# Variations in Prescribing of Subcutaneous End-of-Life Symptom Management Medications Among Home Care Recipients

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A thesis submitted to the School of Epidemiology and Public Health in conformity with the requirements for the degree of Master of Science

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## PREFACE

Deena Fremont was the primary author of all content included in this thesis. This thesis is based on the project proposal approved by the School of Epidemiology and Public Health at the University of Ottawa in June of 2023. The study design was made in collaboration with Dr. Colleen Webber, Dr. James Downar, Dr. Hsien Seow, and Dr. Peter Tanuseputro. Deena was responsible for developing the project proposal, conducting the literature review, writing the dataset creation plan, performing the analysis using SAS software, interpreting the results, and writing this manuscript-based thesis. Deena's supervisor, Dr. James Downar, and members of her Thesis Advisory Committee, Dr. Colleen Webber and Dr. Hsien Seow, provided feedback throughout the entire project timeline.

This project has been approved and submitted to the primary office at ICES uOttawa (TRIM = 0901 401 000). We obtained study data from de-identified and linked health administrative databases housed at ICES. In 2018, the institute formerly known as the Institute for Clinical Evaluative Sciences formally adopted the initialism ICES as its official name. This change acknowledges the growth and evolution of the organization's research since its inception in 1992, while retaining the familiarity of the former acronym within the scientific community and beyond. ICES is an independent, nonprofit research institute funded by an annual grant from the Ontario Ministry of Health (MOH) and the Ministry of Long-Term Care (MLTC). The opinions, results and conclusions reported in this thesis are those of the authors and are independent from the funding sources. No endorsement by ICES, the MOH or MLTC is intended or should be inferred. As a prescribed entity under Ontario's privacy legislation, ICES is authorized to collect and use health care data for the purposes of health system analysis, evaluation, and decision support. Secure access to these data is governed by policies

and procedures that are approved by the Information and Privacy Commissioner of Ontario. The data sets from this study are held securely in coded form at ICES. Although legal data sharing agreements between ICES and data providers (e.g., health care organizations and government) prohibit ICES from making the data sets publicly available, access may be granted to those who meet prespecified criteria for confidential access, available at www.ices.on.ca/DAS (email: das@ices.on.ca). The full data set creation plan and underlying analytic code are available from the authors on request, understanding that the computer programs may rely on coding templates or macros that are unique to ICES and are therefore either inaccessible or may require modification. These data sets were linked using unique encoded identifiers and analyzed at ICES.

This document used data adapted from the Statistics Canada Postal CodeOM Conversion File, which is based on data licensed from Canada Post Corporation, and/or data adapted from the Ontario Ministry of Health Postal Code Conversion File, which contains data copied under license from ©Canada Post Corporation and Statistics Canada. We thank IQVIA Solutions Canada Inc. for use of their Drug Information File. Parts of this material are based on data and/or information compiled and provided by the Ontario Ministry of Health (MOH) and Canadian Institute of Health Information (CIHI). Parts of this material are based on data and information provided by Ontario Health (OH). The opinions, results, view, and conclusions reported in this paper are those of the authors and do not necessarily reflect those of OH. No endorsement by OH is intended or should be inferred. Parts of this report are based on Ontario Registrar General (ORG) information on deaths, the original source of which is ServiceOntario. The views expressed therein are those of the author and do not necessarily reflect those of ORG or the Ministry of Public and Business Service Delivery. This study was supported by the Ontario Health Data Platform (OHDP), a Province of

Ontario initiative to support Ontario's ongoing response to COVID-19 and its related impacts. The opinions, results and conclusions reported in this paper are those of the authors and are independent from the funding sources. No endorsement by the OHDP, its partners, or the Province of Ontario is intended or should be inferred. The funders had no influence in study design; in the collection, analysis, and interpretation of data; in the writing of the report; and in the decision to submit the article for publication. The analyses, conclusions, opinions and statements expressed herein are solely those of the authors and do not reflect those of the funding or data sources; no endorsement is intended or should be inferred. Parts of this material are based on data compiled and provided by Immigration, Refugees and Citizenship Canada (IRCC) current to July of 2024. However, the analyses, conclusions, opinions and statements expressed in the material are those of the authors, and not necessarily those of IRCC. Finally, we would like to thank Ahwon Jeong who complied and matched medication names and Drug Identifier Numbers.

## ABSTRACT

**Background:** Medications are often recommended for symptom control at the end of life (EOL). The objectives of this thesis are to assess the prescribing of subcutaneous symptom management medications during the last six weeks of life among home care recipients and the association of prescribing with various EOL outcomes.

**Methodology:** A retrospective cohort study of home care decedents (2017-2020) in Ontario using ICES data.

**Results:** Of 55,903 decedents, 28.6% received 1+ EOL symptom management prescription. Those with a prescription had a decreased risk of dying in an institution (risk ratio (RR): 0.59, 95% confidence interval (CI): 0.57-0.60), having an emergency department visit (RR: 0.22, 95% CI: 0.20-0.24) or hospitalization (RR: 0.20, 95% CI: 0.18-0.22) in the last two weeks of life.

**Conclusion:** EOL prescribing is associated with a decreased risk of acute care use and death in an institutional setting among home care decedents.

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| | |
|---|---|
| CAPE | Client Agency Program Enrollment |
| CCRS | Continuing Care Reporting System |
| CIC | Citizenship and Immigration Canada |
| CPS | Cognitive Performance Scale |
| DAD | Discharge Abstract Database |
| DIN | Drug Identification Number |
| EOL | End of Life |
| HCD | Home Care Database |
| IKN | ICES Key Number |
| InterRAI-HC | International Resident Assessment Instrument – Home Care |
| IRCC | Immigration, Refugees and Citizenship Canada |
| LTC | Long-Term Care |
| MMSE | Mini Mental State Examination |
| NACRS | National Ambulatory Care Reporting System |
| NRS | National Rehabilitation Reporting System |
| ODB | Ontario Drug Benefit |
| OHIP | Ontario Health Insurance Plan |

| | |
|---|---|
| OMHRS | Ontario Mental Health Reporting System |
| OR | Odds Ratio |
| OT | Occupational Therapist |
| PCCF | Postal Code Conversion File |
| PHIPA | Personal Health Information Protection Act |
| PSW | Personal Support Worker |
| PT | Physiotherapist |
| RAI-HC | Resident Assessment Instrument - Home Care |
| RPDB | Registered Persons Database |
| RPN | Registered Practical Nurse |
| RR | Risk Ratio |
| SRC | Service Receipt Category |
| SDS | Same Day Surgery |

# CHAPTER ONE - INTRODUCTION

## 1.1. Symptoms Experienced at the End of Life

A major concern for individuals with life limiting illnesses as they are nearing the end of life is symptom management during the dying process. These symptoms include but are not limited to physical pain, dysphagia, oropharyngeal secretions, delirium, agitation, nausea, and vomiting.[1] A variety of medications may be prescribed to individuals to manage end-of-life symptoms at this time. These medications can be prescribed by different health care professionals involved in the individual's care, including their primary care doctor, palliative care physicians, and other specialist physicians and nurse practitioners.

If left unmanaged, uncontrolled symptoms can rapidly escalate at the end of life. This may result in distressing emergency department visits or hospitalizations for treatment. Transitions to acute care during this period of declining health can be physically and emotionally difficult for both individuals and their family members.[2] Specifically, these uncontrolled symptoms and transfers out of the home are associated with an increased likelihood of dying in an institutional setting (e.g., hospital), which is contrary to end-of-life goals expressed by most individuals.[2] Appropriate symptom management through the timely prescribing of symptom management medications may help improve the quality of death and prevent these potentially burdensome transitions at the end of life.[3] However, we do not know if end-of-life medications are being prescribed to Ontario's home care recipients.

## 1.2. Study Aim, Objectives, and Hypotheses

The aim of this thesis is to describe variations in the prescribing of subcutaneous medications commonly used for symptom management at the end of life among home care recipients in

Ontario, Canada. Furthermore, I aimed to assess the association between end-of-life symptom management medication prescribing and end-of-life outcomes. From here forward, subcutaneous end-of-life symptom management medication prescriptions will be referred to as end-of-life prescriptions.

### *1.2.1. Objective 1*

The first objective of this thesis is to describe end-of-life prescribing in the last six weeks of life among home care decedents in Ontario. I aimed to identify the variations in prescribing according to both individual and provider/system characteristics. The characteristics of interest included sex, age, neighborhood income quintile, rurality, immigration status, primary language, attachment to a primary care physician, receipt of palliative home care, cognition via the Cognitive Performance Scale, pain, presence of live-in primary caregiver, and caregiver distress. I hypothesized that there will be differences in prescribing across patient, provider, and system characteristics, generally driven by access to care.

### *1.2.2. Objective 2*

The second objective of this thesis is to characterize and compare outcomes of home care decedents according to their receipt of end-of-life prescriptions. Outcomes included place of death (institution vs. community) and late (i.e., in the last two weeks of life) emergency department visits and hospitalizations.

I hypothesize that those who receive an end-of-life prescription will demonstrate a decreased risk for emergency department visits and hospitalizations in the last two weeks of life. Furthermore, I hypothesized that those who receive an end-of-life prescription will be at a decreased risk of dying in an institution compared to those who did not. These hypotheses

stem from the potential of prescriptions providing symptom relief, and thus reducing the likelihood of events necessitating transfers out of the community setting for care.

### 1.3. Rationale for Thesis

Previous work in Ontario has demonstrated considerable variation in end-of-life prescribing among long-term care (LTC) residents.[3,4] However, no research to date has assessed prescribing among Ontario's home care population. Analysis on a large scale (province-wide) is needed to understand to whom these symptom management medications are being prescribed and how prescribing is associated with various outcomes among home care decedents. The Ontario Government continues to invest in and expand home care services for recipients, recognizing the crucial role of home care in delivering essential services.[5] Evidence utilizing Ontario specific data is required to enable policy makers and healthcare providers to make improvements to the healthcare system, and provide comprehensive end-of-life care for home care recipients.

### 1.4. Thesis Organization

This thesis is written in accordance with the “thesis by manuscript” format as described by the University of Ottawa. Following this introductory chapter, chapter two provides extensive background on symptom burden at the end of life, symptom management as an indicator of high-quality end-of-life care, the role of home care in Ontario, medications commonly prescribed at the end of life, end-of-life outcomes, and the current published literature pertaining to end-of-life prescribing at the end of life. Chapter three describes the methodology as to how the study cohort was identified, and describes the various analyses conducted. Chapter four is based on a manuscript formatted for publication in the Journal of Pain and Symptom Management. This chapter describes the variations in end-of-life prescribing, and compares outcomes (location of death, and late (i.e., in last two weeks of

life) emergency department visits and hospitalizations) among home care decedents according to their receipt of end-of-life prescriptions. Chapter five expands upon the analysis presented in chapter four by providing additional results that did not fit within the scope of the manuscript. Chapter six reflects on the findings of the thesis as a whole by synthesizing the evidence from both chapters four and five and placing it into context of the existing literature in this area. Furthermore, this final chapter discusses implications for further research, public health practice, and policy development in Ontario.

# CHAPTER TWO - BACKGROUND

## 2.1. Role of Home Care in Ontario

In Ontario, home care encompasses a range of health and supportive services provided to individuals in their place of residence.[6] Home care services are restricted to individuals who reside in the community, and therefore excludes those receiving care in hospitals or LTC facilities.[7] Home care services aim to support individuals in maintaining their independence and safety while receiving necessary medical and social assistance. Home care services vary, including both short and long-stay services. Short stay services are intended for individuals requiring assistance for a defined period of time, typically lasting days to a few months.[8] Individuals who receive short stay home care services include those recovering from surgery and illnesses, or those requiring care following an accident. On the other hand, long-stay home care services are intended to support individuals, particularly older adults and those with complex medical conditions, for an extended period of time (typically ≥60 days).[8] Individuals who receive long-stay home care services include those with chronic conditions, those who require palliative care, and persons with disabilities requiring prolonged care.

In Ontario, Home and Community Care Support Service organizations provide and facilitate access to community support home care services.[9] The majority of home care in Ontario is provided through the publicly funded program, but some people do pursue alternative options (e.g., private services, services including a client co-payment).[6] Over 900,000 individuals in Ontario rely on home care services, including those waiting to enter LTC, and those that wish to remain in their home.[10] Common goals of home care include improving health status and quality of life, supporting families in coping with their loved ones' increased need for care, and maintaining individuals autonomy and independence.[6]

Home care is delivered through personalized multidisciplinary teams of healthcare providers.[11] These services vary, but may include professionals such as but not limited to nurses, registered practical nurses (RPNs), personal support workers (PSWs), occupational therapists (OTs), physiotherapists (PTs), and social workers. Typically, professionals such as nurses and RPNs manage and carry out pre authorized medical plans, treatments, and medications.[12] PSWs assist with daily living activities, such as personal hygiene care tasks, preparing meals, and movement transfers.[13] OT's and PT's support rehabilitation, with the goal of maximizing function and independence in daily living skills.[14,15] Social workers may assist home care recipients in the planning of end-of-life care, and with adapting to transitions and other challenges.[16] While physicians may be involved in providing care to individuals in their home, it is important to note that physicians do not deliver care through these home care service organizations.

In Ontario, Service Receipt Category (SRC) codes are utilized to differentiate between home care service designations that reflect the types of services and care provided. SRC 95 and 54 are two codes used to designate end of life care.[17] These codes are established and used by home care coordination services. Recipients who have either one of these service designations will receive increased services, recognizing that the intensity of care is a result of approaching the end of life. The SRC 95 designation is intended to be applied to individuals with a diagnosis that is no longer curable, with an expected <6 months left to live.[17]

### 2.2. Symptom Burden at the End of Life

Many people experience physical, psychological, or other symptoms as they approach the end of life.[18–23] Specific to physical symptoms, a study by Hagarty and colleagues in Canada

assessed the prevalence of clinically significant pain at the end of life.[18] They found severe daily pain to be prevalent in 17.2% of decedents.[18] A separate study conducted in Spain assessed physical symptom changes and prevalence in the last week of life among cancer patients.[19] The results showed that asthenia (81.8%), anorexia (80.1%), dry mouth (69.9%), confusion (68.2%), and constipation (55.1%) were the most common symptoms experienced at the end of life.[19]

Other studies have assessed psychological symptoms in addition to physical symptoms experienced at the end of life. Work by Kutner and colleagues found lack of energy (83%), pain (76%), lack of appetite (63%), drowsiness (61%), difficulty concentrating (60%), and sadness (51%) to be the most common symptoms experienced by home hospice patients, as reported by hospice staff.[20] Furthermore, they found that nearly half of all home hospice patients experience moderate to severe anxiety and/or depression during the last week of life.[20] Building on this initial work, Kutner and colleagues investigated how potential distress from end-of-life symptoms pertained to patient quality of life from the perspective of hospice patients.[21] They found that proximity to death, age, diagnosed condition, and functional status are factors that may contribute to perceptions of symptom distress.[21] Although not ranked as most prevalent, pain was found to be the most distressing symptom among hospice patients.[21] In addition, symptoms such as pain that cause greater psychological distress were found to have a negative association with quality of life.[21]

It is important to note that both symptoms, as well as symptom severity, often fluctuate during the end-of-life period. Some research has assessed how symptoms evolve and progress as death nears. Canadian authors Seow and colleagues assessed the trajectory of standardized cancer symptom assessment tools six months before death.[22] They found shortness of breath,

drowsiness, decreased sense of well-being, lack of appetite, and tiredness to all increase in severity as people neared death.[22] Additional work by Seow and colleagues focused on patients receiving home care. They identified loss of appetite (63%), shortness of breath (59%), high health instability (50%), and self-reported poor health (44%) as the most prevalent symptoms in the last week of life.[23] Furthermore, they found covariates of caregiver distress, high health instability, social decline, uncontrolled pain, and depression to worsen the odds of having physical symptoms during the last three months of life.[23] This research highlights how symptoms may progress and fluctuate drastically during the end-of-life period, and emphasizes the importance of ongoing symptom assessment and management during the last few days of life.

To date, the existing literature indicates that experiencing physical and psychological symptoms at the end of life remains prevalent and is highly distressing for patients. Furthermore, symptoms are found to progress as time to death nears, highlighting the need for continued intervention at the end-of-life.

### 2.3. Symptom Management as an Indicator of High-Quality Care at the End of Life

Many individuals report that having good symptom control is an important part of high-quality care at the end of life.[24–26] Some research has analyzed various domains of quality end-of-life care, including symptom control, which has been deemed important by healthcare professionals, patients, and their families.

A qualitative analysis conducted by Singer and colleagues in Toronto, Canada, identified elements of quality end-of-life care from the patient perspective.[24] The study found that

participants identified five domains of quality end-of-life care, one of which was 'receiving adequate pain and symptom management'.[24] A separate study by Steinhauser and colleagues built on this research by determining quality indicators in end-of-life care from the patient, family, and provider perspectives.[25] Freedom from pain, anxiety, and shortness of breath were identified as important indicators of quality of care at the end of life.[25] Further research from this group also found that symptom control during the dying process, particularly the undertreatment of pain, was a significant concern for both patients and providers.[26] In this study, pain and symptom management was deemed one of six core values during end-of-life treatment across a variety of individuals involved in the patients care.[26]

### 2.4. Medications Commonly Used at the End of Life

Drug classifications refer to groupings of medications that possess similar characteristics, such as the mechanism of action, chemical structure, or physiological effect.[27] Common medication classes prescribed for individuals who are at the end of life include but are not limited to analgesics (intended to treat pain), benzodiazepines (intended to treat anxiety), antipsychotics (intended to treat delirium and agitation), barbiturates (intended to induce sedation), anticholinergics (intended to treat excessive respiratory secretions), diuretics (intended to treat pulmonary edema), and prokinetic agents (intended to treat nausea/vomiting).[28–33]

Individuals are likely to experience symptoms of dysphagia and decreased level of consciousness at the end of life.[34] Due to this, medications are often delivered to home care recipients in the community via subcutaneous injections. Subcutaneous injections refer to a route of delivery in which the medication is injected under the skin, but not into the muscle.[35]

This method is favoured for both ease of drug administration, and to control the medications absorption rate.[35] Subcutaneous tissue contains fewer blood vessels than other injection sites, and therefore the drug is diffused into the bloodstream at a steady rate.[36]

## 2.5. End of Life Outcomes

### *2.5.1. Location of Death*

Research shows that dying at home (rather than in hospital) is often the preferred choice for home care recipients.[37] If given appropriate care, dying at home helps to minimize both physical and emotional stress during the end of life period.[38–40] Author Bowling described how people have a right to die with dignity; receiving adequate support at home and having the ability to decide to die at home may enable individuals to feel a sense of autonomy in their end-of-life care.[41]

If admitted to hospital within three months prior to death, the likelihood of dying in hospital increases.[42] The ability to return to the community, and subsequently die at home after a hospitalization, is influenced by a variety of factors. These factors include but are not limited to timely and coordinated discharge by hospital staff, an appropriate home environment to return to (e.g., safe, with caregiver support), and the availability of high quality home support.[42] Access to symptom management prescriptions is an aspect of quality home support that may influence the ability for home care recipients to successfully and comfortably die at home.

### *2.5.2. Emergency Department Visits and Hospitalizations*

Uncontrolled symptoms at the end of life could result in emergency department visits and hospitalizations for home care recipients.[43–45] Transfers to hospital during this period may be

distressing and not align with individuals' end-of-life preferences.[46] Similar to location of death, access to medications for symptom management in the home may reduce the likelihood of these potentially unwanted transfers for care at the end of life as symptoms, including acute exacerbations or emergencies, can be prevented, or managed in a timely fashion within the home environment.

### 2.6. Current Literature on Symptom Management Prescribing at the End of life

Currently, the research pertaining to end-of-life prescribing has been focused on specific conditions, such as cancer and dementia, as well as care settings, including residential care and nursing homes.[3,47–49]

A retrospective cohort study by Saphire and colleagues in the United States assessed patterns of symptom management medication prescribing at the end of life among older adults who died of lung cancer.[47] During the last month of life, they found an increase in the prescribing of symptom management medications intended to treat dyspnea, pain, emotional distress, fatigue, anorexia, and nausea/vomiting.[47] Disparities in prescribing were noted in this population, with a lower prevalence of prescribing among older adults and individuals of ethnic minorities.[47] Similar findings were observed in a separate study among nursing home residents with dementia.[48] With regards to symptoms, they found that pain, agitation, and shortness of breath to be the most commonly reported symptoms at the end of life.[48] Furthermore, this study reported that on the day of death, 77% of residents received opioids and 21% received palliative sedation.[48]

In Canadian LTC homes, current research has reported that two-thirds of decedents were prescribed at least one symptom management medication in the last two weeks of life.[3]

Among these medications, opioids were the most prescribed medication class (62.7%), followed by anticholinergic agents (31.2%), benzodiazepines (20.4%) and antipsychotics (19.3%).[3] There was considerable variation in prescribing across Ontario's 600+ LTC homes. End-of-life prescribing was also associated with transfers to hospital in the last two weeks of life; LTC homes with higher prescribing had lower hospital transfer rates for residents who were nearing death.[3]

Non-specific to a patient care setting, Morin and colleagues assessed the medications being prescribed during the last year of life among all decedents aged 65 and older in Sweden.[49] They found that during the last month of life, analgesics (60.8%), antithrombotic agents (53.8%), diuretics (53.1%), psycholeptics (51.2%), and β-blocking agents (41.1%) were the five most commonly prescribed drug classes.[49]

Taken together, the current literature demonstrates that the prevalence of end-of-life prescribing differs drastically across countries, care settings, and patient populations. In addition, the literature is more focused on the symptoms that are present at the end of life, rather than if medications are being prescribed to alleviate the symptoms. Furthermore, some literature highlights disparities within patient populations, suggesting that potential gaps in access or patient-provider preferences among these populations may exist.

### 2.7. Conclusion

Patients nearing the end of life often experience distressing symptoms that can be effectively managed with common medications. Effective symptom management is recognized as an indicator of good quality care during this time. However, evidence shows that inadequate symptom management remains prevalent, leading to unnecessary suffering, emergency

department visits, and deaths in hospitals; outcomes that often contradict patients' end-of-life preferences. This highlights the need to explore the impact of palliative care symptom management in home care settings, where many individuals receive end-of-life care. Further research in this area could provide valuable insights to ensure that patients achieve a peaceful and dignified end-of-life experience.

# CHAPTER THREE - METHODOLOGY

## 3.1. Study Design and Setting

I conducted a retrospective population-based cohort study in Ontario to examine variations in the prescribing of end-of-life symptom management medications for home care recipients, and the association of this prescribing with end-of-life outcomes. Ontario is Canada's most populous province, being home to more than 15.5 million people.[50] I utilized population-level, routinely collected longitudinal health administrative data collected on all Ontario residents and available at ICES, an independent nonprofit research institute (formerly known as the Institute for Clinical Evaluative Sciences).[51]

## 3.2. Initial Study Population

The initial study population included all publicly funded long-stay home care recipients who died between January 1, 2017, to March 17, 2020, in Ontario. These dates were selected to account for the disruption in service delivery and changes in healthcare use that occurred during the COVID-19 pandemic period. The index date was defined as one month (31 days) prior to death.

All decedents were identified using the Registered Persons Database (RPDB). Decedents identified during this period were linked to data in the Resident Assessment Instrument - Home Care (RAI-HC) and the International Resident Assessment Instrument (InterRAI-HC) databases. These databases contain all records of home care resident assessment conducted, as mandated by the province of Ontario (see section 3.3 for detailed descriptions of the databases used). I included home care recipients with an assessment before the index date, but no greater than 12 months before death (i.e., assessment date between 31 and 365 days

before death). The cohort included all residents aged 66 to 105 at index that received home care services at least one month before death and who were eligible under Ontario's health insurance plan in the last month of life.

The following exclusion criteria were applied to the home care decedent cohort, with justifications provided as necessary:

1) **Invalid identifier for linkage across health administrative databases**
2) **Invalid birth date** (missing or after index date)
3) **Invalid sex**
4) **Non-Ontario residents at index**
5) **Age <66 or >105 one month prior to death:** older adults were selected as the population of interest. Although Ontario Drug Benefit (ODB) eligibility begins at age 65, the minimum age of 66 was selected to ensure complete prescription coverage during the last 12 weeks of life (i.e., if someone died shortly after turning 65, relevant prescribing data would not be available). Therefore, to allow for complete data analysis, the minimum age specified for the cohort was set to age 66 at index. As for the maximum of the age range set, those who appear over 105 years of age in healthcare administrative data often are a result of data entry error. Therefore, to account for this potential error, I excluded individuals over the age of 105.
6) **Those not OHIP eligible during the last month of life:** individuals not eligible for the Ontario health plan in the last month of life would not have relevant data captured for analysis.
7) **Those without a Resident Assessment Instrument (RAI) record in the 31-365 days before death:** RAI assessments were utilized to capture baseline characteristics closest to the index date. Recent RAI assessments, which provide the most relevant

health status before death, are crucial for interpreting analysis results. However, to ensure that the measurement of baseline covariate data was not influenced by outcomes, the decision was made to omit RAI assessments conducted within the 30 days preceding death. This approach ensures that the covariate data is relatively recent (i.e., within the past year), while also avoiding any assessments that might have been impacted by outcomes (i.e., in the last 30 days of life, an assessment for example that was the result of an emergency department visit or hospitalization).

8) **Those who did not receive home care services at least one month prior to death:** individuals were excluded if their home care admission date occurred within a one-month period of their death date. A late admission would not allow sufficient time for resources to be established to support a death in the community. This includes the time it takes for end-of-life symptom management medications to be prescribed. Therefore, these individuals were excluded as their end-of-life experience differs from the focus of the research question.

### 3.3. Data Sources, Access, and Linkage

ICES is an independent, non-profit research institute in Ontario. ICES possesses a repository of record-level, coded and individually linkable health data sets from publicly funded administrative health services.[51] Various datasets are used to capture healthcare utilization across healthcare sectors and personal demographics, including special registry collections, chronic condition cohorts, detailed clinical data, population and demographic data, and supporting data on healthcare providers and institutions.[52] Datasets were linked using unique encoded identifiers (IKN's - ICES Key Numbers based on each resident's encrypted health card number).[52] ICES possesses individually-linked administrative data that is routinely collected through the covered services under Ontario's universal single-payer healthcare

system.[51] Under Ontario's health information privacy law, ICES collects and analyses healthcare data without the need for consent for the purpose of health system evaluation and improvement. The use of the data in this project is authorized under section 45 of Ontario's Personal Health Information Protection Act (PHIPA) and does not require review by a Research Ethics Board. These datasets were linked using unique encoded identifiers and analyzed at ICES.[52]

### *3.3.1. Registered Persons Database (RPDB)*

The RPDB database contains information on individuals registered under the Ontario Health Insurance Plan (OHIP).[53] This database was used to capture all deaths in Ontario between January 1, 2017, and March 17, 2020. This database was utilized to determine variables such as sex, age at death, and postal codes of home care decedents. Postal codes were used to assign area-level income (via linkage to Postal Code Conversion File (PCCF) and CENSUS), and rurality (via linkage to PCCF).

### *3.3.2. Resident Assessment Instrument - Home Care (RAI-HC) and International Resident Assessment Instrument – Home Care (InterRAI-HC)*

The RAI-HC database was used to capture assessments received by long stay home care recipients across Ontario between January 1, 2017, and April 1, 2018. The RAI-HC assessment instrument is utilized to assess adults residing in home and community-based settings.[54] It collects data on administrative, demographic, function, cognition, and health service resource utilization. This information is utilized to not only assess and monitor a patient's health status, but also to aid in understanding populations, improving quality, and allocating resources as a secondary function. The RAI-HC is completed by trained assessors once at admission to long-stay home care, at regular reassessment intervals (approximately every 6 months to 1 year), or when the patient experiences a significant change in clinical

status.[55] A significant change in clinical status is defined as a change that is not self-limited (< 90 days), that instigates review of the care plan to maintain appropriate care.[55] Examples include changes in primary caregiver status, changes to the recipients living arrangements, or changes in recipients health status that impacts their functional abilities.[55]

The interRAI-HC database was used to capture long stay home care recipients across Ontario between April 1st, 2018, and March 17th, 2020. This new instrument expanded on the previous RAI-HC tool by standardizing observation periods, coding of responses, adding more clinically relevant items, and redesigning the quality of life measures.[56] Similar to the RAI-HC, the interRAI-HC is completed once at admission to long-stay home care, at regular reassessment intervals (approximately every 6 months to 1 year), or when the patient experiences a significant change in clinical status.[55]

#### *3.3.3. Home Care Database (HCD)*

The HCD contains information on all home care services provided or coordinated by local Home and Community Care Support Services organizations.[57] This database was used to identify long-stay home care recipients when building the cohort. In addition, this database was used to identify whether palliative home care services were implemented through the use of SRC admission and discharge codes (specifically using codes 95 (at home end-of-life care) and 54 (complex end-of-life care)).[17] Furthermore, the HCD database was utilized to identify community deaths for the location of death outcome.

#### *3.3.4. Drug Identification Number (DIN) Database*

In Canada, DIN's are unique numbers assigned to authorized drug products by Health Canada.[58] The DIN database identifies multiple elements of drug products identified by

DINs, such as the manufacturer, product name, active ingredient(s), strength(s) of active ingredient(s), pharmaceutical form, and route of administration.[58]

### *3.3.5. Ontario Drug Benefit (ODB)*

The ODB program provides prescription drug coverage for a variety of populations, including but not limited to Ontarians aged 65 and older, residents of LTC, home care recipients, and social assistance recipients.[59] The ODB database contains history of prescription recipients, payments, claims, and pharmacy and practitioner information regarding these transactions.[59] The ODB database was used to gather prescription claims, including the DIN's and the prescription fill date, dispensed to home care residents.

### *3.3.6. National Ambulatory Care Reporting System (NACRS)*

The NACRS database contains both hospital and community-based ambulatory care data.[60] This includes information on day surgery, outpatient and community-based clinics, and emergency departments.[60] This database was used to identify emergency department visits in the six weeks before death. In addition, the NACRS database was utilized to distinguish institutional deaths for the location of death outcome.

### *3.3.7. Discharge Abstract Database (DAD)*

The DAD contains information pertaining to hospital discharges.[61] Standardized diagnostic ICD-10-CA codes (Canadian implementation of the International Classification of Diseases, 10th Revision) and procedural or interventional CCI codes (Canadian Classification of Health Interventions) document relevant diagnoses and interventions.[61] This database was utilized to identify hospitalizations in the six weeks before death. In addition, this database was utilized to identify institutional deaths for the location of death outcome.

### *3.3.8. Postal Code Conversion File (PCCF)*

The PCCF links Canadian postal codes to standard geographic areas.[62] In this study, the PCCF was used to link postal codes from the RPDB to CENSUS records to determine both the rurality and area-level median household income quintile in the postal code which the patient resides.

### *3.3.9. CENSUS*

The CENSUS database contains information collected by the national census administered every five years across Canada by Statistics Canada.[63] For this study, the 2016 CENSUS database was utilized as it contains the most relevant information for the target population (2017-2020). In conjunction with the RPDB and PCCF, the CENSUS was utilized to determine patient area-level income quintiles by linking postal codes to the census dissemination area.

### *3.3.10. Client Agency Program Enrollment (CAPE)*

The CAPE database contains information on individuals registered to primary care organizations.[64] In Ontario, patients may be enrolled, or "rostered" to a primary care physician working in particular practice models (e.g., family health group, family health network).[65,66] These physicians are responsible for providing non-emergency primary care services for their rostered patients, which helps to promote accountability and continuity of care.[67] For the purpose of this study, the CAPE dataset was utilized to determine whether an individual was rostered to a family physician prior to death.

### *3.3.11. Ontario Health Insurance Plan (OHIP)*

The OHIP database contains health care billing information for the purpose of service reimbursement made by physicians.[68] Information recorded in this database includes the

diagnosis, type and date of service received, and the fee code associated with the encounter.[68] For individuals not registered in the CAPE database, the OHIP database was utilized to determine if a participant is virtually rostered to a family physician by looking at selected encounter OHIP fee codes in year prior to index.[67] Furthermore, the OHIP database was utilized to distinguish community deaths for the location of death outcome.

### *3.3.12. Citizenship and Immigration Canada (CIC)*

The CIC database contains information regarding landing records for permanent legal immigrants to Ontario since 1986.[69] In 2015, CIC adopted a new name, making the change to Immigration, Refugees and Citizenship Canada (IRCC).[69] Despite the official department name change, the database is still called the CIC at ICES. This database was used to determine immigration status to Ontario since 1985.

### *3.3.13. Same Day Surgery (SDS)*

The Same Day Surgery (SDS) database contains ambulatory care visits for inpatient surgery or to the emergency department.[70] This database was utilized to distinguish institutional deaths for the location of death outcome.

### *3.3.14. Ontario Mental Health Reporting System (OMHRS)*

The Ontario Mental Health Reporting System (OMHRS) database contains data on admissions to mental health designated hospital beds.[71] This database was utilized to distinguish institutional deaths for the location of death outcome.

### *3.3.15. Continuing Care Reporting System (CCRS)*

The Continuing Care Reporting System (CCRS) contains demographic, clinical and functional data on individuals receiving continuing care services either in complex continuing

care facilities or LTC homes.[72] The CCRS was used to distinguish institutional deaths for the location of death outcome.

#### *3.3.16. National Rehabilitation Reporting System (NRS)*

The National Rehabilitation Reporting System (NRS) database contains information from participating adult inpatient rehabilitation facilities and programs across Canada.[73] This database was utilized to distinguish institutional deaths for the location of death outcome.

### 3.4. Study Variable Definitions

#### *3.4.1. Prescribing of End-of-Life Symptom Management Medications*

Medication prescribing data was captured utilizing the ODB. Medications analyzed included opioids (morphine, hydromorphone), non-opioid pain (dexamethasone), benzodiazepines (lorazepam, midazolam), antipsychotics (haloperidol, methotrimeprazine), sedatives (phenobarbital), excessive respiratory secretions (scopolamine, glycopyrrolate), pulmonary edema (furosemide), and nausea and vomiting (metoclopramide). These medications (names and unique DINs) were identified through extensive consultations with palliative care physicians as part of a broader program of research on end-of-life symptom management medication prescribing that was initially focused in Ontario's LTC setting (see table 3-1 below for drug group classification and DINs).[3,4,74]

**Table 3-1.** The complete list of end-of-life prescription medications, including drug class, drug name and DIN.

| Drug Class | Drug Name | DIN(s) |
|---|---|---|
| Opioids | Morphine | 00392561, 00392588, 00617288, 02242484, 09857226, 09857227 |
| | Hydromorphone | 02145901, 02145928, 02145936, 02146126 |
| Non-opioid Pain | Dexamethasone | 00664227, 01977547 |
| Benzodiazepines | Lorazepam | 02243278, 09857216 |
| | Midazolam | 02240286, 09857225, 02242905, 09857436, 09857438, 09857479 |
| Antipsychotics | Haloperidol | 02130297, 02130300, 09853758, 00808652 |
| | Methotrimeprazine | 01927698 |
| Sedatives | Phenobarbital | 02304090, 09857296 |
| Excessive Respiratory Secretions | Scopolamine | 09857384, 09857385, 00363839, 09857213, 00541869, 00541877, 02242810, 02242811, 09857236, 09857237 |
| | Glycopyrrolate | 02039508, 02382857, 09857212, 09857266, 09857521 |
| Pulmonary Edema | Furosemide | 00527033, 09857208 |
| Nausea/Vomiting | Metoclopramide | 02185431, 09857224 |

** DIN = Drug Identification Number

To determine the appropriate time window prior to death to use as a lookback window to capture medication prescribing, I plotted the proportion of decedents per two-week period (0-2, 2-4, 4-6, 6-8, 8-10, 10-12 weeks) that received at least one end-of-life prescription (see figure 3-1). Proportions were computed with the total number of decedents with 1+

prescription in the 12-week period prior to death as the denominator. The timing of the prescription record was based on the date in which the prescription was filled. There was a plateau in the prescribing of medications that occurred from weeks 6-12, with few decedents receiving a prescription more than six weeks before death. Based on this finding, I made the decision to define end-of-life prescribing as that which occurred during the 0–6-week period before death.

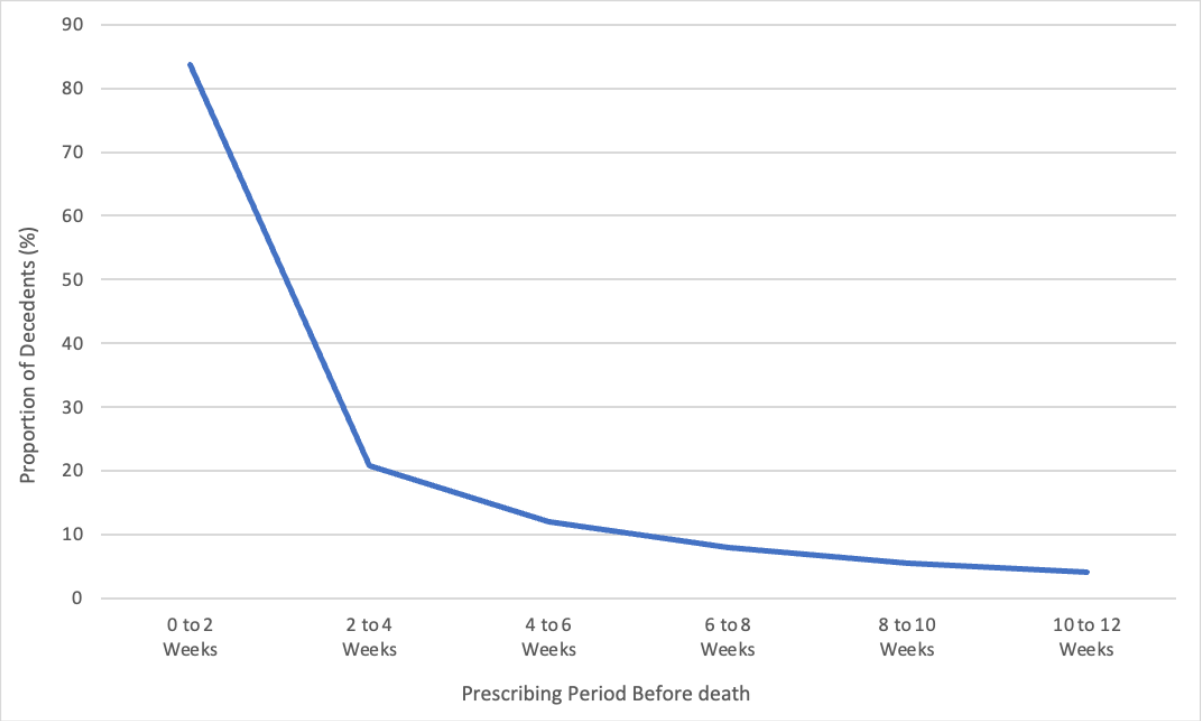



**Figure 3-1.** Proportion of decedents that received at least one of the pre-specified end-of-life prescriptions in the last 12 weeks of life in relation to the total number of people who received any medication across the observation period. Note that decedents can receive a prescription across multiple time periods, so proportions do not add to 100%.

For analyses examining end-of-life prescribing in relation to location of death, medication prescribing across the 0–6-week period before death was used for exposure measurement (i.e., two exposure levels: received a prescription in the 0-6 weeks before death vs. did not receive a prescription in the 0-6 weeks before death). This exposure measurement was chosen

as any prescription during this period could impact an individual's ability to manage symptoms and therefore remain at home to die. However, for analyses examining medication prescribing in relation to hospitalizations and emergency department visits in the last two weeks of life, prescribing was broken down into three exposure levels: home care recipient received a prescription in the 2–6-week period before death, home care recipient only received a prescription in the 0–2-week period before death, or home care recipient did not receive a prescription at any point during the 0–6-week period before death. The intention of separating prescriptions given in the 0-2-week and 2–6-week windows before death was to provide a greater understanding of how the timing of receiving a prescription affects the outcomes. In addition, this exposure definition controls for potential reverse causality as prescribing that occurred in the last two weeks of life may have occurred after an outcome of interest has occurred (e.g., an individual receives a community prescription after an emergency department visit or hospitalization). Figure 3-2 below shows a visual representation of how the prescribing exposure levels were defined.

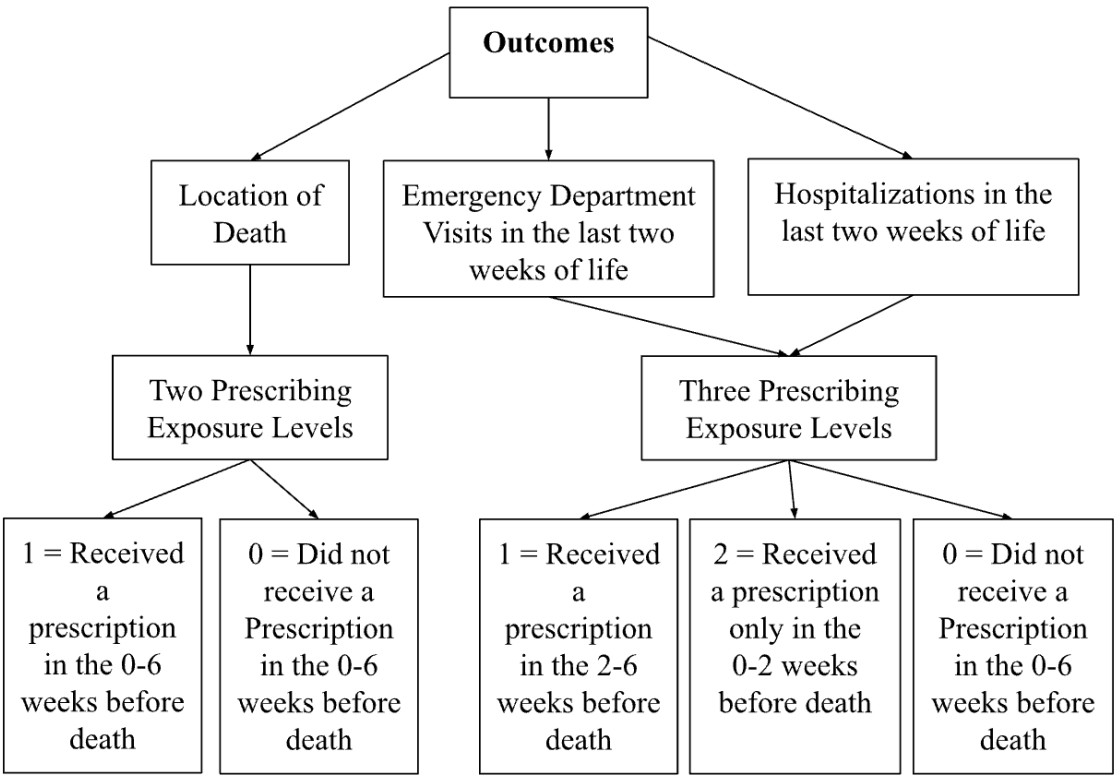



**Figure 3-2.** Prescribing exposure levels for the three study outcomes (location of death, emergency department visits in the last two weeks of life, and hospitalizations in the last two weeks of life).

### *3.4.2. Outcomes: Location of Death, Emergency Department Visits and Hospitalizations*

The three main outcomes for this study included location of death (institution vs. community), and late (i.e., in the last two weeks of life) emergency department visits and hospitalizations. Location of death, defined as occurring in the community or institution, was captured using the ICES location of death macro.[75] This macro uses the discharge disposition status and discharge date for encounters across different healthcare settings. Institutional deaths were identified as occurring in an acute care hospital, emergency department, mental health hospital, complex continuing care, LTC, or rehabilitation facility (datasets: DAD, SDS, NACRS, OMHRS, CCRS, and NRS). Community deaths, defined as decedents without a record of an institutional death, included those who died at home or in a hospice setting

(Datasets: HCD, OHIP). Emergency department visits in the last two weeks of life were captured using the NACRS dataset. Hospitalizations in the last two weeks of life were captured using the DAD.

### *3.4.3. Covariates*

Several covariates were selected to explore variations in prescribing across various characteristics. The covariates were hypothesized to be confounders in the relationship between prescribing and the end-of-life outcomes based on extensive literature review and consultations with expert investigations and clinician scientists. Figure 3-3 below illustrates how the hypothesized covariates, explained further within this section, map onto the relationship between prescribing, and the three study outcomes. It is important to acknowledge that factors, including but not limited to patient preference and prescription adherence, represent potential covariates in this relationship. However due to limitations within the data, we are unable to include these factors in analyses.

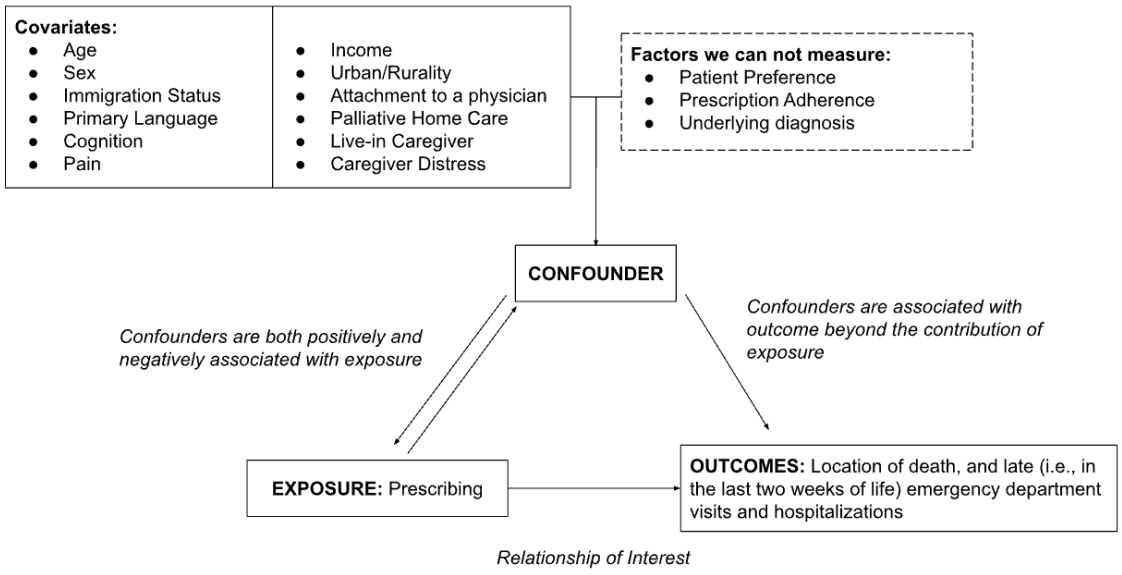



**Figure 3-3.** Figure depicting how the hypothesized covariates map onto the relationship between the exposure (prescribing) and the three study outcomes (location of death, emergency department visits in the last two weeks of life, and hospitalizations in the last two weeks of life).

Furthermore, is also important to acknowledge that while underlying diagnoses and illnesses may act as confounders in the relationship between prescribing and the study outcomes, I was unable to account for them in analysis. Assessing ‘disease trajectory’, which would be the appropriate ICES variable to address this question, is only available in the data up until 2018. Given that my study population includes home care decedents from 2017 to 2020, I was unable to include this covariate in my analysis.

For all covariates measured using the RAI, the closest assessment to index within the 31-365 days preceding death was utilized (see details below). Time of measurement for covariates from databases other than the RAI were measured on the index date (i.e., 31 days prior to death).

#### *3.4.3.1. Sex*

Home care recipients' sex was captured using the RPDB at index. This dichotomous variable separated recipients into either ‘male’ or ‘female’.

#### *3.4.3.2. Age*

Home care recipients' age was captured using the RPDB at index. This continuous variable was categorized into age bands, being 66-75, 76-85, 86-95, and 96-105. Age was categorized in this manner for interpretability during analysis.

#### *3.4.3.3. Neighbourhood Income Quintile*

Home care recipients' neighborhood income quintile at index was captured by linking Statistics Canada PCCF to area-level median household income based on Census data. Home care recipients were categorized into pre-defined quintiles of area-level income (lowest, low, middle, high, and highest income).[62,63]

#### *3.4.3.4. Rurality*

Home care recipients' rurality was captured by linking their postal code in the RPDB at index to the PCCF. The PCCF is an ICES derived macro that links PCCF files to census geographic identifiers. This dichotomous variable separated recipients into being either ‘urban’ or ‘rural’ based on the CSIZE variable in the PCCF. If CSZE = 5, meaning the community size belonging to the individual is <=10,000 people, that individual would be categorized as ‘rural’.[76] All others remaining were categorized as ‘urban’.

#### *3.4.3.5. Immigration Status*

Immigration status since January of 1985 was captured using the CIC database at index using the landing date variable. This database only captures immigrants with a registered landing date in Ontario.[69] Home care recipients were dichotomized into immigrants (having a landing date) vs. long-standing residents (no landing date).

#### *3.4.3.6. Primary Language*

Home care recipients' primary language was captured using the RAI-HC and InterRAI-HC databases. Primary language is defined in the RAI-HC and InterRAI-HC as the language spoken by the resident on a regular basis.[55] Recipients were categorized as either Anglophone (English as their primary language), Francophone (French as their primary language), or Allophone (primary language being any language but English or French).

#### *3.4.3.7. Attachment to a Primary Physician*

Attachment to a primary physician was captured using both the CAPE and OHIP databases using a lookback period of 365 days prior to death. Home care recipients were categorized into three groups; if they were rostered to a primary care physician working in a patient enrollment model, if they were virtually rostered to a primary care physician working in a

fee-for-service model, or if they were unattached to a primary care physician. Rostering was defined as the most responsible regulated health care physician who has overall responsibility for the patient's care (assigned to CAPE).[67] For home care recipients unassigned in CAPE, the method of "virtual rostering" was utilized to identify individuals who had a usual provider of primary care. This method uses physician billing (OHIP codes) in which patients are allocated to a primary care physician based on the largest dollar amount of primary care services given in the previous two-year period.[67]

#### *3.4.3.8. Palliative Home Care*

Home care recipients who were receiving care under an end-of-life designation were captured using Service Recipient Category (SRC) codes closest to index date in the HCD. Recipients were flagged as having palliative home care if they possessed a SRC of 54 or 95 at either admission to or discharge from home care services.

#### *3.4.3.9. Cognitive Performance Scale*

Validated against the widely used Mini Mental State Examination (MMSE), the Cognitive performance scale (CPS) is a composite variable that is measured utilizing variables in the RAI-HC and InterRAI-HC databases.[77] This variable is calculated using five items on the RAI: being comatose, short term memory, cognitive skills for decision making, expressive communication, and eating self-performance.[55] Pre-existing CPS categorization was utilized (intact, borderline intact, mild impairment, moderate impairment, moderate/severe impairment, severe impairment, very severe impairment).[55]

#### *3.4.3.10. Pain*

Home care recipients' pain was captured using the RAI-HC and InterRAI-HC databases. This variable describes the home care recipient's self-perception of intensity or severity of pain.

Pre-existing pain level categorization in the databases was utilized (no pain, mild pain, moderate pain, severe pain, horrible/excruciating pain).[55]

#### *3.4.3.11. Live-in Primary Caregiver*

Home care recipients' live-in primary caregiver status was captured using the RAI-HC and InterRAI-HC databases. This variable is defined as the recipient's primary informal caregiver support system.[55] Recipients were categorized as either having a live-in primary caregiver, not having a live-in primary caregiver, or having no such helper.[55]

#### *3.4.3.12. Caregiver Distress*

Caregiver distress was captured using the RAI-HC and InterRAI-HC databases. This binary response variable (yes/no) was defined as feelings of distress, anger, depression or conflict as a result of caring for the home care recipient.[55]

## 3.5. Data Processing and Statistical Analysis

### *3.5.1. Preliminary Analysis*

In this section, I will outline and explain the approach taken to manage the potential competing risk of days spent in hospital on an individual's ability to receive a community prescription. The decision to consider this factor prior to finalizing my cohort was based on conversations with expert investigators and clinician scientists.

Preliminary analysis was conducted on the initial study population defined above. Descriptive statistics (e.g., mean and standard deviation, frequency and proportion) were used to describe the baseline characteristics of the population (sex, age groupings, neighborhood income quintile, rurality, immigration status, primary language, attachment to a family physician,

palliative home care, cognitive performance scale, pain, whether the home care recipient lives with their primary caregiver, and caregiver distress). Prescribing of end-of-life medications (any medications, as well as specific medication classes) and outcomes were also described. Chi-squared tests were used to evaluate the associations between symptom management prescribing in the six weeks before death and end-of-life outcomes (location of death and emergency department visits and hospitalizations in the last two weeks of life).

To narrow the study population eligibility criteria to best address my objectives, I looked at prescribing in association with the number of days spent in hospital (ranging from 0 - 27 days) during the 2-6-week period before death. In particular, I was interested in the potential impact of hospitalizations during the 2-6 weeks before death on potential competing risk of an individual's ability to receive a prescription, as we are only able to capture prescriptions filled in the community. I hypothesized that the more days an individual spends in hospital during the 2-6 weeks before death, the likelihood of receiving a community prescription decreases. Further, I also explored the relationship between crude counts of days in hospital during the 2-6-week period before death and the three study outcomes (location of death in an institution, and emergency department visits and hospitalizations in the last two weeks of life). As prior hospitalization are strong predictors of future rehospitalizations, I wanted to assess the impact of hospital stays that spanned from the exposure period into the outcome period (the 2-6 and 0-2-week periods respectively).

### *3.5.2. Preliminary Results*

Of the 77,568 individuals in the preliminary cohort, 55,903 spent no days in hospital in the 2–6-week period before death (Table 3-2). Of those who spent no days in hospital, 8.7% received a prescription in the 2-6 weeks before death, while 20% received a prescription only in the last two weeks of life (Table 3-2). Of those with at least 1+ day in hospital in the 2-6

weeks of life, the likelihood of getting a prescription decreased as the days in hospital increased. (Table 3-2). This supports the hypothesis that individuals who were admitted to hospital in the 2-6 weeks before death were less likely to fill a community prescription for symptom management medications.

When assessing the total number of days spent in hospital during the 2-6-week period before death in association with hospitalization in the last two weeks of life, we see that individuals who spent 0 days in hospital had a significantly lower proportion of late (i.e., in the final two weeks of life) hospitalizations (47.2%) than individuals who spent any days in hospital, with the proportion increasing as the number of days increased (e.g., 98.9% for those who spent the entire 2-6 week period in hospital) (Table 3-3). Based on how the data were analyzed, this most likely represents individuals who spent the whole 2-6-week period before death in hospital, with their admission overlapping into the 0-2-week period before death. In addition, we see that if an individual spent the entire 2-6-week period before death in hospital, they were more likely to die in an institution than compared to those who spent 0 days in hospital during the same exposure period (93.9% vs. 65.1%, respectively) (Table 3-4). When assessing emergency department visits in the last two weeks of life in association with days in hospital, we see that individuals who spent the entire 2–6-week period in hospital had a lower proportion of individuals with 1+ emergency department visit than those who spent 0 days in hospital (6.8% vs. 51.4%) (Table 3-3). This may be the result of more than one phenomenon, including hospitalized individuals being discharged with prescriptions to manage symptoms recognizing eminent end-of-life, or individuals whose hospitalization overlapped from the 2-6-week period before death into the 0-2-week period before death (i.e., they were being cared for in the hospital and therefore did not rely on emergency care services).

**Table 3-2.** Comparing total days in hospital during the 2-6-week period (0 - 27 days) in association with prescribing in both the 0-2 and 2-6-week before death time periods.

| Total days in hospital during 2–6-week period | Prescribing | | | Total, n |
|---|---|---|---|---|
| | EOL Rx only in 0–2-week period, n (%) | EOL Rx in 2–6-week period, n (%) | No EOL Rx, n (%) | |
| 0 | 11,156 (20.0) | 4,856 (8.7) | 39,891 (71.4) | **55,903** |
| 1 | 202 (15.0) | 81 (6.0) | 1,062 (79.0) | **1,345** |
| 2 | 201 (14.3) | 66 (4.7) | 1,142 (81.1) | **1,409** |
| 3 | 166 (13.6) | 61 (5.0) | 990 (81.4) | **1,217** |
| 4 | 153 (13.3) | 75 (6.5) | 921 (80.4) | **1,149** |
| 5 | 168 (15.5) | 65 (6.0) | 852 (78.5) | **1,085** |
| 6 | 137 (14.1) | 51 (5.3) | 784 (80.7) | **972** |
| 7 | 133 (14.2) | 42 (4.5) | 762 (81.3) | **937** |
| 8 | 123 (14.6) | 35 (4.2) | 682 (81.2) | **840** |
| 9 | 97 (12.5) | 38 (4.9) | 639 (82.6) | **774** |
| 10 | 96 (13.9) | 29 (4.2) | 567 (82.0) | **692** |
| 11 | 79 (12.4) | 33 (5.2) | 526 (82.5) | **638** |
| 12 | 74 (13.3) | 29 (5.2) | 455 (81.5) | **558** |
| 13 | 75 (13.7) | 23 (4.2) | 450 (82.1) | **548** |
| 14 | 64 (11.3) | 34 (6.0) | 468 (82.7) | **566** |
| 15 | 68 (13.1) | 20 (3.9) | 430 (83.0) | **518** |
| 16 | 59 (12.2) | 21 (4.3) | 405 (83.5) | **485** |
| 17 | 61 (13.3) | 14 (3.0) | 385 (83.7) | **460** |
| 18 | 53 (12.4) | 10 (3.4) | 363 (85.2) | **426** |
| 19 | 49 (12.1) | 13 (3.2) | 343 (84.7) | **405** |
| 20 | 38 (9.2) | 16 (3.9) | 358 (86.9) | **412** |
| 21 | 48 (13.7) | 10 (2.9) | 293 (83.5) | **351** |
| 22 | 44 (11.3) | 9 (2.3) | 335 (86.3) | **388** |
| 23 | 36 (10.5) | 9 (2.6) | 298 (86.9) | **343** |
| 24 | 30 (9.3) | 12 (3.7) | 280 (87.0) | **322** |
| 25 | 41 (13.4) | 13 (4.2) | 253 (82.4) | **307** |
| 26 | 23 (8.7) | 8 (3.0) | 234 (88.3) | **265** |
| 27 | 258 (6.1) | 8 (0.2) | 3,987 (93.8) | **4,253** |
| **Total** | **13,732** | **5,681** | **58,155** | **77,568** |

*EOL Rx = End-of-life Prescription

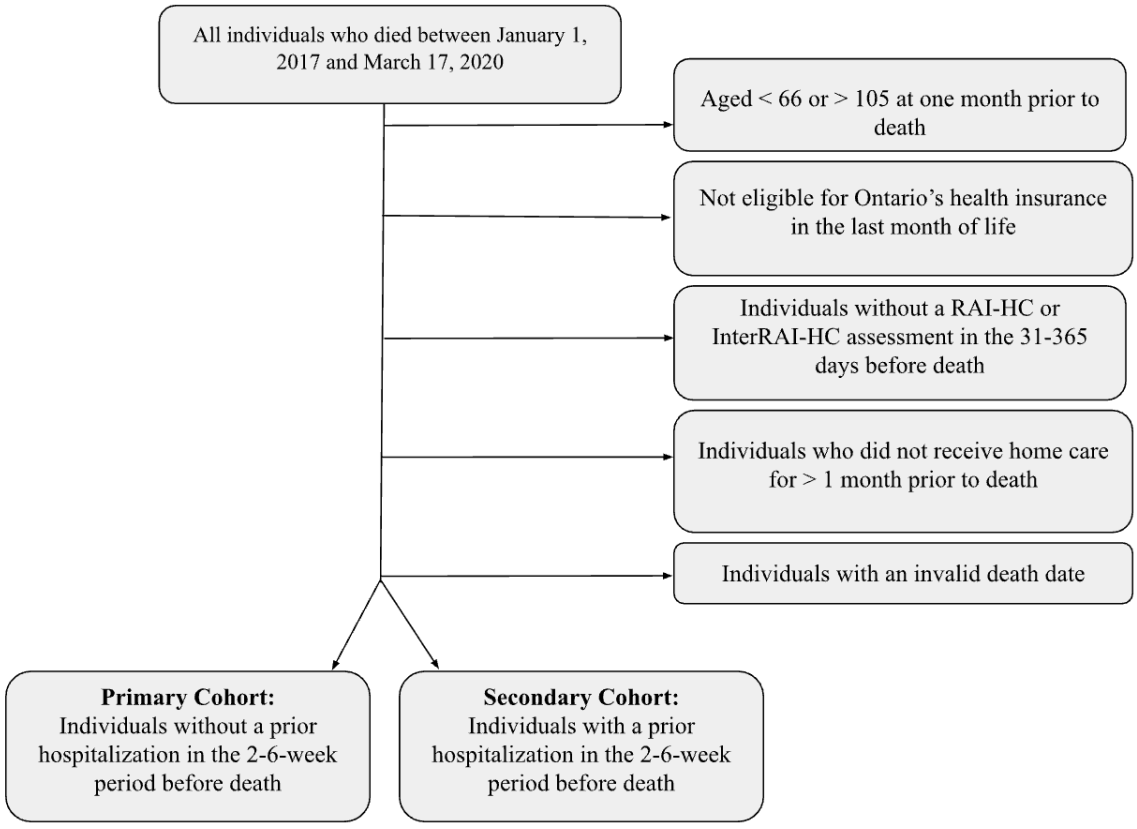
**Table 3-3.** Comparing total days in hospital during the 2-6-week period (0 - 27 days) in association with emergency department visits and hospitalizations in the last two weeks of life.

| Total days in hospital during 2–6-week period | Outcomes | | | | Total, n |
|---|---|---|---|---|---|
| | Emergency Department during the last 0-2 weeks of life, n (%) | | Hospitalization during the last 0-2 weeks of life, n (%) | | |
| | Yes | No | Yes | No | |
| 0 | 28,710 (51.4) | 27,193 (48.6) | 26,386 (47.2) | 29,517 (52.8) | **55,903** |
| 1 | 325 (24.2) | 1,020 (75.8) | 1,141 (84.8) | 204 (15.2) | **1,345** |
| 2 | 303 (21.5) | 1,106 (78.5) | 1,195 (84.8) | 214 (15.2) | **1,409** |
| 3 | 265 (21.8) | 952 (78.2) | 1,051 (86.4) | 166 (13.6) | **1,217** |
| 4 | 251 (21.9) | 898 (78.2) | 969 (84.3) | 180 (15.7) | **1,149** |
| 5 | 219 (20.2) | 866 (79.8) | 917 (84.5) | 168 (15.5) | **1085** |
| 6 | 201 (20.7) | 771 (79.3) | 828 (85.2) | 144 (14.8) | **972** |
| 7 | 191 (20.4) | 746 (79.6) | 789 (84.2) | 148 (15.8) | **937** |
| 8 | 152 (18.1) | 688 (81.9) | 727 (86.6) | 113 (13.5) | **840** |
| 9 | 147 (18.9) | 627 (81.0) | 655 (84.6) | 119 (15.4) | **774** |
| 10 | 129 (18.6) | 563 (81.4) | 592 (85.6) | 100 (14.5) | **692** |
| 11 | 132 (20.7) | 506 (79.3) | 541 (84.8) | 97 (15.2) | **638** |
| 12 | 93 (16.7) | 465 (83.3) | 478 (85.7) | 80 (14.3) | **558** |
| 13 | 86 (15.7) | 462 (84.3) | 463 (84.5) | 85 (15.5) | **548** |
| 14 | 101 (17.8) | 465 (82.2) | 469 (82.9) | 97 (17.1) | **566** |
| 15 | 72 (13.9) | 446 (86.1) | 441 (85.1) | 77 (14.9) | **518** |
| 16 | 90 (18.6) | 395 (81.4) | 419 (86.4) | 66 (13.6) | **485** |
| 17 | 72 (15.7) | 388 (84.4) | 389 (84.6) | 71 (15.4) | **460** |
| 18 | 68 (16.0) | 358 (84.0) | 358 (84.0) | 68 (16.0) | **426** |
| 19 | 53 (13.1) | 352 (86.9) | 338 (83.5) | 67 (16.5) | **405** |
| 20 | 65 (15.8) | 347 (84.2) | 347 (84.2) | 65 (15.8) | **412** |
| 21 | 54 (15.4) | 297 (84.6) | 299 (85.2) | 52 (14.8) | **351** |
| 22 | 49 (12.6) | 339 (87.4) | 321 (82.7) | 67 (17.3) | **388** |
| 23 | 39 (11.4) | 304 (88.6) | 283 (82.5) | 60 (17.5) | **343** |
| 24 | 51 (15.8) | 271 (84.2) | 278 (86.3) | 44 (13.7) | **322** |
| 25 | 46 (15.0) | 261 (85.0) | 251 (81.8) | 56 (18.2) | **307** |
| 26 | 31 (11.7) | 234 (88.3) | 226 (85.3) | 39 (14.7) | **265** |
| 27 | 289 (6.8) | 3964 (93.2) | 4,205 (98.9) | 48 (1.1) | **4,253** |
| **Total** | **32,284** | **45,284** | **45,356** | **32,212** | **77,568** |

**Table 3-4.** Comparing total days in hospital during the 2-6-week period (0 - 27 days) in association with location of death in both the community and in an institution.

| Total days in hospital during 2–6-week period | Outcomes | | Total, n |
|---|---|---|---|
| | Location of Death, n (%) | | |
| | Community | Institution | |
| 0 | 19,485 (34.9) | 36,418 (65.1) | **55,903** |
| 1 | 264 (19.6) | 1,081 (80.4) | **1,345** |
| 2 | 273 (19.4) | 1,136 (80.6) | **1,409** |
| 3 | 245 (20.1) | 972 (79.9) | **1,217** |
| 4 | 232 (20.2) | 917 (79.8) | **1,149** |
| 5 | 221 (20.4) | 864 (79.6) | **1085** |
| 6 | 173 (17.8) | 799 (82.2) | **972** |
| 7 | 173 (18.5) | 764 (81.5) | **937** |
| 8 | 165 (19.6) | 675 (80.4) | **840** |
| 9 | 149 (19.3) | 625 (80.8) | **774** |
| 10 | 119 (17.2) | 573 (82.8) | **692** |
| 11 | 107 (16.8) | 531 (83.2) | **638** |
| 12 | 95 (17.0) | 463 (83.0) | **558** |
| 13 | 94 (17.2) | 454 (82.9) | **548** |
| 14 | 85 (15.0) | 481 (85.0) | **566** |
| 15 | 85 (16.4) | 433 (83.6) | **518** |
| 16 | 70 (14.4) | 415 (85.6) | **485** |
| 17 | 71 (15.4) | 389 (84.6) | **460** |
| 18 | 63 (14.8) | 363 (85.2) | **426** |
| 19 | 58 (14.3) | 347 (85.7) | **405** |
| 20 | 50 (12.1) | 362 (87.9) | **412** |
| 21 | 50 (14.3) | 301 (85.8) | **351** |
| 22 | 52 (13.4) | 336 (86.6) | **388** |
| 23 | 40 (11.7) | 303 (88.3) | **343** |
| 24 | 43 (13.4) | 279 (86.7) | **322** |
| 25 | 43 (14.0) | 264 (86.0) | **307** |
| 26 | 33 (12.5) | 232 (87.6) | **265** |
| 27 | 258 (6.1) | 3,995 (93.3) | **4,253** |
| **Total** | **22,796** | **54,772** | **77,568** |

Due to these results from the interim analysis, I made the decision to separate the cohort into two groups for analysis: those without a hospitalization in the 2-6-week period before death, who formed the primary analytic cohort, and those with a hospitalization (spent 1+ days in hospital) during this same time period, who formed the secondary analytic cohort. Analyses of the primary cohort, who spent the entirety of the 2-6-week prescribing exposure period outside of hospital, would help minimize the potential competing risk of hospitalizations on the likelihood of receiving an end-of-life prescription in the community. The cohort creation flow diagram below illustrates the exclusion steps that were applied to obtain the final study populations used for all future analyses in this thesis (Figure 3-4).




** RAI-HC = Resident Assessment Instrument - Home Care, InterRAI-HC = International Resident Assessment Instrument – Home Care

**Figure 3-4.** Cohort creation flow diagram based on study exclusion criteria.

### *3.5.3. Final Analysis*

All analyses were done on the primary and secondary cohorts separately.

#### *3.5.3.1 Descriptive Analysis*

Similar to the preliminary analysis, exploratory descriptive analysis of baseline characteristics was conducted. Mean and standard deviation was calculated for the continuous variable (age). For binary and categorical variables, frequency and proportions were calculated. These variables included sex, age groupings, neighborhood income quintile, rurality, immigration status, primary language, attachment to a family physician, palliative home care, CPS, pain, whether the recipient lives with their primary caregiver, and caregiver distress. Chi-squared tests were used to compare the outcomes between those who did and did not receive 1+ end-of-life prescriptions.

#### *3.5.3.2. Log-binomial Regression Modeling*

For dichotomous outcomes, such as those present in this study, odds ratios (OR's) and risk ratios (RR's) are the appropriate measures of association.[78] Although often used interchangeably, odds and risk represent two different measures in epidemiological research. Odds ratios, obtained by using logistic regression modeling, compare the odds of an event occurring in one group to the odds of the event occurring in another group.[79] Risk ratios on the other hand represents a ratio of probabilities rather than odds.[79] When the outcome of interest is rare (typically <10%), odds ratios can be used to estimate risk ratios.[80] However if the outcome of interest is common, odds ratios will overestimate risk ratios. As the outcomes of interest are common, log-binomial regression models were chosen as the most appropriate method of analysis.

Log-binomial regression modeling was used to directly estimate relative risks of the three outcomes (location of death in an institution vs. community, and emergency department visits and hospitalizations in the last two weeks of life). Covariates included as confounders for all models included sex, age at death, income, rurality, pain, cognitive performance scale, whether decedent was attached to a family physician, immigration status, palliative home care, primary language, caregiver distress and live in caregiver status. Both crude and adjusted risk ratios were computed for the three outcomes. Figure 3-5 below visually represents the three models (with specified exposure windows) that were built.

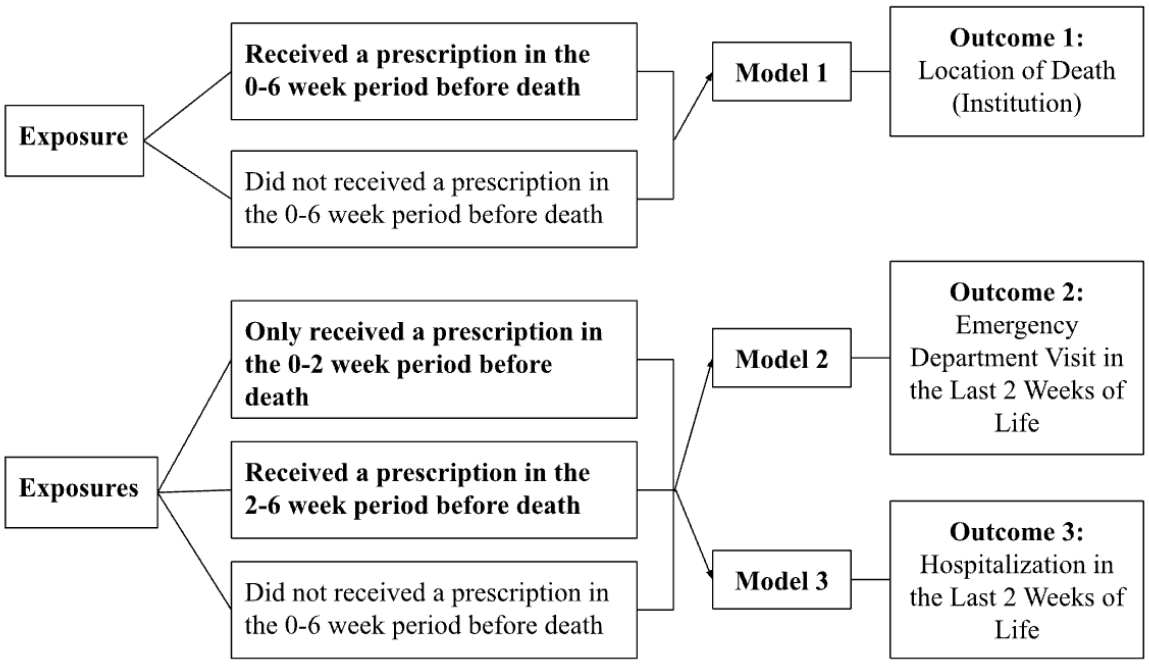



**Figure 3-5.** Log-binomial models run based on the three study outcomes (location of death, emergency department visits in the last two weeks of life, and hospitalizations in the last two weeks of life).

### 3.6. Handling of Missing Data

Individuals with missing characteristics were described in exploratory analysis. Due to the number with missing data being low (n=322, 0.58% of cohort used in primary analysis), these individuals were excluded in the regression modeling and a complete case analysis was used.

# CHAPTER FOUR - VARIATIONS IN END-OF-LIFE SYMPTOM MANAGEMENT MEDICATION PRESCRIBING AMONG HOME CARE RECIPIENTS IN ONTARIO, CANADA

## 4.1. Preface

This chapter contains the completed manuscript titled “Variations in End-of-life Symptom Management Medication Prescribing among Home Care Recipients in Ontario, Canada”. This manuscript was prepared for submission in the Journal of Pain and Symptom Management. Due to this, redundancies exist in the introduction, methods, and discussion sections.

# Variations in End-Of-Life Symptom Management Medication Prescribing Among Home Care Recipients in Ontario, Canada

## Original Study

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**Word Count: 3472**

**Reference Count: 12**

**Table Count: 3**

**Figure Count: 1**

*Running Title:* End of life Prescribing in Home Care

## 4.2. Abstract

**Context:** Nearing the end of life (EOL), a variety of medications can be prescribed for symptom management during the dying process.

**Objectives:** To assess the prescribing of subcutaneous symptom management medications during the last six weeks of life among home care recipients in Ontario, Canada, and the association of prescribing with EOL outcomes.

**Methods:** This retrospective cohort study included all individuals in Ontario who died between January 1, 2017, and March 17th, 2020, aged 66 to 105 at death, and who received publicly-funded home care at least one month prior to death. End-of-life symptom management medications were identified based on an extensive literature review and consultation with Ontario palliative care physicians. We measured the proportion of decedents prescribed an EOL medication in the last six weeks of life. We used log-binomial regression models to evaluate the association between EOL medication prescribing and emergency department visits and hospitalizations in the last two weeks of life, and location of death (community vs. institution).

**Results:** Of the 55,903 home care decedents identified, nearly one quarter (28.6%) received an EOL symptom management prescription. Those who received a prescription had a decreased risk of dying in an institution (risk ratio (RR): 0.59, 95% confidence interval (CI): 0.57-0.60), having an emergency department visit (RR: 0.22, CI: 0.20-0.24), and being hospitalized (RR: 0.20, CI: 0.18-0.22) compared to those without a prescription.

**Conclusion:** Our findings suggest that EOL prescribing is associated with a decreased risk of late acute care use and death in hospital among home care decedents.

**Key Words:** Administrative health data, end-of-life care, prescribing, home care, health system measures

**Key Message:** This article describes a retrospective cohort study that assesses end-of-life prescribing of subcutaneous symptom management medications among home care recipients in Ontario. The results demonstrate that end-of-life prescription of comfort medications for community-residing individuals are associated with a decreased risk of death in an institution, and emergency department visits and hospitalizations in the last two weeks of life.

### 4.3. Introduction

Home care plays an essential role in the care of aging populations. Home care services vary, offering a range of medical and social support services, catering to both individuals short and long-term needs.[1] Home care programs help community-dwelling individuals remain living safely at home. Most people, if given the option, prefer to receive care at home rather than in an institutional setting, such as hospital or long-term care (LTC).[2] In Ontario, home care is publicly funded through the Ontario Government.[3] Over 900,000 individuals in Ontario rely on home care services, including those waiting for LTC and individuals that wish to remain in their familiar home environment.[4] This includes a significant number of people who are at the end of life, who rely on home care services for support during the dying process.

Symptom management during the end-of-life period is an important aspect and a common concern among both home care recipients and family. End-of-life symptoms include but are not limited to physical pain, dyspnea, oropharyngeal secretions, delirium, agitation, nausea, and vomiting.[5] A variety of medications are prescribed for end-of-life symptom management to limit potentially distressing symptom exacerbations which may necessitate transfers to hospital during the dying process. As a result of likely dysphagia and decreased level of consciousness experienced by individuals at the end of life, these medications are often prescribed subcutaneously rather than orally.[6] Furthermore, subcutaneous injections are often the preferred route of delivery as they help to control the medication absorption rate.[6]

Despite their critical role in end-of-life care, it is currently unknown how frequently end-of-life symptom management medications are being prescribed to home care recipients at the end of life in Ontario. In this study, we described the prescribing of subcutaneous symptom management medications and assessed the association of prescribing with outcomes such as

location of death (institution vs. community), and emergency department visits and hospital admissions among home care recipients at the end of life. From here forward, subcutaneous end-of-life symptom management medication prescriptions will be referred to as end-of-life prescriptions.

## 4.4. Methodology

### *4.4.1. Study Design and Setting*

We conducted a retrospective cohort study using routinely collected population-level health administrative data available at ICES in Ontario, Canada (formerly known as the Institute for Clinical Evaluative Sciences). ICES utilizes individually linked administrative data that is collected through the delivery of services covered by the province's universal single-payer healthcare system. Datasets are linked using unique encoded identifiers and analyzed at ICES. Under Ontario's health information privacy law, ICES collects and analyzes healthcare data without the need for consent for the purpose of health system evaluation and improvement. The use of the data in this project is authorized under section 45 of Ontario's Personal Health Information Protection Act (PHIPA) and did not require review by a Research Ethics Board.

### *4.4.2. Population*

The study population included all home care recipients aged 66 to 105 years who died between January 1, 2017, to March 17, 2020, in Ontario. Decedents must have received home care services at least one month before death and be eligible for Ontario's health insurance plan at time of death. We identified home care recipients utilizing the HCD, RAI-HC and InterRAI-HC databases, which contain records and assessment reports of home care residents. To account for the potential competing risk of hospitalization on an individual’s

ability to receive a community prescription during the exposure period, we divided the cohort into two groups for analysis; individuals who were not hospitalized in the two-to-six-week period prior to death, which formed our primary analytic cohort, and individuals who had at least one hospitalization in the same time period, which was our secondary analytic cohort. Cohort creation details and descriptions of the databases are in the supplement eMethods.

#### *4.4.3. Decedent Characteristics*

Resident characteristics in the study included (1) sex, (2) age at death (categorized as 66-75, 76-85, 86-95, 96-105), (3) neighborhood income quintile, (4) rurality, (5) immigration status, (6) linguistic group based on primary language spoken (Anglophone (English), Francophone (French), Allophone (any language other than English or French)), (7) attachment to a primary care physician, including patients formally rostered to a family physician practicing in a patient enrollment model (identified via CAPE), un-rostered but has a usual provider of primary care (via OHIP, from here on out referred to as 'virtually rostered'), or un-rostered and unattached, (8) receipt of palliative focused home care under an end-of-life designation (specifically using Service Recipient Category (SRC) codes 95 (at home end-of-life care) and 54 (complex end-of-life care)), (9) cognition based on the Cognitive Performance Scale, which is scored from 0 (intact) to 6 (very severe impairment), (10) pain level, which is ranked from 'no pain' to 'times when pain is horrible or excruciating,' (11) whether the recipient lived with a primary caregiver, and (12) whether the primary caregiver expressed feelings of distress, anger, or depression.

For all covariates measured using the RAI, the closest assessment to index within the 31-365 days preceding death was utilized. Time of measurement for covariates from databases other than the RAI were measured on the index date (i.e., 31 days prior to death). It is important to acknowledge that due to data limitations (i.e., lack of updated data across the study period),

we were unable to account for underlying illnesses and disease trajectory during analysis. See supplement eMethods for details of study variables.

#### *4.4.4. End-of-life Prescribing*

We measured the proportion of home care decedents who had at least one end-of-life prescription in their last six weeks of life. These medications (names and unique Drug Identification Numbers (DIN)) were identified based on an extensive literature review and consultation with Ontario palliative care physicians and experts.[7] Medications analyzed included morphine, hydromorphone, dexamethasone, lorazepam, midazolam, haloperidol, phenobarbital, scopolamine, glycopyrrolate, furosemide, metoclopramide, and methotrimeprazine. Prescription dispensation data was retrieved through the Ontario Drug Benefit (ODB) plan, which funds all medications prescribed to home care recipients. The maximum lookback time was chosen as end-of-life prescribing was found to be relatively low, greater than six weeks before death (see Chapter 3 figure 3-1, to be added to the supplement for publication).

#### *4.4.5. Location of Death, Emergency Department Visits, and Hospitalizations*

Outcomes included location of death (institution vs. community) and late (i.e., in the last two weeks of life) emergency department visits and hospitalizations. Location of death in the community was captured using both the Home Care Database (HCD) and the Ontario Health Insurance Plan (OHIP) databases. Individuals with a missing place of death in the data were also categorized as having a community death. Institutional deaths, in places such as the hospital or subacute care facilities, were captured using various datasets; the Discharge Abstract Database (DAD), Same Day Surgery (SDS), National Ambulatory Care Reporting System (NACRS), and Ontario Mental Health Reporting System (OMHRS) databases for hospital deaths; and Complex Continuing Care (CCC), Long-Term Care (LTC), and National

Rehabilitation Reporting System (NRS) databases for deaths in subacute care facilities. Emergency department visits in the last two weeks of life were captured using the NACRS dataset. Hospitalizations in the last two weeks of life were captured using the DAD.

#### *4.4.6. Primary Analysis*

All primary analyses were conducted on the cohort that was not hospitalized at any point during the 2-6-week period before death. Exploratory descriptive analysis of baseline characteristics and prescribing was conducted to address the outcomes. Unadjusted and adjusted log-binomial models were used for individuals in the primary cohort who received an end-of-life prescription. Covariates included sex, age at death, income, rurality, pain, Cognitive Performance Scale, whether decedent was attached to a family physician, immigration status, palliative home care, primary language, caregiver distress and live in caregiver status.

For analyses examining end-of-life prescribing in relation to location of death, medication prescribing across the 0-6 weeks before death was used for exposure measurement (i.e., two exposure levels: received a prescription in the 0-6 weeks before death vs. did not receive a prescription in the 0-6 weeks before death). For analyses examining end-of-life prescribing in relation to hospitalizations and emergency department visits in the last two weeks of life, prescribing was broken down into three exposure levels: home care recipient received a prescription in the 2–6-week period before death, home care recipient only received a prescription in the 0–2-week period before death, or home care recipient did not receive a prescription at any point during the 0-6 week period before death. Separating prescriptions given in only the 0-2-week, or during the 2-6-week periods before death helps to understand how timing affects the outcomes, in addition to ensuring the prescription in the last two weeks of life are not influenced by prior outcomes (i.e., an emergency department visit or

hospitalization). Individuals with missing characteristics were described in exploratory but excluded in analytic analysis (log-binomial modeling).

#### *4.4.7. Secondary Analysis*

All analyses were repeated using the cohort that was hospitalized at some point in the 2-6-week before death period (secondary cohort).

### 4.5. Results

#### *4.5.1. Primary Cohort*

We included 55,903 home care recipients who died between January 1, 2017, to March 17, 2020, in Ontario (Table 4-1). Home care recipients were predominantly female (54.4%), aged 86-95 (43.7%), in the lowest income quintile (25.0%), resided in an urban setting (87.4%), Canadian born (93.4%), Anglophone (63.4%), not attached to a primary physician (76.5%), did not receive palliative home care (79.6%), had mild cognitive impairment (42.9%), had moderate pain (36.2%), lived with their primary caregiver (75.8%), and their caregiver did not express distress (58.9%).

Approximately one quarter (28.6 %) of home care decedents received an end-of-life prescription in the 0-6-week period before death (Table 4-1); 20.0% received a prescription only in the 0-2-weeks before death, while 8.7% received their prescription in the 2-6-weeks before death (eTable 2). Hydromorphone was the most common medication prescribed (75.2%) among those who received a prescription (Table 4-2). Compared to those who did not receive a prescription, those who did had higher proportion of decedents enrolled in palliative home care services (42.6 vs. 11.4%), virtually rostered to a family physician (21.3 vs. 17.6%), with an intact CPS rating (14.9 vs. 13.6%), and with their primary caregiver

indicating personal distress (44.5 vs. 39.7). Conversely, those who received a prescription had a lower proportion of decedents in the lowest income quintile (22.2 vs. 26.1%) and who resided in an urban setting (85.9 vs. 88.0%).

Of those with an end-of-life prescription, 64.2% died in the community, compared to the 23.1% who did not receive a prescription (Table 4-3). Those with an end-of-life prescription had a lower proportion with emergency department visits for both the 0-2-week and 2-6-week prescribing periods (24.6% and 12.1%, respectively), than those who did not receive a prescription (63.6%). Finally, those with an end-of-life prescription had a lower proportion with hospitalizations for both the 0-2-week and 2-6-week prescribing periods (17.1% and 10.5%, respectively), than those who did not receive a prescription (60.1%).

After adjusting for covariates, those who received an end-of-life prescription had a decreased risk of dying in an institution than those who did not receive a prescription (risk ratio (RR): 0.59, 95% confidence interval (CI): 0.57 - 0.60) (Figure 4-1). With regards to emergency department visits in the last two weeks of life, receiving a prescription in the 2-6-week period before death was associated with a substantially decreased risk (RR: 0.22 95% CI: 0.20 - 0.24) of a visit in the last two weeks of life. Those who received a prescription in the 0-2-week period had a less substantial, but still significant, decreased risk (RR: 0.43 95% CI: 0.42 - 0.45) of an emergency department visit in the same period. Similarly, with regards to hospitalizations in the last two weeks of life, receiving a prescription in the 2-6-week period before death was associated with a substantially decreased risk (RR: 0.20 95% CI: 0.18 - 0.22) of a hospitalization in the last two weeks of life. Those who received a prescription in the 0-2-week period had a less substantial, but still significant, decreased risk (RR: 0.32, 95% CI: 0.30 - 0.33) of a hospitalization in the same period.

### *4.5.2. Secondary Cohort*

We included 21,665 home care recipients who died between January 1, 2017, to March 17, 2020, in Ontario. (eTable 3). Baseline characteristics and medications within the secondary cohort remained fairly consistent with the analysis from the primary analysis cohort (eTable 4). However, the secondary cohort had a lower proportion of decedents who received an end-of-life medication in the last six weeks of life than compared to the primary cohort (15.7%). Similar to the primary cohort again, a higher proportion of the secondary cohort only received their prescription in the 0-2-week before death period (11.9%) compared to those who received a prescription in the 2-6-week period (3.8%) (eTable 5).

After adjusting for covariates in the secondary analysis cohort, those who received an end-of-life prescription had a decreased risk of dying in an institution than those who did not receive a prescription (RR: 0.40, 95% CI: 0.38 - 0.42) (eTable 6). Similar to the primary analysis cohort, receiving a prescription in the 2-6-week period before death was associated with a substantially decreased risk (RR: 0.70, 95% CI: 0.58 - 0.85) of an emergency department visit in the last two weeks of life. Those who received a prescription in the 0-2-week period had a less substantial, but still significant, decreased risk (RR: 0.85, 95% CI: 0.76 - 0.94) of an emergency department visit in the same period. Similarly, with regards to hospitalizations in the last two weeks of life, receiving a prescription in the 2-6-week period before death was associated with a substantially decreased risk (RR: 0.38, 95% CI: 0.34 - 0.41) of a hospitalization the last two weeks of life. Those who received a prescription in the 0-2-week period had a less substantial, but still significant, decreased risk (RR: 0.83, 95% CI: 0.81 - 0.85) of a hospitalization in the same period.

### 4.6. Discussion

In this population-based retrospective cohort study of decedents who received home care in the final year of life, we found that only 28.6 % were prescribed at least one end-of-life prescription in the final six weeks of life. We also found that people who received an end-of-life prescription in the final six weeks of life were significantly less likely to visit the emergency department or get admitted to hospital in the last two weeks of life or die in an institution than those who did not receive such a prescription. Additionally, the associations between prescribing and late acute care use were stronger among those who received an end-of-life prescription earlier (in the 2-6-week period before death) than compared to those who only received a prescription in the final two weeks of life.

The overall prevalence of prescriptions for symptom management medications appears low, given the known prevalence of symptoms during the end-of-life period.[8] Previous research in Ontario found that two-thirds of decedents (64.7%) in LTC homes were prescribed at least one medication to relieve symptoms in the two weeks before death.[7] Similar to our findings, that study found that opioids were the most prescribed medication (62.7%), with hydromorphone the most common choice within this class (52.1%).[7] The lower prevalence of medication prescription in home care recipients compared to LTC residents may be a result of more than one phenomenon, such as the increased presence of medical care staff available in LTC, and structures set in place for end-of-life care in LTC. It is important to note that the lower prescribing found in home care compared to LTC is not due to residents experiencing fewer symptoms. Previous research has assessed symptom burden at the end-of-life among home care decedents in Ontario. Researchers identified loss of appetite (63%), shortness of breath (59%), high health instability (50%), and self-reported poor health (44%) as the most prevalent symptoms in the last week of life.[9] Furthermore, they

found covariates of caregiver distress, high health instability, social decline, uncontrolled pain, and depression to worsen the odds of having physical symptoms during the last three months of life.[9]

The risk of emergency department visits and hospitalizations in the last two weeks of life were both significantly lower among those who received an end-of-life prescription. This was observed in both our primary cohort of decedents who had no hospitalizations in the 2-6 weeks before death, as well as in the secondary cohort with at least one hospitalization in that period. We hypothesize that access to medications may help to manage distressing end-of-life symptoms in the home, and therefore decrease the risk of emergency department visits and hospitalizations for symptom control. In addition, we found that those who received a prescription were less likely to die in an institutional setting than those who did not receive a prescription. Dying outside of an institutional setting is commonly recognized as both a health system and end-of-life quality indicator.[11,12] When feasible, dying in the community is often the preferred choice for home care recipients as it helps to minimize stress during this already physically and emotionally challenging time.[11]

Of all the baseline characteristics assessed, the largest differences between decedents who did and did not receive a prescription were seen in the enrollment of palliative home care services. Compared to decedents who did not receive an end-of-life prescription in the last six weeks of life, those who did had a higher proportion enrolled in palliative home care services (11.4% and 42.6%, respectively). When assessing the 0-2-week and 2-6-week prescribing periods separately, the 2-6-week period had a higher proportion of recipients enrolled in palliative home care compared to the 0-2-week period (53.7% vs. 37.8%, respectively). Palliative focused services and care are designed to provide relief from symptoms associated

with serious illnesses.[12] While palliative care can be appropriate at any stage of illness, it is often utilized during end-of-life care.[12] Palliative focused care providers are trained to recognize signs that death is imminent and may prepare by prescribing accordingly. Another consideration for those receiving palliative home care services is that these individuals may have more complex conditions (e.g., cancer, dementia), and thus be monitored more closely through scheduled visits. Therefore, we hypothesize that the greater proportion of individuals prescribed an end-of-life medication could be correlated to the fact that a higher proportion of these recipients had access to palliative focused care services.

Finally, it is important to acknowledge that while the association between prescribing and deaths in the community is strong, it remains unclear whether this relationship is causal. Dying at home requires a variety of factors in addition to prescribing, such as not limited to timely care coordination, caregivers, physician home visits, and emotional and spiritual supports. Broadly relying on the prescribing of end-of-life medications may not lead to a significant increase in community deaths.

This study presents some limitations. To begin, administrative databases at ICES capture medication dispensing and not administration. Therefore, we cannot know whether the home care recipients received the medication. Furthermore, we are not able to ascertain whether patients had symptoms necessitating medication, or if patients' symptoms were relieved as a result of the medication. Although questions regarding symptom status are included in RAI assessments, these assessments are not completed frequently enough to comment on whether prescribing was appropriate (i.e., in response to symptoms) or successful (i.e., resulted in a reduction of symptoms). In addition, medication side effects could lead to detrimental outcomes in some cases. All home care residents at the end of life

require tailored individual care; while certain medications may be beneficial for patients in specific situations, they may not be appropriate for all patients at all times. Furthermore, with regards to the use of RAI assessments for covariate measurement, some of the covariate measurements may not accurately reflect one's status in the last six weeks of life (e.g., CPS, pain, and caregiver distress). Along with this, we were unable to capture other potentially important covariates in our analysis due to data limitations, such as individuals' underlying diagnoses and disease trajectories. Finally, it is important to note the potential for competing risk among the secondary analysis cohort. The more days that an individual spends in hospital during the exposure period, the likelihood of receiving a community prescription decreases. Although this represents a potential confounder in the secondary analysis, it is unlikely to be significant given the findings from the primary analysis.

### 4.7. Conclusions and Implications

Only a minority of home care recipients in Ontario receive an end-of-life prescription, but those who do are less likely to visit the emergency department, become hospitalized, or die in an institution than those who do not receive a prescription. As the population ages, healthcare systems will continue to depend on home care services to support the end-of-life needs of the population. Future research should focus on aspects of home care, including symptom management medication prescribing that are associated with positive end-of-life outcomes. This evidence will help policy makers and providers in adapting our current healthcare system to better support the home care needs of our aging population.

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## 4.8. Disclosures and Acknowledgments

### *4.8.1. Disclosures*

The authors have no conflicts of interest to disclose.

### *4.8.2. Acknowledgements*

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### *4.8.3. Funding Sources*

This work received funding from CIHR (grant number: 179916).

### 4.9. Tables and Figures

**Table 4-1.** Decedent baseline characteristics among the primary cohort according to the receipt of an end-of-life prescription in the last six weeks of life**.**

| Variable | Total | Those who have received a EOL Rx | Those who have not received a EOL Rx |
|---|---|---|---|
| **Total - n (%)** | **55,903** | 16,012 (28.6) | 39,891 (71.4) |
| **Sex – n (%)** | | | |
| Male | **25,484 (45.6)** | 7,007 (43.8) | 18,477 (46.3) |
| Female | **30,419 (54.4)** | 9,005 (56.2) | 21,414 (53.7) |
| **Age (years) – n (%)** | | | |
| Overall – Mean (SD) | **85.1 (8.3)** | 85.2 (8.4) | 85.0 (8.3) |
| 66-75 | **8681 (15.5)** | 2,511 (15.7) | 6,170 (15.5) |
| 76-85 | **17,829 (31.9)** | 4,954 (30.9) | 12,875 (32.3) |
| 86-95 | **24,448 (43.7)** | 6,970 (43.5) | 17,478 (43.8) |
| 95-105 | **4,945 (8.9)** | 1,577 (9.8) | 3,368 (8.4) |
| **Neighborhood Income Quintile – n (%)** | | | |
| 1 - Lowest | **13,953 (25.0)** | 3,553 (22.2) | 10,400 (26.1) |
| 2 - Low | **12,434 (22.2)** | 3,351 (20.9) | 9,083 (22.8) |
| 3 - Middle | **10,767 (19.3)** | 3,127 (19.5) | 7,640 (19.2) |
| 4 - High | **9,495 (17.0)** | 3,022 (18.9) | 6,473 (16.2) |
| 5 - Highest | **9007 (16.1)** | 2,871 (17.9) | 6,136 (15.5) |
| Missing | **247 (0.4)** | 88 (0.6) | 159 (0.4) |
| **Rurality n (%)** | | | |
| Urban | **48,833 (87.4)** | 13,748 (85.9) | 35,085 (88.0) |
| Rural | **6,844 (12.2)** | 2,184 (13.6) | 4,660 (11.7) |
| Missing | **226 (0.4)** | 80 (0.5) | 146 (0.4) |
| **Immigration Status – n (%)** | | | |
| Landed Immigrant after 1985 | **3,675 (6.6)** | 700 (4.4) | 2,975 (7.5) |
| Canadian born/long term resident | **52,228 (93.4)** | 15,312 (95.6) | 36,916 (92.5) |

| | | | |
|---|---|---|---|
| **Language – n (%)** | | | |
| Anglophone | **35,427 (63.4)** | 10,597 (66.2) | 24,830 (62.2) |
| Francophone | **1,067 (1.9)** | 316 (2.0) | 751 (1.9) |
| Allophone | **19,403 (34.7)** | 5,098 (31.8) | 14,305 (35.9) |
| Missing | **6 (0.0)** | 1 (0.0) | 5 (0.0) |
| **Attachment to a Family Physician – n (%)** | | | |
| Yes | **2,699 (4.8)** | 779 (4.9) | 1,920 (4.8) |
| Yes - Virtually Rostered | **10,431 (18.7)** | 3,404 (21.3) | 7,027 (17.6) |
| No | **42,773 (76.5)** | 11,829 (73.9) | 30,944 (77.6) |
| **Palliative Home Care – n (%)** | | | |
| Yes | **11,392 (20.4)** | 6,826 (42.6) | 4,566 (11.4) |
| No | **44,511 (79.6)** | 9,186 (57.4) | 35,325 (88.6) |
| **Cognitive Performance Scale – n (%)** | | | |
| Intact | **7,808 (14.0)** | 2,377 (14.9) | 5,431 (13.6) |
| Borderline intact | **7,105 (12.7)** | 1,842 (11.5) | 5,263 (13.2) |
| Mild impairment | **23,983 (42.9)** | 6,011 (37.5) | 17,972 (45.1) |
| Moderate impairment | **7,757 (13.9)** | 2,532 (15.8) | 5,225 (13.1) |
| Moderate/severe impairment | **1,423 (2.6)** | 515 (3.2) | 908 (2.3) |
| Severe impairment | **5,825 (10.4)** | 2,095 (13.1) | 3,730 (9.4) |
| Very severe impairment | **2,002 (3.6)** | 640 (4.0) | 1,362 (3.4) |
| **Pain – n (%)** | | | |
| No pain | **20,487 (36.7)** | 5,782 (36.1) | 14,705 (36.9) |
| Mild | **7,184 (12.9)** | 2,059 (12.7) | 5,125 (12.9) |
| Moderate | **20,230 (36.2)** | 5,773 (36.1) | 14,457 (36.2) |
| Severe | **6,260 (11.2)** | 1,860 (11.6) | 4,400 (11.0) |
| Times when pain is horrible or excruciating | **1,742 (3.1)** | 538 (3.4) | 1,204 (3.0) |
| **Two Key Informal Helpers – Lives with Primary Caregiver – n (%)** | | | |
| Yes | **42,376 (75.8)** | 12,003 (76.2) | 30,173 (75.6) |

| | | | |
|---|---|---|---|
| No | **12,966 (23.2)** | 3,717 (23.2) | 9,249 (23.2) |
| No such helper | **561 (1.0)** | 92 (0.6) | 469 (1.2) |
| **Primary Informal Helper Expresses Feeling of Distress, Anger, or Depression – n (%)** | | | |
| Yes | **22,974 (41.1)** | 7,120 (44.5) | 15,854 (39.7) |
| No | **32,929 (58.9)** | 8,892 (55.5) | 24,037 (60.3) |

*EOL Rx = End-of-life Prescription

**Table 4-2.** End-of-life prescription medications and medication classes among the primary cohort in the last six weeks of life.

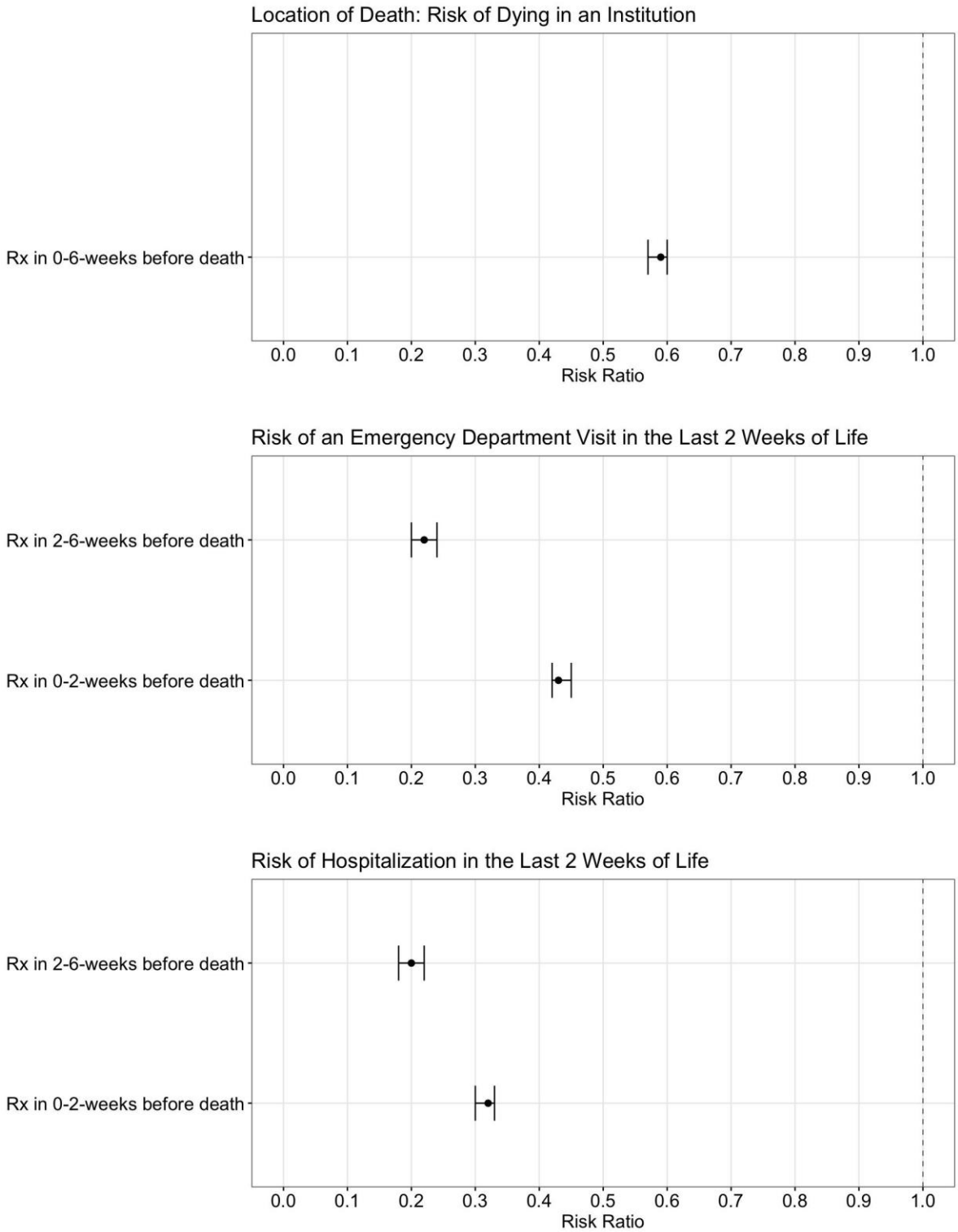
| Medication | Decedents that received an EOL Rx |
|---|---|
| **Any Medication Class – n (%)** | 16,012 (28.6) |
| **Opioids** | |
| Morphine – n (%) | 2,510 (15.7) |
| Hydromorphone – n (%) | 12,034 (75.2) |
| **Pain (non-opioid)** | |
| Dexamethasone – n (%) | 1,404 (8.8) |
| **Benzodiazepines** | |
| Lorazepam – n (%) | 753 (4.7) |
| Midazolam – n (%) | 8,067 (50.4) |
| **Antipsychotics** | |
| Haloperidol – n (%) | 8,416 (52.6) |
| Methotrimeprazine – n (%) | 4,931 (30.8) |
| **Sedatives** | |
| Phenobarbital – n (%) | 177 (1.1) |
| **Excessive Respiratory Secretions** | |
| Scopolamine – n (%) | 7,223 (45.1) |
| Glycopyrrolate – n (%) | 2,413 (15.1) |
| **Pulmonary Edema** | |
| Furosemide – n (%) | 516 (3.2) |
| **Nausea/Vomiting** | |
| Metoclopramide – n (%) | 1,005 (6.3) |

*EOL Rx = End-of-life Prescription

**Table 4-3.** Crude values describing the association between end-of-life prescribing and the study outcomes (location of death, emergency department visits in the last two weeks of life and hospitalizations in the last two weeks of life) among the primary cohort.

| **Location of Death** | | | |
|---|---|---|---|
| **EOL Rx** | **Institution** | **Community** | **Total** |
| Yes: In the 0-6-week period before death | 5,734 (35.8) | 10,278 (64.2) | 16,012 (28.6) |
| No | 30,684 (76.9) | 9,207 (23.1) | 39,891 (71.4) |
| **Total** | 36,418 (65.1) | 19,485 (34.9) | **55,903** |
| **Emergency Department Visit in the 0-2 weeks before death** | | | |
| **EOL Rx** | **Yes** | **No** | **Total** |
| Yes: Only in the 0-2-week period before death | 2,744 (24.6) | 8,412 (75.4) | 11,156 (20.0) |
| Yes: In the 2-6-week period before death | 586 (12.1) | 4,270 (87.9) | 4,856 (8.7) |
| No | 25,380 (63.6) | 14,511 (36.4) | 39,891 (71.4) |
| **Total** | 28,710 (51.4) | 27,193 (48.6) | **55,903** |
| **Hospitalizations in the 0-2 weeks before death** | | | |
| **EOL Rx** | **Yes** | **No** | **Total** |
| Yes: Only in the 0-2-week period before death | 1,902 (17.1) | 9,254 (83.0) | 11,156 (20.0) |
| Yes: In the 2-6-week period before death | 509 (10.5) | 4,347 (89.5) | 4,856 (8.7) |
| No | 23,975 (60.1) | 15,916 (39.9) | 39,891 (71.4) |
| **Total** | 26,386 (47.2) | 29,517 (52.8) | **55,903** |

*EOL Rx = End-of-life prescription




** Rx = Prescription

**Figure 4-1.** Adjusted risk ratios and 95% confidence intervals of end-of-life prescribing in association with location of death in an institution, and emergency department visits and hospitalizations in the last two weeks of life.

## 4.10. Manuscript Supplement

### eMethods

Data Sources Information Linked Datasets Used in Study

Cohort Creation

Outcome Definitions

Covariate Definitions

### eResults

**eFigure 1.** Cohort creation flow diagram based on study exclusion criteria.

**eTable 1.** Associations between end-of-life prescribing and the outcomes among the primary cohort.

**eTable 2.** Baseline characteristics among the primary cohort using both 0-2 and 2-6-week prescribing windows.

**eTable 3**. Baseline characteristics among the secondary cohort using the 0-6 week prescribing window.

**eTable 4.** End-of-life prescription medications and medication classes among the secondary cohort in the last six weeks of life.

**eTable 5.** End-of-life prescribing among the secondary cohort using the 0-2- and 2-6-week prescribing windows.

**eTable 6.** Associations between end-of-life prescriptions and the outcomes among the secondary cohort.

**eTable 7.** Crude values describing the association between end-of-life prescribing and the study outcomes (location of death, emergency department visits in the last two

weeks of life and hospitalizations in the last two weeks of life) among the secondary cohort.

**Data Sources, Information, and Linked Datasets Used in Study**

We obtained study data from de-identified and linked health administrative databases housed at ICES. In 2018, the institute formerly known as the Institute for Clinical Evaluative Sciences formally adopted the initialism ICES as its official name. This change acknowledges the growth and evolution of the organization's research since its inception in 1992, while retaining the familiarity of the former acronym within the scientific community and beyond.

ICES is an independent, non-profit research institute funded by an annual grant from the Ontario Ministry of Health (MOH) and the Ministry of Long-Term Care (MLTC). As a prescribed entity under Ontario's privacy legislation, ICES is authorized to collect and use health care data for the purposes of health system analysis, evaluation, and decision support. Secure access to these data is governed by policies and procedures that are approved by the Information and Privacy Commissioner of Ontario. The datasets from this study are held securely in coded form at ICES. While legal data sharing agreements between ICES and data providers (e.g., healthcare organizations and government) prohibit ICES from making the datasets publicly available, access may be granted to those who meet pre-specified criteria for confidential access, available at www.ices.on.ca/DAS (email: das@ices.on.ca). The full dataset creation plan and underlying analytic code are available from the authors upon request, understanding that the computer programs may rely upon coding templates or macros that are unique to ICES and are therefore either inaccessible or may require modification. These datasets were linked using unique encoded identifiers and analyzed at ICES.

We used the following databases:

ICES databases and associated descriptions used to make the cohort.

| ICES Database | Description |
|---|---|
| Registered Persons Database (RPDB) | Demographic and vital statistics information for those eligible for insurance health services in Ontario, Canada |
| Resident Assessment Instrument - Home Care (RAI-HC) | The RAI-HC database was used to capture home care recipients across Ontario between January 1, 2017 and April 1, 2018 |
| International Resident Assessment Instrument (InterRAI-HC) | The InterRAI-HC database was used to capture home care recipients across Ontario between April 1, 2018 and March 17, 2020 |
| Home Care Database (HCD) | Contains recipient level demographic, diagnostic, and treatment information for all home care visits |
| National Ambulatory Care Reporting System (NACRS) | Recipient-level demographic, diagnostic, and treatment information for hospital and community-based ambulatory care. This dataset includes both outpatient and |

| | |
|---|---|
| | community-based clinics and emergency departments. |
| Discharge Abstract Database (DAD) | Recipient-level demographic, diagnostic, and treatment information for all acute care hospitalizations |
| ODB (Ontario Drug Benefit) | Captures all medications covered by the provincial health insurance prescribed in the community |
| Ontario Health Insurance Plan (OHIP) | Contains records of claims for physician services covered by the provincial government |
| Drug Identification Number (DIN) | Contains information pertaining to unique numbers assigned to all drugs in Canada. The DIN databases identify all drug products, including manufacturer, product name, active ingredient(s), strength(s) of active ingredient(s), pharmaceutical form, and route of administration. |
| Postal Code Conversion File (PCCF) | Contains information on the rurality (urban vs. rural) of home care recipients primary residence address |
| Client Agency Program Enrollment (CAPE) | Contains information pertaining to the rostering of individuals to primary care physicians |
| Citizenship and Immigration Canada (CIC) | Contains landing records for all permanent legal immigrants to Ontario, Canada |
| CENSUS | Contains formation collected by the national census administered every five years across Canada by Statistics Canada (2016 record) |
| Ontario Mental Health Reporting System (OMHRS) | Contains admissions to mental health designated hospital beds |
| CCRS | Contains demographic, clinical and functional data on individuals receiving continuing care services (captures individuals in complex continuing care (CCRS-CCC) and long-term care (CCRS-LTC). |
| National Rehabilitation Reporting System (NRS) | Contains information from participating adult inpatient rehabilitation facilities and programs |

**Cohort Creation**

Home care residents were identified using the RAI-HC and InterRAI-HC databases. Deaths were identified using the Registered Persons Database (RPDB). We also used RPDB to identify those not within our defined age range (<66 and >105) and those that were not eligible for the Ontario Health Insurance Plan in the last month of life.

**Outcome Definition**

The complete list of end-of-life prescription medications used, including drug class, drug name and DIN.

| Medication Classification | Intention for Treatment | End-of-life Symptom Management Medications | DIN(s) |
|---|---|---|---|
| Analgesics | Pain (Opioids) | Morphine | 00392561, 00392588, 00617288, 02242484, 09857226, 09857227 |
| | | Hydromorphone | 02145901, 02145928, 02145936, 02146126 |
| | Pain (Non-opioid) | Dexamethasone | 00664227, 01977547 |
| Benzodiazepines | Anxiety | Lorazepam | 02243278, 09857216 |
| | | Midazolam | 02240286, 09857225, 02242905, 09857436, 09857438, 09857479 |
| Antipsychotics | Delirium/Agitation | Haloperidol | 02130297, 02130300, 09853758, 00808652 |
| | | Methotrimeprazine | 01927698 |
| Barbiturates | Sedatives | Phenobarbital | 02304090, 09857296 |
| Anticholinergics | Excessive Respiratory | Scopolamine | 09857384, 09857385, 00363839, 09857213, |

| | | | |
|---|---|---|---|
| | Secretions | | 00541869, 00541877, 02242810, 02242811, 09857236, 09857237 |
| | | Glycopyrrolate | 02039508, 02382857, 09857212, 09857266, 09857521 |
| Diuretics | Pulmonary Edema | Furosemide | 00527033, 09857208 |
| Prokinetic agents | Nausea/Vomiting | Metoclopramide | 02185431, 09857224 |

**Covariate Definitions**

Covariate definitions based on associated databases. Definitions include harmonization of variables across RAI-HC and InterRAI-HC datasets.

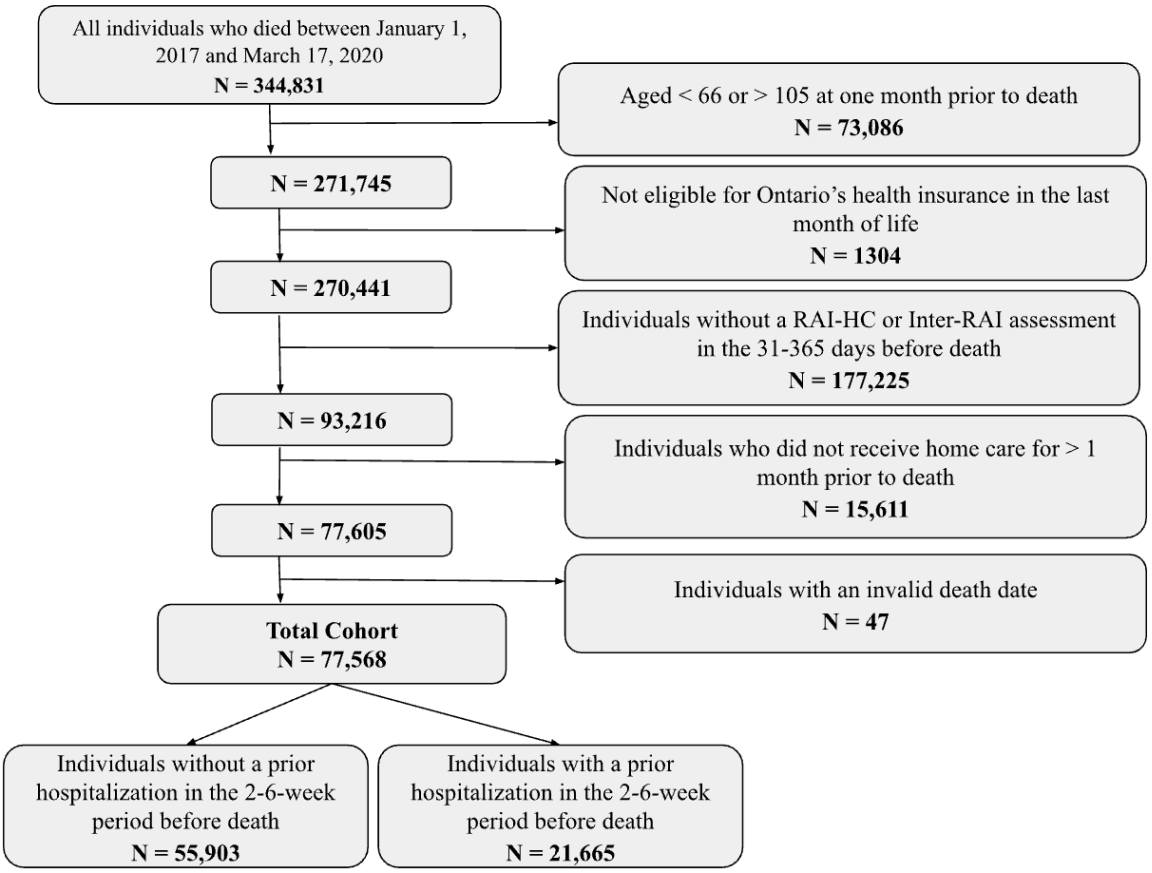
| **Type** | **Database** | **Description** |
|---|---|---|
| Age | RPDB | Age at one month before death<br>- 66 - 75<br>- 76 - 85<br>- 86 - 95<br>- 95 + |
| Sex | RPDB | Biological sex (Male, Female) |
| Primary Language | RAI-HC + InterRAI-HC | RAI-HC = BB5A, InterRAI-HC = B3<br>** Note: Removed art (artificial language), ase/asl/fcs (sign languages), mul (multiple languages) |
| Rurality | RPDB + PCCF | - Rural (If CSIZE = 5 in PCCF, meaning community size <=10,000 people)<br>- Urban (CSIZE ≠ 5) |
| Income | RPDB + PCCF + Census | - Lowest<br>- Low<br>- Middle<br>- High<br>- Highest<br>- Missing |

| | | |
|---|---|---|
| Cognitive Performance Scale | RAI-HC + InterRAI-HC | RAI-HC = COGNITIVE_PERFORMANCE_SCALE, InterRAI-HC = CPS<br>- 0 = Intact<br>- 1 = Borderline intact<br>- 2 = Mild impairment<br>- 3 = Moderate impairment<br>- 4 = Moderate/severe impairment<br>- 5 = Severe impairment<br>- 6 = Very severe impairment |
| Pain | RAI-HC + InterRAI-HC | RAI-HC = K4B_RAIHC, InterRAI-HC = J5B<br>- 0 = No Pain<br>- 1 = Mild<br>- 2 = Moderate<br>- 3 = Severe<br>- 4 = Times when pain is horrible or excruciating |
| Attachment to a Family Physician | CAPE + OHIP | - Yes<br>  - Rostered via CAPE – based on year prior to index --> breakdown by primarily Capitation vs. Primarily fee for service<br>  - Virtual rostered via OHIP – based on encounters in year prior to index<br>- No (If not rostered and unattached, then no family physician) |
| Immigration Status | CIC | - Yes: If landing date<br>- No: If missing landing date |
| Palliative Home Care | HCD | - Yes: Admission or service or discharge SRC = 95 or 54 during the period of observation for EOL Rx<br>- No |
| Primary Informal Helper Expresses Feeling of Distress, Anger, or Depression | RAI-HC + InterRAI-HC | RAI-HC = G2c, InterRAI-HC = P2b<br>○ 0 = No<br>○ 1 = Yes |
| Two Key Informal Helpers – Lives with Primary Person | RAI-HC + InterRAI-HC | RAI-HC = G1ea, InterRAI-HC = P1b1<br>- RAI-HC<br>  - 0 = Yes<br>  - 1 = No |

| | | |
|---|---|---|
| | | - 2 = No such helper<br>- InterRAI-HC<br>  - 0 = No<br>  - 1 = Yes, 6 months or less<br>  - 2 = Yes, more than 6 months<br>  - 8 = No informal helper<br><br>Grouping<br>- Yes (RAI-HC = 0, InterRAI-HC = 1,2)<br>- No (RAI-HC = 1, InterRAI-HC = 0)<br>- No such helper (RAI-HC = 2, InterRAI-HC = 8) |

RPDB: Registered Persons Database; RAI-HC: Resident Assessment Instrument - Home Care; InterRAI-HC: International Resident Assessment Instrument; PCCF - Postal Code Conversion File; CAPE: Client Agency Program Enrollment; OHIP: Ontario Health Insurance Plan; CIC: Citizenship and Immigration Canada; HCD: Home Care Database

### *4.11.5. Results*




**eFigure 1.** Cohort creation flow diagram based on study exclusion criteria.

**eTable 1.** Associations between end-of-life prescribing and the outcomes among the primary cohort.

| Prescribing Period | Unadjusted RR and 95 % CI | Adjusted RR and 95 % CI |
|---|---|---|
| **Location of Death (Institution)** | | |
| Received an EOL Rx in the 0-6-week period before death | 0.46 (0.45 - 0.47) | 0.59 (0.57 - 0.60) |
| **Emergency Department in last two weeks of life** | | |
| Received an EOL Rx in only 0–2-week period before death | 0.39 (0.37 - 0.40) | 0.43 (0.42 - 0.45) |
| Received an EOL Rx in 2–6-week period before death | 0.19 (0.17 - 0.20) | 0.22 (0.20 - 0.24) |
| **Hospitalization in last two weeks of life** | | |
| Received an EOL Rx in only 0–2-week period before death | 0.28 (0.26 - 0.29) | 0.32 (0.30 - 0.33) |
| Received an EOL Rx in 2–6-week period before death | 0.17 (0.16 - 0.19) | 0.20 (0.18 - 0.22) |

*EOL Rx = End-of-life prescription, RR = Risk ratio, CI = Confidence interval

**eTable 2.** Baseline characteristics among the primary cohort using both 0-2 and 2-6-week prescribing windows.

| Variable | Total | EOL Rx only in the 0–2-week period | EOL Rx in the 2–6-week period | No EOL Rx |
|---|---|---|---|---|
| Total - n (%) | **55,903** | 11,156 (20.0) | 4,856 (8.7) | 39,891 (71.4) |
| **Sex – n (%)** | | | | |
| Male | **25,484 (45.6)** | 4,910 (44.0) | 2,097 (43.2) | 18,477 (46.3) |
| Female | **30,419 (54.4)** | 6,246 (56.0) | 2,759 (56.8) | 21,414 (53.7) |
| **Age (years) – n (%)** | | | | |
| Overall – Mean (SD) | **85.03 (8.3)** | 85.88 (8.2) | 83.56 (8.7) | 84.97 (8.3) |
| 66-75 | **8681 (15.5)** | 1,474 (13.2) | 1,037 (21.4) | 6,170 (15.5) |
| 76-85 | **17,829 (31.9)** | 3,335 (29.9) | 1,619 (33.3) | 1,2875 (32.3) |
| 86-95 | **24,448 (43.7)** | 5,124 (45.9) | 1,846 (38.0) | 17,478 (43.8) |
| 96-105 | **4,945 (8.9)** | 1,223 (11.0) | 354 (7.3) | 3,368 (8.4) |
| **Neighborhood Income Quintile – n (%)** | | | | |
| 1 - Lowest | **13,953 (25.0)** | 2,484 (22.3) | 1,069 (22.0) | 10,400 (26.1) |
| 2 - Low | **12,434 (22.2)** | 2,326 (20.9) | 1,025 (21.1) | 9,083 (22.8) |
| 3 - Middle | **10,767 (19.3)** | 2,135 (19.1) | 992 (20.4) | 7,640 (19.2) |
| 4 - High | **9,495 (17.0)** | 2,117 (19.0) | 905 (18.6) | 6,473 (16.2) |
| 5 - Highest | **9007 (16.1)** | 2,029 (18.2) | 842 (17.3) | 6,136 (15.4) |
| Missing | **247 (0.4)** | 65 (0.6) | 23 (0.5) | 159 (0.4) |
| **Rurality – n (%)** | | | | |
| Urban | **48,833 (87.4)** | 9,607 (86.1) | 4,141 (85.3) | 35,085 (88.0) |

| | | | | |
|---|---|---|---|---|
| Rural | **6,844 (12.2)** | 1,489 (13.4) | 695 (14.3) | 4,660 (11.7) |
| Missing | **226 (0.4)** | 60 (0.5) | 20 (0.4) | 146 (0.4) |
| **Immigration Status – n (%)** | | | | |
| Yes | **3,675 (6.6)** | 419 (3.8) | 281 (5.8) | 2,975 (7.5) |
| Canadian born/long term resident | **52,228 (93.4)** | 10,737 (96.2) | 4,575 (94.2) | 36,916 (92.5) |
| **Language – n (%)** | | | | |
| Anglophone | **35,427 (63.4)** | 7,357 (66.0) | 3,240 (66.7) | 24,830 (62.6) |
| Francophone | **1,067 (1.9)** | 208 (1.9) | 108 (2.2) | 751 (1.9) |
| Allophone | **19,403 (34.7)** | 3,590 (32.2) | 1,508 (31.1) | 14,305 (35.9) |
| Missing | **6 (0.0)** | 1 (0.0) | 0 (0.00) | 5 (0.0) |
| **Attachment to a Family Physician – n (%)** | | | | |
| Yes | **2,699 (4.8)** | 536 (4.8) | 243 (5.0) | 1,920 (4.8) |
| Yes - Virtually Rostered | **42,773 (76.5)** | 8,265 (74.1) | 3,564 (73.4) | 30,944 (77.6) |
| No | **10,431 (18.7)** | 2,355 (21.1) | 1,049 (21.6) | 7,027 (17.6) |
| **Palliative Home Care – n (%)** | | | | |
| Yes | **11,392 (20.4)** | 4,219 (37.8) | 2,607 (53.7) | 4,566 (11.5) |
| No | **44,511 (79.6)** | 6,937 (62.2) | 2,249 (46.3) | 35,325 (88.6) |
| **Cognitive Performance Scale – n (%)** | | | | |
| Intact | **7,808 (14.0)** | 1,434 (12.9) | 943 (19.4) | 5,431 (13.6) |
| Borderline intact | **7,105 (12.7)** | 1,175 (10.5) | 667 (13.7) | 5,263 (13.2) |
| Mild impairment | **23,983 (42.9)** | 4,136 (37.1) | 1,875 (38.6) | 17,972 (45.1) |
| Moderate impairment | **7,757 (13.9)** | 1,918 (17.2) | 614 (12.6) | 5,225 (13.1) |

| | | | | |
|---|---|---|---|---|
| Moderate/severe impairment | **1,423 (2.6)** | 392 (3.5) | 123 (2.5) | 908 (2.3) |
| Severe impairment | **5,825 (10.4)** | 1,644 (14.7) | 451 (9.3) | 3,730 (9.4) |
| Very severe impairment | **2,002 (3.6)** | 457 (4.1) | 183 (3.8) | 1,362 (3.4) |
| **Pain – n (%)** | | | | |
| No pain | **20,487 (36.7)** | 4,221 (37.8) | 1,561 (32.2) | 14,705 (36.9) |
| Mild | **7,184 (12.9)** | 1,479 (13.3) | 580 (11.9) | 5,125 (12.9) |
| Moderate | **20,230 (36.2)** | 3,931 (35.2) | 1,842 (37.9) | 14,457 (36.2) |
| Severe | **6,260 (11.2)** | 1,177 (10.6) | 683 (14.1) | 4,400 (11.0) |
| Times when pain is horrible or excruciating | **1,742 (3.1)** | 348 (3.1) | 190 (3.9) | 1,204 (3.0) |
| **Two Key Informal Helpers – Lives with Primary Caregiver – n (%)** | | | | |
| Yes | **42,376 (75.8)** | 8,321 (74.6) | 3,882 (79.9) | 30,173 (75.6) |
| No | **12,966 (23.2)** | 2,764 (24.8) | 953 (19.6) | 9,249 (23.2) |
| No such helper | **561 (1.0)** | 71 (0.6) | 21 (0.4) | 469 (1.2) |
| **Primary Informal Helper Expresses Feeling of Distress, Anger, or Depression – n (%)** | | | | |
| Yes | **22,974 (41.1)** | 5,060 (45.4) | 2,060 (42.4) | 15,854 (39.7) |
| No | **32,929 (58.9)** | 6,096 (54.6) | 2,796 (57.6) | 24,037 (60.3) |

*EOL Rx = End-of-life Prescription

**eTable 3**. Baseline characteristics among the secondary cohort using the 0-6 week prescribing window.

| Variable | Total | Those who have received a EOL Rx | Those who have not received a EOL Rx |
|---|---|---|---|
| **Total - n (%)** | **21,665** | 3,401 (15.7) | 18,264 (84.3) |
| **Sex – n (%)** | | | |
| Male | **10,667 (29.2)** | 1,607 (47.3) | 9,060 (49.6) |
| Female | **10,998 (50.8)** | 1,794 (52.8) | 9,204 (50.4) |
| **Age (years) – n (%)** | | | |
| Overall – Mean (SD) | **84.1 (8.1)** | 84.2 (8.1) | 84.0 (8.1) |
| 66-75 | **3,728 (17.2)** | 590 (17.4) | 3,138 (17.2) |
| 76-85 | **7,701 (35.6)** | 1,153 (33.9) | 6,548 (35.9) |
| 86-95 | **8,887 (41.0)** | 1,435 (42.2) | 7,452 (40.8) |
| 95-105 | **1,349 (6.2)** | 223 (6.6) | 1,126 (6.2) |
| **Neighborhood Income Quintile – n (%)** | | | |
| 1 - Lowest | **5,916 (27.3)** | 813 (23.9) | 5,103 (27.9) |
| 2 - Low | **4,929 (22.8)** | 751 (22.1) | 4,178 (22.9) |
| 3 - Middle | **4,047 (18.7)** | 652 (19.2) | 3,395 (18.6) |
| 4 - High | **3,537 (16.3)** | 598 (17.6) | 2,939 (16.1) |
| 5 - Highest | **3,167 (14.6)** | 572 (16.8) | 2,595 (14.2) |
| Missing | **69 (0.3)** | 15 (0.4) | 54 (0.3) |
| **Rurality n (%)** | | | |
| Urban | **18,828 (86.9)** | 2,878 (84.6) | 15,950 (87.3) |
| Rural | **2,776 (12.8)** | 511 (15.0) | 2,265 (12.4) |
| Missing | **49 (0.3)** | 12 (0.4) | 49 (0.3) |
| **Immigration Status – n (%)** | | | |
| Landed Immigrant after 1985 | **1,582 (7.3)** | 182 (5.4) | 1,400 (7.7) |
| Canadian born/long term resident | **20,083 (92.7)** | 3,219 (94.7) | 16,864 (92.3) |
| **Language – n (%)** | | | |

| | | | |
|---|---|---|---|
| Anglophone | **13,204 (61.0)** | 2,203 (64.8) | 11,001 (60.2) |
| Francophone | **455 (2.1)** | 49 (1.4) | 406 (2.2) |
| Allophone | **8,006 (37.0)** | 1,149 (33.8) | 6,857 (37.5) |
| Missing | **0 (0.0)** | 0 (0.0) | 0 (0.0) |
| **Attachment to a Family Physician – n (%)** | | | |
| Yes | **1,017 (4.7)** | 162 (4.8) | 855 (4.7) |
| Yes - Virtually Rostered | **4,146 (19.1)** | 723 (21.3) | 3,423 (18.7) |
| No | **16,502 (76.2)** | 2,516 (74.0) | 13,986 (76.6) |
| **Palliative Home Care – n (%)** | | | |
| Yes | **2,500 (11.5)** | 1,210 (35.6) | 1,290 (7.1) |
| No | **19,165 (88.5)** | 2,191 (64.4) | 16,974 (92.9) |
| **Cognitive Performance Scale – n (%)** | | | |
| Intact | **3,072 (14.2)** | 551 (16.2) | 2,521 (13.8) |
| Borderline intact | **2,811 (13.0)** | 416 (12.2) | 2,395 (13.1) |
| Mild impairment | **9,876 (45.6)** | 1,401 (41.2) | 8,475 (46.4) |
| Moderate impairment | **2,874 (13.3)** | 476 (14.0) | 2,398 (13.1) |
| Moderate/severe impairment | **537 (2.5)** | 117 (3.4) | 420 (2.3) |
| Severe impairment | **1,887 (8.7)** | 340 (10.0) | 1,547 (8.5) |
| Very severe impairment | **608 (2.8)** | 100 (2.9) | 508 (2.8) |
| **Pain – n (%)** | | | |
| No pain | **7,600 (35.1)** | 1,206 (35.5) | 6,394 (35.0) |
| Mild | **2,672 (12.3)** | 460 (13.5) | 2,212 (12.1) |
| Moderate | **7,969 (38.8)** | 1,230 (36.2) | 6,739 (36.9) |
| Severe | **2,661 (12.3)** | 403 (11.9) | 2,258 (12.4) |
| Times when pain is horrible or excruciating | **763 (3.5)** | 102 (3.0) | 661 (3.6) |
| **Two Key Informal Helpers – Lives with Primary Caregiver – n (%)** | | | |
| Yes | **16,698 (77.1)** | 2,626 (77.2) | 14,072 (77.1) |
| No | **4,716 (21.8)** | 742 (22.8) | 3,974 (21.8) |

| | | | |
|---|---|---|---|
| No such helper | **251 (1.2)** | 33 (1.0) | 218 (1.2) |
| **Primary Informal Helper Expresses Feeling of Distress, Anger, or Depression – n (%)** | | | |
| Yes | **9,316 (43.0)** | 1,476 (43.4) | 7,840 (42.9) |
| No | **12,349 (57.0)** | 1,925 (56.6) | 10,424 (57.1) |

*EOL Rx = End-of-life Prescription

**eTable 4.** End-of-life prescription medications and medication classes among the secondary cohort in the last six weeks of life.

| Medication | Decedents that received an EOL Rx |
|---|---|
| **Any Medication Class – n (%)** | 3,401 (15.7) |
| **Opioids** | |
| Morphine – n (%) | 537 (15.8) |
| Hydromorphone – n (%) | 2,615 (76.9) |
| **Pain (non-opioid)** | |
| Dexamethasone – n (%) | 331 (9.7) |
| **Benzodiazepines** | |
| Lorazepam – n (%) | 174 (5.1) |
| Midazolam – n (%) | 1,834 (53.9) |
| **Antipsychotics** | |
| Haloperidol – n (%) | 1,913 (55.3) |
| Methotrimeprazine – n (%) | 1,254 (36.9) |
| **Sedatives** | |
| Phenobarbital – n (%) | 49 (1.4) |
| **Excessive Respiratory Secretions** | |
| Scopolamine – n (%) | 1,633 (48.0) |
| Glycopyrrolate – n (%) | 626 (18.4) |
| **Pulmonary Edema** | |
| Furosemide – n (%) | 109 (3.2) |
| **Nausea/Vomiting** | |
| Metoclopramide – n (%) | 242 (7.1) |

*EOL Rx = End-of-life Prescription

**eTable 5.** End-of-life prescribing among the secondary cohort using the 0-2- and 2-6-week prescribing windows.

| Variable | Total | EOL Rx only in the 0–2-week period | EOL Rx in the 2–6-week period | No EOL Rx |
|---|---|---|---|---|
| **Total - n (%)** | **21,665** | 2,576 (11.9) | 825 (3.8) | 18,264 (84.3) |

*EOL Rx = End-of-life Prescription

**eTable 6.** Associations between end-of-life prescriptions and the outcomes among the secondary cohort.

| Prescribing Window | Unadjusted RR and 95% CI | Adjusted RR and 95% CI |
|---|---|---|
| **Location of Death (Institution)** | | |
| Received an EOL Rx in the 0-6 weeks before death period | 0.38 (0.36 - 0.40) | 0.40 (0.38 - 0.42) |
| **Emergency Department in the last two weeks of life** | | |
| Received an EOL RX only in the 0–2-week period before death | 0.84 (0.75 - 0.92) | 0.85 (0.76 - 0.94) |
| Received an EOL Rx in the 2–6-week period before death | 0.71 (0.58 - 0.85) | 0.70 (0.58 - 0.85) |
| **Hospitalization in the last two weeks of life** | | |
| Received an EOL Rx only in the 0–2-week period before death | 0.82 (0.90 - 0.83) | 0.83 (0.81 - 0.85) |
| Received an EOL Rx in the 2–6-week period before death | 0.37 (0.33 - 0.40) | 0.38 (0.34 - 0.41) |

*EOL Rx = End-of-life prescription, RR = Risk ratio, CI = Confidence interval

**eTable 7.** Crude values describing the association between end-of-life prescribing and the study outcomes (location of death, emergency department visits in the last two weeks of life and hospitalizations in the last two weeks of life) among the secondary cohort.

| Received an End-of-life Prescription | Location of Death | | Total |
|---|---|---|---|
| | Institution | Community | |
| **Yes: In the 0-6-week period before death** | 1,213 (35.7) | 2,188 (64.3) | 3,401 (15.7) |
| **No** | 17,141 (93.4) | 1,123 (6.2) | 18,264 (84.3) |
| **Total** | 18,354 (84.7) | 3,311 (15.3) | **21,665** |

| Received an End-of-life Prescription | ED in 0-2 weeks before death | | Total |
|---|---|---|---|
| | Yes | No | |
| **Yes: Only in the 0-2-week period before death** | 368 (14.3) | 2,208 (85.7) | 2,576 (11.9) |
| **Yes: In the 2-6-week period before death** | 99 (12.0) | 726 (88.0) | 825 (3.8) |
| **No** | 3,107 (17.0) | 15,157 (83.0) | 18,264 (84.3) |
| **Total** | 3,574 (16.5) | 18,091 (83.5) | **21,665** |

| Received an End-of-life Prescription | Hospitalization in 0-2 weeks before death | | Total |
|---|---|---|---|
| | Yes | No | |
| **Yes: Only in the 0-2-week period before death** | 1,928 (74.8) | 648 (25.2) | 2,576 (11.9) |
| **Yes: In the 2-6-week period before death** | 277 (33.6) | 548 (66.4) | 825 (3.8) |
| **No** | 16,765 (91.8) | 1,499 (8.2) | 18,264 (84.3) |
| **Total** | 18,970 (87.6) | 2,695 (12.4) | **21,665** |

*ED = Emergency Department

# CHAPTER FIVE - ADDITIONAL RESULTS

Utilizing the interim analysis cohort, I captured 77,568 home care recipients that died during the study period (Table 5-1). One quarter (25.0%) of decedents in this group received an end-of-life prescription in the last six weeks of life. Among those who received a prescription, 55.6% were female, 43.3% were aged 86-105, 22.5% were in the lowest income quintile, 85.6% resided in an urban setting, 95.5% were Canadian born, 65.9% were Anglophone, 73.9% were virtually rostered to a family physician, 58.6% did not receive palliative home care, 38.2% had mild cognitive impairment, 36.1% had moderate pain, 76.4% lived with their primary caregiver, and 55.4% had a non-distressed caregiver. Among those who received a prescription, hydromorphone was the most common medication class prescribed (75.5%) in the last six weeks of life (Table 5-2). The next three most commonly prescribed medications included haloperidol (53.2%), midazolam (51.0%), and scopolamine (45.6%).

**Table 5-1.** Baseline characteristics among the interim analysis cohort using the 0-6-week prescribing window.

| Variable | Total | Those who have received a EOL Rx | Those who have not received a EOL Rx |
|---|---|---|---|
| **Total - n (%)** | **77,568** | 19,413 (25.0) | 58,155 (75.0) |
| **Sex – n (%)** | | | |
| Male | **36,151 (46.6)** | 8,614 (44.4) | 27,537 (47.4) |
| Female | **41,417 (53.4)** | 10,799 (55.6) | 30,618 (52.7) |
| **Age (years) – n (%)** | | | |
| Overall – Mean (SD) | **84.8 (8.2)** | 85.0 (8.4) | 84.7 (8.2) |
| 66-75 | **12,409 (16.0)** | 3,101 (16.0) | 9,308 (16.0) |
| 76-85 | **25,530 (32.9)** | 6,107 (31.5) | 19,423 (33.4) |
| 86-95 | **33,335 (43.0)** | 8,405 (43.3) | 24,930 (42.9) |
| 95-105 | **6,294 (8.1)** | 1,800 (9.3) | 4,494 (7.7) |
| **Neighborhood Income Quintile – n (%)** | | | |
| 1 - Lowest | **19,869 (25.6)** | 4,366 (22.5) | 15,503 (26.7) |
| 2 - Low | **17,363 (22.4)** | 4,102 (21.1) | 13,261 (22.8) |
| 3 - Middle | **14,814 (19.1)** | 3,779 (19.5) | 11,035 (19.0) |
| 4 - High | **13,032 (16.8)** | 3,620 (18.7) | 9,412 (16.2) |
| 5 - Highest | **12,174 (15.7)** | 3,443 (17.7) | 8,731 (15.0) |
| Missing | **316 (0.4)** | 103 (0.5) | 213 (0.4) |
| **Rurality n (%)** | | | |
| Urban | **67,661 (87.2)** | 16,626 (85.6) | 51,035 (87.8) |
| Rural | **9,620 (12.4)** | 2,695 (13.9) | 6,925 (11.9) |
| Missing | **287 (0.4)** | 92 (0.5) | 195 (0.3) |
| **Immigration Status – n (%)** | | | |
| Landed Immigrant after 1985 | **5,257 (6.8)** | 882 (4.5) | 4,375 (7.5) |
| Canadian born/long term resident | **72,311 (93.2)** | 18,531 (95.5) | 53,780 (92.5) |
| **Language – n (%)** | | | |

| | | | |
|---|---|---|---|
| Anglophone | **48,631 (62.7)** | 12,800 (65.9) | 35,831 (61.6) |
| Francophone | **1,522 (2.0)** | 365 (1.9) | 1,157 (2.0) |
| Allophone | **27,409 (35.3)** | 6,247 (32.2) | 21,162 (37.0) |
| Missing | **6 (0.0)** | 1 (0.0) | 5 (0.0) |
| **Attachment to a Family Physician – n (%)** | | | |
| Yes | **3,716 (4.8)** | 941 (4.8) | 2,775 (4.8) |
| Yes - Virtually Rostered | **14,577 (18.8)** | 4,127 (21.3) | 10,450 (18.0) |
| No | **59,275 (76.4)** | 14,345 (73.9) | 44,930 (77.5) |
| **Palliative Home Care – n (%)** | | | |
| Yes | **13,892 (17.9)** | 8,036 (41.4) | 5,856 (10.1) |
| No | **63,676 (82.1)** | 11,377 (58.6) | 52,299 (89.9) |
| **Cognitive Performance Scale – n (%)** | | | |
| Intact | **10,880 (14.0)** | 2,928 (15.1) | 7,952 (13.7) |
| Borderline intact | **9,916 (12.8)** | 2,258 (11.6) | 7,658 (13.2) |
| Mild impairment | **33,859 (43.7)** | 7,412 (38.2) | 26,447 (45.5) |
| Moderate impairment | **10,631 (13.7)** | 3,008 (15.5) | 7,623 (13.1) |
| Moderate/severe impairment | **1,960 (2.5)** | 632 (3.3) | 1,328 (2.3) |
| Severe impairment | **7,712 (9.9)** | 2,435 (12.5) | 5,277 (9.1) |
| Very severe impairment | **2,610 (3.4)** | 740 (3.8) | 1,870 (3.2) |
| **Pain – n (%)** | | | |
| No pain | **28,087 (36.2)** | 6,988 (36.0) | 21,099 (36.3) |
| Mild | **9,856 (12.7)** | 2,519 (13.0) | 7,337 (12.6) |
| Moderate | **28,199 (36.4)** | 7,003 (36.1) | 21,196 (36.5) |
| Severe | **8,921 (11.5)** | 2,263 (11.7) | 6,658 (11.5) |
| Times when pain is horrible or excruciating | **2,505 (3.2)** | 640 (3.3) | 1,865 (3.2) |
| **Two Key Informal Helpers – Lives with Primary Caregiver – n (%)** | | | |
| Yes | **59,074 (76.2)** | 14,829 (76.4) | 44,245 (76.1) |
| No | **17,682 (22.8)** | 4,459 (23.0) | 13,223 (22.7) |

| | | | |
|---|---|---|---|
| No such helper | **812 (1.1)** | 125 (0.6) | 687 (1.2) |
| **Primary Informal Helper Expresses Feeling of Distress, Anger, or Depression – n (%)** | | | |
| Yes | **32,290 (41.6)** | 8,596 (44.3) | 23,694 (40.7) |
| No | **45,278 (58.4)** | 10,817 (55.7) | 34,461 (59.3) |

*EOL Rx = End-of-life Prescription

**Table 5-2.** End-of-life prescribing medications and medication classes using the interim analysis cohort in the last six weeks of life.

| Medication | Decedents that received an EOL Rx |
|---|---|
| **Any Medication Class – n (%)** | 19,413 (25.0) |
| **Opioids** | |
| Morphine – n (%) | 3,047 (15.7) |
| Hydromorphone – n (%) | 14,649 (75.5) |
| **Pain (non-opioid)** | |
| Dexamethasone – n (%) | 1,735 (8.9) |
| **Benzodiazepines** | |
| Lorazepam – n (%) | 927 (4.8) |
| Midazolam – n (%) | 9,901 (51.0) |
| **Antipsychotics** | |
| Haloperidol – n (%) | 10,329 (53.2) |
| Methotrimeprazine – n (%) | 6,185 (31.9) |
| **Sedatives** | |
| Phenobarbital – n (%) | 226 (1.2) |
| **Excessive Respiratory Secretions** | |
| Scopolamine – n (%) | 8,856 (45.6) |
| Glycopyrrolate – n (%) | 3,039 (15.7) |
| **Pulmonary Edema** | |
| Furosemide – n (%) | 625 (3.2) |
| **Nausea/Vomiting** | |
| Metoclopramide – n (%) | 1,247 (6.4) |

*EOL Rx = End-of-life Prescription

Again, when assessing the interim analysis cohort, those who received an end-of-life prescription in the last six weeks of life have a higher proportion of deaths in the community (64.2%) than compared to an institution (35.8%) (Table 5-3). Those who receive an end-of-life medication in the 0-2 and 2-6-week periods before death have a lower proportion of emergency department visits in the last two weeks of life (22.7% and 12.1%, respectively) than compared to those without a prescription (49.0%). Similar to emergency department visits, those who received an end-of-life medication in the 0-2 and 2-6-week periods before death have a lower proportion of hospitalizations in the last two weeks of life (27.9% and 13.8%, respectively) than compared to those without a prescription (70.1%).

**Table 5-3.** Crude values describing the association between end-of-life prescribing and the study outcomes (location of death, emergency department visits in the last two weeks of life and hospitalizations in the last two weeks of life) utilizing the interim analysis cohort.

| **Received an End-of-life Prescription** | **Location of Death** | | **Total** |
|---|---|---|---|
| | **Institution** | **Community** | |
| **Yes: In the 0-6-week period before death** | 6,947 (35.8) | 12,466 (64.2) | 19,413 (25.0) |
| **No** | 47,825 (82.2) | 10,330 (17.8) | 58,155 (75.0) |
| **Total** | 54,772 (70.6) | 22,796 (29.4) | **77,568** |

| **Received an End-of-life Prescription** | **ED in 0-2 weeks before death** | | **Total** |
|---|---|---|---|
| | **Yes** | **No** | |
| **Yes: Only in the 0-2-week period before death** | 3,112 (22.7) | 10,620 (77.3) | 13,732 (17.7) |
| **Yes: In the 2-6-week period before death** | 685 (12.1) | 4,996 (87.9) | 5,681 (7.3) |
| **No** | 28,487 (49.0) | 29,668 (51.0) | 58,155 (75.0) |
| **Total** | 32,284 (41.6) | 45,284 (58.4) | **77,568** |

| Received an End-of-life Prescription | Hospitalization in 0-2 weeks before death | | Total |
|---|---|---|---|
| | Yes | No | |
| **Yes: Only in the 0-2-week period before death** | 3,830 (27.9) | 9,902 (72.1) | 13,732 (17.7) |
| **Yes: In the 2-6-week period before death** | 786 (13.8) | 4,895 (86.2) | 5,681 (7.3) |
| **No** | 40,740 (70.1) | 17,415 (30.0) | 58,155 (75.0) |
| **Total** | 45,356 (58.5) | 32,212 (41.5) | **77,568** |

# CHAPTER SIX - OVERALL DISCUSSION AND CONCLUSION

## 6.1. Main Findings

Among the 77,568 decedents eligible for the study population, 55,903 (72.1%) had no hospitalizations in the 2-6-weeks before death. The remaining 21,665 (27.9%) had at least one hospitalization during that time period. The former group formed the cohort for the primary analysis, based on the hypothesis that any amount of time spent in hospital during the exposure period decreases the likelihood of receiving a community prescription. The latter group formed the cohort for the secondary analysis.

In the primary analysis group, approximately one quarter (28.6%) of home care decedents were given at least one end-of-life prescription in the 0-6-week period before death. Hydromorphone was the most common medication prescribed among those who received a prescription (75.2%). Receiving an end-of-life prescription decreased the risk of all three outcomes (dying in an institution, emergency department visit in the last two weeks of life, and hospitalization in the last two weeks of life). When analyzing emergency department visits and hospitalizations, the greatest decrease in risk was seen among individuals who received a prescription in the 2-6-week prescribing window (RR: 0.22 95% CI: 0.20 - 0.24 and RR: 0.20 95% CI: 0.18 - 0.22, respectively), compared to the 0-2-week prescribing period (RR: 0.43 95% CI: 0.42 - 0.45 and RR: 0.32, 95% CI: 0.30 - 0.33, respectively).

In the secondary analysis cohort, only 15.7% of home care decedents were given an end-of-life prescription in the 0-6-week period before death. Again, hydromorphone was the most common medication prescribed (76.9%) among those who received a prescription. Similar to the primary analysis cohort, receiving an end-of-life prescription decreased the risk of all three outcomes (dying in an institution, emergency department visit in the last two weeks of life, and hospitalization in the last two weeks of life). When analyzing late emergency department visits and hospitalizations, the greatest decrease in risk was again seen during the 2-6-week prescribing window (RR: 0.70, 95% CI: 0.58 - 0.85 and RR: 0.38, 95% CI: 0.34 - 0.41, respectively), compared to the 0-2-week prescribing period (RR: 0.85, 95% CI: 0.76 - 0.94 and RR: 0.83, 95% CI: 0.81 - 0.85, respectively).

When comparing the two groups, those in the secondary cohort during the 0-6-week period exhibited a greater relative decrease in risk of dying in an institution compared to those in the primary cohort (60% and 41% decreased risk, respectively). However, when comparing these same groups, those in the secondary cohort exhibited a lesser relative decreased risk of emergency department visits and hospitalizations compared to the primary cohort in both prescribing periods (0-2 and 2-6-weeks before death). When considering the location of death, I hypothesized that those who were in hospital in the two to six weeks before death might be being discharged with the recognition that they were going home to die. Among the secondary cohort, all of whom were hospitalized during the 2-6-weeks before death, 87.6% were also hospitalized during the 0-2-week period before death. In this same group, 84.7% of individuals die in an institution, compared to 65.1% of people in the primary cohort. Knowing a patient is nearing death, individuals may be sent home with prescriptions to manage end-of-life symptoms. Therefore, those in the secondary cohort who were discharged prior to death may be better equipped to die in the community (with the plan to die at home),

and thus exhibited a greater relative decreased risk of death in an institution compared to the primary cohort.

It is also important to note that some of what we are seeing here is related to relative risk reductions. In both the primary and secondary cohorts, the percentage of decedents who died in an institution was nearly identical if they received an end-of-life prescription (35.8% and 35.7%, respectively). However, the risk of dying in an institution for those without a prescription was much higher in the secondary cohort than compared to the primary (93.4% and 76.9%, respectively). This contributes to the much larger relative risk reductions seen in the secondary cohort.

While the association between end-of-life prescribing and dying in the community is strong, it remains unclear whether the relationship is causal. Although prescribing is necessary to relieve symptoms at the end of life, it is not sufficient in allowing individuals to remain the community to die. Dying at home requires a variety of factors in addition to prescribing, such as not limited to timely care coordination, caregivers, physician home visits, and emotional and spiritual supports. Broadly prescribing end-of-life medications may not lead to a significant increase in community deaths. Transfers for emergent care or hospital admission at the end of life is often driven by the need for additional support. The demographic data presented in this thesis suggests that end-of-life prescribing is associated with higher socioeconomic status, likely indicating more robust social support systems and access to caregivers. These factors are known to reduce the likelihood of hospital admission near the end of life. Nevertheless, these results highlight the importance of considering end-of-life prescribing as a potentially modifiable factor from a systems planning prescriptive.

## 6.2. Connections to Existing Research

### *6.2.1. Associations Between Prescribing and End-of-Life Outcomes*

Overall, my findings aligned with the current literature on the association between prescribing and outcomes. Based on the background presented in chapter three, my research builds on the broader literature that shows that good symptom management, which may happen through the appropriate prescribing of end-of-life medications, could help to healthcare utilization (emergency department visits and hospitalizations), and institutional deaths among home care recipients.[43] Furthermore, we see how the types of medications being prescribed remain fairly consistent when comparing Ontario's home care and long-term care populations.[3] Tied together, the current literature (including the results presented in this thesis) demonstrate how timely end-of-life prescribing is associated with improved end-of-life outcomes across patient populations.

### *6.2.2. Facilitators to Prescribing*

A variety of modifiable factors may act as facilitators to receiving an end-of-life prescription. In this study we observed differences in prescribing across various home care recipient health system factors. However, it should be noted that the magnitude of differences in prescribing for each factor were small, suggesting that end-of-life prescribing can occur even in the absence of strong facilitators or barriers. In this section, I will discuss how access to both palliative focused care and a family physician are two potential facilitators to receiving an end-of-life prescription identified in my study.

#### *6.2.2.1. Access to Palliative Focused Care*

In this thesis, when assessing the primary cohort, I found that among those who received an end-of-life prescription in the last six weeks of life, 42.6% were receiving palliative home care services. In comparison, only 11.4% of those who did not receive a prescription during the same time period were receiving palliative home care. Although receiving palliative-focused services does not automatically lead to prescribing, having access to healthcare providers trained to recognize symptoms of decline and death may be a component in having a high-quality death.

Palliative care has been shown to improve end-out-life outcomes, such as but not limited to improved quality of life and symptom management.[81] One study by Peralta and colleagues assessed prescribing patterns in a palliative care unit in Portugal, focusing on both the date of patient admission and the timing of their death.[82] Opioids were the most commonly prescribed medication at both admission (73%) and death (82.6%). Investigators also found that nearing death, prescriptions for butylscopolamine, midazolam, diazepam and levomepromazine increased. A different study from the Netherlands took a similar approach by assessing doses and routes of administrations of the most frequently used medications at both admission and day of death in a palliative care center.[83] This study found that on date of admission, the three most prescribed medications were morphine (21%), midazolam (11%), and haloperidol (23%).[83] The proportion of individuals receiving these medications increased under the observation of palliative focused care to 87%, 58%, and 50%, respectively, on date of death.[83] Although both studies do not compare to the general population, the literature shows that the initiation of palliative care services may provide patients with more individualized and appropriate care nearing the end of life. These services may include symptom management prescribing, which is a large role of palliative care.

#### *6.2.2.2. Access to Family Physician*

In this thesis, among those who received a prescription in the last six weeks of life, there was a higher proportion of individuals who were virtually rostered to a family physician than compared to those who did not receive a prescription (21.3% vs, 17.6%, respectively). On the other hand, among those who received a prescription in the last six weeks of life, there was a lower proportion of un-rostered and unattached individuals to a family physician than compared to those who did not receive a prescription (73.9% vs. 77.6%, respectively). It has been hypothesized that individuals with a regular primary care provider benefit from better care coordination, access to care, continuity and communication with care, and health outcomes.[65] Due to these factors, individuals attached to a family physician may be more likely to receive a community prescription for an end-of-life symptom management medication. Therefore, access or attachment to a family physician may act as a facilitator to prescribing at the end of life.

### *6.2.3. Barriers to Prescribing*

Similar to facilitators, a variety of modifiable factors may act as barriers to receiving an end-of-life prescription. In this section, I will discuss how resident language and health care provider responsibility are two potential barriers to receiving an end-of-life prescription identified in my study.

#### *6.2.3.1. Resident Language*

There was a higher proportion of Anglophones among those who received a prescription in the last six weeks of life compared to those who did not receive a prescription (66.2% vs. 62.2%, respectively). This is also reflected in a lower proportion of Allophones who received an end-of-life prescription compared to those who did get a prescription (31.8% vs. 35.9%,

respectively). Previous research has assessed patient-provider language discordance as a potential barrier to care.

One study by Chan and Woodruff compared palliative care needs of English and non-English-speaking patients receiving palliative care.[84] They found that non-English speaking patients reported a statistically significant worsening of symptom management in the last 2 months of life when compared to English-speaking patients.[84] In addition, these patients were less likely to die at home compared to their English-speaking counterparts.[84] Although differences in end-of-life preferences were not noted in the study, it is important to acknowledge that some of these variations may reflect cultural differences in end-of-life goals and care preferences. In the context of this thesis, the language differences found may be related to potential patient-provider language discordance. This may represent a barrier to prescribing, as patients may be unable to adequately express symptoms and therefore may have adverse outcomes (such as emergency department visits and hospitalizations for symptom management) at the end-of-life.

#### *6.2.3.2. Healthcare Provider Responsibility*

Various healthcare providers may have apprehensions regarding the prescribing of symptom management medication at the end-of-life. One study by Addicott assessed barriers to end-of-life prescribing from a physician's perspective.[85] Through qualitative interviews, physicians emphasized the significant responsibility associated with prescribing due to concerns with use/misuse of medications being left in home without supervision.[85] Another study by Bowers and colleagues assessed general practitioner decision making during end-of-life prescribing in England.[86] This study echoed the findings of the previous study, which noted that medications left in the home are open to misuse, especially if family members have a history of drug abuse.[85,86] Furthermore, this study highlighted that practitioners were hesitant

to delegate care as they remained responsible as the prescriber.[86] After a medication is prescribed, the practitioner may have little knowledge and control over how the medication is utilized. The respondents reported medications being used prematurely, which may cause distress to family members due to hastening of death.[86] Conversely, respondents also reported medications not being administered by nurses when needed, in part due to a lack of recognition that death was approaching.[86] In this thesis, we are limited in the understanding of pressures in responsibility placed on the prescribing provider. Although the data is limited, it is important to highlight that various apprehensions in the prescribing these end-of-life medications may be present among clinicians.

## 6.3. Strengths

### *6.3.1. Study Design*

One of the strengths of this thesis is the use of a retrospective study design with population-based data, which allowed for complete follow-up on all cohort members. This study design reduces potential selection bias, which may occur in prospective cohort studies. Selection bias may arise when one's likelihood of being selected into or out of the cohort (i.e., through loss to follow up) differs according to one's exposure and outcome. Because the outcome occurred at the time of study enrollment in a retrospective design, I was able to minimize bias due to the selection out of the cohort. This approach ensures complete data on the exposure and outcomes for all individuals. In contrast, prospective cohort studies can face bias if individuals who did not receive a prescription experience more symptom exacerbations, contributing to non-response or early study withdrawal. Thus, the retrospective design effectively addresses this potential issue, highlighting a significant strength of the methodology.

Additionally, conducting a prospective study would be challenging because predicting who is going to die is difficult. Enrolling individuals who are close to death and therefore 'eligible' for the exposure would likely result in a very select population, consisting primarily of those dying of conditions with predictable declines (e.g., some cancers). Using a retrospective design allows for the study of all eligible decedents during the study period, and thus provides a more comprehensive view of the population.

Another strength of the study design is the decision to split the cohort into primary and secondary groups for analysis. This decision was made in recognition of the potential competing risk of a prior hospitalization on an individual's ability to receive a prescription in the community. Through the process of analyzing the data, there were considerable differences between the population who were hospitalized during the 2-6-week period before death compared to the population who spent this same time period in the community. By dividing the study population into two cohorts based on prior hospitalization during the 2-6-week period before death, I was able to identify important differences in the effect of prescribing on end-of-life outcomes between the two groups.

### *6.3.2. Health Administrative Data*

Utilizing linked health administrative data, I was able to ascertain a wealth of information pertaining to decedents individual health history and sociodemographic characteristics. Furthermore, issues such as recall bias and loss to follow up are not an issue as seen in other retrospective studies. As the data is documented for health billing purposes, it is detailed and complete. Therefore, we are able to have clarity of the temporal sequence in the data, as we know exactly when an individual was prescribed a medication (exposure), and the outcomes they experienced at the end of life (place of date, emergency department visits in the last two weeks of life, and hospitalizations in the last two weeks of life). In addition, due to the nature

of the data, it is unlikely that we are missing prescription or outcome records. Finally, the depth of the data allows us to assess multiple covariates, such as but not limited to age, sex, and neighborhood income quintile, simultaneously.

#### *6.3.3. Increased Generalizability*

Utilizing population-based administrative data allows us to capture a large sample size for analysis. I was able to ascertain a sample size of 77,568 publicly funded long-stay home care decedents in Ontario during the study period. Larger sample sizes provide greater statistical power and thus provide more precise risk estimates. In addition, with a population-based sample, the generalizability of the findings is improved. Therefore, these results are likely generalizable to other jurisdictions that have similar health care structures (e.g., home care setups).

#### *6.3.4. Novel Research in the Field*

This study is the first to look at end-of-life prescribing among Ontario's home care population. Home care plays an important role in the care of our aging older adult population. As Ontario’s population continues to age, the importance of advancing our understanding of home care and its clients is crucial. Further, these findings are essential to our understanding of the current healthcare system in Ontario overall.

### 6.4. Limitations

#### *6.4.1. Databases and Covariates*

Although the use of health administrative data is a strength of this study, it is also a main limitation. Utilizing this form of data, we are limited to the questions we can ask. For instance, the Ontario Drug Benefit Program data captures medication prescribing rather than

administration. Therefore, we are unable to know whether the home care recipient utilized the medication, or if the medication was successful in relieving symptoms. Furthermore, we are unable to ascertain other important questions in a patient's care, such as preferences or goals of care. Although the literature suggests that home care recipients typically prefer to die in the community, this is not true of everyone. Someone may wish to die in an institutional setting (e.g., in a hospital), for instance, for cultural reasons, or to relieve burden and stress on their loved ones. Another general limitation to the use of health administrative data in this study was the inability to account for underlying diagnoses and disease trajectories. Given that the current data on this variable is only currently available up until 2018, and my study population spanned from 2017 to 2020, I was unable to include it as a potential confounder in my analysis. However, it is important to note that most home palliative care is provided to individuals with cancer. Therefore, while a sensitivity analysis adjusted for home palliative care may be feasible, adjusting for diagnosis (i.e., cancer) would likely not have yield substantially different results. This is due to the fact that the majority of the population would likely already be receiving home palliative care.

Regarding the limitations within specific databases, RAI-HC and InterRAI-HC assessments are completed once at admission to long-stay home care, at regular reassessment intervals (approximately every 6 months to 1 year), or when the patient experiences a significant change in clinical status.[57] Due to this variability in assessment frequency, some individuals may have a more relevant data recorded than others. This may introduce selection bias, or an underrepresentation of individuals with acute or rapidly progressing conditions at death. Although I controlled for assessment timing in the inclusion criteria (individuals were excluded if they did not possess a RAI assessment in the 31–365-day period before death), variability will still exist. This variability may influence variables such as pain and Cognitive

Performance Scale measures, which can fluctuate nearing the end-of-life period. While I used these variables as confounders, it is possible that the data I have does not accurately capture their status in the last two weeks of life. Additionally, while the RAI contains data that might reflect end-of-life symptoms, the assessments are not done frequently enough to understand whether medications were aligned with symptoms or if medications were effective at reducing symptoms.

In addition, the use of the IRCC database presents another limitation to this study. The landing date variable was derived using this database. However, this database only captures landed immigrants to Ontario since 1986. Therefore, if an individual immigrated to a province other than Ontario prior to moving to Ontario, or immigrated to Ontario before 1986, they would not be captured in this database.

Finally, it is important to acknowledge that due to the 6-week prescribing lookback window selected in chapter three, individuals who only received a prescription prior to the 6-week period would be classified as 'unexposed'. This would result in non-differential misclassification, biasing the results towards the null. However, as demonstrated in figure 3-1, few decedents received an end-of-life prescription between the 6-12-week period before death compared to the 0-6-week period. This likely reduces any significant impact on the study results.

### *6.4.2. Appropriate End-of-Life Care*

Individualized care is necessary to provide both safe and appropriate end-of-life care for home care recipients. While medications are an integral aspect of symptom management, not all home care recipients require these medications at the end of life. Further research is needed to determine an appropriate benchmark of end-of-life symptom management

prescribing in the home care setting. While I would not expect 100% of decedents to require a prescription, I also expect that proportion is not 0%. However, the variations observed in this study suggest that there are likely unmet symptom management needs among the home care decedents. First, I am seeing variations in prescribing across characteristics that are not driven by medical need (e.g., primary language and immigration status). This suggests that there is most likely an under delivery and potential inequity in care. If prescribing was being done equitably, and driven completely by clinical indications, meaning prescriptions were given to those in need for symptom management, I would not be seeing these variations in the data. Furthermore, I also found that compared to individuals who do not receive a symptom management prescription, those who do are more likely to die in an institution, go to the emergency department in the last two weeks of life, and be hospitalized in the last two weeks of life. If the group who received no prescriptions included only those who had no clinical need for such medication (i.e., no symptoms), you would see less of a difference in these outcomes.

### 6.5. Implications for Future Research and Public Health

In Canada the number of individuals aged 85 and older has doubled since 2001 and is projected to triple by 2046.[87] Reports from the Canadian Medical Association are currently predicting the cost of elder care to double over the next 10 years alone, increasing from $30 to $60 billion.[88] The aging population will inevitably place immense stress on our healthcare system as the proportion of Canadians requiring medical attention and care increases. Furthermore, the present infrastructure in Ontario set in place for our aging population is not prepared for the projected increased demand. Currently over 40,000 Ontarians are waiting for LTC.[89] This waitlist is expected to grow to an estimated 48,000 individuals by 2029.[89] This

increased demand for acute care services and infrastructure will ultimately force Ontario to rely on home care services for support.[90] Recognizing this increased demand, the Ontario Government announced their plan to invest over one billion dollars to continue the growth of home care programs and initiatives in April of 2022.[5]

Research, such as the novel results presented in this thesis, provide insight to the current state of home care outcomes for older adults at the end of life. Future research should focus on the benefits of implementing structures for high-quality end of life care, such as prescribing order sets for patients recognized to be near the end of life. Public health and policy figures should utilize this evidence to continue growing our home care system to provide comprehensive care that protects and mitigates risk of adverse events for Ontarians at the end of life.

### 6.6. Conclusion

Just over one quarter (28.6%) of long-stay home care recipients in Ontario receive an end-of-life prescription in the last six weeks of life among the primary cohort (i.e., individuals who were in the community during the entire 2-6-week period before death). Those who receive a prescription are less likely to die in an institution, present to the emergency department in the last two weeks of life, and be hospitalized in the last two weeks of life. These associations still held when analyzing those who were hospitalized during the 2-6-week before death prescribing exposure period. In fact, those in the secondary cohort (i.e., individuals who were hospitalized at any point during the 2-6-week period before death) had a greater decreased risk of dying in an institution when they received a symptom management medication, than compared to the primary cohort. This emphasizes the need to provide those discharged from

hospital near the end of life, potentially with the goal of dying at home, with prescriptions to manage symptoms.

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