS score, and shorter prognosis were associated with higher costs. For specific symptoms, the presence and/or greater severity of a symptom was generally significantly associated with greater cost. Exceptions to this pattern included the lower cost associated with the presence and greater severity of dyspnea, and having a cancer diagnosis. There were no differences in the direction of parameter estimates that were significant between the models with and without the addition of PPS.

**Table 5.13:Multivariate model of log mean weekly formal care cost in the first five weeks of service post-assessment of palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score using interRAI PC scales and items, and the PPS, 2011 to 2017 (n=38,160)**

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Intercept | 5.47 (0.05) | <0.0001 |
| Gender (ref=male) | 0.04 (0.008) | <0.0001 |
| Awareness of prognosis (ref=no) | 0.02 (0.009) | 0.03 |
| LHIN of residence (ref=Hamilton Niagara Haldimand Brant) | | |
| Central East | -0.01 (0.02) | 0.46 |
| Central | -0.22 (0.01) | <0.0001 |
| Champlain | -0.28 (0.01) | <0.0001 |
| Central West | -0.01 (0.03) | 0.67 |
| Erie St. Clair | -0.09 (0.02) | <0.0001 |
| Mississauga Halton | 0.09 (0.02) | 0.0002 |
| North East | 0.02 (0.02) | 0.34 |
| North Simcoe Muskoka | -0.19 (0.03) | <0.0001 |
| North West | 0.04 (0.03) | 0.16 |
| South East | -0.003 (0.03) | 0.03 |
| South West | -0.06 (0.02) | 0.006 |
| Toronto Central | -0.12 (0.03) | 0.0004 |
| Waterloo Wellington | -0.000004 (0.02) | 0.9998 |
| Informal helpers | 0.03 (0.0009) | 0.003 |
| Living arrangement (ref=with others) | 0.12 (0.02) | <0.0001 |
| Live-in caregiver (ref=no) | -0.12 (0.01) | <0.0001 |
| Primary caregiver relationship to client (ref=spouse) | | |
| Child/child-in-law | 0.04 (0.01) | 0.0008 |
| Friend/neighbour | 0.11 (0.02) | <0.0001 |
| Other family | 0.07 (0.02) | <0.0001 |
| Informal helper(s) unable to continue in caring activities (ref=no) | 0.09 (0.01) | <0.0001 |
| CaRE | 0.04 (0.007) | <0.0001 |
| Family or close friends report feeling overwhelmed by person's illness (ref=no) | 0.11 (0.01) | <0.0001 |
| End of life home care client type (ref=no) | 0.11 (0.01) | <0.0001 |
| Prognosis (ref=6 months or longer) | | |

| **Parameter** | **Estimate (standard error)** | **p-value** |
|---|---|---|
| Death imminent (within days) | 0.08 (0.09) | 0.41 |
| <6 weeks | 0.12 (0.03) | <0.0001 |
| ≥6 weeks, <6 months | -0.02 (0.01) | 0.06 |
| IADL-ADL Functional Hierarchy Scale | 0.09 (0.002) | <0.0001 |
| CHESS | 0.08 (0.005) | <0.0001 |
| Mode of nutritional intake (ref=normal) | | |
| Modified independent | 0.004 (0.01) | 0.80 |
| Requires diet modification to swallow solid food | 0.07 (0.02) | <0.0001 |
| Requires modification to swallow liquids | 0.09 (0.05) | 0.04 |
| Can swallow only puréed solids | 0.16 (0.04) | 0.0002 |
| Combined oral and parenteral or tube feeding | 0.31 (0.05) | <0.0001 |
| Nasogastric tube feeding only | 0.34 (0.11) | 0.001 |
| Abdominal feeding only | 0.38 (0.03) | <0.0001 |
| Parenteral feeding only | 0.54 (0.09) | <0.0001 |
| Activity did not occur | 0.02 (0.13) | 0.89 |
| Dyspnea (ref=absence of symptoms) | | |
| Absent at rest, but present when performed moderate activities | -0.11 (0.01) | <0.0001 |
| Absent at rest, but present when performed normal day-to-day activities | -0.11 (0.01) | <0.0001 |
| Present at rest | -0.07 (0.01) | <0.0001 |
| Fatigue (ref=none) | | |
| Minimal | 0.05 (0.02) | 0.004 |
| Moderate | 0.08 (0.01) | <0.0001 |
| Severe | 0.10 (0.02) | <0.0001 |
| Unable to commence any normal day-to-day activities | 0.09 (0.02) | <0.0001 |
| Pain scale | 0.04 (0.003) | <0.0001 |
| IV medication (ref=not ordered and did not occur) | | |
| Ordered, not implemented | -0.02 (0.03) | 0.43 |
| 1-2 of last 3 days | 0.07 (0.03) | 0.01 |
| Daily in last 3 days | 0.45 (0.03) | <0.0001 |
| Did not occur, declined offered treatment | -0.13 (0.18) | 0.48 |
| Ventilator or respirator | | |
| Ordered, not implemented | -0.14 (0.13) | 0.30 |
| 1-2 of last 3 days | -0.04 (0.22) | 0.84 |
| Daily in last 3 days | 0.31 (0.06) | <0.0001 |
| Did not occur, declined offered treatment | 0.13 (0.2) | 0.51 |
| Cancer (ref=no) | -0.03 (0.01) | 0.02 |
| Vomiting (ref=no) | 0.04 (0.01) | 0.0007 |
| Expressions of unrealistic fears (ref=no) | 0.04 (0.02) | 0.04 |
| Bladder continence (ref=continent) | | |
| Complete control with any catheter or ostomy over last 3 days | 0.21 (0.02) | <0.0001 |
| Infrequently incontinent | 0.03 (0.02) | 0.09 |
| Occasionally incontinent | 0.08 (0.02) | <0.0001 |

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Frequently incontinent | 0.08 (0.02) | <0.0001 |
| Incontinent | 0.10 (0.03) | 0.001 |
| Did not occur | -0.01 (0.10) | 0.88 |
| Bowel continence (ref=continent) | | |
| Complete control with ostomy | 0.12 (0.02) | <0.0001 |
| Infrequently incontinent | 0.04 (0.02) | 0.10 |
| Occasionally incontinent | 0.11 (0.02) | <0.0001 |
| Frequently incontinent | 0.15 (0.03) | <0.0001 |
| Incontinent | 0.11 (0.03) | 0.0003 |
| Did not occur | 0.16 (0.07) | 0.03 |
| PPS | -0.02 (0.0005) | <0.0001 |

Degrees of freedom = 71; F statistic = 353.2; p-value <0.0001; $R^2$ = 39.7%
ADL = activities of daily living; CaRE = Caregiver Risk Evaluation; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

#### 5.4.3.2.1 Gender-based predictors of formal cost

Gender-stratified results of the finalized models of interRAI PC scales and items in addition to the PPS found some discrepancies in the client characteristics associated with formal care costs. Acceptance of situation was associated significantly with greater care costs for females, while it was nonsignificant for males. For males, having informal helper(s) was positively and significantly associated with higher formal care costs but was nonsignificant for females. Select modes of nutritional intake were also significantly associated with greater care costs (i.e., requires diet modification to swallow solid food and requires modification to swallow liquids) for males but not females. Minimal fatigue was also positively and significantly associated with greater care costs for males, but not females, although levels of fatigue at levels that were moderate, severe, and unable to commence day-to-day activities were positively associated with significant increases in costs for both genders. For females, vomiting was associated with significantly greater increases in cost, but was nonsignificant for males. Finally, males with any level of incontinence were associated with higher formal care costs, while for females, being infrequently incontinent or incontinent were nonsignificant in predicting costs. Results of these models can be found in Table D.3, Appendix D.

#### 5.4.3.3 Predicting the likelihood of being high cost with the PPS and interRAI scales and items

The final logistic regression models of high cost can be found in Table 5.14. Overall, the c-statistics for the models were all above 0.80, suggesting strong probability of predicting high cost. There were a number of characteristics that were significantly associated with the likelihood of being high cost across models, with the directions of significant associations generally consistent across models. One such characteristic was the enabling characteristic LHIN of residence, where residing in Central, Champlain, or North Simcoe Muskoka were associated with a significantly lower likelihood of being high cost than in Hamilton Niagara Haldimand Brant. A second enabling characteristic also significantly associated with a lower likelihood of high cost across models was residing with a caregiver. A third enabling characteristic, being designated as and end of life home care client, was positively associated with the likelihood of being high cost. Related to caregivers, having an informal caregiver unable to continue, and having family or close friends reporting feeling overwhelmed by caring activities were both associated with greater likelihood of being a high cost client.

A number of need characteristics were also associated with the likelihood of being a high cost client. Some of these characteristics were higher IADL-ADL Functional Hierarchy Scale score, CHESS score and Pain Scale score, and lower PPS score. Select modes of nutritional intake, as compared to normal intake, were also significantly associated with the likelihood of being in the high cost group across models. These modes included the need for modification to swallow solid foods, being able to swallow puréed foods only, combined oral and parenteral or tube feeding, and abdominal feeding only. As compared to those without fatigue, those with moderate or severe fatigue also had greater likelihood of being a high cost client, as did those requiring daily IV medication (in comparison to those not requiring IV medication), and those with control over bladder and/or bowel continence with either catheter and/or ostomy when compared to those who were continent. In contrast, the likelihood of being a high cost client was lower for those with dyspnea that was present in normal activities, and present at rest.

**Table 5.14: Logistic regression models of the odds of being a high cost client in the first five weeks of service post assessment for palliative home care clients in Ontario on service for $\geq$5 weeks and with a PPS score, 2011 to 2017 (n=15,165 to 38,422)**

| Characteristic | Probability of top 20% of cost (vs. bottom 20%) n=15,165 c-statistic=0.94 odds ratio (95% CI) | Probability of top 10% of cost (vs. bottom 90%) n=38,162 c-statistic=0.88 odds ratio (95% CI) | Probability of top 90% of cost (vs. bottom 10%) n=38,422 c-statistic=0.81 odds ratio (95% CI) | Probability of top 10% and mid 80% of cost (vs. bottom 10%) n=38,168 c-statistic=0.83 odds ratio (95% CI) |
|---|---|---|---|---|
| Age | NS | NS | 1.01 (1.002-1.01) | NS |
| Gender (ref=male) | 1.21 (1.08-1.35) | 1.12 (1.03-1.23) | NS | 1.09 (1.03-1.15) |
| Marital Status (ref=married) | | | NS | NS |
| Never married | 1.44 (1.12-1.84) | 0.89 (0.69-1.15) | | |
| Partner/Significant other | 0.89 (0.65-1.20) | 0.85 (0.67-1.09) | | |
| Widowed | 1.13 (0.96-1.32) | 0.83 (0.71-0.97) | | |
| Separated | 1.11 (0.78-1.60) | 0.82 (0.59-1.13) | | |
| Divorced | 1.38 (1.10-1.73) | 0.996 (0.80-1.224) | | |
| Awareness of prognosis (ref=no) | 1.17 (1.04-1.31) | 1.13 (1.04-1.24) | NS | NS |
| **LHIN of residence (ref=Hamilton Niagara Haldimand Brant)** | | | | |
| Central East | 1.10 (0.88-1.37) | 0.80 (0.69-0.93) | 1.18 (0.99-1.41) | 0.93 (0.83-1.04) |
| Central | 0.36 (0.30-0.44) | 0.50 (0.43-0.58) | 0.68 (0.59-0.79) | 0.60 (0.54-0.66) |
| Champlain | 0.31 (0.25-0.37) | 0.65 (0.43-0.58) | 0.49 (0.43-0.56) | 0.53 (0.47-0.58) |
| Central West | 1.04 (0.73-1.48) | 0.78 (0.62-0.99) | 1.04 (0.78-1.40) | 0.86 (0.72-1.03) |
| Erie St. Clair | 0.70 (0.55-0.89) | 0.84 (0.69-1.02) | 0.74 (0.62-0.88) | 0.76 (0.66-0.87) |
| Mississauga Halton | 1.52 (1.13-2.04) | 1.49 (1.23-1.80) | 1.05 (0.83-1.35) | 1.37 (1.17-1.60) |
| North East | 1.22 (0.97-1.54) | 0.78 (0.65-0.92) | 1.53 (1.27-1.83) | 1.06 (0.94-1.20) |
| North Simcoe Muskoka | 0.38 (0.27-0.53) | 0.67 (0.50-0.88) | 0.70 (0.55-0.89) | 0.69 (0.58-0.83) |
| North West | 1.37 (0.91-2.06) | 0.76 (0.58-0.88) | 0.89 (0.63-1.25) | 0.81 (0.65-1.01) |
| South East | 0.70 (0.45-1.07) | 0.95 (0.72-1.25) | 0.85 (0.59-1.23) | 0.91 (0.73-1.14) |
| South West | 0.71 (0.53-0.93) | 1.17 (0.94-1.46) | 0.73 (0.60-0.88) | 0.87 (0.75-1.02) |
| Toronto Central | 0.69 (0.46-1.04) | 0.72 (0.51-1.03) | 0.60 (0.45-0.81) | 0.65 (0.51-0.82) |
| Waterloo Wellington | 1.01 (0.81-1.24) | 0.995 (084-1.18) | 0.85 (0.74-0.99) | 0.90 (0.80-1.01) |
| Informal helpers | 1.17 (1.03-1.33) | NS | NS | NS |

| Characteristic | Probability of top 20% of cost (vs. bottom 20%) n=15,165 c-statistic=0.94 odds ratio (95% CI) | Probability of top 10% of cost (vs. bottom 90%) n=38,162 c-statistic=0.88 odds ratio (95% CI) | Probability of top 90% of cost (vs. bottom 10%) n=38,422 c-statistic=0.81 odds ratio (95% CI) | Probability of top 10% and mid 80% of cost (vs. bottom 10%) n=38,168 c-statistic=0.83 odds ratio (95% CI) |
|---|---|---|---|---|
| Living arrangement (ref=with others) | 1.53 (1.19-1.97) | 1.59 (1.33-1.92) | NS | 1.33 (1.17-1.51) |
| **Live-in caregiver (ref=no)** | 0.52 (0.41-0.67) | 0.74 (0.62-0.88) | 0.78 (0.69-0.88) | 0.78 (0.68-0.89) |
| Primary caregiver relationship to client (ref=spouse) | NS | | | |
| Child/child-in-law | | 1.22 (1.06-1.41) | 1.16 (1.05-1.28) | 1.13 (1.05-1.21) |
| Friend/neighbour | | 1.41 (1.07-1.86) | 1.41 (1.15-1.73) | 1.35 (1.15-1.58) |
| None | | - | 1.23 (0.79-1.91) | - |
| Other family | | 1.22 (0.98-1.53) | 1.32 (1.13-1.52) | 1.19 (1.07-1.33) |
| **Informal helper(s) unable to continue in caring activities (ref=no)** | 1.64 (1.34-1.99) | 1.25 (1.10-1.41) | 1.19 (1.01-1.39) | 1.23 (1.11-1.35) |
| CaRE | 1.15 (1.05-1.26) | 1.14 (1.06-1.22) | NS | 1.10 (1.05-1.16) |
| **Family or close friends report feeling overwhelmed by person's illness (ref=no)** | 1.57 (1.37-1.80) | 1.57 (1.42-1.72) | 1.21 (1.09-1.34) | 1.37 (1.27-1.47) |
| **End of life home care client type (ref=no)** | 1.78 (1.53-2.06) | 1.71 (1.49-1.96) | 1.18 (1.07-1.30) | 1.27 (1.18-1.37) |
| Prognosis (ref=6 months or longer) | NS | | | |
| Death imminent (within days) | | 1.39 (0.72-2.68) | 0.59 (0.19-1.87) | 1.26 (0.70-2.26) |
| <6 weeks | | 1.54 (1.27-1.87) | 1.19 (0.77-1.83) | 1.50 (1.28-1.77) |
| ≥6 weeks, <6 months | | 1.11 (0.99-1.24) | 0.90 (0.82-0.99) | 1.01 (0.94-1.09) |
| **IADL-ADL Functional Hierarchy Scale** | 1.43 (1.39-1.47) | 1.31 (1.28-1.34) | 1.18 (1.16-1.21) | 1.25 (1.23-1.27) |
| **CHESS** | 1.41 (1.34-1.49) | 1.08 (1.03-1.14) | 1.36 (1.30-1.43) | 1.20 (1.16-1.24) |
| CPS | NS | NS | 0.93 (0.88-0.98) | NS |
| Ate ≤1 meal on at least 2 of last 3 days (ref=no) | NS | 0.82 (0.74-0.91) | NS | NS |
| **Mode of nutritional intake (ref=normal)** | | | | |
| Modified independent | 1.03 (0.86-1.24) | 0.98 (0.87-1.11) | 1.08 (0.93-1.26) | 1.02 (0.93-1.12) |

| **Characteristic** | **Probability of top 20% of cost (vs. bottom 20%) n=15,165 c-statistic=0.94 odds ratio (95% CI)** | **Probability of top 10% of cost (vs. bottom 90%) n=38,162 c-statistic=0.88 odds ratio (95% CI)** | **Probability of top 90% of cost (vs. bottom 10%) n=38,422 c-statistic=0.81 odds ratio (95% CI)** | **Probability of top 10% and mid 80% of cost (vs. bottom 10%) n=38,168 c-statistic=0.83 odds ratio (95% CI)** |
|---|---|---|---|---|
| Requires diet modification to swallow solid food | 1.27 (1.01-1.61) | 1.19 (1.04-1.37) | 1.30 (1.06-1.59) | 1.25 (1.12-1.40) |
| Requires modification to swallow liquids | 1.40 (0.75-2.64) | 1.26 (0.91-1.74) | 1.52 (0.78-2.96) | 1.33 (1.00-1.77) |
| Can swallow only puréed solids | 6.40 (2.53-16.18) | 1.36 (1.01-1.83) | 3.03 (1.22-7.54) | 1.57 (1.21-2.06) |
| Combined oral and parenteral or tube feeding | 5.90 (2.99-11.64) | 2.07 (1.36-3.14) | 2.93 (1.61-5.34) | 2.28 (1.66-3.14) |
| Nasogastric tube feeding only | 2.28 (0.56-9.24) | 2.26 (0.98-5.21) | 2.25 (0.66-7.61) | 2.79 (1.40-5.57) |
| Abdominal feeding only | 6.75 (3.83-11.90) | 1.94 (1.49-2.51) | 4.53 (2.66-7.72) | 2.42 (1.95-2.99) |
| Parenteral feeding only | 54.54 (7.28-408.38) | 4.31 (2.40-7.74) | 5.31 (0.71-39.73) | 3.95 (2.30-6.80) |
| Activity did not occur | >999.999 (<0.001- >999.999) | 0.99 (0.42-2.36) | >999.999 (<0.0001- >999.999) | 1.09 (0.48-2.48) |
| **Dyspnea (ref=absence of symptoms)** | | | | |
| Absent at rest, but present when performed moderate activities | 0.62 (0.53-0.73) | 0.86 (0.75-0.98) | 0.69 (0.63-0.77) | 0.77 (0.71-0.83) |
| Absent at rest, but present when performed normal day-to-day activities | 0.60 (0.52-0.71) | 0.83 (0.74-0.94) | 0.71 (0.64-0.80) | 0.78 (0.72-0.85) |
| Present at rest | 0.66 (0.56-0.80) | 0.84 (0.73-096) | 0.82 (0.71-0.96) | 0.84 (0.76-0.93) |
| **Fatigue (ref=none)** | | | | |
| Minimal | 1.14 (0.92-1.42) | 1.08 (0.89-1.30) | 1.13 (0.996-1.27) | 1.13 (1.02-1.26) |
| Moderate | 1.35 (1.10-1.66) | 1.33 (1.13-1.57) | 1.24 (1.09-1.41) | 1.27 (1.15-1.40) |
| Severe | 1.76 (1.40-2.21) | 1.32 (1.12-1.56) | 1.33 (1.13-1.56) | 1.30 (1.16-1.45) |
| Unable to commence any normal day-to-day activities | 1.39 (1.01-1.90) | 1.42 (1.18-1.71) | 1.11 (0.83-1.48) | 1.35 (1.17-1.56) |
| **Pain scale** | 1.21 (1.16-1.27) | 1.04 (1.001-1.07) | 1.12 (1.09-1.16) | 1.07 (1.05-1.10) |
| **IV medication (ref=not ordered and did not occur)** | | | | |
| Ordered, not implemented | 0.67 (0.43-1.05) | 0.78 (0.51-1.21) | 1.01 (0.79-1.29) | 0.95 (0.77-1.18) |
| 1-2 of last 3 days | 1.07 (0.75-1.54) | 0.99 (0.72-1.37) | 1.02 (0.82-1.28) | 1.00 (0.84-1.21) |

| Characteristic | Probability of top 20% of cost (vs. bottom 20%) n=15,165 c-statistic=0.94 odds ratio (95% CI) | Probability of top 10% of cost (vs. bottom 90%) n=38,162 c-statistic=0.88 odds ratio (95% CI) | Probability of top 90% of cost (vs. bottom 10%) n=38,422 c-statistic=0.81 odds ratio (95% CI) | Probability of top 10% and mid 80% of cost (vs. bottom 10%) n=38,168 c-statistic=0.83 odds ratio (95% CI) |
|---|---|---|---|---|
| Daily in last 3 days | 11.60 (7.66-17.57) | 2.10 (1.69-2.61) | 4.10 (2.63-6.39) | 2.29 (1.91-2.74) |
| Did not occur, declined offered treatment | 0.26 (0.04-1.53) | 1.69 (0.40-7.13) | 1.05 (0.28-1.34) | 1.39 (0.44-4.34) |
| Ventilator or respirator | NS | | NS | |
| Ordered, not implemented | | 1.002 (0.31-3.20) | | 0.89 (0.36-2.19) |
| 1-2 of last 3 days | | <0.001 (<0.001->999.999) | | 0.70 (1.15-3.37) |
| Daily in last 3 days | | 1.89 (1.24-2.88) | | 1.93 (1.30-2.87) |
| Did not occur, declined offered treatment | | 0.72 (0.18-2.97) | | 0.75 (0.22-2.64) |
| Cancer (ref=no) | NS | 0.85 (0.77-0.94) | NS | 0.85 (0.9-0.93) |
| DRS | NS | 0.97 (0.95-0.996) | NS | 0.97 (0.95-0.99) |
| Vomiting (ref=no) | 1.21 (1.04-1.41) | NS | 1.18 (1.05-1.33) | 1.12 (1.03-1.21) |
| Diarrhea (ref=no) | NS | NS | 0.88 (0.79-0.98) | 0.89 (0.82-0.97) |
| Acid reflux (ref=no) | NS | NS | NS | 0.92 (0.86-0.98) |
| Fecal Impaction (ref=no) | 2.15 (1.19-3.89) | NS | 2.02 (1.16-3.54) | NS |
| **Bladder continence (ref=continent)** | | | | |
| Complete control with any catheter or ostomy over last 3 days | 2.37 (1.81-3.10) | 2.08 (1.78-2.41) | 1.62 (1.23-2.06) | 2.04 (1.79-2.32) |
| Infrequently incontinent | 1.13 (0.88-1.45) | 1.22 (1.02-1.46) | 1.03 (0.85-1.26) | 1.13 (0.99-1.29) |
| Occasionally incontinent | 1.61 (1.28-2.04) | 1.39 (1.20-1.61) | 1.10 (0.90-1.35) | 1.27 (1.13-1.44) |
| Frequently incontinent | 1.41 (1.10-1.80) | 1.31 (1.13-1.53) | 1.19 (0.96-1.48) | 1.28 (1.13-1.45) |
| Incontinent | 1.23 (0.79-1.90) | 1.27 (1.03-1.55) | 1.20 (0.74-1.94) | 1.29 (1.07-1.55) |
| Did not occur | 0.88 (0.20-1.90) | 1.13 (0.48-2.64) | 5.10 (0.68-38.05) | 1.53 (0.79-2.95) |
| **Bowel continence (ref=continent)** | | | | |
| Complete control with ostomy | 1.67 (1.26-2.21) | 1.28 (1.04-1.57) | 1.51 (1.24-1.85) | 1.37 (1.19-1.58) |
| Infrequently incontinent | 0.95 (0.70-1.28) | 1.14 (0.95-1.36) | 1.04 (0.80-1.35) | 1.18 (1.01-1.37) |
| Occasionally incontinent | 1.27 (0.95-1.71) | 1.39 (1.19-1.63) | 1.51 (1.10-2.07) | 1.51 (1.31-1.74) |

| **Characteristic** | **Probability of top 20% of cost (vs. bottom 20%) n=15,165 c-statistic=0.94 odds ratio (95% CI)** | **Probability of top 10% of cost (vs. bottom 90%) n=38,162 c-statistic=0.88 odds ratio (95% CI)** | **Probability of top 90% of cost (vs. bottom 10%) n=38,422 c-statistic=0.81 odds ratio (95% CI)** | **Probability of top 10% and mid 80% of cost (vs. bottom 10%) n=38,168 c-statistic=0.83 odds ratio (95% CI)** |
|---|---|---|---|---|
| Frequently incontinent | 1.46 (0.94-2.27) | 1.57 (1.28-1.92) | 0.88 (0.58-1.34) | 1.59 (1.32-1.93) |
| Incontinent | 1.68 (0.94-2.98) | 1.29 (1.05-1.58) | 1.22 (0.64-2.32) | 1.48 (1.22-1.80) |
| Did not occur | 4.87 (0.05-42.93) | 0.93 (0.55-1.57) | 2.89 (0.40-21.13) | 1.07 (0.67-1.72) |
| Acute change in mental status (ref=no) | 1.42 (1.09-1.85) | 1.28 (1.12-1.46) | NS | 1.18 (1.04-1.33) |
| Expressions of unrealistic fears (ref=no) | NS | NS | NS | 1.18 (1.02-1.37) |
| **PPS** | 0.92 (0.91-0.93) | 0.95 (0.95-0.96) | 0.96 (0.96-0.97) | 0.96 (0.957-0.963) |

NS = not significant; Bolded characteristics are significant across all models.

ADL = activities of daily living; CaRE = Caregiver Risk Evaluation; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

## 5.5 Discussion

The primary objectives of this study were to examine the PPS as a predictor of palliative home care costs and to identify other palliative home care client characteristics predictive of care costs from a public payer perspective. Existing studies have sought to identify predictors of palliative care cost (Cai et al., 2017; Chai et al., 2013; Howell et al., 2011; Masucci et al., 2013; Sun et al., 2017). However, this study was the first to specifically examine the costs of palliative home care using a broad range of clinical variables in large sample of clients from across all LHINs.

Of particular interest in this study was the utility of the PPS in predicting formal palliative home care costs. Earlier studies have identified the PPS as being significantly associated with the intensity of physician, PSW, and nurse home visits, albeit not consistently in the same direction (Cai et al., 2017; Masucci et al., 2013; Sun et al., 2017). The PPS is also the closest measure in Canada to palliative care phase that features prominently in the only existing classification system for palliative care found in Australia (Eagar, Green, & Gordon, 2004), and under consideration in England (Guo et al., 2018; Mather et al., 2018), and in Germany (Becker et al., 2018). As the PPS is not routinely collected as part of home care assessments in Ontario, there was interest in understanding whether existing measures of palliative home care clients from interRAI PC assessments could be used instead. Indeed, analyses conducted in this study demonstrate that scales and items from the interRAI PC are highly predictive of PPS scores, with a high level of explained variance. Further, comparison of variance explanation for the models of log mean weekly formal palliative home care costs showed that the PPS and the combination of interRAI PC scales and items performed equally well. Although interRAI PC scales and items corresponding to the various components of the PPS could be identified, it was interesting to see that the PPS continued to be highly significant in predicting formal care costs in the presence of interRAI PC scales and items. The inclusion of the PPS into these multivariate models also resulted in small increases to the overall explained variance suggesting that the PPS measures palliative home care clients in a manner that is not entirely captured by a wide selection of interRAI PC scales and items both related and unrelated to components of the PPS.

While it was not the intention of this study to develop a crosswalk of the PPS to the interRAI PC, there were a few noteworthy observations from the process of identifying corresponding interRAI PC scales and items to components in the PPS. One such observation was the discontinuity within some of the PPS components. In the case of intake, the outcome of interest appears to shift from the volume of food consumed (i.e., reduced) to mode of intake (i.e., sips), leaving it unclear whether normal intake refers to a measure of volume or mode of intake. A second observation was that the combinations of characteristics across the five components of the PPS may be limited and unrepresentative of the different clinical presentations of palliative home care clients. For example, individuals can be independent in ambulation and self-care while showing moderate levels of health instability. Yet these individuals would not adequately be captured in the PPS, but can likely exist as at least one study has found health instability (CHESS) to be uncorrelated to function (ADL) (Hirdes et al., 2003). In the case of this second observation, the extent to which clients may not be adequately described by the PPS may be worthy of further investigation. A third problem with the PPS is that many of its categories related to characteristics other than functional status are not mutually exclusive. For example, persons with full consciousness are included in all but the 10% levels of PPS. As a result, many clients could be classified into multiple levels of PPS due to inadequately defined group boundaries. The fact that the PPS is most strongly associated with the Functional Hierarchy suggests that it is coded predominantly on the basis of clinician perceptions of functional status and less so based on intake and conscious level. Together, these observations indicate that there may be some ambiguity the assignment of PPS scores for palliative home care clients. From a case-mix perspective, the subjective nature of the PSS and its ambiguity of operationalization suggest that it would not be well suited for that use because of risks related to gaming where financial incentives could lead to upcoding of variables.

The present study results also show that the PPS does not account for numerous variables that explain resource use in palliative home care. A number of characteristics were found to be predictive of formal costs that were not in the PPS. For predisposing characteristics, all contender characteristics were significant in bivariate regression, but were not consistently significant across multivariate generalized linear models and logistic regression models. Client gender and verbalized awareness of prognosis of less than six months were the most commonly significant variables across the multivariate models. The significance of client gender is consistent with at least one earlier study that has found being male to be associated with lower propensity and intensity of home-based palliative care services (Cai et al., 2017; Sun et al., 2017). As hypothesized in these earlier studies, this finding likely reflects the greater access that male clients have to informal caregivers, resulting in reduced reliance on formal care services. Its significance in select logistic regression models of high, mid and low palliative home care costs also suggest that gender may be a better predictor of very high costs (i.e., the top 10 and 20 percent of cost).

Similarly, verbalized awareness of prognosis of less than six months was significant in the two logistic regression models of the top 10% and 20% cost groups, also suggesting that it may be of greater relevance to very high costs. This characteristic was also significant in the multivariate generalized linear models, although the significance of the association and effect sizes appeared to be low. Interestingly, gender-stratified multivariate generalized linear models showed that prognostic awareness was only significantly associated with greater formal care costs for females. Overall, this finding may reflect the greater willingness of palliative home care clients, and especially female clients, to accept or pursue services when they are aware of their prognosis, but is also likely to reflect the shorter prognoses of those with a verbalized awareness of their prognosis (since this item requires individuals to have a prognosis of less than six months). Finally, it was interesting, but unsurprising to see that although age and marital status were significantly associated with propensity for receiving nursing and personal support services in earlier studies (Cai et al., 2017; Howell et al., 2011; Masucci et al., 2013; Sun et al., 2017), these characteristics were not predictive of cost in the present study as higher cost is more likely to reflect overall service intensity rather than the propensity for specific services. In addition, this study made more extensive use of age-related health variables not considered in other research (Cai et al., 2017; Chai et al., 2013; Guerriere et al., 2010; Masucci et al., 2013; Sun et al., 2017) such as cognitive impairment.

A number of enabling characteristics were also identified as predictors of formal palliative home care cost. One such characteristic was living arrangement in which those living alone were associated with greater cost. Similarly, those without a live-in caregiver had higher formal care costs in all bivariate and multivariate regression models examined as part of this study. These findings appear to be somewhat contradictory to an earlier study that found living alone to associated with a lower intensity of nurse visits (Sun et al., 2017). Comparisons are difficult to make, however, since this study included a much broader array of services in its estimation of cost. In addition, if health status is not adequately controlled for, there is a risk of confounding factors being at play. That is, persons who live alone may be able to do so because they are in relatively better health than those who must live with another person to be adequately supported in the community. More generally, too, having informal help was associated with greater formal care costs. Interestingly, when stratified by gender, having informal help was significantly associated with higher formal care costs for male clients and not female clients. As most caregivers are spouses, and many male clients likely have female spouses, this finding could suggest that female caregivers are more likely to advocate, or be better at advocating for formal care services than male caregivers, as has previously been suggested by Masucci et al. (2013).

Another caregiver-related characteristic that was consistently predictive of formal palliative home care costs was caregiver relationship to client. Specifically, as compared to spouse caregivers, all other caregiver types were significantly associated higher formal care cost. This finding likely reflects the greater access of those with spouse caregivers to informal care, thereby reducing the reliance on at least some formal palliative home care services (Cai et al., 2020). The capacity of caregivers to provide care and its relationship with formal care costs was also apparent in the highly significant and positive associations between formal care cost and presence of caregiver burden or distress (i.e., caregivers reporting being unable to continue in care activities, higher risk of caregiver burden (CaRE), and having friends and family that feel overwhelmed). While caregiver burden has not previously been examined, this finding appears to be reasonable and likely reflects either a reduction in caregivers' capacity to provide care, or the inability to provide any additional care resulting in more formal care services.

Unrelated to caregivers, clients' LHIN of residence was also consistently significant in predicting formal palliative home care costs. While not all LHINs were associated with significantly higher or lower costs as compared to those residing in Hamilton Niagara Haldimand Brant, those residing in Central, Champlain, and North Simcoe Muskoka were consistently significantly associated with lower formal care costs across models, and with large effect sizes. The rationale for this finding is unclear, although some explanations may include differences in care models or practice patterns, and rurality of a LHIN. One study that compared palliative care costs in rural areas to urban areas found that home care costs were higher in urban areas (Dumont et al., 2015), and based on interviews with individuals familiar with palliative care in Ontario (Chapter 4), may be due to the lower availability of home care services in rural areas. Although home care places the burden of travel on health care providers rather than on clients, proximity to services can still influence the availability of care as providers in rural or remote areas are likely to spend more of their time traveling relative to providing care. The lower formal care costs in North Simcoe Muskoka, in particular, may be the result of this lower availability of services. In regard to differences in care models or practice patterns, these variations are not exclusive to palliative home care, and have been documented in the home care system more generally (Office of the Auditor General of Ontario, 2017). Specific to palliative home care, pilot programs both within the home care system and in other settings may exist in some regions and influence the utilization of formal palliative home care services. Differences in criteria required to be designated as an end of life client can also contribute to differences in formal palliative home care costs across LHINs (Office of the Auditor General of Ontario, 2014).

The majority of predictors of formal palliative home care costs identified in this study were need characteristics. Many of the characteristics identified have previously been found to be significantly associated with palliative care service utilization and costs. Most notably, function has been identified across a number of studies (Cai et al., 2017; Chai et al., 2013; Eagar, Green, & Gordon, 2004; Masucci et al., 2013; Sun et al., 2017), and indeed was found to be highly significant through both the IADL-ADL Functional Hierarchy Scale and the PPS in the present study. One earlier study has also identified greater symptom severity, measured using the Edmonton Symptom Assessment System (ESAS), to be associated with higher service utilization and costs (Chai et al., 2013). Symptoms found to be consistently significant in predicting formal care costs in this study and are components within the ESAS included pain, fatigue, and dyspnea. While greater pain and the presence of any fatigue were associated with higher costs, the presence of any dyspnea was associated with reduced formal care costs both in bivariate and multivariate analyses. As dyspnea is a highly distressing symptom (Freeman et al., 2016), it is possible that individuals experiencing this symptom might turn increasingly to formal care services outside of the home setting, thus reducing formal palliative home care costs. Other interRAI PC scales and items representing components of the ESAS that were found to be significant in bivariate and select multivariate regression models included depression, expressions of unrealistic fears (anxiety) and having eaten less than one meal on at least two of past three days (lack of appetite). This third characteristic is also consistent with another study that found eating problems to be significantly predictive of palliative home care costs (Howell et al., 2011). Beyond components in the ESAS, bladder and bowel incontinence were associated with greater costs across all models. A number of characteristics were also identified as significant predictors of higher formal palliative home care costs in select multivariate linear and logistic regression models. These characteristics included vomiting, diarrhea, acid reflux, and fecal impaction. Although these characteristics were not significant across all multivariate models in this study, the directions of these associations are consistent with the notion that greater symptomatology is associated with higher formal care costs (Chai et al., 2013).

Aside from specific symptoms, a number of other need characteristics were identified as being significant predictors of palliative home care costs. One such characteristic was health instability (CHESS) in which higher levels of instability were predictive of greater formal care costs. No other studies have examined health instability using CHESS, although it is comprised of components that are similar to the ESAS, and the PCPSS (Chai et al., 2013; Eagar, Green, & Gordon, 2004). For this study, the identification of health instability as a predictor of formal care is reasonable as greater service utilization can be expected as individuals’ health deteriorates (Cai et al., 2017). Higher CHESS scores have also been found to be predictive of greater mortality (Hirdes et al., 2003, 2014b) and so its association with greater formal care costs may also reflect proximity to death, which has been found to be positively associated with cost (Sun et al., 2017). Indeed, this study also found shorter prognoses to be predictive of greater formal palliative home care cost. While prognosis does not necessarily equate to proximity to death (Scitovsky, 2005), its association with greater cost in this study can be expected since palliative home care service allocation decisions are at least partially based on expected survival (Office of the Auditor General of Ontario, 2014).

For need characteristics related to treatments, this study identified that requiring and receiving IV medication, and ventilator treatment to be associated with greater formal palliative home care costs. Similarly, the modes of nutritional intake requiring tube feeding were also significantly associated with higher costs. Although the method of cost estimation used in this study does not include equipment costs, it was nevertheless unsurprising to find that the need and receipt of these treatments to be associated with greater costs since individuals with these treatments would be expected to have more severe symptoms and/or more advanced disease.

A final need characteristic that was significantly associated with lower formal care costs and lower probability of being categorized as high cost was the presence of a cancer diagnosis. This finding is consistent with at least two other studies that have found individuals with a cancer diagnosis in home-based palliative care programs to be less costly than those without a cancer diagnosis (Klinger et al., 2013; Kralik & Anderson, 2008). As the authors of these studies (Klinger et al., 2013; Kralik & Anderson, 2008) and participants in the advisory group described in Chapter 4 suggest, the higher utilization of services by those without a cancer diagnosis is likely to be due to the less predictable nature of noncancer trajectories, as well as the unsuitability of the largely cancer-based palliative care model for noncancer conditions.

### 5.5.1 Limitations

There are a number of limitations to this study that must be noted. Perhaps the greatest limitation to this study was the restriction of the study sample to those who were on palliative home care service for at least five weeks. However, the ability to capture a stable estimate of cost in this study was required and five weeks was judged to adequately even out utilization related to one-off services provided in the first week of service, while maximizing the study sample size. This restriction resulted in the exclusion of those with short prognoses so that the findings from this study may be less generalizable to a small and highly costly group of palliative home care clients. Attempts were made to assess the suitability of the characteristics identified as predictors of formal care costs in those with short prognoses by fitting logistic regression models to assess the probability of being in the top 10% and 20% cost groups. These analyses yielded very high c-statistics in addition to identifying a similar set of characteristics to those identified through multivariate generalized linear models. Together, these observations indicate that despite the underrepresentation of palliative home care clients with short prognoses, characteristics predictive of formal care costs in this study are likely to be suitable for predicting cost in high cost clients with short prognoses as well.

In the inverse, it is important to note that for analyses predicting the log mean weekly formal care costs, a small number of clients receiving no services in the first five weeks of service were excluded from the model since log transformations cannot be applied to values of zero. Clients with no service utilization in the first five weeks of service are outliers, comprising a very small number of clients, and so this limitation is likely to be of little concern to the findings presented in this study.

Relatedly, the restriction of the sample to those with a PPS score must be noted as a limitation since significant differences in the characteristics of those with and without a PPS score were found. Yet the PPS is a central component of this study, given that it is likely to be the closest available measure to the palliative care phase used in the palliative care component of the AN-SNAP system. As such, restricting the sample to those with a PPS score was required. Further examination of the distribution of those with and without a PPS score also found that in spite of the significance in the differences between the two groups, the percentile differences across categories were small.

The absence of information on some aspects of formal palliative home care cost, sociodemographic characteristics, including those of caregivers, and clinical characteristics resulted in some study limitations. With the absence of select sociodemographic information and clinical characteristics, some characteristics identified in earlier studies and by participants in the advisory group described in Chapter 4 could not be examined as potential predictors of formal palliative home care costs. These characteristics include client socioeconomic status, urban/rural area of residence; caregiver age, marital status, and employment status; as well as clients' diagnostic information beyond the presence of a cancer diagnosis. The absence of some sociodemographic information in identifying predictors of formal palliative home care costs may be less important in this study given that the results of this study are meant to inform on resource planning and potentially case-mix development, which should primarily draw on clients' clinical characteristics. The absence of more specific diagnostic information may be of greater relevance to the present study given the need to better understand the needs and indicators of these needs for those on noncancer trajectories. Further, some earlier studies have identified significant differences in cost across different diagnostic groups (Haltia et al., 2018; Howell et al., 2011). However, there appears to be no evidence from the palliative care component of the AN-SNAP system or existing palliative care case-mix development work that diagnoses should be used to classify this population of individuals.

In regard to the estimation of cost in this study, information on nonservice-based costs incurred by LHINs (i.e., overhead and equipment rental costs) were not captured as part of this study. The effect of excluding overhead costs from cost estimates used in this study is likely to be limited since overhead costs are generally assigned equally to study participants in a top-down manner (Chan et al., 2001; Ciałkowska-Rysz et al., 2016; Coyle et al., 1999; Tibi-Lévy et al., 2006), and can be expected to be constant across the study sample. Of greater concern may be the absence of public payer costs associated with equipment and aids from the estimates of cost since these costs can be expected to be variable across clients. However, equipment costs contribute to only a small proportion of palliative care costs (Dumont et al., 2010), and so the result of the exclusion of these costs from this study is expected to be minimal.

While not necessarily a limitation to this study, issues related to the large number of contender variables considered as part of this study should also be mentioned. Of particular concern is the potential for type one errors resulting from multiple testing. One method for adjusting for multiple testing is the Bonferroni correction, which is considered to be the most conservative of correction methods, and would place the target p-value cutoff for analyses in this study at 0.001 (Armstrong, 2014). This correction was not applied in the analyses for this study as the objective was to identify as many potential predictors of formal palliative home care costs as possible. Nevertheless, the majority of covariates in the various models had p-values that were well below 0.001, indicating that the probability of false positive results is low.

## 5.6 Conclusions

This study sought to identify predictors of palliative home care costs using the PPS in addition to scales and items available as part of the interRAI PC assessment instrument. A number of predisposing, enabling and need characteristics were identified as predictors of these costs and were found to explain substantial variations in clients' formal palliative home care costs. These findings can inform on palliative home care resource planning by providing policymakers and case managers with indicators of service need. Together, these findings also suggest that the classification of palliative home care clients into groups with similar clinical characteristics and levels of resource utilization is likely possible, and identifies a number of characteristics that may be considered for classification. However, the results also suggest that the range of variables to be considered for development of a case-mix system is considerably broader than the clinical concepts represented in the PPS. In addition, because of concerns related to potential gaming, the PPS may be inadequately robust for use in a future case-mix based payment system.

# Chapter 6

# Predicting Informal Care Costs for Palliative Home Care Clients

## 6.1 Introduction

Informal care can be defined as the care or assistance that is provided to individuals who are sick or disabled, and which is unremunerated (McNamara & Rosenwax, 2010; O'Reilly et al., 2008). The support provided by informal caregivers (i.e., family and/or friends) plays a substantial role in the care of vulnerable individuals, including those with life-limiting conditions. Without informal care, many individuals with life-limiting conditions at the end of life would be unable to remain at home or in the community (Betini et al., 2017; Health Council of Canada, 2012). From a cost perspective, studies on the costs of palliative care that have taken a societal perspective have also consistently shown that informal care is responsible for a substantial share of the total costs of palliative care across settings, ranging from 14.9% in one study of rural areas (Dumont et al., 2015) to 76.8% in a study of those enrolled in a home-based palliative care program in an urban setting (Chai et al., 2013). An earlier report also showed that over 70% of the care received by home care clients was provided by informal caregivers in five provinces/territories amounting to over 30 hours of care per week for high need clients (Health Council of Canada, 2012). While the share of palliative care costs attributable to informal care vary widely due to differences in the components of cost included and the methods used to cost informal care, existing studies have shown consistently that these costs are substantial (Chai et al., 2013, 2014; Dumont et al., 2009, 2014, 2015; Gardiner et al., 2014; Haltia et al., 2018; Jacobs et al., 2011).

Despite the importance of informal care to palliative care, little work has been done to examine factors associated specifically with receipt of informal care or its costs. In a home-based palliative care context, only three studies have sought to identify factors associated with the costs of informal care. One such study was conducted by Chai et al. (2014) and investigated factors associated with the proportion of home-based palliative care costs attributable to informal care. This study used a human capital approach to estimate the costs of informal care and found that both client and caregiver characteristics were associated with informal care costs as a share of total care costs (Chai et al., 2014). Specifically, older client age, being married, greater symptom severity (based on Edmonton Symptom Assessment System [ESAS] score), receiving radiation therapy or receiving neither chemotherapy nor radiation therapy, and lower socioeconomic status were associated with a greater share of costs attributable to informal care (Chai et al., 2014). Related to caregiver characteristics, younger age, being male, not being employed with pay, and being a friend/neighbour (as compared to a spouse or a child) were associated with a greater share of unpaid care costs (Chai et al., 2014).

More recent studies of informal care have identified determinants of informal care hours for those receiving palliative home care. One study found that younger age, being female, being married (as compared to being divorced, separated, widowed or never married), and living with others were associated with a greater intensity of informal care (Cai et al., 2020). A number of caregiver characteristics were also found to predict a greater intensity of informal care, including younger age, being female, being a spouse to the client, not being employed, being divorced, separated widowed or never married (as compared to married), and having any university education (Cai et al., 2020). This study also examined the effect of formal home-based palliative care service utilization on the intensity of informal care provided to clients and found that receiving home nursing services was predictive of greater intensity of informal care (Cai et al., 2020).

A different study that examined informal care hours further differentiated between care that was provided by primary and non-primary caregivers (Cai et al., 2021). Overall, Cai et al. (2021) found informal care provided to clients by primary caregivers to be complementary to care provided by non-primary caregivers, with somewhat similar client and caregiver characteristics identified as being associated with informal care provided by primary and non-primary caregivers. For primary caregiving, client characteristics that were associated with greater intensity of care included being male and having any university education, while living alone and receiving personal support worker (PSW) services were associated with reduced intensity of care (Cai et al., 2021). Having a primary caregiver who was male, employed or married was associated with lower intensity of care provided by primary informal caregivers, while having primary caregivers who were older or who were spouses to the care recipient were associated with higher intensities of informal care from the primary caregiver (Cai et al., 2021). Both the propensity and intensity of informal care provided by non-primary caregivers were also examined by Cai et al. (2021). Client characteristics negatively associated with the propensity of receiving informal care from a non-primary caregiver were being divorced, separated or widowed, time to death, poorer function, and receipt of PSW services (Cai et al., 2021). Primary caregiver age (older), gender (male) and education level (post-graduate) were also negatively associated with the propensity for non-primary care, while the association was positive for clients with primary caregivers who were the children of care recipients, married, divorced, separated or widowed, and/or employed (Cai et al., 2021). Client characteristics that were associated with a lower intensity of non-primary caregiving were older age, being male, having any university or post-graduate education, longer time to death and poorer function, while being married was associated with a greater intensity of care from non-primary caregivers (Cai et al., 2021). Finally, primary caregiver characteristics that were found to be negatively associated with the intensity of non-primary caregiving included older age, being a spouse to the client and having post-graduate education, and positively associated with being employed and greater intensity of primary caregiving (Cai et al., 2021).

Related to the finding by Cai et al. (2020) of the significant association between the receipt of home nursing services and informal care intensity is the more general discussion around the association between formal and informal care services in the home setting. This topic has been of particular interest since the health system began shifting care from institutional settings to community and home settings, with emphasis on the question of whether formal care acts as a substitute or complement to informal care (Bonsang, 2009; Litwin & Attias-Donfut, 2009; Penning, 2002; Van Houtven & Norton, 2004). In the palliative care context, it would appear that it has only been in recent years that this topic has been addressed in two studies, one of which is the previously described study by Cai et al. (2020). Rather than examine the effect of formal care on informal care, the second study instead examined the effect of informal care on formal care (Sun et al., 2019), particularly in relation to any use and intensity of home-based physician, PSW, and nurse services (Sun et al., 2019). Results of this study indicated that for PSW service, informal care did not have a significant effect on the propensity of service use, but increased informal care was associated with a significant reduction in number of hours of PSW services received (Sun et al., 2019). For physician services, informal care was associated with a greater propensity for, and intensity of visits, although the relationship with the intensity of service was not significant (Sun et al., 2019). The reverse was found for nursing visits such that informal care was positively, but non-significantly associated with the propensity for home nurse visits, and positively and significantly associated with the intensity of nursing visits (Sun et al., 2019). Due to the potential for reverse causality between formal and informal care, it is also important to note that Sun et al. (2019) found informal care to be exogenous to the propensity of PSW service, but endogenous to the intensity of PSW service. Put another way, reverse causality was found only in the association between informal care and the intensity of PSW. Informal care was also found to be exogenous to the propensity and intensity of both nursing and physician visits, thus indicating that reverse causality was not identified (Sun et al., 2019).

Aside from studies examining only informal care, two studies sought to identify factors associated with palliative care costs from the societal perspective that included both formal and informal care costs. These studies included costs from multiple care settings, in addition to out-of-pocket and third-party payer costs (Guerriere et al., 2010; Haltia et al., 2018). Nonspecific to the home setting, Haltia et al. (2018) found that younger age, living alone and the presence of prostate cancer were associated with greater combined formal and informal care costs. A second study found reduced function, living with others, and greater proximity to death to be associated with greater costs in those enrolled in a home-based palliative care program (Guerriere et al., 2010).

Outside of the palliative care literature, research has found that the likelihood of receiving combined formal and informal care at home, as compared to receiving no care, was negatively associated with younger age, being male, having less education, living with others, and having only mild functional limitations (Y. Lee & Penning, 2019). Being White, having a lower household income, being in poorer physical health, and having moderate levels of cognitive impairment (compared with severe cognitive impairment) were positively associated with the likelihood of receiving combined formal and informal care relative to no care at home (Y. Lee & Penning, 2019). The likelihood of receiving both informal and formal care relative to receiving only informal care was also considered by the study authors with similar results (Y. Lee & Penning, 2019).

Finally, some case-mix research from the home care setting have also identified characteristics that are associated with societal costs of home care. The Resource Utilization Groups Version III for Home Care (RUG-III/HC) case-mix system, which is structured based on the RUG-III system used in nursing home settings (Fries et al., 1994), classifies individuals into one of seven hierarchical categories that include special rehabilitation, extensive services, special care, clinically complex, impaired cognition, behaviour problems and reduced physical functions, with additional subcategories within each hierarchical level to form a 23 group system (Björkgren et al., 2000). The clinically complex category is particularly relevant to palliative home care clients as one of the criterion that can be used for assignment to this category is end-stage disease (expected survival of less than six months) (Björkgren et al., 2000; Fries et al., 1994). In the RUG-III/HC, the clinically complex category contains three subcategories. Assignment to one of these three subcategories is based on a measure of activities of daily living (ADLs), and for one subcategory, is further split based on a measure of instrumental activities of daily living (IADLs) (Björkgren et al., 2000). Altogether, the RUG-III/HC was found to explain 37.3% of variation in combined formal and informal home care costs in a validation study of long-stay home care clients from Ontario (Poss et al., 2008). A study examining the performance of the RUG-III/HC in home care clients with select neurological conditions (amyotrophic lateral sclerosis, dementia and multiple sclerosis) also found the classification system to explain a substantial proportion of variation in combined formal and informal care costs (21.0% to 43.1%), and identified a number of client characteristics that further contributed the explanation of cost variance (Cheng et al., 2020). Some of the identified characteristics with particularly large effect sizes included region of residence, residing with a caregiver, IADL and ADL limitations (even when controlling for RUG-III/HC case-mix index values based on formal and informal costs), and health-related quality of life (Cheng et al., 2020). For select neurological diagnoses, some additional characteristics that were strongly associated with combined formal and informal care costs included hallucinations, dysphagia, requiring help or being unable to use stairs, unsteady gait, incontinence, and weight loss (Cheng et al., 2020).

## 6.2 Rationale and objectives

It is essential to understand informal care costs and predictors of these costs given the important role informal care plays in the care of palliative home care clients. While some studies have examined palliative care costs attributable to informal care, literature on identifying determinants of these costs is scant, and existing studies have relied on small samples of individuals with cancer enrolled in a single palliative care program in an urban environment (Cai et al., 2020, 2021; Chai et al., 2014). Together, these studies have identified only a small number of client and/or caregiver characteristics predictive of informal care costs in palliative home care, of which few are need characteristics (Cai et al., 2020; Chai et al., 2014). Palliative care research nonspecific to the home setting (Guerriere et al., 2010; Haltia et al., 2018) and more general home care cost and case-mix research (Björkgren et al., 2000; Cheng et al., 2020; Y. Lee & Penning, 2019; Poss et al., 2008) offer some guidance, but the identification of need characteristics predictive of cost for palliative home care is particularly important for resource planning and to any potential classification work. As such, the first objective of this study was to identify predictors of informal care costs for individuals receiving palliative home care. Relatedly, a second objective of this study was to examine the association between informal and formal care costs to better understand how the two types of care might be organized in order to maximize benefits to palliative home care clients. Finally, understanding factors that predict combined formal and informal costs is also required for resource planning and any future palliative home care case-mix development work since it is the combined adequacy of formal and informal care that permits individuals to remain at home. The third objective of this study was therefore to identify predictors of combined formal and informal palliative home care costs.

## 6.3 Methods

This study was a retrospective study using secondary analyses of clinical assessment and administrative health data. These data included information collected through the interRAI Palliative Care (PC) assessment instrument, and Health Shared Services Ontario's (HSSOntario) Client Health Related Information System (CHRIS), which includes home care client referral and service utilization data. These data sources were described in detail in the methods section of Chapter 3. Ethics clearance for this study was provided by the University of Waterloo's Office of Research Ethics (ORE #41489) and Wilfrid Laurier University's Research Ethics Board (File #6486).

### 6.3.1 Sample

The same subsample of palliative home care clients that was used as part of the formal cost analyses in Chapter 5 of this dissertation was used for the analyses in this chapter. This subsample was drawn from the 68,731 palliative home care clients identified in Chapter 3, and limited to those on service for five weeks or more with a PPS score. The decision to use this subsample was made so that findings from this study could be compared to findings from the prior study on formal care costs.

### 6.3.2 Dependent variables

#### 6.3.2.1 Mean weekly informal care cost

Information on the quantity of informal care provided to palliative home care clients over the three days prior to assessment was obtained from the hours of informal care and active monitoring item in the social supports section of the interRAI PC assessment instrument. A unit cost for each hour of informal care was then applied to the number of hours of informal care over the three-day period. Three different unit costs were calculated based on differing methodologies for estimating informal care costs. Two of these methods included the application of a replacement cost, and a third method was based on the application of an opportunity cost.

The first replacement cost considered applied a unit cost of $17.93 (Canadian Dollar [CAD], 2020), which is half the hourly rate of a PSW. A unit cost based on half the hourly rate of a PSW has been used in prior case-mix-related work, and is based on the notion that an informal caregiver would be less effective in providing personal support than a PSW, thus justifying the reduced hourly unit cost (Björkgren et al., 2000; Poss et al., 2008). The second replacement cost considered was based on the estimated cost of unpaid work in Canada in 1992 based on activities that would be expected to be completed by males and by females (Chandler, 1994), and has been used in previous studies examining the societal costs of palliative care in Canada (Dumont et al., 2009, 2010). Informal care activities provided to palliative home care clients in this study were assumed to be evenly split by male and female caregivers, and were then adjusted for inflation resulting in a unit cost of $19.59 (CAD, 2020) (Bank of Canada, 2020). Unlike earlier studies, however, the present study included all caregiving time rather than caregiving time in excess of time that would otherwise have been spent on household work (Dumont et al., 2009, 2010).

Finally, the use of an opportunity cost was also considered. The method for valuing informal care using opportunity cost has been used in a number of studies examining the societal costs of palliative care. These studies adopted a human capital approach that involved assuming the value of caregiver time lost to the labour market, as well as leisure and household work by age and gender, while accounting for employer-paid benefits and vacation days (Chai et al., 2013, 2014; Guerriere et al., 2010; Haltia et al., 2018; Yu et al., 2015). Given limited data on caregiver characteristics and time lost to paid and unpaid work, and leisure, it was thought that an accurate estimate of opportunity cost could not be calculated at the client-level. As such, the opportunity cost for informal care was instead based on the gross opportunity cost in Canada in 1992 (Chandler, 1994), with the assumption that opportunity costs were incurred equally between male and female caregivers, and with adjustment for inflation. This approach resulted in an hourly unit cost of $22.00 (CAD, 2020) (Bank of Canada, 2020).

For each of the three methods, the mean weekly informal care cost was calculated by dividing the costs of informal care over the previous three days by three, and then multiplying by seven. As cost data are right-skewed in nature, informal care costs were log-transformed for regression analyses.

#### 6.3.2.2 Mean weekly combined care cost

The mean weekly combined care cost was calculated three ways to reflect the three methods considered in estimating the mean weekly informal care cost (i.e., half PSW replacement cost, unpaid work replacement cost, and opportunity cost of informal care). For each of the three calculations of combined cost, the mean weekly informal care cost (described above), was summed with the mean weekly formal care cost over the first five weeks of service post-assessment described in the methods section of Chapter 5. As with informal care costs, a log transformed combined weekly care cost was used in regression analyses.

### 6.3.3 Independent variables

Almost all of the same independent variables considered in the study of formal care costs were selected as contender variables in this study. The exception was the exclusion of the Caregiver Risk Evaluation (CaRE) Algorithm due to its inclusion of number of hours of informal care in the prior three days into the assignment of a CaRE score. Instead, the item for primary informal helper expresses feelings of distress anger or depression, which is included in the CaRE Algorithm, was included as a contender variable in this study. These variables were selected based on factors identified as predictors of both formal and informal palliative care costs in the literature, in addition to characteristics identified by the advisory group members, as described in Chapter 4. A list of these characteristics can be found in Table 6.1 below.

**Table 6.1: Contender variables for identifying predictors of informal care costs**

| Characteristic type | interRAI PC item/scale (continuous variables unless stated otherwise) |
|---|---|
| Predisposing | Age<br>Gender[1]<br>Marital status[2] |

| Characteristic type | interRAI PC item/scale (continuous variables unless stated otherwise) |
|---|---|
| | Verbalizes awareness of terminal prognosis of less than 6 months to live[3] |
| | Accepting of situation[3] |
| Enabling | LHIN of residence[4] |
| | Informal helper(s) |
| | Living arrangement[5] |
| | Live-in caregiver[3] |
| | Primary caregiver relationship to client[6] |
| | End of life home care client type[3] |
| | Informal helper(s) unable to continue in caring activities[3] |
| | Primary informal helper expresses feelings of distress, anger or depression[3] |
| | Family or close friends report feeling overwhelmed by person's illness[3] |
| Need | Prognosis[7] |
| | IADL-ADL Functional Hierarchy Scale |
| | CHESS |
| | CPS |
| | Fluid intake <1,000 cc per day[3] |
| | Ate ≤1 meal on at least 2 of last 3 days[3] |
| | Mode of nutritional intake[8] |
| | Dyspnea[9] |
| | Fatigue[10] |
| | Nausea[3] |
| | Vomiting[3] |
| | Acid reflux[3] |
| | Bloating[3] |
| | Constipation[3] |
| | Diarrhea[3] |
| | Fecal impaction[3] |
| | Pain Scale |
| | IV medication[11] |
| | Ventilator or respirator[11] |
| | Cancer[3] |
| | DRS |
| | Expressions, including nonverbal, of what appear to be unrealistic fears[3] |
| | Repetitive health complaints[3] |
| | Repetitive anxious complaints/concerns (non-health related)[3] |
| | Bladder continence[12] |
| | Bowel continence[12] |
| | Fluctuating state of consciousness[3] |
| | Acute change in mental status[3] |
| | PPS |

ADL = activities of daily living; CaRE = Caregiver Risk Evaluation; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating

Scale; LHIN = Local Health Integration Network; IADL = instrumental activities of daily living; IV = intravenous
[1] Categories are 'Male,' 'Female'
[2] Categories are 'Never married,' 'Married,' 'Partner/Significant other,' 'Widowed,' 'Separated,' 'Divorced'
[3] Dichotomous 'No,' 'Yes'
[4] Categories are the 14 LHINs in Ontario
[5] Categories are 'Alone,' 'With others'
[6] Categorical 'Child or child-in-law,' 'Spouse/Partner/Significant other,' 'Other family,' 'Friend/Neighbour,' 'None'
[7] Categories are 'Death imminent (within days),' 'Less than 6 weeks,' '6 weeks or longer, but less than 6 months,' '6 months or longer'
[8] Categories are 'Normal,' 'Modified independent,' 'Requires diet modification to swallow solid food,' 'Requires modification to swallow liquids,' 'Can swallow only puréed solids,' 'Combined oral and parenteral or tube feeding,' 'Nasogastric tube feeding only'
[9] Categories are 'Absence of symptom,' 'Absent at rest, but present when performed moderate activities,' 'Absent at rest, but present when performed normal day-to-day activities,' 'Present at rest'
[10] Categories are 'None,' 'Minimal,' 'Moderate,' 'Severe,' 'Unable to commence any normal day-to-day activities'
[11] Categories are 'Not ordered AND did not occur,' 'Ordered, not implemented,' '1-2 of last 3 days,' 'Daily in last 3 days,' 'Did not occur, declined offered treatment'
[12] Categories are 'Continent,' 'Complete control with any catheter or ostomy over last 3 days,' 'Infrequently incontinent,' 'Occasionally incontinent,' 'Frequently incontinent,' 'Incontinent,' 'Did not occur'

### 6.3.4 **Analyses**

All analyses for this study were conducted using SAS version 9.4 (*SAS System*, 2013). The mean weekly quantity of informal care hours was first calculated. The mean weekly cost of informal care was then estimated using each of the three unit costs described previously, followed by the estimation of the mean weekly combined cost of palliative home care. In addition, the share of the combined costs attributable to informal care were calculated for each of the three informal care cost methods considered as part of this study. These estimates of cost were expressed as means, standard deviations (SDs), medians, and interquartile ranges (IQRs).

Subsequent analyses were conducted using the half-PSW valuation for informal care costs. This method was selected due to its use in prior case-mix-related analyses (Björkgren et al., 2000; Cheng et al., 2020; Poss et al., 2008). Bivariate generalized linear models were first fit between the log informal care cost and the independent variables found in Table 6.1. Variables that were significant at the 95% level in bivariate regression were then entered into one of three multivariate models representing each of the three categories outlined as part of Andersen and Newman's (2005) health service utilization framework. Models were finalized using manual backwards elimination of nonsignificant variables, followed by re-entry of removed variables one at a time in order to identify as many significant covariates as possible into the finalized models of predisposing, enabling, and need characteristics. For need characteristics, two models were finalized – one that excluded the PPS and one that included the PPS – and was done in order to assess the effect the inclusion of the PPS had on the overall level of explained variance ($R^2$).

With the exception of the PPS, variables identified as being significantly associated with informal care costs in bivariate analyses were then entered into a multivariate generalized linear model containing all predisposing, enabling and need characteristics. A model containing only factors significantly associated with log informal care costs at the 95% level was identified using manual backwards elimination. In order to retain as many covariates as possible, variables that were eliminated through backwards elimination were re-introduced one at a time. Those variables found to be significant at the 95% level upon reintroduction were then retained into a finalized model of log informal weekly care costs using interRAI PC scales and items only. These steps were then repeated with the inclusion of the PPS in order to identify a finalized model of log informal weekly care costs using the interRAI PC scales and items, as well as the PPS. Collinearity between variables in the both the final multivariate regression models were then assessed based on the variance inflation factor (VIF) using a cut-off of four (O'Brien, 2007). Covariates present in the finalized model of informal costs containing interRAI PC scales and items, and the PPS were then fit separately for males and for females in order to identify gender-based differences in predictors of costs.

Next, the association between formal care costs and informal care costs was examined. Due to the possible reverse causality between formal and informal care costs (Sun et al., 2017), Durbin-Wu-Hausman tests for endogeneity were conducted. For these tests, a dichotomous variable representing residence in a northern LHIN (i.e., North East, North Simcoe Muskoka and North West) was used as an instrumental variable. Residence in a northern LHIN was selected based on findings from the study described in Chapter 4 in which participants described differences in palliative home care access in the north that would be expected to affect formal care but not informal care. Indeed, residence in a northern LHIN was found to be significantly correlated with formal care costs (r=0.04, p-value <0.0001) but not informal care costs (r=0.01; p-value=0.09). Designation as an end of life client was also initially considered as a potential instrumental variable but was ultimately not used since it was found to be correlated with both formal and informal care costs. Thus, the first Durbin-Wu-Hausman test was conducted with only the north variable regressed on the log mean weekly formal care costs in the first stage of the test. The second test was conducted with the instrumental variable in addition to all exogenous variables. Exogenous variables were considered to be those characteristics identified as significant predictors of log informal care costs in the previous analyses, including the PPS. Ordinary least squares (OLS) and two-stage least squares (2SLS) regression models were subsequently fit. In the OLS model, the log mean weekly formal care costs and the exogenous variables were regressed on the log weekly informal care costs. For the 2SLS model, log mean weekly formal care costs and log weekly informal care costs were assumed to be endogenous, residence in a northern LHIN was identified as the instrumental variable to be used in the first stage of the model, and all previously identified predictors of log informal care costs were considered to be the exogenous variables.

Finally, generalized linear models were fit to identify predictors of the log mean weekly combined formal and informal care costs. The same steps taken to identify the predictors of log informal care costs, as described above, were used for the analyses of combined care costs.

## 6.4 Results

### 6.4.1 Informal care costs

The mean weekly informal care hours across the sample was 31.5 hours (SD=31.7), with a median of 23.3 hours (IQR=14.0-37.3). Estimates of the costs of informal care can be found in Table 6.2.

**Table 6.2: Estimates of mean weekly informal and combined care costs for palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score, 2011 to 2017 (n=39,072)**

| | **Weekly informal care cost** | | **Weekly combined formal and informal care cost** | | **Share of combined cost attributable to informal care*** |
|---|---|---|---|---|---|
| **Cost method** | **Mean ± SD** | **Median (IQR)** | **Mean ± SD** | **Median (IQR)** | **%** |
| Half-PSW replacement cost | $565.24 ± 569.14 | $418.37 (251.02-669.39) | $918.15 ± 800.49 | $689.67 (401.81-1141.87) | 61.6 |
| Unpaid work replacement cost | $617.57 ± 621.83 | $457.10 (274.26-731.36) | $970.48 ± 846.71 | $726.58 (424.57-1205.70) | 63.6 |
| Opportunity cost of unpaid work | $693.55 ± 698.33 | $513.33 (308.00-821.33) | $1,046.45 ± 915.06 | $784.32 (456.05-1296.41) | 66.3 |

*The shares of costs expressed in this table are calculated by dividing the mean weekly informal care cost by the mean weekly combined formal and informal care cost (i.e., $565.24 divided by $918.15 for the half-PSW replacement method).

### 6.4.2 Predicting informal care costs

Bivariate analyses between weekly informal care costs and candidate variables found all variables except for diarrhea to be significant. The variance explanation of contender variables in bivariate regression can be found in Table 6.3.

**Table 6.3: Explained variance of candidate variables in bivariate regression of log mean weekly informal care cost of palliative home care clients in Ontario, 2011 to 2017 (n=37,436)**

| Characteristic type | interRAI PC item/scale | Explained variance |
|---|---|---|
| Predisposing | Age | 0.5%*** |
| | Gender | 0.1%*** |
| | Marital status | 3.5%*** |
| | Verbalizes awareness of terminal prognosis of less than 6 months to live | 0.3%*** |
| | Accepting of situation | 0.4%*** |
| Enabling | LHIN of residence | 4.4%*** |
| | Informal helper(s) | 0.3%*** |
| | Living arrangement | 7.7%*** |
| | Live-in caregiver | 6.8%*** |
| | Primary caregiver relationship to client | 3.3%*** |
| | End of life home care client type | 1.5%*** |
| | Informal helper(s) unable to continue in caring activities | 0.3%*** |
| | Primary informal helper expresses feelings of distress, anger or depression | 2.3%*** |
| | Family or close friends report feeling overwhelmed by person’s illness | 3.8%*** |
| Need | Prognosis | 4.1%*** |
| | IADL-ADL Functional Hierarchy Scale | 32.6%*** |
| | CHESS | 7.8%*** |
| | CPS | 8.8%*** |
| | Fluid intake <1,000 cc per day | 1.1%*** |
| | Ate ≤1 meal on at least 2 of last 3 days | 1.3%*** |
| | Mode of nutritional intake | 3.1%*** |
| | Dyspnea | 1.1%*** |
| | Fatigue | 9.0%*** |
| | Nausea | 0.1%*** |
| | Vomiting | 0.2%*** |
| | Acid reflux | 0.2%*** |
| | Bloating | 0.1%*** |
| | Constipation | 0.3%*** |
| | Diarrhea | 0.00% |

| Characteristic type | interRAI PC item/scale | Explained variance |
|---|---|---|
| | Fecal impaction | 0.1%*** |
| | Pain Scale | 0.2%*** |
| | IV medication | 0.1%*** |
| | Ventilator or respirator | 0.3%** |
| | Cancer | 2.1%*** |
| | DRS | 0.8%*** |
| | Expressions, including nonverbal, of what appear to be unrealistic fears | 0.7%*** |
| | Repetitive health complaints | 0.3%*** |
| | Repetitive anxious complaints/concerns (non-health related) | 0.4%*** |
| | Bladder incontinence | 5.2%*** |
| | Bowel incontinence | 5.2%*** |
| | Fluctuating state of consciousness | 2.0%*** |
| | Acute change in mental status from person’s usual functioning | 2.3%*** |
| | PPS | 23.4*** |

***p-value <0.0001; **p-value <0.01; *p-value <0.05
ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

The finalized model of all predisposing characteristics found all characteristics except gender to be significant, and had an explained variance of 4.7%. For enabling characteristics, the finalized model saw the removal of the item for informal helper(s) unable to continue in caring activities. The level of explained variance for this model was 17.8%. In the finalized model of need characteristics with the interRAI scales and items only, the explained variance was 34.6% with the following items removed due to nonsignificance: ate ≤1 meal on at least 2 of last 3 days, mode of nutritional intake, ventilator or respirator, cancer, DRS score, vomiting, bloating, constipation, fecal impaction, repetitive health complaints, and repetitive anxious complaints/concerns (non-health related). The inclusion of PPS score into the finalized model of need characteristics yielded an explained variance of 35.3%.

The finalized multivariate model of log informal care costs containing predisposing, enabling and need characteristics from interRAI PC had an explained variance of 41.4%. Candidate variables that were removed from this model included gender, fluid intake <1,000 cc per day, ate ≤1 meal on at least 2 of last 3 days, mode of nutritional intake, ventilator or respirator, cancer, primary informal helper expresses feelings of distress, anger or depression, DRS, vomiting, bloating, constipation, fecal impaction, bladder incontinence and acute change in mental status. This model can be found in Table E.1, Appendix E.

Results of the final multivariate model with both the interRAI PC scales and items, and the PPS can be found in Table 6.4. The addition of PPS score resulted in the removal of gender, prognosis, fluid intake <1,000 cc per day, mode of nutritional intake, ventilator or respirator, cancer, primary informal helper expresses feelings of distress, anger or depression, DRS, vomiting, bloating, constipation, fecal impaction, bladder incontinence, and acute change in mental status. The level of explained variance for this model was 42.1%. All variables retained in the final model of the log informal care costs had a VIF below four and so collinearity was not considered to be a concern for this model.

For predisposing characteristics, older age and marital status other than married were significantly associated with lower informal care costs, while verbalized awareness of prognosis and being accepting of the situation were associated with higher informal care costs. Considering enabling characteristics, all LHINs of residence had significantly different care costs than in Hamilton Niagara Halidimand Brant. These costs were higher in about half of LHINs with particularly large parameter estimates observed in Central East, Central, Mississauga Halton, North East, North West, and South East LHINs. Amongst LHINs with significantly lower costs than Hamilton Niagara Haldimand Brant, the largest difference appeared to be in North West. Related to informal caregivers, having and residing with a caregiver was associated with much greater informal care costs. Having a primary caregiver that was a friend or neighbour as compared to a spouse was associated with lower informal care costs, as was living alone. For caregivers' abilities to provide informal care, having caregivers who felt unable to continue in care activities was associated with lower log weekly informal care costs, while having family or close friends feeling overwhelmed was associated with higher costs. In regard to need characteristics, the presence and/or greater severity of a symptom, health instability, and functional dependence were generally associated with higher log weekly informal care costs. Some exceptions included having eaten less than one meal on at least two of past three days, dyspnea, bowel incontinence, and fluctuating state of consciousness, which were associated with lower log weekly informal care costs.

**Table 6.4: Multivariate model of log weekly informal care costs for palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score, 2011 to 2017 (n=36,736)**

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Intercept | 5.52 (0.05) | <0.0001 |
| Age | -0.002 (0.0003) | <0.0001 |
| Marital Status (ref=married) | | |
| Never married | -0.09 (0.02) | <0.0001 |
| Partner/Significant other | -0.04 (0.02) | 0.02 |
| Widowed | -0.02 (0.01) | 0.14 |
| Separated | -0.11 (0.03) | <0.0001 |
| Divorced | -0.13 (0.02) | <0.0001 |
| Awareness of prognosis (ref=no) | 0.05 (0.008) | <0.0001 |
| Accepting of situation (ref=no) | 0.04 (0.009) | <0.0001 |
| LHIN of residence (ref=Hamilton Niagara Halidimand Brant) | | |
| Central East | 0.11 (0.01) | <0.0001 |
| Central | -0.13 (0.01) | <0.0001 |
| Champlain | 0.08 (0.01) | <0.0001 |
| Central West | 0.09 (0.02) | <0.0001 |
| Erie St. Clair | -0.09 (0.02) | <0.0001 |
| Mississauga Halton | 0.14 (0.02) | <0.0001 |
| North East | 0.19 (0.01) | <0.0001 |
| North Simcoe Muskoka | -0.06 (0.02) | 0.01 |
| North West | -0.48 (0.03) | <0.0001 |
| South East | 0.23 (0.03) | <0.0001 |
| South West | -0.07 (0.02) | <0.0001 |
| Toronto Central | -0.10 (0.03) | 0.0006 |
| Waterloo Wellington | -0.08 (0.01) | <0.0001 |
| Informal helpers | 0.06 (0.008) | <0.0001 |
| Living arrangement (ref=with others) | -0.06 (0.02) | 0.0003 |
| Live-in caregiver (ref=no) | 0.33 (0.02) | <0.0001 |
| Primary caregiver relationship to client (ref=spouse) | | |
| Child/child-in-law | 0.005 (0.01) | 0.71 |
| Friend/neighbour | -0.13 (0.02) | <0.0001 |
| None | -0.43 (0.15) | 0.005 |
| Other family | -0.03 (0.02) | 0.12 |
| Informal helper(s) unable to continue in caring activities (ref=no) | -0.04 (0.01) | 0.0008 |
| Family or close friends report feeling overwhelmed by person's illness (ref=no) | 0.09 (0.009) | <0.0001 |

| **Parameter** | **Estimate (standard error)** | **p-value** |
|---|---|---|
| End of life home care client type (ref=no) | 0.02 (0.01) | 0.01 |
| IADL-ADL Functional Hierarchy Scale | 0.11 (0.002) | <0.0001 |
| CHESS | 0.03 (0.004) | <0.0001 |
| CPS | 0.04 (0.004) | <0.0001 |
| Ate ≤1 meal on at least 2 of last 3 days (ref=no) | -0.02 (0.01) | 0.01 |
| Dyspnea (ref=absence of symptoms) | | |
| Absent at rest, but present when performed moderate activities | -0.04 (0.01) | 0.0003 |
| Absent at rest, but present when performed normal day-to-day activities | -0.07 (0.01) | <0.0001 |
| Present at rest | -0.07 (0.01) | <0.0001 |
| Fatigue (ref=none) | | |
| Minimal | 0.009 (0.01) | 0.50 |
| Moderate | 0.06 (0.01) | <0.0001 |
| Severe | 0.13 (0.01) | <0.0001 |
| Unable to commence any normal day-to-day activities | 0.22 (0.02) | <0.0001 |
| Pain scale | 0.01 (0.003) | 0.0002 |
| IV medication (ref=not ordered and did not occur) | | |
| Ordered, not implemented | 0.03 (0.03) | 0.25 |
| 1-2 of last 3 days | 0.11 (0.02) | <0.0001 |
| Daily in last 3 days | 0.07 (0.02) | 0.003 |
| Did not occur, declined offered treatment | 0.11 (0.13) | 0.41 |
| Nausea (ref=no) | 0.03 (0.008) | 0.0005 |
| Acid reflux (ref=no) | 0.07 (0.009) | <0.0001 |
| Expressions of unrealistic fears (ref=no) | 0.08 (0.02) | <0.0001 |
| Repetitive health complaints (ref=no) | 0.05 (0.02) | 0.005 |
| Repetitive non-health related complaints/concerns (ref=no) | 0.05 (0.01) | 0.001 |
| Bowel continence (ref=continent) | | |
| Complete control with ostomy | -0.005 (0.02) | 0.79 |
| Infrequently incontinent | -0.01 (0.02) | 0.51 |
| Occasionally incontinent | 0.02 (0.02) | 0.25 |
| Frequently incontinent | -0.05 (0.03) | 0.03 |
| Incontinent | -0.19 (0.02) | <0.0001 |
| Did not occur | -0.008 (0.06) | 0.91 |
| Fluctuating state of consciousness (ref=no) | -0.05 (0.02) | 0.02 |
| PPS | -0.009 (0.0004) | <0.0001 |

Degrees of freedom = 60; F statistic = 444.8; p-value <0.0001; $R^2$ = 42.1%

ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

#### 6.4.2.1 Gender-based predictors of informal care cost

Some gender-based differences in predictors of informal care costs were identified when results of the model found in Table 6.4 were gender-stratified. These gender-stratified models can be found in Table E.2, Appendix E. For both genders, having a marital status that indicated not being in a relationship was generally predictive of lower informal care costs as compared to clients who were married. For females, however, having a partner/significant other was associated with lower informal care costs as well, while the association was nonsignificant for males. Although older age was associated with significantly lower informal care costs, this association was only borderline significant for males (p-value = 0.05), but was highly significant for females (p-value <0.0001).

There were also differences identified in the enabling characteristics associated with informal care costs when stratified by gender. In regard to a primary caregiver's relationship to the client, having a family caregiver other than a child/child-in-law or spouse was also significantly associated with lower informal care costs for males, while this association was nonsignificant for females. Having a caregiver that was unable to continue in caring activities was associated with significantly lower informal care costs for females, but was not associated significantly for males. Differences between males and females could also be observed in the significance of associations between informal cost and select LHINs (i.e., Central West, North Simcoe Muskoka and Toronto Central).

Finally, some differences in need characteristics predictive of informal care costs in males and females could also be observed. Having expressions of unrealistic fears and repetitive health complaints were positively and significantly associated with informal care costs for males, while these characteristics were nonsignificant for females. In contrast, females with nausea were associated with greater care costs, while this association was not significant in males. Fluctuating states of consciousness was also predictive of lower informal care costs for females, but not for males.

### 6.4.3 Examining the effect of formal palliative home care costs on informal care costs

Results of the first Durbin-Wu-Hausman test that regressed only the instrumental variable (residence in a northern LHIN) on formal care cost in the first step of the test found the residual of formal cost to be nonsignificant (p-value=0.41) in the second stage of the test, thus indicating no endogeneity between formal and informal costs. In contrast, endogeneity was indicated in the second Durbin-Wu-Hausman test that regressed the instrumental variable in addition to all exogenous variables in the first step found the residual to be highly significant ($p < 0.0001$) in the second stage.

Given the conflicting results of the two Durbin-Wu-Hausman tests, both OLS and 2SLS models were fit and can be found in Table 6.5. For most characteristics, the direction of the associations remained the same in both models. Of note, both the directions of the association, and the levels of significance differed for the Pain and CHESS scales in the two models, although pain was only borderline significant in the 2SLS model. For the main variable of interest, the log mean weekly formal palliative home care cost, both models found it to be positively and significantly associated with log weekly informal care costs. The OLS model indicated that informal care costs would increase by 0.05% for every one percent increase in formal care costs, while that increase would be 0.44% in the 2SLS model.

**Table 6.5: Multivariate models of log weekly informal care cost of palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score using interRAI PC scales and items, the PPS, and log mean weekly formal care costs in the first five weeks of service post-assessment (n=36,736)**

| | 2SLS | | OLS | |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| Intercept | 2.76 (0.65) | <0.0001 | 5.26 (0.05) | <0.0001 |
| log mean weekly formal care cost | 0.44 (0.12) | 0.0002 | 0.05 (0.005) | <0.0001 |
| Age | -0.002 (0.0004) | <0.0001 | -0.002 (0.0003) | <0.0001 |
| Marital Status (ref=married) | | | | |
| Never married | -0.08 (0.03) | 0.004 | -0.10 (0.02) | <0.0001 |
| Partner/Significant other | 0.000001 (0.03) | 0.9997 | -0.04 (0.02) | 0.08 |
| Widowed | -0.02 (0.02) | 0.34 | -0.02 (0.01) | 0.23 |
| Separated | -0.11 (0.03) | 0.0005 | -0.10 (0.03) | 0.0001 |
| Divorced | -0.15 (0.02) | <0.0001 | -0.13 (0.02) | <0.0001 |
| Awareness of prognosis (ref=no) | 0.06 (0.01) | <0.0001 | 0.07 (0.008) | <0.0001 |
| Accepting of situation (ref=no) | 0.03 (0.01) | 0.008 | 0.03 (0.009) | 0.007 |
| Informal helpers | 0.03 (0.01) | 0.004 | 0.05 (0.009) | <0.0001 |
| Living arrangement (ref=with others) | -0.16 (0.03) | <0.0001 | -0.06 (0.02) | 0.0004 |
| Live-in caregiver (ref=no) | 0.36 (0.02) | <0.0001 | 0.34 (0.02) | <0.0001 |
| Primary caregiver relationship to client (ref=spouse) | | | | |
| Child/child-in-law | -0.01 (0.02) | 0.45 | -0.002 (0.01) | 0.86 |
| Friend/neighbour | -0.17 (0.03) | <0.0001 | -0.13 (0.02) | <0.0001 |
| None | -0.37 (0.19) | 0.05 | -0.43 (0.16) | 0.006 |
| Other family | -0.05 (0.02) | 0.04 | -0.03 (0.02) | 0.10 |
| Informal helper(s) unable to continue in caring activities (ref=no) | -0.10 (0.02) | <0.0001 | -0.05 (0.01) | <0.0001 |
| Family or close friends report feeling overwhelmed by person's illness (ref=no) | 0.06 (0.01) | <0.0001 | 0.09 (0.009) | <0.0001 |
| End of life home care client type (ref=no) | -0.002 (0.03) | 0.93 | 0.07 (0.009) | <0.0001 |
| IADL-ADL Functional Hierarchy Scale | 0.06 (0.01) | <0.0001 | 0.11 (0.002) | <0.0001 |
| CHESS | -0.01 (0.009) | 0.21 | 0.02 (0.004) | <0.0001 |

| | **2SLS** | | **OLS** | |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| CPS | 0.04 (0.005) | <0.0001 | 0.05 (0.004) | <0.0001 |
| Ate ≤1 meal on at least 2 of last 3 days (ref=no) | -0.02 (0.01) | 0.06 | -0.01 (0.01) | 0.20 |
| Dyspnea (ref=absence of symptoms) | | | | |
| Absent at rest, but present when performed moderate activities | 0.02 (0.02) | 0.34 | -0.02 (0.01) | 0.09 |
| Absent at rest, but present when performed normal day-to-day activities | -0.01 (0.02) | 0.54 | -0.05 (0.01) | <0.0001 |
| Present at rest | -0.02 (0.02) | 0.14 | -0.05 (0.01) | <0.0001 |
| Fatigue (ref=none) | | | | |
| Minimal | 0.01 (0.02) | 0.48 | 0.02 (0.01) | 0.14 |
| Moderate | 0.05 (0.02) | 0.008 | 0.07 (0.01) | <0.0001 |
| Severe | 0.06 (0.02) | 0.003 | 0.12 (0.01) | <0.0001 |
| Unable to commence any normal day-to-day activities | 0.16 (0.03) | <0.0001 | 0.22 (0.02) | <0.0001 |
| Pain scale | -0.01 (0.006) | 0.05 | 0.009 (0.003) | 0.007 |
| IV medication (ref=not ordered and did not occur) | | | | |
| Ordered, not implemented | -0.02 (0.03) | 0.62 | 0.01 (0.03) | 0.63 |
| 1-2 of last 3 days | 0.04 (0.03) | 0.16 | 0.10 (0.02) | <0.0001 |
| Daily in last 3 days | -0.14 (0.06) | 0.005 | 0.04 (0.02) | 0.10 |
| Did not occur, declined offered treatment | 0.14 (0.15) | 0.36 | 0.10 (0.13) | 0.44 |
| DRS | -0.006 (0.003) | 0.08 | -0.004 (0.003) | 0.10 |
| Acid reflux (ref=no) | 0.11 (0.01) | <0.0001 | 0.08 (0.009) | <0.0001 |
| Nausea (ref=no) | 0.02 (0.01) | 0.04 | 0.03 (0.008) | 0.0003 |
| Expressions of unrealistic fears (ref=no) | 0.09 (0.03) | 0.0004 | 0.09 (0.02) | <0.0001 |
| Repetitive health complaints (ref=no) | 0.05 (0.02) | 0.02 | 0.02 (0.02) | 0.25 |
| Repetitive non-health related complaints/concerns (ref=no) | 0.03 (0.02) | 0.13 | 0.04 (0.02) | 0.01 |
| Bowel continence (ref=continent) | | | | |
| Complete control with ostomy | -0.07 (0.03) | 0.006 | -0.01 (0.02) | 0.45 |
| Infrequently incontinent | -0.07 (0.03) | 0.004 | -0.03 (0.02) | 0.18 |
| Occasionally incontinent | -0.08 (0.03) | 0.01 | 0.002 (0.02) | 0.91 |
| Frequently incontinent | -0.20 (0.04) | <0.0001 | -0.08 (0.03) | 0.002 |

| | 2SLS | | OLS | |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| Incontinent | -0.27 (0.04) | <0.0001 | -0.18 (0.02) | <0.0001 |
| Did not occur | -0.15 (0.08) | 0.07 | -0.003 (0.07) | 0.97 |
| Fluctuating state of consciousness (ref=no) | -0.04 (0.03) | 0.14 | -0.04 (0.02) | 0.04 |
| PPS | 0.00005 (0.002) | 0.98 | -0.009 (0.0004) | <0.0001 |

2SLS: degrees of freedom = 49; F statistic = 338.3; p-value <0.0001; $R^2$ = 34.6%

OLS: degrees of freedom = 49; F statistic = 504.9; p-value <0.0001; $R^2$ = 40.2%

ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

### 6.4.4 Predicting combined formal and informal palliative home care costs

Gender was nonsignificant in bivariate regression of the log combined formal and informal care costs. All other contender variables were found to be significant in bivariate analyses. Variance explanation of these models can be found in Table 6.6.

**Table 6.6: Explained variance of candidate variables in bivariate regression of log mean weekly combined cost in first five weeks of service post-assessment for palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score, 2011 to 2017 (n=39,069)**

| Characteristic type | interRAI PC item/scale | Explained variance |
|---|---|---|
| Predisposing | Age | 1.3%*** |
| | Gender | 0.0% |
| | Marital status | 2.8%*** |
| | Verbalizes awareness of terminal prognosis of less than 6 months to live | 0.5%*** |
| | Accepting of situation | 0.6%*** |
| Enabling | LHIN of residence | 4.4%*** |
| | Informal helper(s) | 1.1%*** |
| | Living arrangement | 5.0%*** |
| | Live-in caregiver | 4.1%*** |
| | Primary caregiver relationship to client | 3.0%*** |
| | End of life home care client type | 2.7%*** |
| | Informal helper(s) unable to continue in caring activities | 0.7%*** |
| | Primary informal helper expresses feelings of distress, anger or depression | 3.5%*** |
| | Family or close friends report feeling overwhelmed by person’s illness | 5.2%*** |
| Need | Prognosis | 7.4%*** |
| | IADL-ADL Functional Hierarchy Scale | 44.2%*** |
| | CHESS | 14.4%*** |
| | CPS | 11.7%*** |
| | Fluid intake <1,000 cc per day | 2.1%*** |
| | Ate ≤1 meal on at least 2 of last 3 days | 2.3%*** |
| | Mode of nutritional intake | 4.8%*** |
| | Dyspnea | 1.9%*** |
| | Fatigue | 12.6%*** |
| | Nausea | 0.1%*** |
| | Vomiting | 0.3%*** |
| | Acid reflux | 0.1%*** |
| | Bloating | 0.2%*** |
| | Constipation | 0.5%*** |

| **Characteristic type** | **interRAI PC item/scale** | **Explained variance** |
|---|---|---|
| | Diarrhea | 0.0%* |
| | Fecal impaction | 0.2%*** |
| | Pain Scale | 0.8%*** |
| | IV medication | 0.5%*** |
| | Ventilator or respirator | 0.5%*** |
| | Cancer | 3.5%*** |
| | DRS | 1.2%*** |
| | Expressions, including nonverbal, of what appear to be unrealistic fears | 0.8%*** |
| | Repetitive health complaints | 0.3%*** |
| | Repetitive anxious complaints/concerns (non-health related) | 0.4%*** |
| | Bladder incontinence | 8.8%*** |
| | Bowel incontinence | 8.9%*** |
| | Fluctuating state of consciousness | 2.9%*** |
| | Acute change in mental status from person's usual functioning | 2.9%*** |
| | PPS | 37.5%*** |

***p-value <0.0001; **p-value <0.01; *p-value <0.05
ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

In the multivariate model of predisposing characteristics, age, marital status, awareness of terminal prognosis and acceptance of the situation were all significantly associated with the log combined formal and informal care costs. The explained variance for this model was 5.0%. A multivariate model of enabling characteristics found all variables to be significantly associated with the log combined care costs, and had an explained variance of 18.3%. For need characteristics, a multivariate model containing only scales and items from the interRAI PC found a number of variables to be nonsignificant including ate ≤1 mean on at least 2 of last 3 days, DRS score, diarrhea, bloating, constipation, repetitive anxious complaints/concerns that were non-health related, fluctuating state of consciousness, and acute change in mental status. This multivariate model had an explained variance of 48.0%. Inclusion of PPS the model of need characteristics led to the nonsignificance and subsequent removal of cancer and repetitive health complaints, and had an explained variance of 50.1%.

A finalized multivariate model of log combined formal and informal care costs containing interRAI PC scales and items of predisposing, enabling and need characteristics had an explained variance of 51.7%. Items excluded from the finalized model included living arrangement, fluid intake <1,000 cc per day, ate ≤1 mean on at least 2 of last 3 days, informal helper(s) unable to continue in caring activities, DRS, diarrhea, bloating, constipation, fecal impaction, repetitive health complaints, fluctuating state of consciousness, and acute change in mental status. This model can be found in Table E.3, Appendix E. The model containing interRAI PC scales and items, in addition to the PPS had an explained variance of 53.3%, although cancer and nausea became nonsignificant in this model. This final multivariate model containing both interRAI PC scales and items and the PPS can be found in Table 6.7.

A number of predisposing characteristics were significantly associated with the log mean weekly combined formal and informal costs. Older age and having a marital status other than married were generally associated with lower combined costs. The exception was for those widowed as compared to those who were married, where the association was nonsignificant. Characteristics representative of clients' beliefs towards death and dying including verbalizing an awareness of prognosis of <6 months and being accepting of the situation were associated with greater combined costs.

A number of enabling characteristics were also significantly associated with log mean weekly combined formal and informal care costs. Over half of LHINs were significantly associated with lower combined costs as compared to those residing in the Hamilton Niagara Haldimand Brant LHIN, with exceptions being Central East, Central West, Mississauga Halton, North East and South East LHINs. Related to caregivers, having informal help, having a live-in caregiver, having a caregiver that expressed feelings of distress, anger or depression, as well as family or close friends report feeling overwhelmed were all significantly associated with greater costs.

The majority of significant predictors of the log mean weekly combined formal and informal cost were need characteristics. With the exception of dyspnea, where greater severity of the symptom was associated with lower cost, the presence or greater severity of a need characteristic was generally associated with greater cost. The IADL-ADL Functional Hierarchy Scale appeared to have a particularly great effect on the log mean weekly combined formal and informal care cost. Any tube feeding compared to normal nutritional intake, fatigue, the daily use of IV medications, and daily use of a ventilator/respirator were all associated with large increases in cost as well.

**Table 6.7: Multivariate model of log mean weekly combined formal and informal costs in the first five weeks of service for palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score, 2011 to 2017 (n=38,160)**

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Intercept | 6.22 (0.03) | <0.0001 |
| Age | -0.001 (0.0002) | <0.0001 |
| Marital Status (ref=married) | | |
| Never married | -0.08 (0.02) | <0.0001 |
| Partner/Significant other | -0.04 (0.009) | 0.02 |
| Widowed | -0.008 (0.02) | 0.37 |
| Separated | -0.08 (0.01) | <0.0001 |
| Divorced | -0.08 (0.02) | <0.0001 |
| Awareness of prognosis (ref=no) | 0.04 (0.007) | <0.0001 |
| Accepting of situation (ref=no) | 0.02 (0.008) | 0.01 |
| LHIN of residence (ref=Hamilton Niagara Haldimand Brant) | | |
| Central East | 0.04 (0.01) | 0.004 |
| Central | -0.17 (0.01) | <0.0001 |
| Champlain | -0.06 (0.01) | <0.0001 |
| Central West | 0.04 (0.02) | 0.07 |
| Erie St. Clair | -0.10 (0.01) | <0.0001 |
| Mississauga Halton | 0.12 (0.02) | <0.0001 |
| North East | 0.12 (0.01) | <0.0001 |
| North Simcoe Muskoka | -0.12 (0.02) | <0.0001 |
| North West | -0.23 (0.02) | <0.0001 |
| South East | 0.15 (0.02) | <0.0001 |
| South West | -0.08 (0.02) | <0.0001 |
| Toronto Central | -0.06 (0.03) | 0.01 |
| Waterloo Wellington | -0.07 (0.01) | <0.0001 |
| Informal helpers | 0.09 (0.007) | <0.0001 |
| Live-in caregiver (ref=no) | 0.19 (0.009) | <0.0001 |
| Primary informal helper expresses feelings of distress, anger or depression (ref=no) | 0.02 (0.009) | 0.04 |
| Family or close friends report feeling overwhelmed by person's illness (ref=no) | 0.10 (0.009) | <0.0001 |
| End of life home care client type (ref=no) | 0.06 (0.008) | <0.0001 |
| Prognosis (ref=6 months or longer) | | |

| **Parameter** | **Estimate (standard error)** | **p-value** |
|---|---|---|
| Death imminent (within days) | -0.06 (0.07) | 0.41 |
| <6 weeks | 0.04 (0.02) | 0.05 |
| ≤6 weeks, >6 months | -0.03 (0.008) | 0.001 |
| IADL-ADL Functional Hierarchy Scale | 0.11 (0.002) | <0.0001 |
| CHESS | 0.06 (0.004) | <0.0001 |
| CPS | 0.02 (0.003) | <0.0001 |
| Mode of nutritional intake (ref=normal) | | |
| Modified independent | 0.003 (0.01) | 0.81 |
| Requires diet modification to swallow solid food | 0.03 (0.01) | 0.04 |
| Requires modification to swallow liquids | -0.03 (0.03) | 0.46 |
| Can swallow only puréed solids | 0.01 (0.03) | 0.73 |
| Combined oral and parenteral or tube feeding | 0.11 (0.03) | 0.001 |
| Nasogastric tube feeding only | 0.10 (0.08) | 0.22 |
| Abdominal feeding only | 0.15 (0.02) | <0.0001 |
| Parenteral feeding only | 0.22 (0.07) | 0.001 |
| Activity did not occur | -0.07 (0.10) | 0.52 |
| Dyspnea (ref=absence of symptoms) | | |
| Absent at rest, but present when performed moderate activities | -0.07 (0.009) | <0.0001 |
| Absent at rest, but present when performed normal day-to-day activities | -0.10 (0.009) | <0.0001 |
| Present at rest | -0.10 (0.01) | <0.0001 |
| Fatigue (ref=none) | | |
| Minimal | 0.04 (0.01) | 0.001 |
| Moderate | 0.10 (0.01) | <0.0001 |
| Severe | 0.14 (0.01) | <0.0001 |
| Unable to commence any normal day-to-day activities | 0.20 (0.02) | <0.0001 |
| Pain scale | 0.03 (0.003) | <0.0001 |
| IV medication (ref=not ordered and did not occur) | | |
| Ordered, not implemented | 0.003 (0.02) | 0.91 |
| 1-2 of last 3 days | 0.09 (0.02) | <0.0001 |
| Daily in last 3 days | 0.23 (0.02) | <0.0001 |
| Did not occur, declined offered treatment | -0.25 (0.13) | 0.06 |
| Ventilator or respirator | | |
| Ordered, not implemented | 0.03 (0.10) | 0.79 |
| 1-2 of last 3 days | 0.11 (0.16) | 0.50 |
| Daily in last 3 days | 0.18 (0.05) | 0.0002 |
| Did not occur, declined offered treatment | 0.27 (0.15) | 0.07 |
| Vomiting (ref=no) | 0.03 (0.009) | 0.0002 |
| Acid reflux (ref=no) | 0.03 (0.007) | <0.0001 |
| Expressions of unrealistic fears (ref=no) | 0.08 (0.02) | <0.0001 |
| Repetitive non-health related complaints/concerns (ref=no) | 0.04 (0.01) | 0.0005 |

| **Parameter** | **Estimate (standard error)** | **p-value** |
|---|---|---|
| Bladder continence (ref=continent) | | |
| Complete control with any catheter or ostomy over last 3 days | 0.05 (0.01) | 0.0004 |
| Infrequently incontinent | 0.01 (0.01) | 0.44 |
| Occasionally incontinent | 0.04 (0.01) | 0.005 |
| Frequently incontinent | 0.03 (0.01) | 0.03 |
| Incontinent | -0.0004 (0.02) | 0.99 |
| Did not occur | 0.02 (0.07) | 0.83 |
| Bowel continence (ref=continent) | | |
| Complete control with ostomy | 0.03 (0.02) | 0.07 |
| Infrequently incontinent | 0.004 (0.02) | 0.79 |
| Occasionally incontinent | 0.06 (0.02) | 0.0004 |
| Frequently incontinent | 0.02 (0.02) | 0.45 |
| Incontinent | -0.08 (0.02) | 0.0004 |
| Did not occur | 0.04 (0.06) | 0.45 |
| PPS | -0.01 (0.0004) | <0.0001 |

Degrees of freedom = 74; F statistic = 590.9; p-value <0.0001; $R^2$ = 53.3%
ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

#### 6.4.4.1 Gender-based predictors of combined formal and informal costs

Stratification of the finalized model of combined formal and informal care costs containing both the interRAI PC scales and items and the PPS identified some differences in predictors of costs between males and females (Table E.4, Appendix E). Older age was significant in predicting greater combined care costs in females. In regard to marital status, having never been married and being divorced were associated with lower costs for both genders as compared to being married. However, having a partner or significant other was also significantly associated with lower costs for females but not males, while being separated was associated with lower care costs in males only. Select LHINs (i.e., Central East, Central West and Toronto Central) were nonsignificant in predicting costs for females, but were significant for males. While having a primary caregiver feeling distress, anger or depression was associated with significantly greater combined care costs for female clients, this caregiver characteristic was nonsignificant in male clients. A number of need characteristics were also differently significant in males than in females. These characteristics included expected survival (of less than six months but more than six weeks), mode of nutritional intake (parenteral feeding only), IV medication (did not occur or declined offered treatment), and bladder incontinence (occasional).

## 6.5 Discussion

The objectives of this study were to identify characteristics predictive of informal costs and combined formal and informal palliative home care costs. To that end, the analyses in this study have identified a number of palliative home care client characteristics that are significantly associated with these types of costs, building on a very limited body of existing literature. As compared to these other studies, this study relied on a much larger sample of palliative home care clients from all regions of Ontario. The use of clinical information captured as part of the interRAI PC assessments also permitted the identification of a wide array of characteristics associated with informal costs only and combined formal and informal care costs for those receiving palliative home care. The final model based on a large array of predisposing, enabling, and need variables provided a high level of explained variance that was comparable to or exceeded $R^2$ values reported in the case-mix literature for home care and palliative care. Notably, this value for ambulatory palliative care component of the Australian National Sub-Acute and Non-Acute Patient System was 17.1% (Eagar, Green, & Gordon, 2004), compared with 53.3% that was achieved in this study.

Although not a primary objective of this study, this study did estimate the costs of informal care and found them to be substantial irrespective of the estimation method used. Direct comparisons to existing studies are difficult to make due to differences in the definition of caregiving time, and informal care valuation methods used. The approaches considered as part of this study appear to be closest to the methods used by Dumont et al. (2009, 2010) in regard to the valuation of informal care using the replacement cost of unpaid work. These comparisons were made by adjusting the findings by Dumont et al. (2009, 2010) to reflect weekly costs. Their estimates of cost were found to be substantially lower than the weekly informal care costs estimated in this study, likely since they included only caregiving time spent in excess of time spent on household activities prior to the client/patient's illness. In addition, the studies by Dumont et al. (2009, 2010) were not limited to those receiving palliative care at home, which may lead to differences since those receiving care at home may also have greater access to informal caregivers (Walshe et al., 2009). In contrast, the informal care costs estimated in this study were substantially lower than the costs estimated in a study using the human capital approach (Guerriere et al., 2010). This finding can be expected due to the inclusion of costs associated with leisure time, which has previously been found to make up the bulk of informal care costs (Guerriere et al., 2008). Together, these differences in methodology can also explain the differences in the shares of cost attributable to informal care in this study and existing studies (Chai et al., 2013, 2014), including previous research comparing hours of informal care to hours of formal care (Health Council of Canada, 2012). Despite challenges in comparing the costs of informal care across studies, this present study was consistent with the existing literature in finding informal care costs to be substantial, and to represent a large proportion of service-related palliative home care costs (Chai et al., 2014; Dumont et al., 2009, 2014, 2015; Gardiner et al., 2014; Haltia et al., 2018; Jacobs et al., 2011).

In regard to informal care costs, this study found a number of predisposing, enabling, and need characteristics to be associated with informal care costs. For predisposing characteristics, two characteristics had previously been identified, which were age and marital status (Cai et al., 2020; Chai et al., 2014). Similar to Cai et al. (2020), older age was associated with lower informal care intensity in this study. One explanation for this finding might be related the capacity of clients' caregivers to provide care. Specifically, since the majority of primary caregivers are the spouses, partners, or significant others to clients, these caregivers are likely in turn to also be older and have a lower capacity to provide care than younger caregivers. Seemingly in contrast, it should be noted that Chai et al. (2014) previously found older client age to be associated with a higher share of informal care costs. The relevance of this finding may be limited, however, due to the differing outcome of interest. As the authors hypothesize, this finding could reflect the lower reliance of older individuals on formal care (Chai et al., 2014).

For marital status, the results from this study are consistent with both earlier studies in finding being married to be positively associated with informal care intensity, or the share of costs attributable to informal care costs (Cai et al., 2020; Chai et al., 2014). As with these earlier studies, the higher costs associated with married clients is likely to be the result of greater access to a caregiver. Results from the gender-stratified models in this study also show that marital status influences males and females differently. Not being in a relationship for any reason appears to reduce informal care costs for males, while informal care costs are only significantly reduced for divorced and never married females. For males, having a partner/significant other rather than being married does not significantly influence informal care costs, while having a spouse within the context of marriage appears to matter for female clients. As many caregivers are spouses and are oftentimes of the opposite gender to the client, it could reflect differences in attitudes held by males and females regarding caregiving responsibilities depending on the nature of a relationship.

Two other predisposing characteristics were identified as predictors of informal care costs in this study. These characteristics included having verbalized awareness of having a prognosis of less than six months and being accepting of the situation, which were both associated with greater informal care costs. In the palliative care context, those aware, willing to discuss, and accepting of their approaching death may have a greater willingness to accept care from others (Zimmermann, 2012). The acknowledgement and acceptance of impending death may also lead clients and their families to spend a greater amount of remaining time together, and/or may reflect the desire for more privacy (Gott & Ingleton, 2011). Specific to those verbalizing awareness of a prognosis of less than six months, higher costs also likely reflect clients' greater proximity to death, which has previously been found to predict informal care costs (Cai et al., 2020).

A number of enabling characteristics were also identified in this study as being predictors of informal care costs. Interestingly, LHIN of residence was one of these characteristics associated with informal care costs. While regional differences in palliative care are known to exist (Brick et al., 2017; Dumont et al., 2015), this study appears to be the first to identify health regions as determinants of informal care. It is possible that these differences reflect variations in the models of care or practice patterns for formal care across the LHINs (Hsu & Tanuseputro, 2017) which can in turn influence the role and reliance on informal care. Similarly, proximity to palliative care centres is associated with access to formal care (Lavergne et al., 2015; Maddison et al., 2012) so that individuals residing further away from care centres may rely more strongly on informal caregivers in the absence of formal care. Greater distances to care centres may also require caregivers to spend more time traveling with palliative home care clients to medical appointments, as appears to be the case for individuals residing in rural areas (Dumont et al., 2015). Individuals residing in rural areas have also been found to have a lower likelihood of receiving palliative care (Tanuseputro et al., 2017) and to use health services differently (Brazil et al., 2013). Differences in rural caregiving culture have also been suggested, with residents of rural areas being "characterized by friendliness and all members knowing one another," as well as having a greater "willingness to look out for one another" (Chwalisz et al., 2011).

Other enabling characteristics that were identified as predictors of informal care costs were related to caregivers. Not surprisingly, having an informal caregiver was associated with higher informal care costs. Residing with a caregiver was associated with particularly large increases in informal care costs, while living alone was associated with slightly lower informal care costs. For all three of these findings, these associations likely reflect the availability and accessibility of informal care to these palliative home care clients, as has been previously suggested (Cai et al., 2020).

Three caregiver characteristics were also predictive of clients' informal care costs. When stratified by gender, this study found that for males but not females, having a primary caregiver who was a family member but was not a spouse or child/child-in-law was associated with lower informal care costs. This finding could reflect differences in the size and strength of family and social networks between the two genders whereby females may be more likely to have stronger bonds with family members outside of their immediate family, and/or have a greater number of potential caregivers so that overall levels of informal care remain similar. More generally, this study found having a friend/neighbour caregiver was associated with lower informal care costs. This association appears to be consistent with the earlier finding that spouse caregivers are associated with a greater number of informal care hours, which may be due to greater access to their caregiver, as well as stronger bonds between clients and family members (Betini et al., 2017; Cai et al., 2020). Individuals with friends or neighbours as their primary caregiver may also have fewer people with whom to share caregiving activities resulting in lower levels of informal care overall. The finding from this study is seemingly at odds, however, with Chai et al.'s (2014) work on identifying predictors of the share of costs attributable to informal care, which found having a friend/neighbour caregiver to be associated with a greater share of unpaid care costs. While the applicability of findings on the share of costs to informal care costs is unclear, Chai et al. (2014) hypothesized that friend/neighbour caregivers may be more likely to describe their activities with clients as caregiving activities. Another explanation for the Chai et al. (2014) finding may be that clients with a friend/neighbour as their primary caregiver may not have any family caregivers who may be more likely to advocate for formal care services (Cai et al., 2017; Masucci et al., 2013). Inadequate controlling for characteristics associated with greater level of illness in the study by Chai et al. (2014) could also mean that palliative home care clients with a friend/neighbour caregiver may be in better health and do not (yet) require substantial involvement of formal services.

Remaining caregiver characteristics identified as a predictors of informal care costs in this study were having family or friends who reported feeling overwhelmed, and having informal caregivers unable to continue in caring activities. Unsurprisingly, having caregivers who felt unable to continue in caring activities was negatively associated with informal care costs since it reflects the reduced capacity of informal caregivers. Gender-stratified models showed, however, that this association was only significant for female clients. Again, this finding could reflect caregiver gender such that spouse caregivers to male clients are likely to be female, and female caregivers could be less likely to withdraw care than male caregivers. At least in a paediatric palliative care, female caregivers have been found to experience greater distress or burden, but also derive greater meaning in their caregiving (Schneider et al., 2011), offering one explanation as to why female caregivers may be less likely to withdraw care even when they feel unable to continue. Interestingly, the inverse relationship was found for clients with family who reported feeling overwhelmed, which was positively associated with informal care costs overall, and for clients of both genders. One existing study has found the risk of caregiver burden to be associated with the number of informal care hours provided (Guthrie et al., 2020), and similarly, it is likely that family and friends providing more care are likelier to feel overwhelmed.

The majority of characteristics identified as predictors of informal care costs in this study were need characteristics. One characteristic that was associated with a particularly large increase in informal care costs was client function, as measured by the IADL-ADL Functional Hierarchy Scale, and the PPS. This finding appears to be reasonable given that caregivers are known to provide a substantial amount of assistance with functional activities (Brazil et al., 2003) and it has previously been suggested that those with higher levels of functional dependence receive more informal care (Guerriere et al., 2016). This finding also appears to be consistent with earlier studies that have found lower function to be predictive of greater informal care hours, albeit nonsignificantly (Cai et al., 2020; Chai et al., 2014).

Other need characteristics identified as part of this study were clients' symptoms. The presence and greater severity of symptoms were generally associated with greater informal care costs. These symptoms included poorer cognitive performance, low appetite, fatigue, pain, acid reflux, nausea, expressions of unrealistic fears, repetitive health complaints, and repetitive non-health related complaints. These findings appear to be consistent with the existing palliative home care literature, which has found greater symptom severity (measured using the ESAS) to be associated with larger shares of costs attributable to informal care (Chai et al., 2013, 2014). Although direct comparisons between these two studies and the present study are difficult because of the differing outcomes of interest, the association between the presence and greater severity of symptoms and higher informal care costs appears to be reasonable since those with greater symptomatology can also be expected to have greater care needs.

Similarly, greater health instability, measured by the CHESS scale, was also found to be predictive of higher informal care costs in this study, and may also reflect the greater care needs of those with more health instability. Higher CHESS scores have also been found to predict mortality (Hirdes et al., 2012) and so its association with greater informal care costs may also reflect clients' proximity to death, which has previously been found to be associated with increased informal care hours (Cai et al., 2020). Interestingly, this study did not find client prognosis to be significantly associated with informal care cost, although it is important to note that prognosis does not necessarily equate to proximity to death (Scitovsky, 2005). The ability for caregivers to estimate expected survival and their more general level of prognostic awareness may also be poor (Gray et al., 2020) and so they may instead respond to specific client symptoms.

The present study did also find symptom-based characteristics predictive of lower informal care costs to include dyspnea, bowel incontinence and having a fluctuating state of consciousness. For fluctuating state of consciousness, which typically occurs for clients in the very final stages of the dying trajectory (Claessens et al., 2012), the presence of this symptom could represent a time in which little additional care can be provided to clients by their family and friends. With dyspnea, its association with lower informal care costs may reflect the complexity and distressing nature of this symptom for both clients and their caregivers (Fisher, Seow, Cohen, et al., 2015; Freeman et al., 2016). For caregivers, this distress may translate into a lower capacity to provide informal care. The presence of dyspnea can also mark a point at which a greater involvement of formal palliative care services is needed, including those outside of home and community settings. Indeed, one study has found costs for those with dyspnea to be attributable primarily to inpatient care (Dzingina et al., 2017), a setting in which reliance on informal care is reduced (Dumont et al., 2009). With regard to bowel continence, it was being completely incontinent, in particular, that was associated with very large decreases in informal care costs. Here too, it is possible that the presence and severity of this symptom is indicative of the need for additional formal palliative home care services and/or care provided in other care settings. Specifically, those with long-lasting bowel incontinence have previously been found to be more frail, and have greater mortality risks (Chassagne et al., 1999). While the presence of these symptoms may reflect clients' proximity to death, it can also reflect caregivers' capacity to continue to provide care. As with dyspnea, bowel incontinence has been found to be associated with greater caregiver distress (Hirdes et al., 2012), which can limit the capacity of caregivers to provide informal care and lead to greater reliance on formal care services like respite care.

The relationship between formal palliative home care costs and informal care costs was also examined as part of this study. Interestingly, the results of the Durbin-Wu-Hausman tests performed as part of this study indicated conflicting results as to the endogeneity of formal and informal palliative home care costs. One potential explanation for the significance of the second endogeneity test performed as part of this study may be related to the multiple testing problem given the large number of covariates present in this second model. However, the p-value of the formal cost residual suggests a strong level of significance, making this explanation unlikely. The more likely explanation is the weakness of the instrumental variable selected for this analysis, which has been known to result in invalid results from the Durbin-Wu-Hausman test (Hahn et al., 2011). With regard to the association between formal and informal palliative home care costs, both the OLS and 2SLS models indicated formal and informal care costs to be complementary. With over half of formal care costs attributable to nursing services, this finding is consistent with the earlier study that found nursing services to be complementary to informal care (Cai et al., 2020). The other major component to formal palliative home care costs is for PSW services, which Sun et al. (2019) found to act as a substitute to informal care. The opposing directions of association for nurse and PSW services may help to explain the small effect sizes for formal care costs in this study, as the effects of nursing and PSW costs essentially cancel the other out. Although it has only been identified as a concern in small samples, it is nevertheless important to note that 2SLS results may be biased towards OLS results in the presence of weak instruments (Bound et al., 1995).

It was also the objective of this study to identify predictors of combined formal and informal palliative home care costs. Overall, this study found the variance explanation for combined care cost models to be greater than for informal care cost models in most cases. As expected, many of the characteristics predictive of informal care costs were also predictive of the combined formal and informal palliative home care costs since over half of combined costs are comprised of informal care costs. Further, characteristics that reflect the need for greater levels of informal care may also reflect the need for greater levels of formal care. Nevertheless, there were some noteworthy differences between the predictors of informal and combined care costs. One such difference was the relationship between the primary caregiver and the client. This characteristic was significant in the informal cost model, but nonsignificant in the combined cost model. In particular, having a friend/neighbour as a primary caregiver was significantly associated with lower care costs in the informal care model (family client-caregiver relationships were nonsignificant). The most likely explanation for the nonsignificance of this characteristic in predicting combined costs is that those with a family caregiver receive less formal care and more informal care, while those with a friend/neighbour caregiver receive less informal care and more formal care at levels that result in similar overall costs. For clients with friend/neighbour caregivers, the increase in formal care costs is likely to be from PSW services as informal caregivers are known to primarily provide care that would otherwise be provided by PSWs (Sun et al., 2019). Other characteristics that were significant in predicting informal care costs, but not combined formal and informal palliative home care costs included living alone and eating one or fewer meals on at least last two of three days. The reason for these differences may be that they are positively associated with formal care costs so that they offset any effect from informal care costs.

Other differences between the finalized informal care cost model and the combined cost model were comprised primarily of need characteristics that were found to be significantly associated with higher combined care costs but nonsignificant in predicting informal care costs. These differences included having a prognosis of less than six months; having nutritional intake that required modifications to swallow solid food, combined oral and parenteral or tube feeding, abdominal feeding only, and parenteral feeding only; daily use of a ventilator or respirator; and having bladder continence with a catheter or ostomy, and being occasionally or frequently incontinent. For these characteristics, it is likely that their positive association with combined care costs reflect care needs that are complex and require formal palliative home care services in order to address the underlying symptoms. Specific to client prognosis, the significance of the characteristic in predicting combined care costs may be explained by the reliance of formal palliative home care system on prognosis to inform resource allocation decisions (Hsu et al., 2016), with one example being the end of life designation. There was also one enabling characteristic that was positively associated with combined formal and informal palliative home care costs but not informal costs alone. This characteristic was having family or close friends reporting feeling overwhelmed. Here too, this finding indicates that its effect is primarily on formal care only, and implies that while informal caregivers may not change their provision of care from feeling overwhelmed, they may rely more heavily on respite services and/or advocate for more formal care services.

In regard to the results of this study as compared to existing studies of combined formal and informal care costs, direct comparisons were difficult to make since these studies included costs across care settings and identified only a small number of characteristics to be predictive of cost (Guerriere et al., 2010; Haltia et al., 2018). This study was consistent in finding reduced function to be associated with greater cost both in the palliative care setting (Guerriere et al., 2010), and more broadly in home care settings (Björkgren et al., 2000; Cheng et al., 2020; Y. Lee & Penning, 2019; Poss et al., 2008). Findings from earlier studies were contradictory on the association between living arrangement and combined palliative care costs (Guerriere et al., 2010; Haltia et al., 2018). Interestingly, the present study also found that living with others was nonsignificant in predicting combined palliative home care costs, but residing with a caregiver was significantly associated with greater combined formal and informal palliative home care costs. This finding indicates that simply residing with another individual is not necessarily “enough” and that it is residing with a caregiver that influences cost. This finding also suggests that the contradictory findings from earlier studies could be potentially explained by differing definitions for living arrangements.

### 6.5.1 Limitations

There are some limitations to this study, including those related to the subsample selected for analyses in this study. As the subsample used in this study was the same as that used in the analyses of formal palliative home care costs in the previous chapter, limitations associated with the use of this subsample will not be discussed again here. Limitations associated with the estimation of formal palliative home care costs have also been discussed in the previous chapter and will also not be discussed here.

Related to the estimation of informal care costs, limitations exist from the reliance of these analyses on the number of hours of informal care received in the three days prior to assessment reported in the interRAI PC. Aside from potential recall bias, there may also be inconsistencies across clients and caregivers with regard to the activities they consider to be related to caregiving. Further, given that the estimate of informal care hours is retrospective, it assumes that informal care costs remain constant in the period post-assessment. These limitations are similar to the ones present in other studies (Björkgren et al., 2000; Cheng et al., 2020; Poss et al., 2008), however, and must be balanced against the need for research on informal care.

The drawbacks of the valuation of informal care time using a replacement cost method in this study should also be discussed. Specifically, it can be difficult to attach an accurate value to the various activities and corresponding levels of skill performed by caregivers (Coyle et al., 1999). It also does not account for burdens of caregiving beyond the direct personal support and homemaking activities carried out by caregivers such as being "on call" to palliative home care clients (Coyle et al., 1999). As the implications of this study are to inform on resource planning and palliative home care case-mix development, this restriction of informal care costing to direct care activities may be entirely appropriate in representing the service needs of palliative home care clients. Selection of half the hourly wage rate of a PSW was also reasonable given that caregivers primarily perform homemaking and personal support activities for home care clients, albeit with less skill than can likely be expected from a PSW. This method is also consistent with earlier studies on home care case-mix systems (Björkgren et al., 2000; Cheng et al., 2020; Poss et al., 2008).

Finally, the identification of predictors of informal, and combined formal and informal palliative home care costs in this study were limited by the items available as part of the interRAI PC. While the breadth and depth of the interRAI PC is already far greater than any of the other data collection instruments used in the existing literature, additional demographic information on clients' caregivers would have been beneficial to understanding the informal care costs of palliative home care clients. The ability to identify whether it is a primary caregiver who is unable to continue in caring activities, or who feels overwhelmed or distressed could also be important since there appear to be some differences in factors that influence primary and non-primary caregiving, as identified by Cai et al. (2021). Yet the utility of caregiver characteristics in informing on resource planning and future case-mix development work is likely to be less important since such decisions on, and classifications of clients should rely primarily on need characteristics (Hornbrook, 1982). Beyond caregiver characteristics, having additional variables that could have served as instruments in analyses of the relationship between formal and informal care costs is of greater relevance. This study was neither able to conclusively address the endogeneity question, nor the substitution question as the only potential instrument that could be identified proved to be weak. However, it is unclear what specific variables may have served as instruments in the analyses required to address these questions since many characteristics related to formal care costs are also related to informal care costs, at least in the palliative home care setting.

## 6.6 Conclusions

The objectives of this study were to identify predictors of informal, and combined formal and informal care costs, as well as to examine the relationship between formal and informal care costs for those receiving palliative home care. This study identified a number of characteristics that were associated with both types of cost, which can be used to identify clients with care needs that may not be addressed through formal care, but nevertheless require the attention of policy makers and case managers developing care plans. High variance explanation of informal costs and even higher variance explanation of combined care costs in this study indicate that palliative home care client costs can be predicted at levels comparable to or in excess of those shown in previous studies, and that combined formal and informal palliative home care costs should be considered in the development of any case-mix classification for this care setting. Finally, predictors of informal and combined care costs in this study can inform on characteristics that may be used to classify clients.

# Chapter 7

# General Discussion

## 7.1 Summary of findings

The need for palliative care is expected to increase as Canada's population continues to age, and as more individuals continue to die from life-limiting chronic conditions that result in a more gradual dying process. There is particular emphasis on the provision of palliative care services in communities and at home due to the preference for individuals to remain at home for as long as possible and potential to reduce end of life care costs (Scheerens et al., 2020; Seow et al., 2019). One recent report estimated that only 15% of Canadians who died received palliative care in their final year of life, which may be due to an inadequate supply of resources resulting from poor resource planning (Canadian Institute for Health Information, 2018; Office of the Auditor General of Ontario, 2014, 2016). To address this inadequacy, more information on resourcing and utilization patterns are required. As such, this dissertation sought to address existing questions on palliative home care utilization and to identify predictors of formal and informal palliative home care costs.

### 7.1.1 Palliative home care client characteristics and service utilization patterns

Overall, palliative home care clients in Ontario identified as part of this dissertation appeared to be distinct from general, long-stay home care clients. They were younger, and slightly more likely to be male. Many palliative home care clients also appeared to have moderate to high levels of functional impairment and health instability, over half had a prognosis of less than six months, and 85% had a cancer diagnosis. Once assessed, services to clients were initiated quickly. The intensity of service during the first week post-assessment was greater than in the weeks immediately following assessment. At least half of clients received service on the day of assessment, even when excluding the assessment visit. Case management services were particularly common in the first week post-assessment, likely representing the assessment visit, but remained the third most common service provided to clients in subsequent weeks, after nursing and personal support. For at least some clients, weekly palliative home care services may not have been required immediately post-assessment, and it did not appear that the absences of service were indicative of service interruptions. While service utilization declined after the first couple weeks of an episode, they increased again as clients continued to remain on service. Overall, these findings suggest the system responds to clients' needs as they are initially identified by the interRAI Palliative Care (PC) assessment instrument and as clients' health statuses continue to change. However, evaluation of the adequacy, appropriateness, and quality of these responses are beyond the scope of this dissertation. Variations in service utilization patterns could also be observed across Local Health Integration Networks (LHINs). These variations existed in clients' length on palliative home care service, their propensity for receiving personal support services, and their intensity of nursing and personal support service use. Finally, informal care hours provided to palliative home care clients were substantial and generally increased in parallel with receipt of formal care.

### 7.1.2 Predictors of formal, informal and combined palliative home care costs

Most formal, informal, and combined palliative home care costs were driven by need characteristics, although some predisposing and enabling characteristics were also identified. Across models examining formal, informal and combined costs, variance explanation was lowest for predisposing characteristics, while enabling characteristics had moderate levels of explained variance that ranged between 12.7% (formal costs) and 18.3% (combined costs). As expected, the variance explanation of enabling factors were particularly great for informal and combined care costs since most of these characteristics considered were related to caregivers. Variance explanation was highest across models of need characteristics (both with and without the Palliative Performance Scale [PPS]), indicating that service utilization costs are largely dependent on clients' clinical characteristics. The positive association between the presence and greater severity of symptoms with cost, and the large number of need characteristics identified also suggest that it is clinical complexity that determines care costs. In regard to care costs, variance explanation was generally highest for models of combined formal and informal cost, and was as high as 53.3% when predisposing, enabling and need characteristics (including the PPS) were considered.

The PPS was of particular interest in this dissertation as it is likely the closest measure to phase of illness that is used in the Australian National Sub-Acute and Non-Acute Patient (AN-SNAP) system, which is also under consideration in England and Germany. Across all models, the PPS was inversely associated with cost, indicating that poorer function was associated with greater formal, informal, and combined palliative home care costs. It performed well in explaining variations in these costs in bivariate regression. As compared to the other measure of function examined in this dissertation, the Instrumental Activities of Daily Living-Activties of Daily Living (IADL-ADL) Functional Hierarchy Scale, the PPS had a similar level of explained variance in predicting formal costs. However, variance explanation for informal and combined costs were much poorer for the PPS, as compared to the IADL-ADL Functional Hierarchy Scale. When introduced alongside other client characteristics, the PPS contributed to small increases in the levels of explained variance for formal, informal and combined care costs. Altogether, these findings indicate that the PPS is a strong determinant of palliative home care costs, although it is unclear how its performance would compare to phase of illness. Further, while it performed less well in predicting informal and combined care costs when compared to the IADL-ADL Functional Hierarchy Scale, it explained a modest amount of additional variance (0.7 to 2.6%) across all costs that were not otherwise captured by scales and items from the interRAI PC.

Aside from the PPS, there was substantial overlap in the client characteristics that were predictive of formal, informal and combined palliative home care costs, and the directions of these associations were consistent. A comparison of the significance and the association between formal, informal and combined care costs with interRAI PC scales and items, and the PPS can be found in Appendix F. Characteristics that were consistently significant across the cost models and with the same direction of the association included the regional variations based on LHINs, awareness of prognosis, family/friends reporting feeling overwhelmed, designation as an end of life home care client, level of function (IADL-ADL Functional

Hierarchy Scale and the PPS), health instability (CHESS), fatigue, pain, receipt of intravenous (IV) medication, and expressions of unrealistic fears. These characteristics were all positively associated with the three types of cost, and amongst the need characteristics, imply that these issues are addressed in the home setting through greater formal and informal care. In contrast, the presence of dyspnea was associated negatively with formal, informal, and combined costs, which would indicate greater reliance on services beyond the scope of palliative home care.

There were also two characteristics that were predictive of formal, informal and combined costs, but with varying directions of association. One of these characteristics was having a live-in caregiver, which was positively associated with informal and combined care costs, but negatively associated with formal care costs. This finding would indicate that clients with greater access to a caregiver receive more informal care, but less formal care. In contrast, bowel incontinence was associated with lower informal and combined care costs, and higher formal care costs, suggesting that caregivers provide less care in the presence of bowel incontinence that is offset somewhat by formal care services.

Finally, some of the characteristics that were significant in predicting only informal care costs, or formal care costs are worth mentioning. One characteristic that was only predictive of formal care costs included having a cancer diagnosis where the association with formal cost was negative, suggesting that while diagnosis informs care planning decisions on the provision of formal care, informal caregivers do not alter the care they provide based on this characteristic. Another consideration is the organization of the palliative care system around cancer trajectories, as discussed by study participants in Chapter 4. There were also some characteristics that were associated with formal and combined costs, but not informal costs. These characteristics included prognosis, mode of nutritional intake, use of a ventilator/respirator, and bladder incontinence. The significance of these characteristics in formal and combined cost models indicate that these needs are primarily addressed by formal care and not informal care. In contrast, poorer cognitive performance (Cognitive Performance Scale), and having repetitive health or non-health complaints/concerns were positively and significantly associated with informal and combined care costs, but not formal care costs. These findings suggest that these symptoms are primarily addressed by informal caregivers rather than by formal palliative home care services.

## 7.2 Implications and considerations

### 7.2.1 Identification and access

While palliative care is meant to be initiated early in the course of illness and provided to those with any life-limiting health condition, palliative home care clients in Ontario continue to primarily be individuals with a cancer diagnosis, and individuals with a prognosis of less than six months. To ensure that all individuals who may benefit from palliative home care are able to access these services, greater emphasis on early identification of palliative care needs, as well as identification of individuals with non-cancer diagnoses is required. In Ontario, Quality Standards for palliative care have been developed, including a Quality Statement on the identification and assessment of needs for all individuals with progressive, life-limiting conditions (Health Quality Ontario, 2019). Recommendations made as part of this Quality Standard are vague, however, recommending only that clinicians assess individuals for disease progression, functional decline, pain and other symptoms, and effects on their full range of needs (Health Quality Ontario, 2019). The ambiguity of these recommendations likely reflects the large variation in clinical presentations of palliative care clients/patients, but also indicates that a better understanding of illness trajectories is required, particularly for organ failure and frailty. Indicators corresponding to this Quality Statement also exist and include the proportion of individuals with palliative needs that have documented assessments, the proportion of care providers that have the tools required to identify and assess these needs, as well as the number of days from first palliative care service to death (Health Quality Ontario, 2019). These indicators can be used to monitor progress over time, although stratification of these indicators (e.g., by care setting or diagnostic groups) would improve the actionability of indicator results.

Beyond identification of palliative care needs, some consideration must also be given to how palliative home care clients, or palliative care patients more generally, are conceptualized. Put another way, when or how does an individual with palliative care needs become a palliative client or patient? This question is important to consider as there are practical implications to such labeling. In Ontario's home care system, being a palliative home care client (i.e., a home care client with identified palliative care needs, as it is defined in this dissertation) is not formally recognized. Instead, some palliative home care clients are designated as end of life clients on the basis of factors that can include eligibility criteria, case manager, and client preference, and those clients who are able to attain this designation are awarded greater access to home care services and equipment. Clients with identified palliative care needs who are not designated as end of life clients are still expected to have needs that are distinct from more general, long-stay home care clients, however. Indeed, for clinicians, concerns regarding identification of the need for palliative care can be secondary to concerns on the availability of supports that can deliver care with a palliative approach (Urquhart et al., 2018). As in other care settings, this group of home care clients is only expected to grow in coming years with the increasing emphasis on earlier and broader identification of palliative care needs. Budgetary constraints mean that room for broadening criteria for the end of life designation is likely limited, even if not all clients would require a greater service intensity immediately after qualifying for the end of life designation. Yet having a group of home care clients with distinct needs that is not formally recognized through access to different, if not necessarily more, care also makes identification efforts disingenuous. To put this quandary into policy terms, cost benefits of early identification require these individuals to have early access to palliative care (Scheerens et al., 2020). Defining palliative home care clients as clients with identified palliative care needs, and formally recognizing that these individuals have distinct needs through case management efforts at the client level, and in the resource allocation decision-making process at the health system level offer two ways to help ensure that the identification of palliative care needs is meaningful and beneficial to clients.

Access to palliative home care in Ontario also appears to be dependent on clients' region of residence. Previous research has demonstrated considerable regional variations in Canada with respect to trajectories of decline, long-term care placement, hospitalization, and mortality among persons in home care and long-term care (Hébert et al., 2019), as well as differences in access to, and quality of end of life care (Maddison et al., 2012). There are a few explanations for such variations, which need to be addressed through different approaches. One explanation pertains to distinct challenges in rural and/or northern regions in Ontario. For home care, the greater distances between clients and their health care providers can mean that care providers spend more time on travel and less time on direct client care. Distances between providers and other providers can also make interdisciplinary care, which is particularly important for individuals with complex care needs, difficult to provide (Forbes & Edge, 2009). Beyond distance, the supply of health human resources in these regions tends to be low. These challenges have previously been discussed in the home care setting, and recommendations for addressing these issues have emphasized recruitment and retention efforts; improvements to education, working conditions and organizational support; as well as leveraging and integrating existing resources outside of the home care system (Forbes & Edge, 2009).

Yet differences across LHINs are not limited to the urban/rural divide and at least some differences are likely to exist at the LHIN-level. One such difference may be the practice of allocating funds to health regions on the basis of historical funding, which has previously been identified as a contributor to inequitable home care across regions (Office of the Auditor General of Ontario, 2010). It is unclear whether this practice continues today, or whether (or what) other funding practices that lead to care inequities across LHINs exist. Nevertheless, a closer examination of funding practices is warranted. Different models of care and care practices, including the presence of pilot programs, can also lead to LHIN-based differences. Cross-regional learning opportunities can help to address some differences in access, and may bring improvements to the delivery of palliative home care in Ontario more generally. Other LHIN-level differences may be policy-based, with the most obvious example being the elusive eligibility criteria for the end of life designation. Standardization of these criteria and related policies can help to address differences in access to palliative home care. However, care should be taken not to develop criteria that reinforce existing biases in care. In particular, standardizing the use of the interRAI

PC for assessment across LHINs can help to ensure that client needs are addressed consistently and comprehensively. The use of this instrument has ceased in some LHINs in more recent years, and so efforts to remove barriers to the use of this instrument can contribute to reducing LHIN-based variations in access to palliative home care services. In cases where the interRAI Home Care (HC) assessment is used in place of the PC, there may be a need to include a supplement with some palliative-specific items not included in the assessment. In particular, some items that are in the interRAI PC but not the interRAI HC and are significantly predictive of formal, informal and combined care costs include clients' awareness of prognosis and fatigue.

A final consideration is the merging of LHINs with Ontario Health, which was initially scheduled to occur on April 1, 2020, but was postponed due to the COVID-19 pandemic. While the Ministry of Health has previously stated that this merger will not affect the delivery of home care services, it is conceivable that centralization of funding, planning and coordination functions of the LHINs can influence the provision of palliative home care services either directly through changes to palliative home care policy, or indirectly through changes made to other components of the health system. Centralization may be beneficial to bringing greater consistency to palliative home care across regions in Ontario. However, it may also limit the ability to respond to local needs and preferences that may be unique to small populations or regions, and be biased towards the needs of the majority at the expense of more marginalized groups. Seemingly in contrast, some home care functions that were previously the responsibility of LHINs are meant to be transferred to Ontario Health Teams (of which there are 42 as of May 2021) (Government of Ontario, 2021b). How this transfer will occur is presently unclear but altogether, these changes and their effects on palliative home care services will need to be closely monitored.

### 7.2.2 Service provision and funding

The provision of services can be influenced by the organization of palliative care services, and palliative care experts interviewed as part of this dissertation spoke of how the system is structured around a cancer trajectory. This structure reflects the oncological beginnings of palliative care (Clark, 2007), and corresponds to the predictable cancer trajectory in which death is preceded by a marked period of decline (Lunney et al., 2003). For palliative home care, this well-demarcated period of decline serves as an indicator for enhanced service provision, while the predictable time to death allows LHINs to anticipate costs. In contrast, the structure of the palliative care system is less well suited to the organ failure trajectory with its fluctuating course, and the frailty trajectory where death may be expected but is lingering (Lunney et al., 2003). Indeed, this dissertation found that even when controlling for need characteristics, cancer was significantly associated with lower formal palliative home care costs, suggesting that the system is more efficient at providing care to clients with cancer. The organization of palliative care around the cancer trajectory is not unique to the home setting (Quinn et al., 2021). Improving the fit between the care needs and service provision for those without a cancer diagnosis will require changes across settings. These changes must be predicated on a better understanding of noncancer trajectories, which may emerge as more individuals without cancer diagnoses are provided with palliative care. In the interim, the consistent and comprehensive assessment of palliative home care clients using instruments like the interRAI PC can help case managers to develop care plans that provide clients with services that adequately address their care needs, irrespective of diagnosis.

While client needs are central to care planning, informal caregivers must also be considered as part of the planning process. Informal caregivers provide a substantial amount of care to palliative home care clients alongside the formal care that is provided through the public health care system. Without the care of these informal caregivers, many palliative home care clients would be unable to remain at home (Gomes & Higginson, 2006). As such, it is essential to ensure that caregivers can continue caring for palliative home care clients by supporting the well-being of caregivers. In particular, caregivers experiencing burden or distress may become less effective at providing care, and their capacity to provide care may be reduced (Hirdes et al., 2012). Addressing these negative feelings might be achieved by targeting specific client characteristics that are associated with caregiver distress. Cognitive impairment and high health instability have previously been found to be amongst the strongest determinants of caregiver distress (Hirdes et al., 2012), and so provision of formal palliative home care services that prioritize addressing these client characteristics may be helpful. This dissertation also found that while cognitive impairment and repetitive health and non-health related complaints were associated with higher informal care costs, they were not associated with formal care costs, suggesting that informal caregivers carry the burden of addressing these client needs. Ensuring that informal caregivers are well supported in addressing these client needs can help caregivers to continue in providing care. More generally, caregiver burden or distress must be considered as part of the care planning process that determines the amount of formal care that is provided to palliative home care clients, as well as identifies supports for caregivers like respite care, training, and education. The ability to identify caregivers experiencing or at risk of experiencing burden or distress is therefore crucial. The Caregiver Risk Evaluation Algorithm, which measures caregivers' risk of burden using items in the interRAI PC, can help to identify caregivers who may require support without the need for additional caregiver assessment (Guthrie et al., 2020).

At the system level, quality indicators can also help ensure that the services being provided to palliative home care clients are appropriate and lead to better outcomes for clients and their families, in addition to identifying areas for improvement. The quality indicators for identification and assessment discussed earlier in this chapter represent useful process indicators, but different indicators are required to be able to reflect clients' needs, change trajectories or care outcomes. Psychosocial symptoms and pain, for example, are responsive to change through appropriate intervention and are suitable for measurement and monitoring through quality indicators (Seow, Guthrie, et al., 2021; Seow, Stevens, et al., 2021). Earlier research has shown that palliative care quality indicators can be developed using administrative data and would allow for efficient population-level monitoring (Grunfeld et al., 2006). There is presently also work underway to create and validate a set of standardized indicators for the home setting using items from the interRAI HC (Guthrie et al., 2019; Harman et al., 2019). Efficacy of quality indicators will require health care providers to better understand the function of these indicators, however, and in particular that the purpose of quality indicators is not to direct care at the person-level or monitor the care practices of individual providers (Grunfeld et al., 2008). Thus, engagement and knowledge translation activities are needed in both the development and introduction of these quality indicators (Grunfeld et al., 2008).

Finally, resource planning is central to the provision of palliative home care services, but remains a challenge in Ontario due to the absence of sector-specific information on palliative care costs (Office of the Auditor General of Ontario, 2016). That only a minority of community-dwelling individuals receive palliative home care in their final month of life (Health Quality Ontario, 2019) may indicate a gap between the need for, and availability of palliative home care services in Ontario. Without planning, this gap will continue to grow as the demand for palliative care increases in coming years due to demographic changes, emphasis on the early introduction of palliative care, and the growing scope of palliative care beyond cancer. For palliative home care, this increase in demand will be further compounded by health system efforts to reduce care costs at the end of life, as well as the preference of many individuals to remain at home for as long as possible. Findings from this dissertation can inform on resource planning, including the level resources that will be required in order to meet the growing demands for palliative home care. Some particularly relevant findings include patterns of service utilization that are stratified by service type and based on actual service records, estimates of formal care costs calculated using billing/payment data, as well as the identification of client characteristics that are predictive of palliative home care costs. The predictors of cost, in particular, can allow for planning that takes into consideration the characteristics of the client population through the development of a case-mix classification system for palliative home care. Such a system would allow for more accurate estimates of the supply of services required to meet client demands. Yet such planning is only meaningful if funding mechanisms exist to respond to these plans. Attaching at least some palliative home care funding to any classification system that is developed would help to narrow present and future gaps in the demand for, and supply of palliative home care services.

### 7.2.3 Case-mix development

Findings from this dissertation suggest that the classification of palliative home care clients using a broad array of clinical need indicators to predict resource use is possible with substantial levels of explained variance. Similar characteristics that were predictive of cost were also predictive of high costs, suggesting that these characteristics are appropriate even for those with short prognoses. While predisposing, enabling and need characteristics were identified, emphasis should be on need characteristics since case-mix groups must be clinically meaningful. In addition, although they provide policy-relevant contextual information, reliance on predisposing and enabling characteristics can reinforce structural biases that result in health inequities.

Although there is a risk of reification of systemic biases, gender is being considered in the development of palliative care case-mix systems in Germany (Becker et al., 2018). In England, both gender and age are being considered for potential inclusion into a palliative care case-mix system (Guo et al., 2018), despite concerns about ageism in palliative care that have previously been raised (Gott et al., 2011). Enabling characteristics related to caregivers are also being considered in England (Guo et al., 2018) and are concerning since caregiver characteristics reflect caregivers' availability and capacity to provide informal care. The inclusion of such characteristics into a case-mix system would essentially punish individuals with (greater) access to informal care by limiting access to formal palliative care services. Although it does not appear that indicators of socioeconomic status are being considered in any of the case-mix development work for palliative care, such characteristics would also limit access to publicly-funded, formal palliative home care services to those with the resources to procure private services.

The large number of highly significant need characteristics with substantial effect sizes and variance explanation identified in this dissertation can help any future case-mix development efforts for palliative home care in Ontario to prioritize classification using characteristics that are based on clinical need. However, not all need characteristics are free of concerns. Process measures (e.g., use of respirators or ventilators, or IV medications) can encourage the utilization of devices/technologies/services even in the absence of clinical need in order to obtain greater levels of funding (Costa, Poss, et al., 2015), and so inclusion of these characteristics into case-mix systems should be avoided. Although such characteristics were identified as predictors of costs in this dissertation, a number of other characteristics were identified that will likely be stronger contenders for consideration in the development of a case-mix system for palliative home care.

Based on their significance across models of formal, informal and combined care costs and the high levels of variance explained by these characteristics in bivariate regression, characteristics that might be considered as part of future case-mix development work include function, level of health instability (CHESS), fatigue, and bowel incontinence. Chief amongst these characteristics is function, which was found to have particularly high levels of explained variance for formal, informal and combined care costs. As it is, measures of function like ADLs and IADLs can be found in the classification of long-stay home care clients (Björkgren et al., 2000), and the inclusion of measures of function have been shown to improve the predictive ability and in-group homogeneity in case-mix systems (Hopfe et al., 2016). As such, the inclusion of function into any classification system for palliative home care can be expected, although the measure of function to be used can be discussed. Findings from this dissertation show the PPS and the IADL-ADL Functional Hierarchy Scale perform similarly in explaining formal cost variations, although the latter performs substantially better for informal and combined care costs. The PPS does have the benefit of being a common measure within palliative care settings, while the IADL-ADL Functional Hierarchy is applicable across home and continuing care settings where interRAI assessment instruments are used. The inclusion of both scales could also be considered as this dissertation found the addition of the PPS to contribute to small increases in the explained variances of multivariate models containing the IADL-ADL Functional Hierarchy Scale and a number of other scales and items from the interRAI PC. However, the PPS is not routinely used to assess palliative home care clients in Ontario, which would limit the derivation sample for any case-mix development work, as well as the classification of clients, should a system be developed. From this dissertation, it also appears that not all palliative home care clients may be adequately described by a PPS score based on the scoring criteria across components of the scale and so assignment of such a score may not accurately capture clients' physical status. Further, the potential ambiguity in the assignment of PPS scores to palliative home care clients can leave any case-mix system that may be developed vulnerable to upcoding, which is the practice of miscoding/misclassifying patients in order to increase funding (Steinbusch et al., 2007). The only potential limitation to using the IADL-ADL Functional Hierarchy Scale as the only measure of function might be a marginally lower variance explanation of formal cost, which is a tradeoff that seems trivial compared to the inability to classify one fifth of clients. The upcoding of the IADL-ADL Functional Hierarchy Scale is also less likely given that its classification criteria are far less ambiguous as it is based on a number of clearly operationalized and reliable items in the interRAI PC.

There is another data consideration that should be made regarding information on client characteristics. Case-mix systems must be developed using large samples, and so data on client characteristics that are captured through routine clinical practice are required. The interRAI PC represents a good assessment instrument for capturing such data as it is both comprehensive in the information it collects, and has been widely used in Ontario. More recently, however, some LHINs have shifted away from the use of this instrument, reverting to the interRAI's general assessment instrument for home care (interRAI HC). The primary purpose of this instrument is the assessment of the more general home care population, and so there is less emphasis on the assessment of signs and symptoms commonly experienced by those receiving palliative care. Nevertheless, both the interRAI HC and the interRAI PC have many of the same items in common, and the same scales can be generated using data from both instruments (Hirdes, Ljunggren, et al., 2008). Thus, although the specific characteristics that might be used to classify palliative home care clients are unclear, many of the characteristics that are predictive of costs can be found in the interRAI HC as well.

One argument for using the interRAI HC instrument might be if the case-mix system for palliative home care is appended to the existing case-mix system for long-stay home care clients (the Resource Utilization Groups Version III for home care [RUG-III/HC]). The decision to extend the RUG-III/HC may be appropriate if the primary splits in the classification of palliative home care clients are consistent with the existing classification rules in the RUG-III/HC. It may also be appropriate if case-mix development efforts identify only a small number of classes. However, early identification efforts and the broadening scope of palliative care could lead to even greater variability across palliative home care clients, which would be reflected in the need for a classification system with a greater number of classes. A greater number of classes could suggest that a standalone case-mix system may be more appropriate, although ultimately, such a decision will require some preliminary analyses to identify potential client groups, and consideration of issues like how palliative home clients are identified and defined, the types of services that are considered to be palliative, as well as the preferences of policy makers.

The estimate of cost used for developing a classification system for palliative home care must also be considered. In Australia, development of the AN-SNAP system was modelled on per diem costs estimated over clients' phase of illness (Eagar, Green, & Gordon, 2004), while development of an inpatient palliative care case-mix system in Germany has taken an episodic approach (Becker et al., 2018). Case-mix systems that explain episodic costs are appropriate in settings where the length of stay is shorter and more predictable, but are less appropriate where variations in time on service are great and unpredictable (Björkgren et al., 2000; Costa, Poss, et al., 2015). Use of an episodic cost in palliative home care can be thought of as less appropriate since clients begin service at different points on their illness trajectory, can have vastly different trajectories based on their health conditions, and prognostication remains a challenge for noncancer conditions. Thus, the alternative per diem approach is likely the better approach for palliative home care, and the use of a mean weekly cost in this dissertation is consistent with the existing case-mix system for long-stay home care clients in Ontario (Björkgren et al., 2000; Poss et al., 2008).

Another cost consideration is of the components that should be included. This dissertation included only service-based costs, which is reasonable since home care budgets are largely allocated towards the provision of care services. In addition to informing on resource planning, part of the objective of this study was also to contribute to an understanding of palliative home care service utilization required for case-mix development. For case-mix, emphasis is placed on the capturing of costs that are variable across clients, which are primarily related to service-based costs. While the use of administrative home care data in this dissertation means that estimates of publicly-funded formal care costs can be expected to be fairly accurate, some thought should be given to the inclusion of privately funded in-home services into estimates of costs. Existing work has shown the costs of home-based services incurred by individuals receiving palliative care and their families are substantial at around $2000 (2008 Canadian dollars) per month for the approximately one-fifth of individuals acquiring private home-based care services (Guerriere et al., 2010). It is unclear from Guerriere et al.'s (2010) work what factors contribute to the pursuit of privately-funded, home-based care. Client and/or family preferences could be one contributing factor, although an inadequate supply of care could be another factor. In either case, pursuit of privately-funded, home-based palliative care is limited to those economically able to do so. In what is meant to be a comprehensive, universal publicly-funded health care system in Ontario, these costs should be included to ensure that funding levels correspond with the expected costs of providing care services that adequately address clients' care needs (Martin et al., 2018). The burden of excluding such costs would primarily be carried by those with fewer financial resources. The absence of data on the privately-funded costs of care present a challenge to the inclusion of such costs, although data collection efforts could be undertaken for the purposes of case-mix development. For more routine collection of such information, introduction of a section on privately-funded services and/or other out of pocket costs could be added to the clinical assessment process, much like the social supports section of the interRAI PC instrument.

Another important consideration is on the inclusion of informal care costs. The reliance of palliative home care clients on both formal and informal care to remain at home indicates that the combined formal and informal care cost would be most appropriate. As with the argument on the inclusion of privately-funded, home-based care costs into estimates of formal cost, informal care costs should be included to ensure that the resource needs required to adequately care for palliative home care clients is captured. However, the inclusion of informal care costs does indicate that the valuation of informal care hours should be investigated further because even though it is unlikely to affect index values attached to case-mix groups substantially, they do inform on the funding levels that are attached to the index values (Poss et al., 2008). Further, analyses from the development of the RUG-III/HC show that the inclusion of informal care costs improves the performance of the classification system (Björkgren et al., 2000). Analyses from this dissertation suggest that a similar finding is likely to be the case for the palliative home care setting as models of combined formal and informal care costs had the highest levels of explained variance. Use of half the hourly rate of a personal support worker (PSW) may offer a good starting point as it has been used in previous home care case-mix studies (Björkgren et al., 2000; Cheng et al., 2020; Poss et al., 2008), in addition to its use in this dissertation. Two other potential payment rates were used in this dissertation to estimate the costs of informal and combined palliative home care costs and may warrant consideration. These payment rates include the replacement cost of unpaid work, as well as the opportunity cost of providing informal care. Both estimates of cost from these payment rates are greater than with the half PSW approach, but differences in the share of combined care costs attributable to informal care remain similar irrespective of the method selected. Findings from earlier study of the RUG-III/HC would suggest that a lower valuation of informal care maximizes the variance explanation (Björkgren et al., 2000). Conceptually, valuation using a replacement cost also has greater face validity for informing on resource planning from the public payer perspective. Nevertheless, the three methods appear to offer a reasonable range for the valuation of informal care time, and so sensitivity analyses used to select an appropriate unit cost for informal care time might aim to maximize variance explanation within this range.

For formal costs, analyses from this dissertation on the service utilization patterns of palliative home care clients indicate that service utilization is greater, and the mix of services is different in the first week post-assessment. As such, a five-week post-assessment period over which costs were averaged was selected for this dissertation in order to maximize sample variation and size, and to ensure cost estimates were stable and reflective of clients' weekly service utilization patterns. Even at five weeks, only a very small proportion of clients with expected survival of days and less than six weeks were retained, indicating that prolonging the post-assessment period would likely eliminate the representation of this group of clients from any analytic sample. Estimates of cost in each of the first five weeks of service also show that the mean cost over the five-week period remained greater than the costs in the second through fifth weeks on service due to the higher costs of care in the first post-assessment week. Selection of a shorter post-assessment period would therefore result in a less stable estimate of cost. Based on these findings, a five-week post-assessment period for the estimation of mean weekly formal cost appears appropriate in balancing the tradeoff between sample variation and stability of cost. Nevertheless, further sensitivity analyses may be conducted to investigate how different post-assessment periods (over which costs are averaged out to estimate the mean weekly formal costs) may affect the classification of palliative home care clients.

Finally, some thought might be given to the generalizability of the findings from this dissertation. In Ontario, the function of palliative home care is to help clients remain in their homes for as long as possible, primarily through the provision of nursing and personal support services. Yet the provision of publicly-funded home care services is not limited to private dwellings, and can be provided in residential hospices as well. In this setting, predictors of formal palliative home care costs that are need characteristics are likely to remain relevant since it is also primarily nursing and personal support services that are provided to individuals in residential hospices (Hirdes & Kehyayan, 2014). As residential hospices in Ontario function primarily to provide care at the late stages of the dying trajectory, individuals receiving palliative home care services can be expected to have greater symptomatology, functional dependence and health instability, as well as shorter prognoses. Although individuals with these characteristics represented a small proportion of the study sample used to identify predictors of costs in this dissertation, the present analyses did show that many of the characteristics predictive of formal costs were the same as those characteristics predictive of the likelihood of being a high cost client. The greatest limitation to the relevance of characteristics identified as determinants of palliative home care costs is due to the differences in availability and accessibility of other care services in residential hospices, which can influence utilization of publicly-funded home care services. In particular, findings on informal and combined care costs may be less relevant. While informal care in private dwellings is mostly provided by family and friend caregivers, volunteers play a much greater role in the provision of care to those in residential hospices (Hospice Palliative Care Ontario, 2015) and are not captured as part of the informal care costs estimated in this dissertation. A specific consideration to estimating volunteer care costs that has not been addressed in existing palliative care literature would be the valuation of such care since volunteers may be more experienced than a general family or friend caregiver, but less skilled than a formal care provider. Overall, predictors of palliative home care costs identified in this dissertation may have some relevance to the publicly-funded home care services provided in residential hospice settings, although determining the degree of this relevance would require further examination into how these services are being used in this unique care setting.

Another generalizability consideration includes the applicability of findings in this dissertation to other jurisdictions. Assuming that palliative home care plays a similar role in other jurisdictions, the findings from this dissertation are likely to be relevant to these other jurisdictions as well. Further, for case-mix development, it is the variability rather than the representativeness of the analytic sample that is important. Although not necessarily representative, analytic samples drawn to identify predictors of palliative home care costs in this dissertation captured clients with a wide range of characteristics so that findings are likely to be applicable even where there are differences in the profile of palliative home care clients. This applicability may be particularly relevant as the palliative care system continues to emphasize early initiation of palliative care, and expand its scope beyond those with a cancer diagnosis. However, the evolution of palliative care can also bring changes to the role of palliative home care, which can in turn influence service utilization patterns. Such changes may require questions addressed as part of this dissertation to be revisited.

### 7.2.4 Data and research

Data and research considerations have been discussed throughout this chapter, but nevertheless bear repeating. The ability to provide palliative home care to clients that adequately addresses their many varying and complex needs rests on the ability to identify these needs. The interRAI PC assessment instrument can be used to identify these needs by collecting information on individuals that is both comprehensive and reliable. In addition to identifying client needs, information collected as part of these assessments can be used for research that will inform on and improve the provision of palliative home care services, and should include gaining an understanding of those on noncancer illness trajectories. When linked to home care service provision records, one application would be the development of a palliative home care case-mix system.

Some of the case-mix development considerations discussed in this chapter should be addressed prior to commencing development efforts. These considerations relate primarily to policy and include the need to define palliative home care, including its clients and corresponding services, the future of assessment for palliative home care clients, as well as the appetite for a case-mix system for palliative home care and any preferences for an extension to the existing RUG-III/HC or a standalone system. Addressing these considerations will require considerable engagement with stakeholders at all levels from on-the-ground case managers or care providers to ministry (of health) representatives, in addition to clients/patients and their families.

Research on the identification and examination of structural factors that result in care inequities should also be undertaken. This dissertation identified some factors like gender, region of residence and even diagnosis, but future research might involve further analyses that examine minority and/or marginalized groups in order to understand how characteristics that predict cost may be different or differently associated with costs for these groups. In particular, this dissertation included only individuals who had their palliative care needs identified and had access to palliative home care services. A review of Canadian research identified a number of studies that found age and income to be associated with access to palliative care (Maddison et al., 2011) and may be factors that warrant further investigation. Structural factors should not be used to classify individuals for case-mix and are not the primary influencers of cost based on findings in this dissertation. Nevertheless, case-mix systems can still inadvertently perpetuate inequities if they are developed without adequate awareness and acknowledgement of these factors. As Commissioner Roy J. Romanow indicated in the *Building on Values: The Future of Health Care in*

*Canada* report, health care utilization should be driven by clinical need, while equity of access to and outcomes of health care should be addressed through policy (Government of Canada, 2002). To this end, case-mix systems have a unique role in intersecting clinical and policy considerations.

Other research like sensitivity analyses related to the determination of a costing period or the valuation of informal care cost can be addressed as part of the case-mix development process. In addition, this dissertation did not examine potential interactions between the wide array of client characteristics included as potential predictors of cost because of the large number of potential interactions. Instead, these interactions should be examined using methods like decision tree and random forests analyses as part of the case-mix development process. Importantly, stakeholder engagement and equity considerations must continue throughout this process to ensure that any case-mix system that is developed is relevant and effective.

## 7.3 Conclusions

Palliative home care clients in Ontario identified in this dissertation had high care needs that were reflected by a high intensity of formal services and informal help, resulting in substantial care costs. A large proportion of variance in these costs could be explained using a broad array of clinical measures available in the interRAI PC. Client characteristics that were predictive of palliative home care costs were primarily need characteristics, with function, health instability, fatigue and bowel incontinence being identified as particularly strong predictors of costs. Yet need characteristics were not the only predictors of costs. Costs were also influenced by enabling characteristics like region of residence and caregiver characteristics, and although they should not be used for case-mix classification, they are contextually relevant. The results shown in this dissertation suggest that an improved understanding of resource utilization based on the clinical characteristics of adults in community-based palliative care is possible using information from interRAI PC assessments and the Client Health Related Information System administrative database. This knowledge can be used to inform on the development of a case-mix based payment system for palliative home care that can help to reduce regional and person-level inequities in the provision of palliative home care services. Important challenges remain, however, including the definition of palliative home care clients and associated services, as well as the identification of palliative care needs among noncancer patients. Nevertheless, the present results suggest that future palliative case-mix system efforts have considerable potential to succeed.

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# Appendices

## Appendix A

**Table A.1: Study objectives of reviewed articles**

| Article | Main Objective |
|---|---|
| Allan et al., 2005 | To build on past research in order to better understand temporal changes in use of specialized palliative home care services using administrative data. |
| Bogasky et al., 2014 | To describe hospice users and examine magnitude of resource use during hospice episodes, as well as compare patterns of hospice use based on length of episode of care, and whether they used home-based hospice services only or multiple levels of hospice care. |
| Brick et al., 2017 | To estimate formal and informal costs of care in the last year of life for those in three different regions of Ireland. |
| Cai et al., 2017 | Examine the relationship between palliative care and socioeconomic status. |
| Chai et al., 2013 | To inform on the financial implications of end-of-life to alleviate financial strain associated with home death for patients and caregivers. |
| Chai et al., 2014 | Inform decision-making by practitioners, managers and policy makers with respect to financial and service supports for family caregivers through a full appraisal of the magnitude of unpaid time/caregiving costs. |
| Chan et al., 2001 | To contribute to knowledge on the cost of care for hepatocellular cancer as very little is known about it. |
| Coyle et al., 1999 | To monitor resource use by patients receiving palliative care across care settings as most palliative patients are likely to receive care from more than one setting. |
| Dumont et al., 2009 | To use a prospective approach to answer resource use question from societal perspective. |
| Dumont et al., 2010 | To provide information on variations in palliative care costs (including inpatient, outpatient and informal care) over the last 5 months of life from societal cost. |
| Dumont et al., 2014 | Contribute to research on costs during palliative phase of care and how these costs are shared in rural areas. |
| Dumont et al, 2015 | Inform policy makers to improve or develop financial policies to prevent inequitable cost burdens for vulnerable families as a result of insufficient health care resources. |
| Eagar, Green and Smith, 2004; Eagar, Green and Gordon, 2004 | To develop a case-mix system for palliative care that can be used across care settings. |

| | |
|---|---|
| Fassbender et al., 2005 | To describe development of palliative care services from 1993 to 2000 and measure resulting costs from the development of palliative care programs. |
| Guerriere et al. 2010 | To contribute to knowledge on the cost of palliative care within the context of burden on the family. |
| Guest et al., 2006 | To inform relative effectiveness of different palliative care delivery systems for the commissioning of health care. |
| Haltia et al., 2017 | Understand composition of costs of palliative care clients with cancer. |
| Howell et al., 2011 | To inform on health care planning and resource allocation decisions when gold standard palliative care programs become available. |
| Johnson et al., 2009 | To evaluate a pilot interdisciplinary model of home palliative care that includes examining service utilization and costs to inform others that may be looking to implement integrated palliative home program. |
| Klinger et al., 2013 | Identify an effective and efficient approach to palliative care delivery through the EOL Shared Care Project. |
| Kralik and Anderson, 2008 | To inform debate around concepts and practice of palliative care as more individuals with non-cancer conditions continue to use palliative care. |
| Look Hong et al., 2020 | To determine the incremental resources used or saved for those identified as having palliative care needs early. |
| Masucci et al., 2013 | To improve overall efficiency and equity in the provision of EOL care through improving knowledge of predictors for the separate service categories. |
| McCaffrey et al., 2013 | To evaluate cost, resource use and outcomes for patients enrolled in a home palliative program relative to usual care. |
| Nesrallah et al., 2018 | To inform on quality improvement initiatives being undertaken for those with renal disease by gaining a better understanding of home palliative care for these individuals. |
| Shnoor et al., 2007 | To inform the need to balance community and hospital-based service to reduce hospital-based expenditures. |
| Sun et al., 2017 | To build on past research in order to better understand temporal changes in use of specialized palliative home care services. |
| Yu et al., 2015 | To identify cost-effective and sustainable models of palliative care provision. |

EOL = end of life

**Table A.2: Study sample characteristics of reviewed articles**

| Article | Country | Sample size | % Cancer | % Female | Mean age |
|---|---|---|---|---|---|
| Allan et al., 2005 | Canada | 2,341 | Not stated | 50.9 | N/A |
| Bogasky et al., 2014 | USA | 3,008,137 | 29.7 | 58 | N/A |
| Brick et al., 2017 | Ireland | 214 | 71.3 in Midlands; 74.7 in Mid-West; 83.3 in South East | 50.0 in Midlands; 48.0 in Mid-West; 51.7 in South East | 74.7 in Midlands; 72.8 in Mid-West; 75.4 in South East |
| Cai et al., 2017 | Canada | 181 | 100 | 54.0 | 71.9 |
| Chai et al., 2013 | Canada | 137 caregivers | 100 | 55.0 | 71 |
| Chai et al., 2014 | Canada | 129 | 100 | 55.0 | 71.1 |
| Chan et al., 2001 | Hong Kong | 204 | 100 | 17.0 | 57 |
| Coyle et al., 1999 | England/Wales | 212 | 69 | 60.0 | N/A |
| Dumont et al., 2009 | Canada | 248 | Not stated | 49.6 | 67 |
| Dumont et al., 2010 | Canada | 160 in total. Ranged between 14 and 58 for patients; 13 and 56 for caregivers for the five study sites. | Not stated | 48.0 | 66 urban<br>68 rural |
| Dumont et al., 2014 | Canada | 86 | Not stated | 40.2 | 67.7 |
| Dumont et al, 2015 | Canada | 125 urban<br>80 rural | | | |
| Eagar, Green and Smith, 2004; Eagar, Green and Gordon, 2004 | Australia | 1,868 inpatient episodes; 2,728 ambulatory episodes | Not stated | Not stated | Not stated |
| Fassbender et al., 2005 | Canada | 16,282 | 100 | 48.0 | 68.7 |
| Guerriere et al. 2010 | Canada | 136 | 100 | 55.0 | 71.3 |
| Guest et al., 2006 | United Kingdom | 547 | 100 | Varied by cancer type | Not stated |
| Haltia et al., 2017 | Finland | 70 | 100 | 39.0 | 69 |
| Howell et al., 2011 | Canada | 418 | 100 | 48.0 | 68.6 |

| | | | | | |
|---|---|---|---|---|---|
| Johnson et al., 2009 | Canada | 213 | 100 | 52 | N/A |
| Klinger et al., 2013 | Canada | 95 | 87 | 50.5 | 71 |
| Kralik and Anderson, 2008 | Australia | 180 with cancer<br>42 without cancer | 81 | Not stated | Not stated |
| Look Hong et al., 2020 | Canada | 1,185 | 100 | 45.0 intervention group;<br>45.2 control group | 69.8 intervention group;<br>71.3 control group |
| Masucci et al., 2013 | Canada | 109 | 100 | 53.0 | 71.1 |
| McCaffrey et al., 2013 | Australia | 31 | 81 | 41.9 | 63.6 |
| Nesrallah et al., 2018 | Canada | 9,611 | 27 | 40.6 | N/A |
| Shnoor et al., 2007 | Israel | 146 | 100 | 44.0 | 66 |
| Sun et al., 2017 | Canada | 130 in 2005-2007<br>207 in 2010 to 2012<br>105 in 2014-2015 | 100 | 54.0 | 72 |
| Yu et al., 2015 | Canada | 186 | 100 | 55.0 | 73 |

**Table A.3: Study settings and services included as part of reviewed articles**

| Article | Perspective | Setting(s) | Service(s) |
|---|---|---|---|
| Allan et al., 2005 | Unstated; appears to be public payer | Ambulatory<br>Inpatient<br>Home<br>Long-term care | GP visits per year; specialist visits per year; nights spent in hospital per year; hours of home support received per month; and home nursing care visits received per month. |
| Bogasky et al., 2014 | Unstated; appears to be public payer | Home<br>Inpatient care | Routine home care, Continuous home care, Inpatient respite care, general inpatient care |
| Brick et al., 2017 | Societal | Community<br>Hospital<br>Nursing home | Community services, specialist palliative care, allied health professionals, hospital, nursing home, medication, equipment, informal care. |
| Cai et al., 2017 | N/A – no costing; however, only publicly-paid services included | Home | Physician, nurse, PSW |
| Chai et al., 2013 | Societal | Ambulatory<br>Inpatient<br>Home | Appointments with HCPs, clinic visits, lab/diagnostic tests, treatment, medications, supplies/equipment, ED visits, hospitalizations, nursing home care, hospice care, home nursing, PSWs, OT, PT, oxygen therapy, diagnostic tests, IV medications and tube feeding.<br>Private/third-party payer costs included HCP visits, home caregivers, travel expenses, medications, supplies and equipment, insurance payments.<br>Unpaid caregiving from time lost |
| Chai et al., 2014 | Societal | Ambulatory<br>Inpatient<br>Home | Health professional appointments, clinic visits, laboratory and diagnostic tests, treatment, medications, supplies and equipment, ED visits, hospitalizations, NH, hospice, home nursing, PSW, OT, PT, oxygen therapy, diagnostic tests |
| Chan et al., 2001 | Societal | Inpatient<br>Outpatient<br>Hospice | Short term inpatient care, continuing inpatient care, hospice care, outpatient services (drugs, clinics and diagnostic tests)<br>Chinese/herbal medications, privately obtained supplies, income lost by caregivers and patients. |

| | | | |
|---|---|---|---|
| Coyle et al., 1999 | Not stated; appears to be public payer | Home<br>GP office<br>Hospital<br>Hospice | Home visits by GP, consultant, district nurse, hospice nurse, social worker, meals on wheels, home help, GP office consults, inpatient stay at hospital or hospice, day visit at hospital or hospice, radiotherapy, chemotherapy, surgery, oxygen therapy, transfusion, x-rays, scans |
| Dumont et al., 2009 | Societal | Inpatient hospital<br>ambulatory<br>home care<br>LTC | inpatient, ambulatory, home care, long-term care, transportation, prescription medication, medical equipment, OOP costs, caregiving time costs |
| Dumont et al., 2010 | Societal | Inpatient (including LTC)<br>Outpatient (including home care)<br>Informal care | Inpatient hospitalization, LTC, ambulatory care, home care, medical equipment/aids, OOP costs, transportation costs, prescription medications, caregiving |
| Dumont et al., 2014 | Societal | Hospital<br>LTC<br>Outpatient<br>Home | Inpatient hospital care, ambulatory care, home care, long-term care, transportation, prescription medications, medical equipment/aids, out of pocket costs, informal caregiving time. |
| Dumont et al, 2015 | Not stated; appears to be societal | Hospital<br>LTC<br>Outpatient<br>Home | Costs incurred from hospital, LTC, outpatient care settings, home, medical equipment, travel and caregiving costs |
| Eagar, Green and Smith, 2004; Eagar, Green and Gordon, 2004 | Not stated; appears to be payer | Inpatient<br>Ambulatory | Nursing, PT, Psychosocial, other staff, goods and services, medical/surgical supplies, imaging costs, pathology costs, drug costs, capital costs, medical costs |
| Fassbender et al., 2005 | Payer | Inpatient<br>NH<br>Residential hospice<br>Home care | Acute specialist consultations, community specialist consultations, residential hospice care, palliative home care and tertiary palliative care. |
| Guerriere et al. 2010 | Societal | Home<br>Ambulatory | Hospital admission, radiation, oncology, ED visit, oncologist, CAT/CT scan, physician specialist, other, MRI, blood work, blood |

| | | | |
|---|---|---|---|
| | | Hospitalization<br>Medications<br>Supplies and equipment | transfusion, family physician visit, ultrasound, dentist, x-ray, bone scintigraphy, pre-op clinic, EKG, nurse, PT, home based PSW, nurse, palliative care physician, PT, family physician, dietitian, OT, SW, lab technician, case coordinator, respiratory therapist, privately financed naturopath, chiropodist, dietician, massage therapy, acupuncture, additional PSW, paid housework, nurse, massage therapist, other, home oxygen, lab tech |
| Guest et al., 2006 | Public payer | Outpatient<br>Home<br>Hospital | Prescribed drugs, GP visits, visits to/by a palliative physician, hospital admissions. |
| Haltia et al., 2017 | Not stated; appears to be societal | Inpatient<br>Outpatient<br>Hospice | Hospitals, hospice, home hospital, home hospice, medication, travel, care received at private facilities |
| Howell et al., 2011 | Not stated; appears to be public payer | Home | visiting nurses, PSWs, primary care physicians, OTs, PTs, SWs, lab services and equipment |
| Johnson et al., 2009 | Public payer | Home | Personal support, lab tests, nursing, nutritional counselling, OT, enhanced personal support, enhanced nursing, medical supplies, equipment, drugs, OHIP codes submitted by salaried physicians. |
| Klinger et al., 2013 | Public payer | Home<br>ED<br>Hospital | CCAC: dietitian, homemaking, specialized nursing, OT, PT, SW, SLP<br>Extended Palliative Care Team: Nursing, psycho-spiritual support, bereavement counseling, advanced practice nurse, palliative care physician, case management<br>Physicians: repeat physician visits, hospitalization |
| Kralik and Anderson, 2008 | N/A - no costing; however, only publicly-paid services included | Home palliative care | Consultant and clinical nurses working with local GPs, allied health professionals, regional palliative care services, oncology and radiation specialists. |
| Look Hong et al., 2020 | Public payer | Home<br>Inpatient<br>ED | Inpatient, hospital outpatient clinics, same-day surgery, ED, outpatient cancer centre, physician billings, OHIP, New Drug Funding Program, Ontario drug benefit, home care services, complex continuing care. |

| | | | |
|---|---|---|---|
| Masucci et al., 2013 | N/A - no costing; however, only publicly-paid services included | Home<br>Ambulatory | Home-based nurse visits, home-based PSW visits, home-based physician visits, ambulatory physician visits, other ambulatory and home-based visits. |
| McCaffrey et al., 2013 | Public payer | Home<br>Inpatient<br>Outpatient | Home palliative program costs (staff administration, travel, direct patient contact time, overheads, consumables), specialist palliative care service use, acute hospital and palliative care unit inpatient stays, outpatient visits. |
| Nesrallah et al., 2018 | Not stated; appears to be public payer | Home<br>ED<br>Inpatient<br>Community outpatient | Home care, palliative care clinics, hospice care facilities, inpatient palliative consultative services. |
| Shnoor et al., 2007 | Not stated; appears to be payer (but not necessarily public) | Home hospice<br>Hospital | Medications, lab tests, radiographs/other imaging tests, procedures, respiratory equipment, hospital days in general hospital, visits to ED, surgical procedures, any other treatment where service providers were paid. |
| Sun et al., 2017 | N/A - no costing; however, only publicly-paid services included | Home | Physician, nurse, PSW |
| Yu et al., 2015 | Societal | Hospital<br>LTC<br>Outpatient<br>Home<br>Unpaid caregiver | Public: Medications, supplies, tests, appointments inside the home, appointments outside the home, residential hospices paid publicly, inpatient costs; ED visit costs<br>Private: OOP medications, supplies and appointments in the home, travel costs; Unpaid caregiver time lost from household work, leisure, employment; third party costs for medications, supplies, appointments inside the home and residential hospices |

CAT/CT = computerized tomography; CCAC = Community Care Access Centre; EKG = electrocardiogram; ED = emergency department; GP = general practitioner; HCPs = health care practitioners; LTC = long-term care; N/A = not applicable; NH = nursing home; OOP = out of pocket; OT = occupational therapist; PSW = personal support worker; PT = physiotherapist; SLP = speech language pathologist; SW = social work.

# Appendix B

**Table B.1: Characteristics of palliative home care clients in Ontario with and without personal support services, 2011 to 2017 (n=68,731)**

| Characteristic | Without PSW services n=26,439 % (n) | With PSW services n=42,292 % (n) | $X^2$ (df) | p-value |
|---|---|---|---|---|
| **IADL-ADL Functional Hierarchy*** | | | 10,437 (7) | <0.0001 |
| 0 | 12.7 (3,266) | 2.6 (1,055) | | |
| 1-2 | 26.4 (6,816) | 12.2 (4,920) | | |
| 3-4 | 30.0 (7,730) | 17.2 (6,922) | | |
| 5 | 9.7 (2,487) | 10.2 (4,107) | | |
| 6-7 | 8.9 (2,281) | 16.1 (6,488) | | |
| 8 | 5.0 (1,296) | 14.3 (5,738) | | |
| 9-10 | 6.3 (1,627) | 21.8 (8,771) | | |
| 11 | 1.1 (281) | 5.4 (2,188) | | |
| **CHESS*** | | | 3,233.9 (2) | <0.0001 |
| 0 | 7.4 (1,893) | 2.0 (779) | | |
| 1-2 | 38.3 (9,865) | 23.6 (9,445) | | |
| ≥3 | 54.3 (13,992) | 74.5 (29,797) | | |
| **PPS*** | | | 5,115.3 (3) | <0.0001 |
| 0 | 0.1 (12) | 0.1 (47) | | |
| 10-40 | 11.8 (2,516) | 35.3 (12,023) | | |
| 50-70 | 78.1 (16,679) | 62.9 (21,436) | | |
| 80-100 | 10.0 (2,143) | 1.6 (557) | | |
| **Estimated survival** | | | 2,372.7 (3) | <0.0001 |
| Days | 1.3 (334) | 2.4 (1,008) | | |
| <6 weeks | 4.8 (1,279) | 10.3 (4,355) | | |
| ≥6 weeks but <6 months | 43.7 (11,564) | 54.8 (23,166) | | |
| ≥6 months | 50.2 (13,262) | 32.5 (13,736) | | |

*Sum of n does not equal to 68,731 due to missing data.

ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; PPS = Palliative Performance Scale

**Table B.2: Characteristics of palliative home care clients in Ontario with and without service interruptions (method one), 2011 to 2017 (n=68,731)**

| Characteristic | Without interruptions n=41,282 % (n) | With interruptions n=27,449 % (n) | $X^2$ (df) | p-value |
|---|---|---|---|---|
| **IADL-ADL Functional Hierarchy*** | | | 10,607.8 (7) | <0.0001 |
| 0 | 2.7 (1,034) | 12.1 (3,287) | | |
| 1-2 | 11.3 (4,388) | 27.1 (7,348) | | |
| 3-4 | 17.9 (6,961) | 28.4 (7,691) | | |
| 5 | 10.1 (3,944) | 9.8 (2,650) | | |
| 6-7 | 15.5 (6,037) | 10.1 (2,732) | | |
| 8 | 13.7 (5,333) | 6.3 (1,701) | | |
| 9-10 | 22.9 (8,899) | 5.5 (1,499) | | |
| 11 | 5.9 (2,281) | 0.7 (188) | | |
| **CHESS*** | | | 4,816.2 (2) | <0.0001 |
| 0 | 1.9 (722) | 7.2 (1,950) | | |
| 1-2 | 21.1 (8,172) | 41.1 (11,138) | | |
| ≥3 | 77.0 (29,786) | 51.7 (14,003) | | |
| **PPS*** | | | 6,280.2 (3) | <0.0001 |
| 0 | 0.1 (44) | 0.1 (15) | | |
| 10-40 | 38.1 (12,594) | 8.7 (1,945) | | |
| 50-70 | 60.1 (19,868) | 81.6 (18,247) | | |
| 80-100 | 1.7 (550) | 9.6 (2,150) | | |
| **Estimated survival** | | | 7,027.4 (3) | <0.0001 |
| Days | 3.2 (1,317) | 0.1 (25) | | |
| <6 weeks | 12.4 (5,130) | 1.8 (504) | | |
| ≥6 weeks but <6 months | 55.3 (22,825) | 43.4 (11,905) | | |
| ≥6 months | 29.1 (12,010) | 54.7 (15,015) | | |

* Sum of n does not equal to 68,731 due to missing data.

ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; PPS = Palliative Performance Scale

**Table B.3: Characteristics of palliative home care clients in Ontario with and without service interruptions (method two), 2011 to 2017 (n=68,731)**

| Characteristic | Without interruptions n=43,452 % (n) | With interruptions n=25,279 % (n) | $X^2$ (df) | p-value |
|---|---|---|---|---|
| **IADL-ADL Functional Hierarchy*** | | | 8,442.1 (7) | <0.0001 |
| 0 | 3.6 (1,462) | 11.5 (2,859) | | |
| 1-2 | 12.3 (5,033) | 26.9 (6,703) | | |
| 3-4 | 18.5 (7,583) | 28.3 (7,069) | | |
| 5 | 10.0 (4,107) | 10.0 (2,487) | | |
| 6-7 | 15.0 (6,168) | 10.4 (2,601) | | |
| 8 | 13.2 (5,409) | 6.5 (1,625) | | |
| 9-10 | 21.9 (8,962) | 5.8 (1,436) | | |
| 11 | 5.6 (2,292) | 0.7 (2,292) | | |
| **CHESS*** | | | 3,587.7 (2) | <0.0001 |
| 0 | 2.5 (1,013) | 6.7 (1,659) | | |
| 1-2 | 22.4 (9,158) | 40.7 (10,152) | | |
| ≥3 | 75.1 (30,648) | 52.7 (13,141) | | |
| **PPS*** | | | 5,718.5 (3) | <0.0001 |
| 0 | 0.1 (45) | 0.1 (14) | | |
| 10-40 | 36.5 (12,689) | 9.0 (1,850) | | |
| 50-70 | 60.9 (21,174) | 82.0 (16,941) | | |
| 80-100 | 2.5 (850) | 9.0 (1,850) | | |
| **Estimated survival** | | | 5,259.4 (3) | <0.0001 |
| Days | 3.0 (1,319) | 0.1 (23) | | |
| <6 weeks | 11.9 (5,161) | 1.9 (473) | | |
| ≥6 weeks but <6 months | 54.4 (23,643) | 43.9 (11,087) | | |
| ≥6 months | 30.7 (13,329) | 54.2 (13,696) | | |

* Sum of n does not equal to 68,731 due to missing data.

ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; PPS = Palliative Performance Scale

**Table B.4: Characteristics of palliative home care clients in Ontario with and without service interruptions (method three), 2011 to 2017 (n=68,731)**

| Characteristic | Without interruptions n=62,143 % (n) | With interruptions n=6,589 % (n) | $X^2$ (df) | p-value |
|---|---|---|---|---|
| **IADL-ADL Functional Hierarchy*** | | | 551.2 (7) | <0.0001 |
| 0 | 6.9 (4,122) | 3.1 (199) | | |
| 1-2 | 17.9 (10,667) | 16.6 (1,069) | | |
| 3-4 | 22.6 (13,421) | 19.1 (1,231) | | |
| 5 | 9.8 (5,812) | 12.1 (782) | | |
| 6-7 | 12.7 (7,555) | 18.8 (1,214) | | |
| 8 | 10.2 (6,085) | 14.7 (949) | | |
| 9-10 | 16.0 (9,509) | 13.8 (889) | | |
| 11 | 3.9 (2,341) | 2.0 (128) | | |
| **CHESS*** | | | 29.8 (2) | <0.0001 |
| 0 | 4.2 (2,490) | 2.8 (182) | | |
| 1-2 | 29.3 (17,350) | 30.4 (1,960) | | |
| ≥3 | 66.6 (39,474) | 66.8 (4,315) | | |
| **PPS*** | | | 264.3 (3) | <0.0001 |
| 0 | 0.1 (54) | 0.1 (5) | | |
| 10-40 | 26.9 (13,427) | 20.4 (1,112) | | |
| 50-70 | 67.8 (33,880) | 77.7 (4,235) | | |
| 80-100 | 5.2 (2,601) | 1.8 (99) | | |
| **Estimated survival** | | | 414.9 (3) | <0.0001 |
| Days | 2.2 (1,334) | 0.1 (8) | | |
| <6 weeks | 8.7 (5,423) | 3.2 (211) | | |
| ≥6 weeks but <6 months | 50.4 (31,347) | 51.3 (3,383) | | |
| ≥6 months | 38.7 (24,038) | 45.3 (2,987) | | |

* Sum of n does not equal to 68,731 due to missing data.

ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; PPS = Palliative Performance Scale

# Appendix C

**One-on-one interview guide**

1. Tell me a bit about your current role in palliative care and what types of patients you typically see?
2. How do palliative home care clients differ from regular home care? What are the differences in the care that is provided between the two types of clients?
3. If you were to describe a client with high care needs, what characteristics would you use to describe them?
    a. Other than the [type of characteristics] you have suggested, are there any [demographic, clinical, informal support] characteristics that you can think of to describe these clients?
4. If you were to describe a client with low care needs, what characteristics would you use to describe them?
    a. Other than the [type of characteristics] you have suggested, are there any [demographic, clinical, informal support] characteristics that you can think of to describe these clients?
5. Are there any combinations of characteristics that you see that appear to work together to make clients have higher needs?
6. Aside from client characteristics, what other factors impact the amount of care that a client receives?
    a. Are there any guidelines establishing service level or service limits? Where do these guidelines come from?
    b. Are there any practical considerations for determining the amount of care a client receives such as service provider availability?

# Appendix D

**Table D.1: Palliative Performance Scale**

| % | Ambulation | Activity and Evidence of Disease | Self-Care | Intake | Conscious Level |
|---|---|---|---|---|---|
| 100 | Full | Normal Activity<br>No Evidence of Disease | Full | Normal | Full |
| 90 | Full | Normal Activity<br>Some Evidence of Disease | Full | Normal | Full |
| 80 | Full | Normal Activity with Effort<br>Some Evidence of Disease | Full | Normal or Reduced | Full |
| 70 | Reduced | Unable Normal Job/Work<br>Some Evidence of Disease | Full | Normal or Reduced | Full |
| 60 | Reduced | Unable Hobby/Housework<br>Significant Disease | Occasional Assistance Necessary | Normal or Reduced | Full or Confusion |
| 50 | Mainly Sit/Lie | Unable to Do Any Work<br>Extensive Disease | Considerable Assistance Required | Normal or Reduced | Full or Confusion |
| 40 | Mainly in Bed | As Above | Mainly Assistance | Normal or Reduced | Full or Drowsy or Confusion |
| 30 | Totally Bed Bound | As Above | Total Care | Reduced | Full or Drowsy or Confusion |
| 20 | As Above | As Above | Total Care | Minimal Sips | Full or Drowsy or Confusion |
| 10 | As Above | As Above | Total Care | Mouth Care Only | Drowsy or Coma |
| 0 | Death | - | - | - | - |

Source: Anderson et al., 1996

**Table D.2: Multivariate model of log mean weekly formal palliative home care cost in the first five weeks of service post-assessment for palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score using interRAI scales and items, 2011 to 2017 (n=38,160)**

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Intercept | 4.22 (0.03) | <0.0001 |
| Gender (ref=male) | 0.05 (0.008) | <0.0001 |
| Awareness of prognosis (ref=no) | 0.02 (0.009) | 0.01 |
| LHIN of residence (ref=Hamilton Niagara Haldimand Brant) | | |
| Central East | -0.02 (0.02) | 0.19 |
| Central | -0.25 (0.02) | <0.0001 |
| Champlain | -0.32 (0.02) | <0.0001 |
| Central West | -0.01 (0.03) | 0.67 |
| Erie St. Clair | -0.11 (0.02) | <0.0001 |
| Mississauga Halton | 0.08 (0.02) | 0.0004 |
| North East | -0.03 (0.02) | 0.05 |
| North Simcoe Muskoka | -0.21 (0.03) | <0.0001 |
| North West | -0.01 (0.03) | 0.71 |
| South East | -0.04 (0.03) | 0.19 |
| South West | -0.07 (0.02) | 0.002 |
| Toronto Central | -0.1 (0.03) | 0.005 |
| Waterloo Wellington | -0.06 (0.02) | 0.0002 |
| Informal helpers | 0.03 (0.01) | 0.0006 |
| Living arrangement (ref=with others) | 0.13 (0.02) | <0.0001 |
| Live-in caregiver (ref=no) | -0.12 (0.02) | <0.0001 |
| Primary caregiver relationship to client (ref=spouse) | | |
| Child/child-in-law | 0.04 (0.01) | <0.0001 |
| Friend/neighbour | 0.12 (0.02) | <0.0001 |
| Other family | 0.07 (0.02) | <0.0001 |
| End of life home care client type (ref=no) | 0.14 (0.01) | <0.0001 |
| Prognosis (ref=6 months or longer) | | |
| Death imminent (within days) | 0.16 (0.09) | 0.09 |
| <6 weeks | 0.18 (0.03) | <0.0001 |
| ≥6 weeks, <6 months | -0.005 (0.01) | 0.67 |
| IADL-ADL Functional Hierarchy Scale | 0.12 (0.002) | <0.0001 |
| CHESS | 0.11 (0.005) | <0.0001 |
| Ate ≤1 meal on at least 2 of last 3 days (ref=no) | 0.03 (0.01) | 0.01 |
| Mode of nutritional intake (ref=normal) | | |
| Modified independent | 0.01 (0.01) | 0.28 |
| Requires diet modification to swallow solid food | 0.08 (0.02) | <0.0001 |
| Requires modification to swallow liquids | 0.08 (0.05) | 0.07 |
| Can swallow only puréed solids | 0.16 (0.04) | 0.0002 |
| Combined oral and parenteral or tube feeding | 0.29 (0.05) | <0.0001 |

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Nasogastric tube feeding only | 0.28 (0.11) | 0.009 |
| Abdominal feeding only | 0.36 (0.03) | <0.0001 |
| Parenteral feeding only | 0.52 (0.09) | <0.0001 |
| Activity did not occur | 0.08 (0.14) | 0.55 |
| Dyspnea (ref=absence of symptoms) | | |
| Absent at rest, but present when performed moderate activities | -0.11 (0.01) | <0.0001 |
| Absent at rest, but present when performed normal day-to-day activities | -0.09 (0.01) | <0.0001 |
| Present at rest | -0.06 (0.01) | <0.0001 |
| Fatigue (ref=none) | | |
| Minimal | 0.02 (0.02) | 0.26 |
| Moderate | 0.09 (0.01) | <0.0001 |
| Severe | 0.14 (0.02) | <0.0001 |
| Unable to commence any normal day-to-day activities | 0.16 (0.02) | <0.0001 |
| Pain scale | 0.05 (0.004) | <0.0001 |
| IV medication (ref=not ordered and did not occur) | | |
| Ordered, not implemented | -0.02 (0.004) | <0.0001 |
| 1-2 of last 3 days | 0.06 (0.03) | 0.03 |
| Daily in last 3 days | 0.46 (0.03) | <0.0001 |
| Did not occur, declined offered treatment | -0.12 (0.18) | 0.51 |
| Ventilator or respirator | | |
| Ordered, not implemented | -0.11 (0.13) | 0.43 |
| 1-2 of last 3 days | -0.21 (0.22) | 0.34 |
| Daily in last 3 days | 0.34 (0.06) | <0.0001 |
| Did not occur, declined offered treatment | 0.19 (0.20) | 0.35 |
| Cancer (ref=no) | -0.06 (0.01) | <0.0001 |
| Informal helper(s) unable to continue in caring activities (ref=no) | 0.10 (0.01) | <0.0001 |
| CaRE | 0.04 (0.007) | <0.0001 |
| Family or close friends report feeling overwhelmed by person's illness (ref=no) | 0.12 (0.01) | <0.0001 |
| Vomiting (ref=no) | 0.04 (0.01) | 0.0004 |
| Diarrhea (ref=no) | -0.03 (0.01) | 0.01 |
| Bladder continence (ref=continent) | | |
| Complete control with any catheter or ostomy over last 3 days | 0.24 (0.02) | <0.0001 |
| Infrequently incontinent | 0.04 (0.02) | 0.03 |
| Occasionally incontinent | 0.10 (0.02) | <0.0001 |
| Frequently incontinent | 0.10 (0.02) | <0.0001 |
| Incontinent | 0.14 (0.03) | <0.0001 |
| Did not occur | 0.008 (0.10) | 0.93 |
| Bowel continence (ref=continent) | | |
| Complete control with ostomy | 0.12 (0.02) | <0.0001 |

| **Parameter** | **Estimate (standard error)** | **p-value** |
|---|---|---|
| Infrequently incontinent | 0.05 (0.02) | 0.03 |
| Occasionally incontinent | 0.14 (0.02) | <0.0001 |
| Frequently incontinent | 0.19 (0.03) | <0.0001 |
| Incontinent | 0.20 (0.03) | <0.0001 |
| Did not occur | 0.19 (0.08) | 0.01 |

Degrees of freedom = 77; F statistic = 301.0; p-value <0.0001; $R^2$ = 37.8%

ADL = activities of daily living; CaRE = Caregiver Risk Evaluation; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

**Table D.3: Multivariate model of log mean weekly formal care cost in the first five weeks of service post-assessment of palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score using interRAI PC scales and items, and the PPS, by gender, 2011 to 2017 (n=18,707 males; n=19,453 females)**

| | Male | | Female | |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| Intercept | 5.46 (0.07) | <0.0001 | 5.54 (0.07) | <0.0001 |
| Awareness of prognosis (ref=no) | 0.005 (0.01) | 0.68 | 0.03 (0.01) | 0.007 |
| LHIN of residence (ref=Hamilton Niagara Haldimand Brant) | | | | |
| Central East | -0.01 (0.02) | 0.67 | -0.01 (0.02) | 0.52 |
| Central | -0.23 (0.02) | <0.0001 | -0.21 (0.02) | <0.0001 |
| Champlain | -0.30 (0.02) | <0.0001 | -0.27 (0.02) | <0.0001 |
| Central West | -0.005 (0.04) | 0.89 | -0.02 (0.03) | 0.63 |
| Erie St. Clair | -0.11 (0.03) | <0.0001 | -0.07 (0.03) | 0.006 |
| Mississauga Halton | 0.08 (0.03) | 0.02 | 0.09 (0.03) | 0.004 |
| North East | 0.02 (0.02) | 0.31 | 0.005 (0.02) | 0.94 |
| North Simcoe Muskoka | -0.22 (0.04) | <0.0001 | -0.17 (0.04) | <0.0001 |
| North West | 0.01 (0.03) | 0.80 | 0.08 (0.04) | 0.09 |
| South East | -0.05 (0.04) | 0.26 | -0.02 (0.05) | 0.05 |
| South West | -0.07 (0.03) | 0.02 | -0.05 (0.03) | 0.11 |
| Toronto Central | -0.16 (0.05) | 0.001 | -0.09 (0.05) | 0.05 |
| Waterloo Wellington | -0.04 (0.02) | 0.06 | 0.04 (0.02) | 0.07 |
| Informal helpers | 0.04 (0.01) | 0.001 | 0.01 (0.01) | 0.37 |
| Living arrangement (ref=with others) | 0.13 (0.03) | <0.0001 | 0.12 (0.02) | <0.0001 |
| Live-in caregiver (ref=no) | -0.11 (0.03) | 0.0004 | -0.12 (0.02) | <0.0001 |
| Primary caregiver relationship to client (ref=spouse) | | | | |
| Child/child-in-law | 0.04 (0.01) | 0.02 | 0.04 (0.01) | 0.008 |
| Friend/neighbour | 0.11 (0.03) | 0.00009 | 0.11 (0.03) | 0.0007 |
| Other family | 0.04 (0.02) | 0.03 | 0.08 (0.02) | 0.0001 |
| Informal helper(s) unable to continue in caring activities (ref=no) | 0.07 (0.02) | 0.0007 | 0.10 (0.02) | <0.0001 |
| CaRE | 0.03 (0.01) | 0.001 | 0.05 (0.009) | <0.0001 |

| | Male | | Female | |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| Family or close friends report feeling overwhelmed by person's illness (ref=no) | 0.10 (0.01) | <0.0001 | 0.11 (0.01) | <0.0001 |
| End of life home care client type (ref=no) | 0.11 (0.01) | <0.0001 | 0.12 (0.02) | <0.0001 |
| Prognosis (ref=6 months or longer) | | | | |
| Death imminent (within days) | -0.10 (0.13) | 0.45 | 0.28 (0.14) | 0.05 |
| <6 weeks | 0.11 (0.04) | 0.003 | 0.13 (0.04) | 0.0003 |
| ≥6 weeks, <6 months | -0.02 (0.02) | 0.13 | -0.02 (0.01) | 0.24 |
| IADL-ADL Functional Hierarchy Scale | 0.09 (0.003) | <0.0001 | 0.09 (0.003) | <0.0001 |
| CHESS | 0.09 (0.007) | <0.0001 | 0.08 (0.007) | <0.0001 |
| Mode of nutritional intake (ref=normal) | | | | |
| Modified independent | 0.009 (0.02) | 0.64 | -0.004 (0.02) | 0.83 |
| Requires diet modification to swallow solid food | 0.10 (0.02) | <0.0001 | 0.05 (0.02) | 0.06 |
| Requires modification to swallow liquids | 0.16 (0.06) | 0.01 | 0.03 (0.06) | 0.70 |
| Can swallow only puréed solids | 0.19 (0.06) | 0.001 | 0.13 (0.06) | 0.04 |
| Combined oral and parenteral or tube feeding | 0.31 (0.06) | 0.001 | 0.30 (0.08) | 0.0001 |
| Nasogastric tube feeding only | 0.32 (0.14) | 0.03 | 0.37 (0.16) | 0.02 |
| Abdominal feeding only | 0.42 (0.04) | <0.0001 | 0.33 (0.05) | <0.0001 |
| Parenteral feeding only | 0.62 (0.14) | <0.0001 | 0.50 (0.11) | <0.0001 |
| Activity did not occur | -0.07 (0.20) | 0.74 | 0.09 (0.19) | 0.61 |
| Dyspnea (ref=absence of symptoms) | | | | |
| Absent at rest, but present when performed moderate activities | -0.12 (0.02) | <0.0001 | -0.10 (0.02) | <0.0001 |
| Absent at rest, but present when performed normal day-to-day activities | -0.12 (0.02) | <0.0001 | -0.09 (0.02) | <0.0001 |
| Present at rest | -0.09 (0.02) | <0.0001 | -0.05 (0.02) | 0.008 |
| Fatigue (ref=none) | | | | |
| Minimal | 0.05 (0.02) | 0.01 | 0.04 (0.02) | 0.11 |
| Moderate | 0.07 (0.02) | 0.0005 | 0.08 (0.02) | 0.0001 |
| Severe | 0.09 (0.02) | <0.0001 | 0.10 (0.02) | <0.0001 |
| Unable to commence any normal day-to-day activities | 0.07 (0.03) | 0.02 | 0.10 (0.03) | 0.0009 |

|  | **Male** |  | **Female** |  |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| Pain scale | 0.04 (0.004) | <0.0001 | 0.04 (0.005) | <0.0001 |
| IV medication (ref=not ordered and did not occur) |  |  |  |  |
| Ordered, not implemented | -0.04 (0.05) | 0.43 | -0.02 (0.004) | <0.0001 |
| 1-2 of last 3 days | 0.09 (0.04) | 0.01 | 0.04 (0.04) | 0.26 |
| Daily in last 3 days | 0.46 (0.04) | <0.001 | 0.44 (0.04) | <0.0001 |
| Did not occur, declined offered treatment | -0.31 (0.25) | 0.20 | 0.05 (0.26) | 0.85 |
| Ventilator or respirator |  |  |  |  |
| Ordered, not implemented | 0.10 (0.20) | 0.62 | -0.30 (0.17) | 0.08 |
| 1-2 of last 3 days | 0.09 (029) | 0.75 | -0.26 (0.34) | 0.44 |
| Daily in last 3 days | 0.28 (0.08) | 0.0005 | 0.38 (0.11) | 0.0004 |
| Did not occur, declined offered treatment | 0.09 (0.28) | 0.73 | 0.11 (0.29) | 0.70 |
| Cancer (ref=no) | -0.03 (0.02) | 0.08 | -0.03 (0.02) | 0.08 |
| Vomiting (ref=no) | 0.03 (0.02) | 0.05 | 0.04 (0.02) | 0.005 |
| Expressions of unrealistic fears (ref=no) | 0.03 (0.03) | 0.31 | 0.05 (0.03) | 0.07 |
| Bladder continence (ref=continent) |  |  |  |  |
| Complete control with any catheter or ostomy over last 3 days | 0.18 (0.02) | <0.0001 | 0.28 (0.03) | <0.0001 |
| Infrequently incontinent | 0.06 (0.03) | 0.04 | 0.01 (0.02) | 0.61 |
| Occasionally incontinent | 0.14 (0.03) | <0.0001 | 0.05 (0.02) | 0.02 |
| Did not occur, declined offered treatment | -0.31 (0.25) | 0.20 | 0.05 (0.26) | 0.85 |
| Bowel continence (ref=continent) |  |  |  |  |
| Complete control with ostomy | 0.10 (0.03) | 0.0006 | 0.15 (0.03) | <0.0001 |
| Infrequently incontinent | 0.03 (0.03) | 0.45 | 0.05 (0.03) | 0.10 |
| Occasionally incontinent | 0.13 (0.03) | <0.0001 | 0.09 (0.03) | 0.003 |
| Frequently incontinent | 0.17 (0.04) | 0.006 | 0.12 (0.04) | 0.003 |
| Incontinent | 0.12 (0.04) | 0.006 | 0.11 (0.05) | 0.02 |
| Did not occur | 0.24 (0.12) | 0.05 | 0.10 (0.09) | 0.30 |
| PPS | -0.02 (0.0007) | <0.0001 | -0.02 (0.0007) | <0.0001 |

Males: degrees of freedom = 70; F statistic = 169.42; p-value <0.0001; $R^2$ = 38.9%
Females: degrees of freedom = 70; F statistic = 189.5; p-value <0.0001; $R^2$ = 40.6%

ADL = activities of daily living; CaRE = Caregiver Risk Evaluation; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

# Appendix E

**Table E.1: Multivariate model of log mean weekly informal care cost in the first five weeks of service post-assessment of palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score using interRAI PC scales and items, 2011 to 2017 (n=36,736)**

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Intercept | 4.83 (0.04) | <0.0001 |
| Age | -0.002 (0.0003) | 0.0001 |
| Marital Status (ref=married) | | |
| Never married | -0.09 (0.02) | <0.0001 |
| Partner/Significant other | -0.05 (0.02) | 0.02 |
| Widowed | -0.02 (0.01) | 0.19 |
| Separated | -0.11 (0.03) | <0.0001 |
| Divorced | -0.12 (0.02) | <0.0001 |
| Awareness of prognosis (ref=no) | 0.06 (0.008) | <0.0001 |
| Accepting of situation (ref=no) | 0.04 (0.009) | <0.0001 |
| LHIN of residence (ref=Hamilton Niagara Haldimand Brant) | | |
| Central East | 0.11 (0.01) | <0.0001 |
| Central | -0.14 (0.01) | <0.0001 |
| Champlain | 0.05 (0.01) | <0.0001 |
| Central West | 0.09 (0.02) | <0.0001 |
| Erie St. Clair | -0.09 (0.02) | <0.0001 |
| Mississauga Halton | 0.14 (0.02) | <0.0001 |
| North East | 0.16 (0.01) | <0.0001 |
| North Simcoe Muskoka | -0.06 (0.02) | 0.007 |
| North West | -0.51 (0.03) | <0.0001 |
| South East | 0.23 (0.03) | <0.0001 |
| South West | -0.08 (0.02) | <0.0001 |
| Toronto Central | -0.09 (0.03) | 0.003 |
| Waterloo Wellington | -0.11 (0.01) | <0.0001 |
| Informal helpers | 0.06 (0.009) | <0.0001 |
| Living arrangement (ref=with others) | -0.06 (0.02) | 0.0007 |
| Live-in caregiver (ref=no) | 0.33 (0.02) | <0.0001 |
| Primary caregiver relationship to client (ref=spouse) | | |
| Child/child-in-law | 0.01 (0.01) | 0.39 |
| Friend/neighbour | -0.12 (0.02) | <0.0001 |
| None | -0.41 (0.15) | 0.008 |
| Other family | -0.03 (0.02) | 0.18 |
| End of life home care client type (ref=no) | 0.04 (0.01) | 0.0001 |
| Informal helper(s) unable to continue in caring activities (ref=no) | -0.04 (0.01) | 0.005 |

| **Parameter** | **Estimate (standard error)** | **p-value** |
|---|---|---|
| Family or close friends report feeling overwhelmed by person's illness (ref=no) | 0.10 (0.009) | <0.0001 |
| Prognosis (ref=6 months or longer) | | |
| Death imminent (within days) | -0.05 (0.08) | 0.55 |
| <6 weeks | 0.06 (0.02) | 0.007 |
| ≤6 weeks, >6 months | -0.006 (0.009) | 0.56 |
| IADL-ADL Functional Hierarchy Scale | 0.13 (0.002) | <0.0001 |
| CHESS | 0.05 (0.004) | <0.0001 |
| CPS | 0.04 (0.004) | <0.0001 |
| Dyspnea (ref=absence of symptoms) | | |
| Absent at rest, but present when performed moderate activities | -0.04 (0.01) | 0.0002 |
| Absent at rest, but present when performed normal day-to-day activities | -0.07 (0.01) | <0.0001 |
| Present at rest | -0.07 (0.01) | <0.0001 |
| Fatigue (ref=none) | | |
| Minimal | -0.007 (0.01) | 0.63 |
| Moderate | 0.07 (0.01) | <0.0001 |
| Severe | 0.15 (0.01) | <0.0001 |
| Unable to commence any normal day-to-day activities | 0.25 (0.02) | <0.0001 |
| Pain scale | 0.02 (0.003) | <0.0001 |
| IV medication (ref=not ordered and did not occur) | | |
| Ordered, not implemented | 0.03 (0.03) | 0.24 |
| 1-2 of last 3 days | 0.10 (0.02) | <0.0001 |
| Daily in last 3 days | 0.07 (0.02) | 0.002 |
| Did not occur, declined offered treatment | 0.13 (0.13) | 0.31 |
| Nausea (ref=no) | 0.03 (0.008) | 0.0007 |
| Acid reflux (ref=no) | 0.07 (0.009) | <0.0001 |
| Expressions of unrealistic fears (ref=no) | 0.08 (0.02) | 0.0001 |
| Repetitive health complaints (ref=no) | 0.05 (0.02) | 0.009 |
| Repetitive non-health related complaints/concerns (ref=no) | 0.05 (0.01) | 0.0008 |
| Bowel continence (ref=continent) | | |
| Complete control with ostomy | -0.00008 (0.02) | 0.997 |
| Infrequently incontinent | -0.007 (0.02) | 0.70 |
| Occasionally incontinent | 0.04 (0.02) | 0.05 |
| Frequently incontinent | -0.03 (0.03) | 0.19 |
| Incontinent | -0.12 (0.02) | <0.0001 |
| Did not occur | 0.01 (0.07) | 0.86 |
| Fluctuating state of consciousness (ref=no) | -0.04 (0.02) | 0.03 |

Degrees of freedom = 61; F statistic = 424.5; p-value <0.0001; $R^2$ = 41.4%

ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

**Table E.2: Multivariate model of log mean weekly informal care cost in the first five weeks of service post-assessment of palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score using interRAI PC scales and items, and the PPS, by gender, 2011 to 2017 (n=18,058 males; n=18,728 females)**

| | Male | | Female | |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| Intercept | 5.51 (0.07) | <0.0001 | 5.55 (0.07) | <0.0001 |
| Age | -0.0009 (0.0005) | 0.05 | -0.003 (0.0005) | <0.0001 |
| Marital Status (ref=married) | | | | |
| Never married | -0.07 (0.03) | 0.04 | -0.09 (0.03) | 0.002 |
| Partner/Significant other | -0.02 (0.03) | 0.45 | -0.07 (0.03) | 0.01 |
| Widowed | -0.05 (0.02) | 0.02 | 0.004 (0.02) | 0.84 |
| Separated | -0.17 (0.04) | <0.0001 | -0.06 (0.03) | 0.08 |
| Divorced | -0.16 (0.03) | <0.0001 | -0.09 (0.02) | 0.0001 |
| Awareness of prognosis (ref=no) | 0.06 (0.01) | <0.0001 | 0.05 (0.01) | <0.0001 |
| Accepting of situation (ref=no) | 0.04 (0.01) | 0.005 | 0.04 (0.01) | 0.003 |
| LHIN of residence (ref=Hamilton Niagara Haldimand Brant) | | | | |
| Central East | 0.12 (0.02) | <0.0001 | 0.11 (0.02) | <0.0001 |
| Central | -0.14 (0.02) | <0.0001 | -0.12 (0.02) | <0.0001 |
| Champlain | 0.07 (0.02) | 0.0001 | 0.08 (0.02) | <0.0001 |
| Central West | 0.15 (0.03) | <0.0001 | 0.04 (0.03) | 0.23 |
| Erie St. Clair | -0.10 (0.02) | <0.0001 | -0.07 (0.02) | 0.003 |
| Mississauga Halton | 0.14 (0.03) | <0.0001 | 0.14 (0.03) | <0.0001 |
| North East | 0.16 (0.02) | <0.0001 | 0.22 (0.02) | <0.0001 |
| North Simcoe Muskoka | -0.07 (0.03) | 0.04 | -0.05 (0.03) | 0.15 |
| North West | -0.50 (0.04) | <0.0001 | -0.47 (0.04) | <0.0001 |
| South East | 0.25 (0.04) | <0.0001 | 0.21 (0.04) | <0.0001 |
| South West | -0.06 (0.03) | 0.02 | -0.08 (0.03) | 0.004 |
| Toronto Central | -0.19 (0.04) | <0.0001 | -0.03 (0.04) | 0.52 |
| Waterloo Wellington | -0.09 (0.02) | <0.0001 | -0.07 (0.02) | 0.0009 |
| Informal helpers | 0.04 (0.01) | <0.0001 | 0.07 (0.01) | <0.0001 |

| | **Male** | | **Female** | |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| Living arrangement (ref=with others) | -0.07 (0.03) | 0.009 | -0.05 (0.02) | 0.01 |
| Live-in caregiver (ref=no) | 0.34 (0.03) | <0.0001 | 0.33 (0.02) | <0.0001 |
| Primary caregiver relationship to client (ref=spouse) | | | | |
| Child/child-in-law | 0.01 (0.02) | 0.51 | 0.0002 (0.02) | 0.99 |
| Friend/neighbour | -0.10 (0.03) | 0.003 | -0.15 (0.03) | <0.0001 |
| None | -0.52 (0.21) | 0.01 | -0.32 (0.23) | 0.16 |
| Other family | -0.07 (0.03) | 0.02 | -0.005 (0.03) | 0.85 |
| Informal helper(s) unable to continue in caring activities (ref=no) | -0.03 (0.02) | 0.06 | -0.05 (0.02) | 0.005 |
| Family or close friends report feeling overwhelmed by person's illness (ref=no) | 0.07 (0.01) | <0.0001 | 0.12 (0.01) | <0.0001 |
| End of life home care client type (ref=no) | 0.02 (0.01) | 0.07 | 0.02 (0.01) | 0.10 |
| IADL-ADL Functional Hierarchy Scale | 0.11 (0.003) | <0.0001 | 0.11 (0.003) | <0.0001 |
| CHESS | 0.03 (0.005) | <0.0001 | 0.04 (0.005) | <0.0001 |
| CPS | 0.04 (0.005) | <0.0001 | 0.04 (0.005) | <0.0001 |
| Ate ≤1 meal on at least 2 of last 3 days (ref=no) | -0.04 (0.01) | 0.005 | -0.008 (0.01) | 0.54 |
| Dyspnea (ref=absence of symptoms) | | | | |
| Absent at rest, but present when performed moderate activities | -0.04 (0.01) | 0.003 | -0.03 (0.01) | 0.03 |
| Absent at rest, but present when performed normal day-to-day activities | -0.07 (0.01) | <0.0001 | -0.08 (0.02) | <0.0001 |
| Present at rest | -0.06 (0.02) | 0.0004 | -0.08 (0.02) | <0.0001 |
| Fatigue (ref=none) | | | | |
| Minimal | 0.005 (0.02) | 0.80 | 0.01 (0.02) | 0.49 |
| Moderate | 0.07 (0.02) | 0.0002 | 0.06 (0.02) | 0.002 |
| Severe | 0.13 (0.02) | <0.0001 | 0.13 (0.02) | <0.0001 |
| Unable to commence any normal day-to-day activities | 0.21 (0.03) | <0.0001 | 0.23 (0.03) | <0.0001 |
| Pain scale | 0.01 (0.004) | 0.004 | 0.02 (0.005) | 0.01 |
| IV medication (ref=not ordered and did not occur) | | | | |
| Ordered, not implemented | 0.04 (0.04) | 0.33 | 0.03 (0.04) | 0.47 |
| 1-2 of last 3 days | 0.09 (0.03) | 0.004 | 0.12 (0.03) | 0.0003 |

| | Male | | Female | |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| Daily in last 3 days | 0.08 (0.03) | 0.009 | 0.05 (0.03) | 0.11 |
| Did not occur, declined offered treatment | 0.007 (0.20) | 0.97 | 0.19 (0.17) | 0.27 |
| Nausea (ref=no) | 0.02 (0.01) | 0.07 | 0.03 (0.01) | 0.004 |
| Acid reflux (ref=no) | 0.09 (0.01) | <0.0001 | 0.06 (0.01) | <0.0001 |
| Expressions of unrealistic fears (ref=no) | 0.08 (0.03) | 0.006 | 0.08 (0.03) | 0.005 |
| Repetitive health complaints (ref=no) | 0.09 (0.03) | 0.0003 | 0.01 (0.02) | 0.64 |
| Repetitive non-health related complaints/concerns (ref=no) | 0.04 (0.02) | 0.05 | 0.06 (0.02) | 0.007 |
| Bowel continence (ref=continent) | | | | |
| Complete control with ostomy | -0.005 (0.02) | 0.83 | -0.004 (0.03) | 0.88 |
| Infrequently incontinent | -0.01 (0.03) | 0.71 | -0.01 (0.03) | 0.62 |
| Occasionally incontinent | 0.03 (0.03) | 0.20 | 0.01 (0.02) | 0.68 |
| Frequently incontinent | -0.07 (0.04) | 0.07 | -0.04 (0.04) | 0.23 |
| Incontinent | -0.14 (0.03) | <0.0001 | -0.22 (0.03) | <0.0001 |
| Did not occur | 0.15 (0.10) | 0.13 | -0.12 (0.09) | 0.18 |
| Fluctuating state of consciousness (ref=no) | -0.008 (0.03) | 0.78 | -0.09 (0.03) | 0.002 |
| PPS | -0.009 (0.0006) | <0.0001 | -0.009 (0.0006) | <0.0001 |

Males: degrees of freedom = 60; F statistic = 215.6; p-value <0.0001; $R^2$ = 41.8%

Females: degrees of freedom = 60; F statistic = 230.1; p-value <0.0001; $R^2$ = 42.5%

ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

**Table E.3: Multivariate model of log combined mean weekly formal and informal costs in the first five weeks of service post-assessment for palliative home care clients in Ontario on service for ≥5 weeks of service and with a PPS score using interRAI PC scales and items, 2011 to 2017 (n=38,160)**

| Parameter | Estimate (standard error) | p-value |
|---|---|---|
| Intercept | 5.26 (0.03) | <0.0001 |
| Age | -0.0008 (0.0003) | 0.005 |
| Marital Status (ref=married) | | |
| Never married | -0.07 (0.02) | 0.0001 |
| Partner/Significant other | -0.04 (0.02) | 0.01 |
| Widowed | -0.002 (0.01) | 0.85 |
| Separated | -0.07 (0.02) | 0.0007 |
| Divorced | -0.08 (0.02) | <0.0001 |
| Awareness of prognosis (ref=no) | 0.04 (0.007) | <0.0001 |
| Accepting of situation (ref=no) | 0.02 (0.007) | <0.0001 |
| LHIN of residence (ref=Hamilton Niagara Haldimand Brant) | | |
| Central East | 0.03 (0.01) | 0.02 |
| Central | -0.20 (0.01) | <0.0001 |
| Champlain | -0.09 (0.01) | <0.0001 |
| Central West | 0.04 (0.02) | 0.07 |
| Erie St. Clair | -0.11 (0.01) | <0.0001 |
| Mississauga Halton | 0.12 (0.02) | <0.0001 |
| North East | 0.07 (0.01) | <0.0001 |
| North Simcoe Muskoka | -0.13 (0.02) | <0.0001 |
| North West | -0.28 (0.02) | <0.0001 |
| South East | 0.14 (0.03) | <0.0001 |
| South West | -0.09 (0.02) | <0.0001 |
| Toronto Central | -0.04 (0.03) | 0.10 |
| Waterloo Wellington | -0.13 (0.01) | <0.0001 |
| Informal helpers | 0.06 (0.007) | <0.0001 |
| Live-in caregiver (ref=no) | 0.18 (0.009) | <0.0001 |
| Primary caregiver relationship to client (ref=spouse) | | |
| Child/child-in-law | 0.02 (0.01) | 0.05 |
| Friend/neighbour | -0.02 (0.02) | 0.25 |
| None | -0.58 (0.04) | <0.0001 |
| Other family | 0.01 (0.02) | 0.39 |
| End of life home care client type (ref=no) | 0.08 (0.008) | <0.0001 |
| Prognosis (ref=6 months or longer) | | |
| Death imminent (within days) | 0.01 (0.07) | 0.85 |
| <6 weeks | 0.09 (0.02) | <0.0001 |
| ≤6 weeks, >6 months | -0.01 (0.008) | 0.12 |
| IADL-ADL Functional Hierarchy Scale | 0.14 (0.001) | <0.0001 |
| CHESS | 0.08 (0.004) | <0.0001 |
| CPS | 0.02 (0.003) | <0.0001 |

| **Parameter** | **Estimate (standard error)** | **p-value** |
|---|---|---|
| Mode of nutritional intake (ref=normal) | | |
| Modified independent | 0.01 (0.01) | 0.18 |
| Requires diet modification to swallow solid food | 0.03 (0.01) | 0.01 |
| Requires modification to swallow liquids | -0.03 (0.03) | 0.45 |
| Can swallow only puréed solids | 0.02 (0.03) | 0.61 |
| Combined oral and parenteral or tube feeding | 0.10 (0.04) | 0.006 |
| Nasogastric tube feeding only | 0.06 (0.08) | 0.44 |
| Abdominal feeding only | 0.13 (0.02) | <0.0001 |
| Parenteral feeding only | 0.21 (0.07) | 0.002 |
| Activity did not occur | -0.005 (0.10) | 0.97 |
| Dyspnea (ref=absence of symptoms) | | |
| Absent at rest, but present when performed moderate activities | -0.08 (0.009) | <0.0001 |
| Absent at rest, but present when performed normal day-to-day activities | -0.10 (0.009) | <0.0001 |
| Present at rest | -0.09 (0.01) | <0.0001 |
| Fatigue (ref=none) | | |
| Minimal | 0.01 (0.01) | 0.22 |
| Moderate | 0.11 (0.01) | <0.0001 |
| Severe | 0.18 (0.01) | <0.0001 |
| Unable to commence any normal day-to-day activities | 0.26 (0.02) | <0.0001 |
| Pain scale | 0.04 (0.003) | <0.0001 |
| IV medication (ref=not ordered and did not occur) | | |
| Ordered, not implemented | 0.009 (0.02) | 0.71 |
| 1-2 of last 3 days | 0.09 (0.02) | <0.0001 |
| Daily in last 3 days | 0.24 (0.02) | <0.0001 |
| Did not occur, declined offered treatment | -0.25 (0.14) | 0.07 |
| Ventilator or respirator | | |
| Ordered, not implemented | 0.05 (0.10) | 0.62 |
| 1-2 of last 3 days | -0.05 (0.17) | 0.79 |
| Daily in last 3 days | 0.19 (0.05) | <0.0001 |
| Did not occur, declined offered treatment | 0.32 (0.15) | 0.04 |
| Cancer (ref=no) | -0.04 (0.009) | <0.0001 |
| Primary informal helper expresses feelings of distress, anger or depression (ref=no) | 0.02 (0.01) | 0.04 |
| Family or close friends report feeling overwhelmed by person's illness (ref=no) | 0.11 (0.009) | <0.0001 |
| Nausea (ref=no) | 0.02 (0.008) | 0.02 |
| Vomiting (ref=no) | 0.03 (0.01) | 0.005 |
| Acid reflux (ref=no) | 0.03 (0.007) | <0.0001 |
| Expressions of unrealistic fears (ref=no) | 0.08 (0.02) | <0.0001 |
| Repetitive non-health related complaints/concerns (ref=no) | 0.04 (0.01) | 0.0002 |
| Bladder continence (ref=continent) | | |

| **Parameter** | **Estimate (standard error)** | **p-value** |
|---|---|---|
| Complete control with any catheter or ostomy over last 3 days | 0.08 (0.01) | <0.0001 |
| Infrequently incontinent | 0.02 (0.01) | 0.14 |
| Occasionally incontinent | 0.05 (0.01) | 0.0002 |
| Frequently incontinent | 0.05 (0.01) | 0.0004 |
| Incontinent | 0.04 (0.02) | 0.10 |
| Did not occur | 0.03 (0.07) | 0.65 |
| Bowel continence (ref=continent) | | |
| Complete control with ostomy | 0.03 (0.02) | 0.04 |
| Infrequently incontinent | 0.006 (0.02) | 0.73 |
| Occasionally incontinent | 0.07 (0.02) | <0.0001 |
| Frequently incontinent | 0.04 (0.02) | 0.07 |
| Incontinent | -0.01 (0.02) | 0.47 |
| Did not occur | 0.07 (0.06) | 0.21 |

Degrees of freedom = 79; F statistic = 519.0; p-value <0.0001; $R^2$ = 51.7%
ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

**Table E.4: Multivariate model of log mean weekly combined formal and informal care cost in the first five weeks of service post-assessment of palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score using interRAI PC scales and items, and the PPS, by gender, 2011 to 2017 (n=18,839 males; n=19,574 females)**

| | Male | | Female | |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| Intercept | 6.14 (0.06) | <0.0001 | 6.28 (0.06) | <0.0001 |
| Age | -0.0002 (0.0004) | 0.65 | -0.002 (0.0004) | <0.0001 |
| Marital Status (ref=married) | | | | |
| Never married | -0.10 (0.02) | <0.0001 | -0.06 (0.02) | 0.002 |
| Partner/Significant other | -0.02 (0.02) | 0.39 | -0.06 (0.03) | 0.01 |
| Widowed | -0.004 (0.02) | 0.80 | 0.01 (0.01) | 0.25 |
| Separated | -0.14 (0.03) | <0.0001 | -0.04 (0.03) | 0.11 |
| Divorced | -0.10 (0.02) | <0.0001 | -0.06 (0.02) | 0.0002 |
| Awareness of prognosis (ref=no) | 0.04 (0.01) | <0.0001 | 0.04 (0.01) | <0.0001 |
| Accepting of situation (ref=no) | 0.02 (0.01) | 0.15 | 0.02 (0.01) | 0.05 |
| LHIN of residence (ref=Hamilton Niagara Haldimand Brant) | | | | |
| Central East | 0.04 (0.02) | 0.02 | 0.03 (0.02) | 0.08 |
| Central | -0.18 (0.02) | <0.0001 | -0.16 (0.02) | <0.0001 |
| Champlain | -0.07 (0.02) | <0.0001 | -0.05 (0.02) | 0.001 |
| Central West | 0.07 (0.03) | 0.009 | -0.001 (0.03) | 0.97 |
| Erie St. Clair | -0.11 (0.02) | <0.0001 | -0.09 (0.02) | <0.0001 |
| Mississauga Halton | 0.13 (0.02) | <0.0001 | 0.11 (0.02) | <0.0001 |
| North East | 0.10 (0.02) | <0.0001 | 0.14 (0.02) | <0.0001 |
| North Simcoe Muskoka | -0.14 (0.03) | <0.0001 | -0.09 (0.03) | 0.001 |
| North West | -0.26 (0.03) | <0.0001 | -0.20 (0.03) | <0.0001 |
| South East | 0.17 (0.03) | <0.0001 | 0.13 (0.04) | 0.0003 |
| South West | -0.08 (0.02) | 0.0004 | -0.07 (0.02) | 0.002 |
| Toronto Central | -0.12 (0.04) | 0.0008 | -0.01 (0.04) | 0.70 |
| Waterloo Wellington | -0.10 (0.02) | <0.0001 | -0.05 (0.02) | 0.01 |
| Informal helpers | 0.07 (0.009) | <0.0001 | 0.10 (0.01) | <0.0001 |
| Live-in caregiver (ref=no) | 0.21 (0.01) | <0.0001 | 0.18 (0.01) | <0.0001 |

|  | Male |  | Female |  |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| Primary informal helper expresses feelings of distress, anger or depression (ref=no) | 0.008 (0.01) | 0.51 | 0.03 (0.01) | 0.02 |
| Family or close friends report feeling overwhelmed by person's illness (ref=no) | 0.09 (0.01) | <0.0001 | 0.11 (0.01) | <0.0001 |
| End of life home care client type (ref=no) | 0.05 (0.01) | <0.0001 | 0.06 (0.01) | <0.0001 |
| Prognosis (ref=6 months or longer) |  |  |  |  |
| Death imminent (within days) | -0.17 (0.09) | 0.08 | 0.07 (0.10) | 0.48 |
| <6 weeks | 0.02 (0.03) | 0.36 | 0.05 (0.03) | 0.06 |
| ≤6 weeks, >6 months | -0.03 (0.01) | 0.002 | -0.18 (0.01) | 0.12 |
| IADL-ADL Functional Hierarchy Scale | 0.11 (0.002) | <0.0001 | 0.11 (0.002) | <0.0001 |
| CHESS | 0.06 (0.005) | <0.0001 | 0.07 (0.005) | <0.0001 |
| CPS | 0.03 (0.004) | <0.0001 | 0.02 (0.005) | 0.0001 |
| Mode of nutritional intake (ref=normal) |  |  |  |  |
| Modified independent | 0.007 (0.01) | 0.62 | -0.0007 (0.01) | 0.96 |
| Requires diet modification to swallow solid food | 0.03 (0.02) | 0.07 | 0.03 (0.02) | 0.17 |
| Requires modification to swallow liquids | 0.04 (0.05) | 0.43 | -0.09 (0.05) | 0.07 |
| Can swallow only puréed solids | 0.05 (0.04) | 0.30 | -0.03 (0.05) | 0.58 |
| Combined oral and parenteral or tube feeding | 0.10 (0.04) | 0.02 | 0.15 (0.06) | 0.01 |
| Nasogastric tube feeding only | 0.18 (0.11) | 0.08 | 0.009 (0.12) | 0.94 |
| Abdominal feeding only | 0.17 (0.03) | <0.0001 | 0.12 (0.04) | 0.004 |
| Parenteral feeding only | 0.39 (0.10) | 0.0002 | 0.11 (0.09) | 0.18 |
| Activity did not occur | -0.05 (0.15) | 0.75 | -0.08 (0.14) | 0.58 |
| Dyspnea (ref=absence of symptoms) |  |  |  |  |
| Absent at rest, but present when performed moderate activities | -0.07 (0.01) | <0.0001 | -0.07 (0.01) | <0.0001 |
| Absent at rest, but present when performed normal day-to-day activities | -0.10 (0.01) | <0.0001 | -0.10 (0.01) | <0.0001 |
| Present at rest | -0.09 (0.02) | <0.0001 | -0.10 (0.02) | <0.0001 |
| Fatigue (ref=none) |  |  |  |  |
| Minimal | 0.03 (0.02) | 0.03 | 0.04 (0.02) | 0.01 |

| | Male | | Female | |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| Moderate | 0.09 (0.02) | <0.0001 | 0.11 (0.02) | <0.0001 |
| Severe | 0.13 (0.02) | <0.0001 | 0.16 (0.02) | <0.0001 |
| Unable to commence any normal day-to-day activities | 0.17 (0.02) | <0.0001 | 0.22 (0.02) | <0.0001 |
| Pain scale | 0.03 (0.004) | <0.0001 | 0.03 (0.004) | <0.0001 |
| IV medication (ref=not ordered and did not occur) | | | | |
| Ordered, not implemented | -0.02 (0.04) | 0.60 | 0.02 (0.03) | 0.60 |
| 1-2 of last 3 days | 0.09 (0.03) | 0.001 | 0.10 (0.03) | 0.0003 |
| Daily in last 3 days | 0.24 (0.03) | <0.0001 | 0.22 (0.03) | <0.0001 |
| Did not occur, declined offered treatment | -0.51 (0.18) | 0.005 | 0.01 (0.20) | 0.96 |
| Ventilator or respirator | | | | |
| Ordered, not implemented | 0.11 (0.15) | 0.46 | -0.03 (0.13) | 0.82 |
| 1-2 of last 3 days | -0.01 (0.21) | 0.96 | 0.27 (0.26) | 0.30 |
| Daily in last 3 days | 0.20 (0.06) | 0.0008 | 0.16 (0.08) | 0.05 |
| Did not occur, declined offered treatment | 0.31 (0.21) | 0.13 | 0.17 (0.22) | 0.45 |
| Vomiting (ref=no) | 0.03 (0.01) | 0.02 | 0.03 (0.01) | 0.01 |
| Acid reflux (ref=no) | 0.04 (0.01) | <0.0001 | 0.02 (0.01) | 0.02 |
| Expressions of unrealistic fears (ref=no) | 0.08 (0.02) | 0.001 | 0.08 (0.02) | 0.0003 |
| Repetitive non-health related complaints/concerns (ref=no) | 0.05 (0.02) | 0.004 | 0.04 (0.02) | 0.02 |
| Bladder continence (ref=continent) | | | | |
| Complete control with any catheter or ostomy over last 3 days | 0.04 (0.02) | 0.02 | 0.07 (0.03) | 0.005 |
| Infrequently incontinent | 0.03 (0.02) | 0.26 | -0.002 (0.02) | 0.90 |
| Occasionally incontinent | 0.07 (0.02) | 0.002 | 0.01 (0.02) | 0.42 |
| Frequently incontinent | 0.03 (0.02) | 0.26 | 0.03 (0.02) | 0.14 |
| Incontinent | 0.02 (0.03) | 0.49 | -0.02 (0.03) | 0.61 |
| Did not occur | 0.007 (0.10) | 0.94 | -0.005 (0.11) | 0.97 |
| Bowel continence (ref=continent) | | | | |
| Complete control with ostomy | 0.02 (0.02) | 0.25 | 0.03 (0.02) | 0.13 |
| Infrequently incontinent | 0.003 (0.02) | 0.89 | 0.007 (0.02) | 0.75 |
| Occasionally incontinent | 0.06 (0.02) | 0.009 | 0.05 (0.02) | 0.03 |

| | Male | | Female | |
|---|---|---|---|---|
| **Parameter** | **Estimate (standard error)** | **p-value** | **Estimate (standard error)** | **p-value** |
| Frequently incontinent | 0.01 (0.03) | 0.72 | 0.02 (0.03) | 0.44 |
| Incontinent | -0.07 (0.03) | 0.04 | -0.09 (0.03) | 0.009 |
| Did not occur | 0.17 (0.09) | 0.06 | -0.05 (0.07) | 0.51 |
| PPS | -0.01 (0.0005) | <0.0001 | -0.01 (0.0005) | <0.0001 |

Males: degrees of freedom = 74; F statistic = 284.6; p-value <0.0001; $R^2$ = 52.9%

Females: degrees of freedom = 74; F statistic = 308.8; p-value <0.0001; $R^2$ = 54.0%

ADL = activities of daily living; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale

# Appendix F

**Table F.1: Comparison of multivariate models of log mean weekly formal, informal and combined costs in the first five weeks of service post-assessment for palliative home care clients in Ontario on service for ≥5 weeks and with a PPS score using the interRAI PC scales and items, and the PPS, 2011 to 2017 (n=36,736 to 38,160)**

| Parameter | Combined model n= 38,160 | Formal model n= 38,160 | Informal model n= 36,736 |
|---|---|---|---|
| Age | - | NS | - |
| Gender (ref=male) | NS | + | NS |
| Marital Status (ref=married) | | NS | |
| Never married | - | | - |
| Partner/Significant other | - | | - |
| Widowed | NS | | - |
| Separated | - | | - |
| Divorced | - | | - |
| Awareness of prognosis (ref=no) | + | + | + |
| Accepting of situation (ref=no) | + | NS | + |
| LHIN of residence (ref=Hamilton Niagara Haldimand Brant) | | | |
| Central East | + | NS | + |
| Central | - | - | - |
| Champlain | - | - | + |
| Central West | NS | NS | + |
| Erie St. Clair | - | - | - |
| Mississauga Halton | + | + | + |
| North East | + | NS | + |
| North Simcoe Muskoka | - | - | - |
| North West | - | NS | - |
| South East | + | - | + |
| South West | - | - | - |
| Toronto Central | - | - | - |
| Waterloo Wellington | - | NS | - |
| Informal helpers | + | + | + |
| Living arrangement (ref=alone) | NS | + | - |
| Live-in caregiver (ref=no) | + | - | + |
| Primary caregiver relationship to client (ref=spouse) | NS | | |
| Child/child-in-law | | + | NS |

| **Parameter** | **Combined model n= 38,160** | **Formal model n= 38,160** | **Informal model n= 36,736** |
|---|---|---|---|
| Friend/neighbour | | + | - |
| None | | N/A | - |
| Other family | | + | NS |
| Informal helper(s) unable to continue in caring activities (ref=no) | NS | + | - |
| CaRE | N/A | + | N/A |
| Primary informal helper expresses feelings of distress, anger or depression (ref=no) | + | N/A | NS |
| Family or close friends report feeling overwhelmed by person's illness (ref=no) | + | + | + |
| End of life home care client type (ref=no) | + | + | + |
| Prognosis (ref=6 months or longer) | | | NS |
| Death imminent (within days) | NS | NS | |
| <6 weeks | + | + | |
| ≤6 weeks, >6 months | - | NS | |
| IADL-ADL Functional Hierarchy Scale | + | + | + |
| CHESS | + | + | + |
| CPS | + | NS | + |
| Ate ≤1 meal on at least 2 of last 3 days (ref=no) | NS | NS | - |
| Fluid intake <1,000 cc per day | NS | NS | NS |
| Mode of nutritional intake (ref=normal) | | | NS |
| Modified independent | NS | NS | |
| Requires diet modification to swallow solid food | + | + | |
| Requires modification to swallow liquids | NS | + | |
| Can swallow only puréed solids | NS | + | |
| Combined oral and parenteral or tube feeding | + | + | |
| Nasogastric tube feeding only | NS | + | |
| Abdominal feeding only | + | + | |
| Parenteral feeding only | + | + | |
| Activity did not occur | NS | NS | |
| Dyspnea (ref=absence of symptoms) | | | |
| Absent at rest, but present when performed moderate activities | - | - | - |
| Absent at rest, but present when performed normal day-to-day activities | - | - | - |
| Present at rest | - | - | - |
| Fatigue (ref=none) | | | |
| Minimal | + | + | NS |

| **Parameter** | **Combined model n= 38,160** | **Formal model n= 38,160** | **Informal model n= 36,736** |
|---|---|---|---|
| Moderate | + | + | + |
| Severe | + | + | + |
| Unable to commence any normal day-to-day activities | + | + | + |
| Pain scale | + | + | + |
| IV medication (ref=not ordered and did not occur) | | | |
| Ordered, not implemented | NS | NS | NS |
| 1-2 of last 3 days | + | + | + |
| Daily in last 3 days | + | + | + |
| Did not occur, declined offered treatment | NS | NS | NS |
| Ventilator or respirator | | | NS |
| Ordered, not implemented | NS | NS | |
| 1-2 of last 3 days | NS | NS | |
| Daily in last 3 days | + | + | |
| Did not occur, declined offered treatment | NS | NS | |
| Cancer (ref=no) | NS | - | NS |
| DRS | NS | NS | NS |
| Vomiting (ref=no) | + | + | NS |
| Acid reflux (ref=no) | + | NS | + |
| Nausea (ref=no) | NS | NS | + |
| Bloating (ref=no) | NS | NS | NS |
| Constipation (ref=no) | NS | NS | NS |
| Diarrhea (ref=no) | NS | NS | NS |
| Fecal impaction (ref=no) | NS | NS | NS |
| Expressions of unrealistic fears (ref=no) | + | + | + |
| Repetitive health complaints (ref=no) | + | NS | + |
| Repetitive non-health related complaints/concerns (ref=no) | + | NS | + |
| Bladder continence (ref=continent) | | | NS |
| Complete control with any catheter or ostomy over last 3 days | + | + | |
| Infrequently incontinent | NS | NS | |
| Occasionally incontinent | + | + | |
| Frequently incontinent | + | + | |
| Incontinent | NS | + | |
| Did not occur | NS | NS | |
| Bowel continence (ref=continent) | | | |
| Complete control with ostomy | NS | + | NS |
| Infrequently incontinent | NS | + | NS |

| **Parameter** | **Combined model n= 38,160** | **Formal model n= 38,160** | **Informal model n= 36,736** |
|---|---|---|---|
| Occasionally incontinent | + | + | NS |
| Frequently incontinent | NS | + | - |
| Incontinent | - | + | - |
| Did not occur | NS | + | NS |
| Fluctuating state of consciousness (ref=no) | NS | NS | - |
| Acute change in mental status (ref=no) | NS | NS | NS |
| PPS | - | - | - |

N/A = not applicable; NS = not significant; '-' = significant negative association; '+' = significant positive association

ADL = activities of daily living; CaRE = Caregiver Risk Evaluation; CHESS = Changes in Health, End-stage Disease, Signs, and Symptom; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale; IADL = instrumental activities of daily living; IV = intravenous; LHIN = Local Health Integration Network; PPS = Palliative Performance Scale