CAREGIVER DISTRESS – ITS BURDEN, TRAJECTORIES, CONTRIBUTORS, AND IMPACT ON CARE-RECIPIENTS OVER TIME

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AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis will be made electronically available to the public.

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DEDICATION

I dedicate this thesis to Michael Ip – a brilliant colleague and a wonderful friend whom we lost much too soon. We miss you, Michael.

ABSTRACT

Background: Canada relies heavily on family and friend caregivers to care for its increasing older population. However, many caregivers experience distress, which can jeopardize their ability to continue care provision and the health of their care-recipients.

Objectives: This thesis research has three objectives: 1) Provide an overview of the burden and trajectories of caregiver distress in Ontario, and to compare differences in the experience of distress between caregivers of men and women; 2) Determine the association between caregiver distress and care-recipients' location of death; 3) Develop and test a comprehensive model of the relationships between caregiving factors, caregiver and care-recipient profiles, and caregiver distress.

Methods: The main data source for objectives 1 and 2 is the Resident Assessment Instrument for Home Care, linked to multiple health administrative datasets at ICES. For objective 1, older (50+) community-dwelling adults in Ontario and their caregivers were examined. Descriptive analyses were performed to identify baseline and one-year change in caregivers' distress status, stratified by year of baseline assessment and care-recipients' level of care needs. Logistic regression was performed to identify the associations between care-recipients' gender on caregiver distress. For objective 2, a retrospective cohort study of adult decedents in Ontario was conducted. Their caregivers' distress status within one-year of death was described, and logistic regression was performed to determine the association between caregiver distress and the odds of dying in non-palliative acute care.

The data source for objective 3 is the General Social Survey-Caregiving & Care-receiving (cycle 26) conducted by Statistics Canada. The study population included respondents who have provided unpaid care within one year of survey. Exploratory factor analysis and structural equation modelling

were performed to test a theoretical model of caregiver distress and its contributing factors and covariates.

Results: From 2008 to 2015, there was a steady increase in prevalent, incident, and sustained caregiver distress. The increase was especially prominent among caregivers of individuals with lower care needs. Caregivers of older men were more likely to be distressed than caregivers of older women, largely because older men have greater health and functional impairments and required more care. Individuals cared for by distressed (vs. non-distressed) caregivers spent more time in non-palliative acute care in their last month of life and were more likely to die in non-palliative acute care. Receipt of home care and palliative home care greatly reduced the odds of dying in non-palliative acute care. Exploratory factor analysis established a well-fit model that represented caregiver distress and its five contributing factors: caregiving burden, disruptions of family and social life, caregiving history, caregiving network and support, and positive emotional experiences. Subsequent structural equation modelling found that disruptions of family and social life and positive emotional experiences had the largest associations with caregiver distress.

Implications: Supporting older Canadians and their caregivers is a policy priority. This thesis research highlighted a rising trend of caregiver distress, identified risk and protective factors of distress, and determined the effect of caregiver distress on care-recipients' place of death. These findings can inform policy decisions and facilitate health systems planning. The risk factors found in this research can also be integrated into clinical assessments to identify caregivers at high risk of distress to provide them with timely and appropriate support. Enabling caregivers to provide quality care without being distressed is crucial for reducing cost incurred by the negative impacts of caregiving, ultimately reducing the overall healthcare cost of the aging population.

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LIST OF ABBREVIATIONS

ADL: Activities of daily living

ALC: alternative levels of care

CI: Confidence interval

CIHI: Canadian Institute for Health Information

CFI: Comparative Fit Index

CHD: Coronary heart disease

CHESS: Changes in Health, End-Stage Disease, Signs, and Symptoms Scale

CHF: Congestive heart failure

CPS: Cognitive Performance Scale

CVD: Cardiovascular diseases (including stroke, coronary heart diseases, and congestive heart failure)

DAD: Discharge Abstract Database

DRS: Depression rating scale

ED: Emergency department

EFA: Exploratory factor analysis

ESEM: Exploratory structural equation modelling

FL: factor loading

GSS2012: General Social Survey Cycle 26

HCD: Home Care Database

IADL: Instrumental activities of daily living

InterRAI-HC: interRAI home care assessment

IQR: inter-quartile range

LHIN: Local Health Integration Networks

LOS_AC: length of stay in non-palliative acute care

LOS_ALC: length of stay in alternative levels of care

LTC: long-term care

MAPLe: Method for Assigning Priority Levels

NACRS: National Ambulatory Care Reporting System

OHIP: Ontario Health Insurance Plan

OHT: Ontario Health Teams

OR: Odds ratio

RAI-HC: Resident assessment instrument for home care

RAI-MDS: Resident Assessment Instrument – Minimum Data Set 2.0

RPDB: Registered Persons Database

RMSEA: Root Mean Square Error of Approximation

SD: Standard deviation

SDS: Same Day Surgery

SEM: structural equation modelling

SRMR: Standardized Root Mean Square Residual

TLI: Tucker-Lewis Index

WLSMV: Mean- and Variance-Adjusted Weighted Least Squares

ZBI: Zarit Burden Interview

Chapter 1

INTRODUCTION

1.1 Rationale and research questions

Canada's population of older adults (over 65 years of age) is projected to increase from 16% in 2015 to 25% in 2036[1]. With the proportion of older adults having already surpassed that of youth under 15 in 2015[1], Canada will need to care for an increasing older and frail population with support from fewer working-age individuals. 80% of the care provided to community-dwelling older adults and 30% for those in institutions are provided by family and friend caregivers (henceforth referred to as "caregivers") – individuals who provide ongoing care and assistance, without pay, for family members and friends in need of support for physical, cognitive, mental, or aging-related conditions[2]. Like many countries in the world, Canada relies heavily on caregivers, with nearly one in four Canadians aged over 15 years (or 7.8 million people in 2018) having provided care to a family or friend[3]. By 2046, nearly 12 million Canadians will need to provide over 2.6 billion hours of unpaid care to 2.5 million seniors[4]. Similar heavy reliance is found in the United States, with 21.3% of Americans (or 53.0 million people in 2020) estimated to be caregivers, 42 million of which cared for older adults (aged over 50 years)[5]. It is important to enable and support caregivers in their caregiving duties as it not only reduces the social costs associated with health services and institutionalization, but also allow care recipients to remain at home and maintain a positive quality of life[3].

Caregiving has been described as a chronic stress experience[6,7]. Not only do caregivers face heavy physical, financial, and emotional tolls from their caregiving duties, many also have to juggle parental or employment duties and face disruptions to their personal lives[8,9]. Many caregivers also lack the appropriate skills to manage the complex care needs of their loved ones and are unprepared

to face sudden changes or deteriorations. As such, it is well-established that caregivers are more likely to experience various negative outcomes, including physical health impairments[6,10,11], higher risks of depressive and anxiety disorders[11,12], and reductions of self-care behaviours and preventive care leading to increased risks of hospitalizations and mortality[13–15]. Of particular concern is the alarmingly high rates of distress among caregivers[8,16,17]. A report by the Canadian Institute for Health Information (CIHI) found that at least one-third of caregivers in Canada are distressed[18], and the prevalence is even higher, at 45%, among caregivers of individuals with dementia[19]. With many caregivers being elderly or frail themselves, the additional burden and distress from caregiving can worsen their health. This, in turn, jeopardizes their capacity to provide care, the quality of care provided, and the health of their care-recipients[20,21], ultimately leading earlier or greater risk of institutionalization[22,23] and an increase in the burden on the health care systems[24,25]. Thus, understanding the factors associated with caregiver distress is crucial for informing policy and developing strategies to support caregivers and reduce institutionalization of care-recipients[26,27].

While a plethora of research on caregiver distress exists, there remains several gaps in literature. Past studies have rarely examined caregiver distress longitudinally to describe its trajectories over time. Though cross-sectional studies of caregiver distress have been conducted on the population level[17,28], no studies on changes in distress over time (i.e., distress trajectories), to our knowledge, were population-based. Many studies also restrict their study populations to individuals with specific illness (e.g., dementia), resulting in small sample sizes, reduced generalizability, and the inability to separate the effects of the distress versus its underlying symptoms/functional consequences. Furthermore, past research on gender differences in caregiver distress have focused almost exclusively on caregiver's gender[23,29–32] rather than that of the care-recipient. Among many studies of caregiver distress, care-recipient's gender is either not reported[33–37], not included in modelling[38–40], or adjusted for without reporting its effect size[41–43].

Existing studies on the contributors of caregiver distress were often limited by the lack of data on the multiple domains of potential risk factors and covariates of caregiver distress. Much of the inconsistent results on the risk and protective factors of caregiver distress were likely due to differences in the modelling methods used and the risk factors and covariates that were included or not included. Individual domains of risk factors were often examined in isolation while, in real life, these domains impact distress simultaneously. Therefore, complex modelling techniques and large data capacity are needed to examine the direct and indirect associations between caregiver distress, its multiple domains of risk and factors, and covariates.

My proposed thesis research addresses these gaps and issues in several ways. First, the two data sources used - one from routinely collected health data and another a national survey - are respectively representative of the Ontario and Canadian populations with little selection bias. Using routinely collected health administrative data, it is possible to examine changes in caregiver distress longitudinally and to follow care-recipients over time for their health outcomes and service use. From routinely administered assessments, we were able to obtain information on care-recipients' health, functional status, and service use, all of which could be accounted for in statistical analyses to minimize residual confounding. The other data source used is a national survey targeted for caregiving and care-receiving, and thus contains detailed and comprehensive information on the demographics and health of both caregivers and care-recipients, the types, amount, and context of caregiving, formal services and government resources used, and caregiving network. Hence, it is the ideal data source for testing a comprehensive model of caregiver distress and its multiple domains of contributors and covariates. The objectives of my thesis research are as follows:

<u>Objective 1:</u>

i) Provide an overview of the health profiles and resource utilization of older adults in Ontario as well as their caregivers' caregiving burden, distress status at baseline, and one-year

change in distress status; ii) Compare and explain differences in the characteristics, health profiles, care needs, and caregiver distress trajectories of older men and women receiving care.

Objective 2:

Determine if individuals cared for by distressed caregivers, compared to those cared for by non-distressed caregivers, are more likely to die in non-palliative acute care.

Objective 3:

Develop and test a model of the associations between caregiver distress and its domains of contributors and covariates.

1.2 Structure of dissertation

The structure of this dissertation is paper-based, with findings for objectives 1-ii, 2, and 3 (corresponding to Chapters 5-7) having been written and presented as journal articles. At the time of submission of this dissertation, the paper corresponding to objective 1-ii, titled "*Caring for Older Men and Women: Whose Caregivers are More Distressed? A Population-Based Retrospective Cohort Study*", has been published by BMC Geriatrics. The paper corresponding to objective 2, titled "*The association between caregiver distress and dying in non-palliative acute are – a retrospective cohort study*", is in the process of being submitted to the Canadian Medical Association Journal. The paper corresponding to objective 3, titled "Using exploratory structural equation modelling to examine caregiver distress and its contributors", has been submitted to BMC Geriatrics.

Chapter 2 of this dissertation presents a scoping review of literature on caregiver distress, its contributors, and its impact on care-recipients' health and resource use over time. An overview of the context and data sources is then described in Chapter 3, while further details of the study population, data sources, and statistical methods are presented in the chapters corresponding to each objective. Chapters 4 presents findings for Objective I-i on the overview of the prevalence and one-

year trajectories of distress among caregivers of older community-dwelling adults in Ontario. The three published/submitted papers then follow in Chapters 5 to 7. Finally, an overarching discussion of the implications of these findings for policy and future research is presented in Chapter 8.

Chapter 2

SCOPING LITERATURE REVIEW

2.1 Definitions and measurements of caregiver distress

Caregiver distress is often used interchangeably with other terms such as caregiver strain, stress, and burnout[23,44]. While research on caregiver distress is abundant, there is currently no standard definition or measurement of distress. Generally, caregivers are considered distressed if they experience physical, mental and emotional exhaustion[45–47] as well as symptoms of depression, anger, and/or anxiety[17,21,48]. Popular operationalizations of caregiver distress, used independently or in combination, include the Beck Depression Inventory[49], the Geriatric Depression Scale[50], the Zarit Burden Interview (ZBI)[51], and various health and mental health questionnaires. In the Canadian context, the Canadian Institute for Health Information has developed an indicator using interRAI data which defines caregiver distress as "a caregiver who express feelings of distress, anger or depression and/or any caregiver who is unable to continue in their caring activities". This approach of operationalizing caregiver distress has been used extensively in past studies[17,52,53], and is the definition of caregiver distressed for objectives 1-3.

It is important to note that the concepts of caregiver burden and distress are often intertwined, as caregiver distress is often incorporated into the definitions of caregiver burden, and vice versa, in many studies. For example, the ZBI, a popular measure of caregiving burden and distress[23,44,54–56], includes items that assesses caregivers' psychological well-being[51]. Another definition of caregiving burden is the extent to which caregivers perceive that caregiving has an adverse effect on their emotional, psychological, social, financial, and physical functioning[57,58], which greatly overlaps with caregiver distress. Thus when reviewing existing literature on caregiver distress, we have also included studies examining caregiving burden. In the analyses

conducted for this thesis, however, we differentiate distress from burden so that distress encompasses psychological and emotional experiences such as stress, depression, anxiety, and anger. Caregiving burden, on the other hand, encompasses the types and amount of assistance caregivers have provided.

2.2 Associations between care-recipient characteristics and caregiver distress

Care-recipients' health and behaviours have been heavily featured in literature on caregiver distress, though there are variations in their inclusions and inconsistencies in findings. Care-recipients' functional status, including their abilities to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs), as well as cognitive impairments have been well-established risk factors for caregiver distress[17,38,52,59,60]. Behavioural symptoms, such as agitation, irritability, aggression, and abnormal motor and night behavior, have also been noted as main causes of caregiver burden or depression[36,59,61–63]. Furthermore, many studies have reported higher risks of distress among those caring for patients with specific diagnoses such as dementia[64–67], cancer[60,66,68,69], Parkinson's disease[17,54], cardiovascular diseases[70–72], and various mental illness such as schizophrenia[73,74] and bipolar disorder[75]. Similarly, caregivers of family members with substance abuse or addiction have also been shown to experience persistent stress, anger, depression, shame, guilt, and anxiety[76–78]. These aforementioned conditions are associated with greater functional impairments and behavioural issues, hence requiring greater amount and types of care and place greater emotional strain and stress on the caregivers.

There are inconsistencies on whether these risk factors were independently associated with caregiver distress. For example, while caregivers of individuals with Parkinson's disease have been reported to be more distressed[54,79,80], some studies have found that the effect of Parkinson's disease on caregiver distress is no longer significant after adjusting for individuals' functional and behavioural issues[52]. What is consistent in literature is that individuals' functional

status, as measured by their ability to complete ADL and IADL tasks, and behavioural issues were predictive of caregiver distress, regardless of disease diagnoses[17,43,53,64,65]. The Method of Assigning Priority Levels score, derived from several items measuring behavioural symptoms and impairments in ADL and cognition, has also been associated with caregiver distress independently of individuals' disease diagnoses[52,81,82].

Many studies have also reported on the associations between care-recipients' socio-demographic characteristics and caregiver distress, though there were also inconsistencies. Some studies have found that care-recipient characteristics had no or only minor effects on caregiver distress after controlling for other factors[62,83]. Others have found that older[17,52] and male[17,52] care-recipients were more likely to have distressed caregivers. Covinsky et al., however, found that caring for younger patients were associated with higher risk of caregiver depression and distress[59].

2.3 Associations between caregiver characteristics and caregiver distress

Caregiver's sociodemographic characteristics, including age, sex, relationship to care-recipient, and co-residence status, have been investigated as predictors of caregiver distress[17,53,59,84,85]. Studies have consistently shown that spousal caregivers, compared to other types of kinship to care-recipients, were most likely to be distressed[16,17,59]. Studies on the age of caregivers, however, have yielded inconclusive results. While some showed that younger caregivers were more likely distressed than older caregivers[27,64], others have found the opposite[62] or an absence of effects for age[86]. These differences may be due to differences in the confounding, moderating, or mediating factors that were accounted for. Additionally, elderly caregivers were more likely to be spouses, provide more care, experience health issues, and co-reside with their care-recipients[30]. Younger caregivers, in contrast, were more likely to be adult children who, concurrently to caregiving, have employment and child-rearing responsibilities[30].

These differences may affect their caregiving context and burden, subsequently affecting their experience of distress. For example, studies on caregivers of individuals with Alzheimer's disease found that children caregivers often make drastic lifestyle changes (e.g., terminating their employment[26]) and experience more guilt[87]. Spousal caregivers, on the other hand, view caregiving as part of their marital role and may therefore perceive little agency and choice in undertaking caregiving duties[87]. It remains unclear, however, whether children[6,26] or spousal caregivers[24,25] experience more distress, or if their age or co-residence status have moderating effects[25].

Studies on the associations between caregiver's sex and distress have consistently shown that female caregivers experience higher burden and distress than their male counterparts[26,31,64,71,86,88,89]. Some have postulated that the greater distress experienced by female caregivers were due to social expectations placed on women to partake caregiving responsibilities without question or consideration of alternative options[36]. Thus, women tend to experience more role captivity or a lack of choice, leading to more emotional distress[90], physical strain[91], and other negative health outcomes[91].

Past research have also shown that lower income[92] or perceived income inadequacy were predictors of distress among caregivers of individuals with Alzheimer's and/or dementia[93]. In contrast, having high resiliency reduced the likelihood of distress, with a systematic review of caregivers of individuals with dementia showing that higher levels of personal mastery and self-efficacy as well as increased use of positive coping strategies were especially protective of caregiver distress[94].

Finally, there exists many cultural differences in caregiving context, burden, and experiences of distress. A meta-analysis by Pinquart and Sorensen (2005) found that minority caregivers, compared to White caregivers, provided more hours of care and greater caregiving

tasks, and that Latino and Asian American caregivers reported higher rates of depression[16]. A survey study conducted in the United States, however, found that Chinese and Latino caregivers were less distressed compared to White caregivers, though this was qualified by significant ethnicity by resource and ethnicity by education interactions[95]. However, the intersectionality of culture, gender, and immigrant status makes it difficult to tease out their separate effects. The country or region from which study populations were sampled from may also differ in their healthcare systems, policies, and resource availability, thus further limiting the generalizability of these findings.

2.4 Associations between caregiving context and caregiver distress

Past research have shown that compound caregiving (i.e., caring for multiple people concurrently)[96] and prolonged caregiving[47] could increase caregivers' level of distress, though the increase may plateau after a certain amount of time[97]. Having to juggle the responsibilities of multiple roles (e.g., being a student, parent, and/or employed in addition to being a caregiver) may also increase distress[98,99]. Other risk factors of caregiver distress include having to navigate and coordinate care between multiple health care systems[100,101], a lack of family-oriented services, information, and training for caregivers[5,102], and living in isolated rural areas[8,103,104].

2.5 Impacts of caregiver distress on care-recipient' outcomes and health care use

Several studies of the older and/or frail populations have reported that distressed caregivers are less capable of continuing care provision, leading to earlier transitions into nursing homes (i.e., long-term care facilities)[22,105–107]. Cohort studies of individuals with Alzheimer's and/or dementia also found baseline caregiver distress to be predictive of time-to-institutionalization, with care-recipients' health and functional problems also being strong predictors[23,85,108–112]. Men and women also have different reasons for institutionalization – men mostly for medical and care needs, while women were more likely for reasons related to family

caregiving patterns[109]. However, population-level or longitudinal studies are scarce. To our knowledge, Betini et al.[28] is the only population study that examined the effect of baseline caregiver distress on time-to-LTC entry. They found caregiver distress to be predictive of institutionalization, even after controlling for care-recipient's care needs, age, relationship to caregiver, and co-residence status. Contradictive findings exist, however. A study by Hebert et al. of individuals with dementia in Canada found that, though caregiver depression was predictive of the *desire* to institutionalize, only caregiving burden, not distress, was predictive of time-to-institutionalization[56]. Several studies from the United States and European countries also found caregiver distress and strain to have no effect on institutionalization, especially after adjusting for other factors[113–117].

Research on caregivers of individuals with Alzheimer's and/or dementia have also shown associations between caregiver distress and negative health outcomes experienced by their care-recipients, including increased risk of future falls and fracture[21], functional decline[118], worsened quality of life[118], and worsened behavioral and psychological symptoms[23]. Findings on the effect of caregiver distress on emergency department (ED) visits and hospitalization have been mixed. A study by Voisin et al. in France found that caregiver distress was significantly associated with future hospitalization[25]. Another study by Salam et al. of individuals in hospice palliative care in southern Ontario found that being cared by distressed caregivers increased the likelihood of emergency room visits and hospitalizations[119]. However, studies by Sugiyama et al. (Japan)[120] and Ng et al. (USA)[121] found no associations to hospitalization and ED visits, respectively. These are, however, cohort studies with small sample sizes, and population-level studies on older and/or frail adults in general have been rare. Finally, the effect of caregiver distress on place of death is also scarce. The only study on this topic, to our knowledge, was conducted by Fukui et al. examining predictors of place of death among patients with advanced-stage malignant disease in

Japan[122]. While they found that individuals cared for by distressed caregivers had greater odds of dying in hospital, the generalizability of these findings is limited given its restricted cohort and small sample size.

Several studies also investigated whether interventions aimed at supporting caregivers would improve care-recipient outcomes. Interventions that effectively reduced caregiver distress or burden also led to care-recipients subsequently having less neuropsychiatric symptoms[123], less or delayed institutionalization[123,124], and less behavioural issues[125]. Some interventions had mixed effects on care-recipient outcomes, such as a study by Belle et al. whose intervention improved caregiver's quality of life and reduced problem behaviours of care-recipients, but did not impact institutionalization[126].

Chapter 3

CONTEXT AND OVERVIEW OF MAIN DATA SOURCES

To achieve objectives 1-2, we used population-based, health administrative data in Ontario, a multicultural and the most populous province in Canada. Almost all residents in Ontario, including citizens, permanent residents, landed immigrants, refugees, and indigenous Canadians, are covered by the Ontario Health Insurance Plan (OHIP), a universal healthcare plan which provides individuals with publicly-funded healthcare and home and community care services. These include physician services, hospital and emergency care, and publicly-funded home care and long-term care. Most of the routinely-collected health, clinical, and administrative data from individuals' interactions with these services have been collected, anonymized, coded, and linked at the individual- and record-level at the ICES (formerly the Institute of Clinical and Evaluative Science) Data Repository since 1986. As an independent, non-profit research institute funded by the Ontario Ministry of Health and the Ministry of Long-Term Care and a prescribed entity under Ontario's privacy legislation, ICES is authorized to collect and use personal health information, without consent, for the purposes of health system analysis, evaluation, decision support, and research under section 45 of the Ontario's Personal Health Information Protection Act. Secure access to these data is governed by policies and procedures that are approved by the Information and Privacy Commissioner of Ontario.

Since 2002, the Resident Assessment Instrument-Home Care (RAI-HC) has been used by case managers and care coordinators to determine the needs of clients expected to be a long term recipient of publicly-funded home care or wishing to apply for admission into a long-term care facility[127]. This standardized, validated[127–130], and reliable[127–129] routinely administered assessment documents information on the client's physical, cognitive, and social functions, service use, as well as characteristics of their informal caregiver and types and amount of care provided[17]. On April 27,

2018, the RAI-HC was replaced by its updated version, the interRAI-HC assessment[131,132]. While the interRAI-HC assessment provides opportunities to measure additional and improved outcomes, most of its assessment items are identical or comparable to those in the RAI-HC[131,133]. All clients who received a RAI-HC or interRAI-HC assessment have additional care needs, though not everyone receives home care as some may decline it or be admitted to other care settings while waiting for home care to be initiated. Some clients receive multiple assessments, as existing policies state that a reassessment should be completed at least every six months or when significant changes in care needs arise (e.g., functional decline, new disease diagnosis, or post-hospital discharge). As the purpose of the RAI-HC is to assess clients, caregivers themselves are not followed longitudinally. However, clients who receive multiple assessments provides an opportunity to follow their caregivers' distress status over time.

The data from the RAI-HC and interRAI-HC assessments are linked, at the individual level using uniquely encoded identifiers, to other health administrative datasets housed at ICES. More information about each dataset and the variables obtained from each are shown in Supplementary Materials 1, and described in greater detail in the papers corresponding to each objective.

The data source for objective 3 was the General Social Survey (GSS2012) cycles 26[134] - a national survey conducted from March to December 2012 by Statistics Canada. It surveyed non-institutionalized Canadians, over 15 years of age, and residing in the ten provinces who received care or help due to long-term health conditions or aging-related issues, and those who provided unpaid help or care to friends and families for these issues. It is cross-sectional and followed a two-stage sampling design. Respondents answered questions about the types and frequency of care received or provided, who their caregivers and/or care-recipients are, formal support received, caregiving network, and consequences of caregiving. All respondents were also surveyed on their health,

employment, and socio-demographic characteristics. With a large sample size of over 20,000 respondents, findings from both surveys are representative at national and provincial levels.

Chapter 4

OVERVIEW OF CAREGIVER DISTRESS AND ITS TRAJECTORIES

4.1 Overview and methods

This chapters provides findings on the health profiles and resource utilization of the older adults in Ontario as well as their caregivers' caregiving burden, distress status at baseline, and one-year change in distress status. Details of the cohort creation process, data sources, and variable definitions are described in the published paper in Chapter 5, as the study population and variables analyzed were the same for objectives 1-i and I-ii. In brief, we included older adults (aged 50+) residing in Ontario who have received a RAI-HC "initial assessment" (i.e., baseline) between April 2008 and June 30, 2015 and have indicated the presence of a primary caregiver. All additional RAI-HC assessments completed within one year of individuals' baseline assessment were examined to determine distress trajectories.

Caregiver distress was identified using two items on the RAI-HC assessment, with caregivers defined as distressed if either or both items were answered "yes":

1) A caregiver is unable to continue in caring activities.

2) The primary caregiver expresses feelings of distress, anger or depression.

Caregivers' baseline distress status was determined using their care-recipients' initial RAI-HC assessment. Within one-year of baseline assessment, the caregivers had one of the following outcomes: 1) their care-recipients did not receive another assessment within one year, and therefore their distress trajectories are unknown; 2) initially non-distressed caregivers *remained non-distressed* in all subsequent assessments; 3) initially non-distressed caregivers who *became distressed* in a subsequent assessment; 4) initially distressed caregivers who *remained distressed* in all subsequent assessments; or 5) initially distressed caregivers who *became non-*

distressed in a subsequent assessment. Descriptive analyses were performed to identify the proportions of caregivers who were distressed at baseline and the proportions who experienced each distress trajectory, for the total cohort and by year of initial assessment.

It is also of interest to determine the prevalence and trends of caregiver distress according to individuals' level of care needs. The Method of Assigning Priority Levels (MAPLe) score, developed by interRAI and embedded in the RAI-HC, is a measure of individuals' health care needs that is used in Ontario to prioritize needs for community- or facility-based services such as home care and long-term care[81]. Thus, the aforementioned descriptive analyses were performed separately for each of the five MAPLe score levels.

The following care-recipient characteristics at baseline RAI-HC were also examined according to caregivers' baseline distress status using descriptive analyses: demographic information (age, sex, marital status, place of residence); assessment related factors (year of baseline assessment, place of residence and who they lived with at time of referral); functional status indicated by their abilities to perform activities of daily living (ADLs; measured by the ADL Self-Performance Hierarchy Scale[135]) and instrumental activities of daily living (IADLs; measured by the IADL Difficulty Scale[135]) as well as presence of continence issues; cognition (measured by the Cognitive Performance Scale[135]) and presence of delirium; health instabilities as measured by the Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) Scale[135]; level of care needs as indicated by the MAPLe score; mood and behavioural issues; and disease diagnoses. We also described their primary caregiver's kinship, co-residence status, and the amount and types of care provided.

For all aforementioned descriptive analyses, statistical significance was not tested nor reported given that the nature of these analyses and the conclusions drawn are descriptive in

nature. Additionally, even differences that are too minor to be clinically or practically relevant would be statistically significant at the typical alpha level of 0.05 given our large sample size.

4.2 Results

Table 4.1 shows the characteristics of individuals in the study cohort, who their primary caregivers were, and the types and amount of care caregivers provided according to distress status at baseline. Individuals cared by distressed caregivers, compared to those cared by non-distressed caregivers, were slightly older (aged 79.3 years versus 77.9 years), more likely married (55.4% versus 39.5%), and more likely to have been living with their spouse and/or child(ren). Distressed caregivers, compared to non-distressed caregivers, were more likely to be spouses (45.7% versus 31.5%), to have co-resided with the care-recipient (68.1% versus 50.5%), to have provided care for IADL and ADL tasks, and to have provided more hours of care.

Table 4.1. Socio-demographic and assessment-related characteristics of care-recipients and their primary caregivers, by caregivers' baseline distress status.

Care-recipient's demographic and assessment-related characteristics		**Non-Distressed Caregivers** (n=372410) **% (n)** [1]	**Distressed Caregivers** (n=112997) **% (n)**	**Total Cohort** (n=485407) **% (n)**
Age	Mean ± SD	77.9 ± 10.7	79.3 ± 9.7	78.6 (10.2)
	Median (IQR[2])	80.0 (15.0)	81.0 (12.0)	80.0 (13.0)
Sex	Female	62.9 (233783)	53.0 (59938)	60.5 (293721)
Marital status	Married	39.5 (147230)	55.4 (62617)	43.2 (209847)
	Never Married	5.9 (22133)	4.2 (4786)	5.5 (26919)
	Widowed/separated/divorced	53.2 (198067)	39.1 (44161)	49.9 (242228)
	Other	1.3 (4980)	1.3 (1433)	1.3 (6413)
Year of assessment	2008	12.8 (47533)	9.4 (10588)	10.9 (53121)
	2009	16.3 (60733)	11.3 (12769)	15.1 (73502)
	2010	14.9 (55367)	11.0 (12443)	14.0 (67810)
	2011	13.4 (49711)	12.8 (14442)	13.2 (64153)
	2012	13.0 (48347)	14.6 (16516)	13.4 (64863)
	2013	11.9 (44316)	15.4 (17368)	12.7 (61684)
	2014	11.5 (42738)	16.6 (18739)	12.7 (61477)
	2015	6.4 (23665)	9.0 (10132)	7.0 (33797)
Place of residence at time of referral	Private home with home care	75.5 (281114)	79.1 (89381)	76.3 (370495)
	Private home without home care	14.0 (52265)	13.9 (15678)	14.0 (67943)
	Non-private home	10.4 (38986)	7.0 (7924)	9.7 (46910)
	Missing	<0.1 (45)	<0.1 (14)	<0.1 (59)
Who care-recipient lived with at the time of referral	Lived alone	37.2 (138479)	21.1 (23850)	33.4 (162329)
	Lived with spouse only	30.3 (112813)	44.3 (50001)	33.5 (162814)
	Lived with spouse and others	7.3 (27127)	9.3 (10514)	7.8 (37641)
	Lived with child (not spouse)	12.7 (47189)	15.9 (17947)	13.4 (65136)
	Lived with others/in group setting	12.6 (46757)	9.4 (10671)	11.8 (57528)
	Missing	<0.1 (45)	<0.1 (14)	<0.1 (59)
Characteristics of the primary caregiver and care provided				

[1] All p-values for differences between women and men care-recipients are <0.0001 unless otherwise specified

[2] IQR: inter-quartile range

Caregiver lived with care-recipient	Yes	50.5 (188120)	68.1 (76953)	54.6 (265073)
Caregiver's relationship to care-recipient	Child/child-in-law	50.8 (189208)	43.5 (49172)	49.1 (238380)
	Spouse	31.5 (117121)	45.7 (51613)	34.8 (168734)
	Other relatives	10.4 (38862)	7.5 (8464)	9.7 (47326)
	Friend/neighbor	7.3 (27219)	3.3 (3748)	6.4 (30967)
Caregiver provides emotional support	Yes	97.3 (362423)	97.6 (110331)	97.4 (472754)
Caregiver provides care for instrumental activities of daily living (IADL)	Yes	88.6 (329846)	92.4 (104446)	89.5 (434292)
Caregiver provides care for activities of daily living (ADL)	Yes	37.3 (138975)	56.4 (63718)	41.8 (202693)
Hours of care provided for ADL and IADL activities in the last 7 days	10 or fewer hours	45.1 (168081)	18.3 (20637)	38.9 (188718)
	11-20 hours	19.8 (73647)	18.4 (20748)	19.4 (94395)
	21+ hours	24.4 (90943)	46.2 (52202)	29.5 (143145)
	missing	10.7 (39739)	17.2 (19410)	12.2 (59149)

Table 4.2 shows the health and functioning of individuals cared by distressed and non-distressed caregivers. In general, those cared by distressed caregivers had greater health instabilities and functional impairments (indicated by greater proportions with high ADL, IADL, and CHESS scores and incontinence), greater care needs as indicated by higher MAPLe scores, greater cognitive impairments (indicated by greater proportions with high CPS scores and delirium), and more mood and behavioural issues. 36.4% of individuals cared by distressed caregivers had Alzheimer's disease and/or dementia, compared to only 16.7% of those cared by non-distressed caregivers.

Table 4.2. Health, functional status, and behavioural symptoms of individuals cared by distressed and non-distressed caregivers.

		Non-Distressed Caregivers (n=372,410)	**Distressed Caregivers** (n=112,997)	**Total Cohort** (n= 485,407)
Functional status		**% (n)**	**% (n)**	**% (n)**
ADL self-performance hierarchy	0: Independent	65.9 (245314)	40.2 (45379)	59.9 (290693)
	1: Supervision required	9.5 (35386)	16.4 (18508)	11.1 (53894)
	2: Limited impairment	12.1 (45034)	18.9 (21403)	13.7 (66437)
	3: Extensive assistance required (I)	4.7 (17524)	9.6 (10885)	5.9 (28409)
	4: Extensive assistance required (II)	4.2 (15486)	7.9 (8913)	5.0 (24399)
	5: Dependent	3.0 (11077)	5.5 (6193)	3.6 (17270)
	6: Total Dependence	0.7 (2589)	1.5 (1716)	0.9 (4305)
IADL difficulty scale	0: No difficulty in any IADLs	6.7 (24759)	1.2 (1356)	5.4 (26115)
	1: Some difficulty in one IADL	8.2 (30616)	2.0 (2303)	6.8 (32919)
	2: Some difficulty in two IADLs	15.1 (56300)	7.1 (8072)	13.3 (64372)
	3: Some difficulty in all three IADLs	1.9 (7043)	2.5 (2862)	2.0 (9905)
	4: Great difficulty in one IADL	20.9 (77906)	14.0 (15791)	19.3 (93697)
	5: Great difficulty in two IADLs	36.3 (135112)	45.2 (51059)	38.4 (186171)
	6: Great difficulty in all three IADLs	10.9 (40674)	27.9 (31554)	14.9 (72228)
Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) Scale	0: No health instability	23.5 (87527)	11.9 (13431)	20.8 (100958)
	1: Minimal health instability	34.0 (126651)	26.0 (29340)	32.1 (155991)
	2: Low health instability	26.8 (99828)	33.3 (37673)	28.3 (137501)
	3: Moderate health instability	12.9 (47896)	20.5 (23132)	14.6 (71028)
	4: High health instability	2.6 (9788)	7.7 (8721)	3.8 (18509)
	5: Very high health instability	0.2 (720)	0.6 (700)	0.3 (1420)
MAPLe Score	1: Low	18.9 (70518)	3.71 (4194)	15.4 (74712)
	2: Mild	14.9 (55436)	4.7 (5256)	12.5 (60692)
	3: Moderate	31.2 (116070)	27.3 (30857)	30.3 (146927)
	4: High	26.6 (98931)	38.5 (43490)	29.3 (142421)
	5: Very high	8.5 (31455)	25.8 (29200)	12.5 (60655)
Bladder/bowel incontinence	Incontinence present in last 7 days	36.3 (237166)	52.1 (112997)	40.0 (194104)
Pain intensity	Mild or no pain	53.2 (198025)	53.3 (60194)	53.2 (258219)
	Moderate	34.2 (126168)	32.6 (36788)	33.8 (163956)
	Severe	10.0 (37288)	10.6 (11963)	10.1 (49251)
	Pain is horrible	2.7 (9929)	3.6 (4052)	2.9 (13981)
Cognitive abilities				
Cognitive Performance Scale	0: Intact	49.7 (185269)	20.9 (23616)	43.0 (208885)

	1: Borderline intact	16.9 (63082)	14.6 (16498)	16.4 (79580)
	2: Mild impairment	15.6 (57913)	19.6 (22147)	16.5 (80060)
	3: Moderate impairment	14.3 (53247)	35.2 (39775)	19.2 (93022)
	4: Moderately severe impairment	1.2 (4292)	3.3 (3729)	1.7 (8021)
	5: Severe impairment	1.7 (6645)	5.4 (6102)	2.6 (12747)
	6: Very severe impairment	0.5 (1962)	1.0 (1130)	0.6 (3092)
Had delirium in last 90 days	Yes	4.2 (15543)	13.6 (15381)	6.4 (30924)
Mood and behavior				
Wandering behavior	Yes	1.6 (5827)	6.6 (7417)	2.7 (13244)
Verbally and/or physically abusive	Yes	1.8 (6880)	8.9 (10038)	3.5 (16918)
Socially inappropriate/ disruptive	Yes	1.0 (3719)	4.1 (4673)	1.7 (8392)
Comorbidities				
Has Alzheimer's/dementia	Yes	16.7 (62105)	36.4 (41145)	21.3 (103250)
Has any cardiovascular diseases[3]	Yes	40.0 (149166)	42.9 (48422)	40.7 (197588)
Has Parkinson’s disease	Yes	3.0 (11304)	4.8 (112997)	3.4 (16704)
Has any fractures	Yes	13.0 (48540)	11.1 (12528)	12.6 (61068)
Has cancer	Yes	18.3 (68162)	14.5 (16363)	17.4 (84525)

[3] Includes stroke, coronary heart diseases, congestive heart failure, or peripheral vascular disease

Figure 4.1 shows the time trend of the proportions of caregivers who were distressed at baseline RAI-HC assessment. Overall, there has been a steady increase of prevalent caregiver distress, from 18.2% in 2008 to 30.0% in 2015. When stratified by care-recipients' MAPLe score (Figure 4.2), the same increase in proportion of distressed caregivers over time were observed across all MAPLe score levels. Across all years, the proportions of distressed caregivers were higher for higher MAPLe scores, with over 50% of caregivers of individuals in the highest MAPLe score level being distressed from 2012 onwards.

Figure 4.1. Proportions of caregivers who were distressed at baseline, by year of baseline RAI-HC assessment.

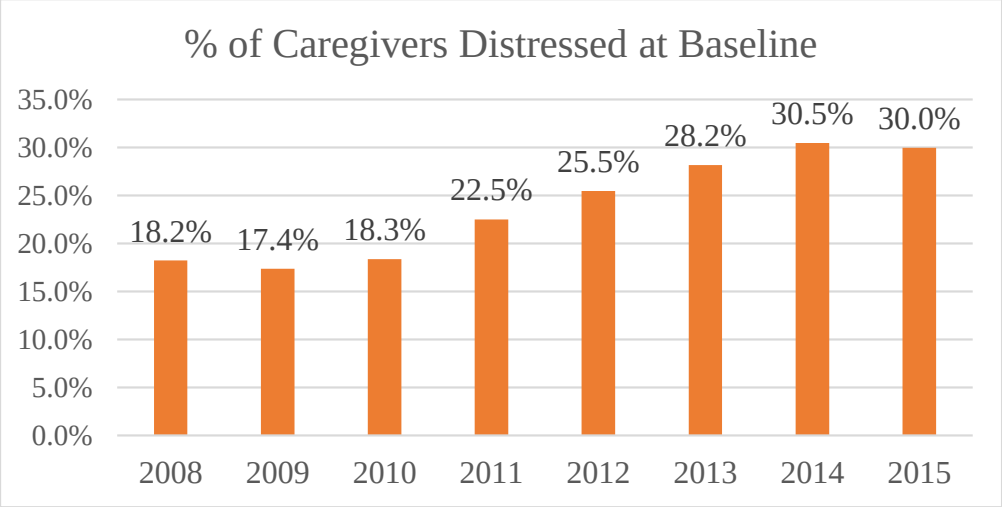
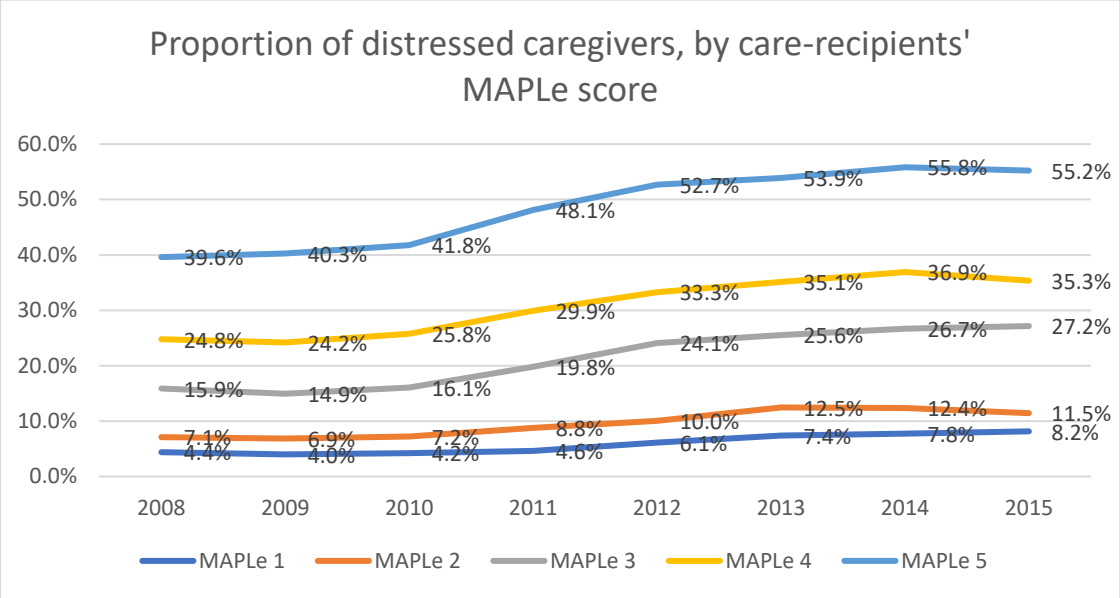


Figure 4.2. Proportions of caregivers who were distressed at baseline, by year of baseline RAI-HC assessment and stratified by care-recipients' MAPLe score



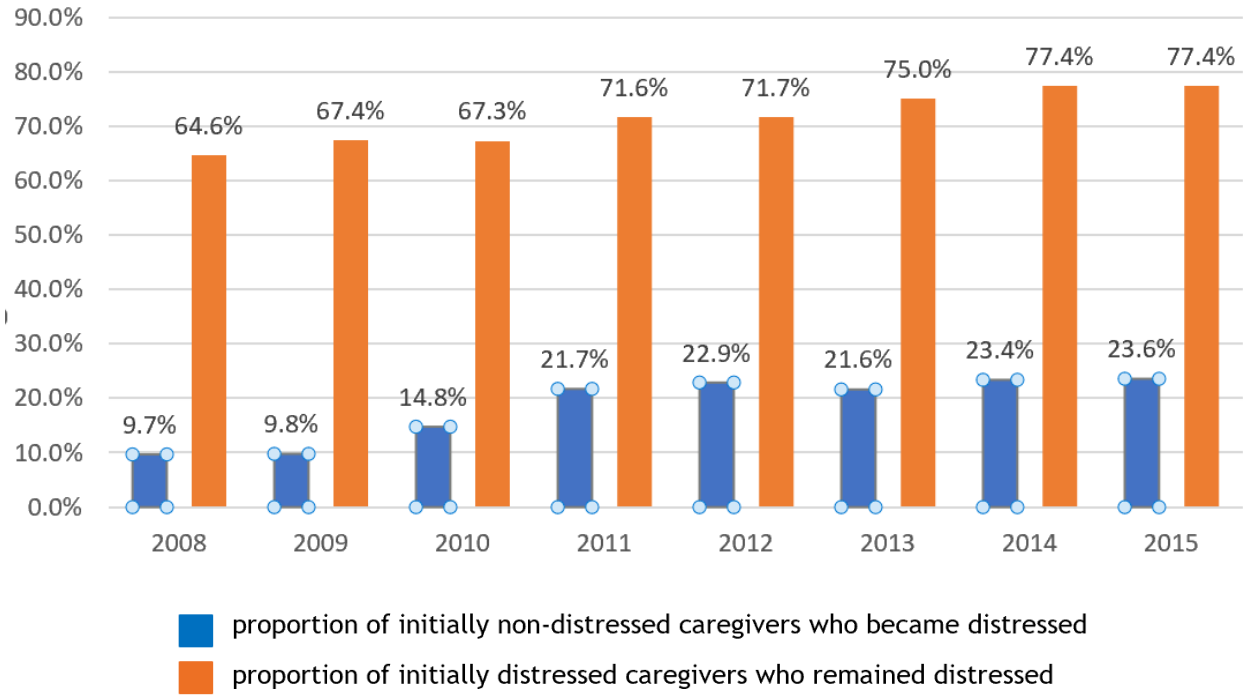
Changes to caregivers' one-year distress trajectories over time were also examined. Over the eight years of observation, the proportions of individuals with only baseline RAI-HC assessments were similar, ranging from 52.9% to 55.6%. Among those with additional RAI-HC assessments within one year of baseline assessment, Table 3 shows the proportions of caregivers who became distressed, remained distressed (i.e., sustained distress), became non-distressed, or remained non-distressed at a subsequent assessment. From 2008 to 2015, there was a clear, steady increase in the proportions of caregivers who became distressed (from 7.9% in 2008 to 15.4% in 2015) and remained distressed (from 12.1% in 2008 to 26.8% in 2015). The number of caregivers who became distressed also consistently outnumber the number of caregivers who became non-distressed. The same time trends were observed across all MAPLe score levels (see Supplementary Materials 2 for results of time trends of one-year distress trajectories, stratified by MAPLe score). In particular, the increases in individuals who became distressed and remained distressed were especially prominent among the

lower MAPLe scores levels. Among caregivers of individuals with a MAPLe score of 1, the proportion who became distressed more than tripled from 2008 (4.7%) to 2015 (17.0%) while sustained distress more than doubled from 3.1% in 2008 to 7.4% in 2015. Among caregivers of individuals with MAPLe score of 5, in contrast, proportions of caregivers who became distressed and remained distressed increased from 10.3% and 28.1% in 2008 to only 13.9% and 46.3% in 2015, respectively.

Table 4.3. Percentages (number) of caregivers who became distressed, remained distressed, became non-distressed, or remained non-distressed at a subsequent assessment, by year of baseline assessment.

Year	Became distressed	Remained distressed	Became non-distressed	Remained non-distressed
2008	7.9 (2158)	12.1 (3309)	6.6 (1810)	73.4 (20119)
2009	8.0 (2769)	12.1 (4153)	5.8 (2011)	74.1 (25536)
2010	10.3 (3055)	13.5 (4023)	6.6 (1952)	69.6 (20678)
2011	13.3 (3773)	18.3 (5209)	7.3 (2062)	61.1 (17363)
2012	13.2 (3912)	21.0 (6214)	8.3 (2455)	57.6 (17084)
2013	14.5 (4042)	24.7 (6892)	8.2 (2297)	52.5 (14646)
2014	15.1 (4223)	26.8 (7473)	8.5 (2378)	49.6 (13826)
2015	15.4 (2316)	26.8 (4019)	7.8 (1173)	50.0 (7502)

Figure 4.3. Proportions of initially non-distressed caregivers who became distressed, and proportions of initially distressed caregivers who remained distressed, by year of initial assessment.



4.3 Discussion

As the Canadian population ages, an increasing number of older and frail individuals are projected to require home and community care to manage their health conditions and live safely at home. Caregivers play a crucial role in their care-recipients' health, well-being, and capacity to remain in the community. In 2017, the federal and provincial government endorsed 'A Common Statement of Principles on Shared Health Priorities' – one of which was to improve access to home and community care – accompanied by $11 billion of federal investment over 10 years[136]. In 2018, twelve pan-Canadian indicators were developed to measure improvements in these priority areas, including an indicator for caregiver distress developed by CIHI (using the same two items from interRAI data as did this research) as a measure of access to and the effectiveness of home care and community-services[136].

Our findings showed that, among caregivers of Ontario community-dwelling older adults, proportions of distressed caregivers have been rising substantially over time to more than 30% in 2015. This rising trend has continued based on a recent report by CIHI which showed that 35.2% caregivers of home care clients nationally (39.5% in Ontario) were distressed in 2019-2020[137]. This is consistent with the finding that the number of caregivers who have become newly distressed continuously outnumber the number of caregivers who have become non-distressed. These findings may reflect insufficiencies in the amount and/or effectiveness of home and community services and resources – problems that are likely to persist given the growing older population and limited government resources. It would be important to continue tracking trends of caregiver distress trajectories to determine if the recent additional government investments are effective in reducing or reversing the increase of distress.

Consistent with past findings[81], proportions of distress were higher among caregivers of individuals with higher MAPLe scores. Though this is true across all years, it is important to note

that the increases in incident and sustained caregiver distress over time were greater among the lower MAPLe scores than the increases observed among the higher MAPLe scores. This suggests that caregivers of individuals with lower care needs may not be adequately supported by existing resources and policies. Home and community care are designed to prioritize individuals with high care needs and help address immediate health needs such as medical needs and personal care. Individuals with lower MAPLe scores often may not be prioritized to receive certain services or may have different or more personalized needs that cannot be addressed by standard home care. It is clear, however, that many of their caregivers quickly become distressed or stay distressed, likely due to declines in their care-recipients' health and also possibly because the (often multi-facetted) causes of their distress was never addressed. Given that most care-recipients will inevitably decline, early and more personalized supports, especially education and training, should be provided to caregivers even if their care-recipients do not yet have high care needs. Such early measures will help caregivers be more prepared, psychologically and practically, to manage changes in their care-recipients' health and care needs, thus both preventing/reducing caregiver distress and improving the care provided to care-recipients.

4.4 Limitations and Considerations

The operationalization of caregiver distress using items from the RAI-HC assessment has been discussed extensively by an Expert Advisory Group at CIHI and is currently used provincially and nationally as a population-level performance indicator to evaluate access to services and support. However, several limitations and considerations should be noted. First, while publicly-funded healthcare and home care is available to all residents in Ontario with a valid OHIP card (including refugees and landed-immigrants), certain vulnerable populations, such as individuals who are homeless, may lack access to these services and are therefore under-represented in health administrative databases. Some minority groups, such as new immigrants or individuals with

language barriers, may also be less informed about these services. Thus, conclusions derived from data collected through the RAI-HC, despite being population-based, may not be applicable to these vulnerable/minority populations. Additionally, this binary definition of caregiver distress is crude and does not measure levels of distress or the various aspects of distress. There is also potential for inaccuracies or biases in the identification of distress – the assessor is instructed to ask the caregiver and care-recipients, separately, for their reports of distress and the ability to continue caregiving, as well as to "consider the current situation as well as a projection of future needs" and to use their clinical judgement in coding the two variables. While this reduces the potential reporting biases from relying solely on self-reported information, it is also possible for the assessor's judgement to be biased or inaccurate.

As such, there are several considerations in the usage and interpretation of this caregiver distress indicator. While measured on a population level and appropriate as a high-level indicator of health systems performance and access to/need for services, this operationalization is too crude for etiological research examining specific causes of distress or for designing interventions to target specific aspects of distress. It may also be inappropriate for understanding caregiver distress among the aforementioned sub-populations, as they may lack access to publicly-funded healthcare services and are therefore under-represented in health administrative data. Furthermore, this operationalization of caregiver distress may be inadequate for research examining caregiver distress among cultural or ethnic groups – for example, individuals from certain cultures may feel obligated to provide care to their loved ones[138,139], and thus may be less inclined to use home and community services and/or tend to under-report distress.

Chapter 5

CARING FOR OLDER MEN AND WOMEN: WHOSE CAREGIVERS ARE MORE DISTRESSED? A POPULATION-BASED RETROSPECTIVE COHORT STUDY

5.1 Background

Family or friend caregivers (henceforth referred to as "caregivers") are commonly defined as individuals providing unpaid care to family or friends with health-related impairments[2]. With a growing aging population, Canada relies on caregivers to support 70% to 80% of older persons in the community[56,140]. Other countries also depend heavily on caregivers, with one in six Americans having cared for someone over 50 in 2020[5], and up to 80% of long-term care in Europe being performed by family or friend caregivers[141]. Caregivers are often distressed[142], defined broadly as "the overall impact of physical, psychological, social, and financial demands of caregiving"[58]. This jeopardizes the quality of care provided, their own health and capacity to continue caregiving activities, and the health of those under their care (henceforth referred to as "care-recipients")[20].

Population demographic trends can change the landscape of who will be requiring care, who can provide it, and the distress caregivers experience. One notable trend is the narrowing of the gender gap in life expectancy[143], with the age-adjusted men-to-women mortality ratio in Canada dropping from 1.47 in 1992 to 1.28 in 2012[144]. Its implication is complex – on the one hand, there may be lower rates of widowhood and greater availability of spousal caregivers for women. On the other, more older men will require support, with the caregiving burden mostly falling onto their spouses who may be frail themselves, limited in capacity, and particularly susceptible to becoming distressed[31,145,146].

Differences in the health and social challenges older men and women face may also impact their care needs and their caregiver's experience of distress. Past research has demonstrated

important sex and gender differences in mortality and morbidity - in North America, older men have higher rates of mortal conditions (e.g., cardiovascular diseases) and are more likely to be hospitalized or admitted into long-term care facilities[147–149]. In contrast, older women live longer both with and without disability and have more morbid conditions (e.g., arthritis)[148,149]. Due to widowhood and social expectations, women receive less unpaid care but are often expected to undertake greater caregiving responsibilities, even when they themselves require care[5,31]. Thus, understanding gender differences in care-recipients' characteristics, health, and care needs is crucial for identifying caregivers at high risk of distress and for providing targeted interventions to alleviate stress and burden.

Past research on gender differences in caregiver distress have focused almost exclusively on caregiver's gender[23,29–32] rather than that of the care-recipient. Among most studies of caregiver distress, care-recipient's gender is either not reported[33–37], not included in modelling[38–40], or adjusted for without reporting its effect size[41–43]. Only one cross-sectional, population-level study reported descriptively that caregivers of men are more likely distressed than caregivers of women (18.2% versus 9.9%)[147]. Those that included care-recipient's sex as a covariate in regression modelling also found that caring for men increases the odds of distress, but did not elaborate further[17,52]. Most existing studies also restrict to patients with specific health profiles (e.g., dementia or cancer), or only examine distress cross-sectionally[17,38]. To our knowledge, no population-level studies have explored trajectories of caregiver distress longitudinally.

Our study addressed these gaps by using population-level, longitudinal data to examine whether primary caregivers of older men and women differ in their distress trajectories. This study had two main objectives: first, we described and compared the characteristics and health of older men and women receiving care as well as their caregivers' characteristics and caregiving profile. Second, we described how caregiver distress (at baseline and over time) differed according to the

care-recipient's gender. We hypothesized that caregivers of older men are more likely to be distressed than caregivers of older women. This is at least partly because older men have more health conditions and functional impairments[147], which require greater care. We also expected caregivers of older men to more likely be spouses and co-residing – as women are generally younger and still outlive their husbands – both of which increase the likelihood of distress[38,52].

5.2 Method

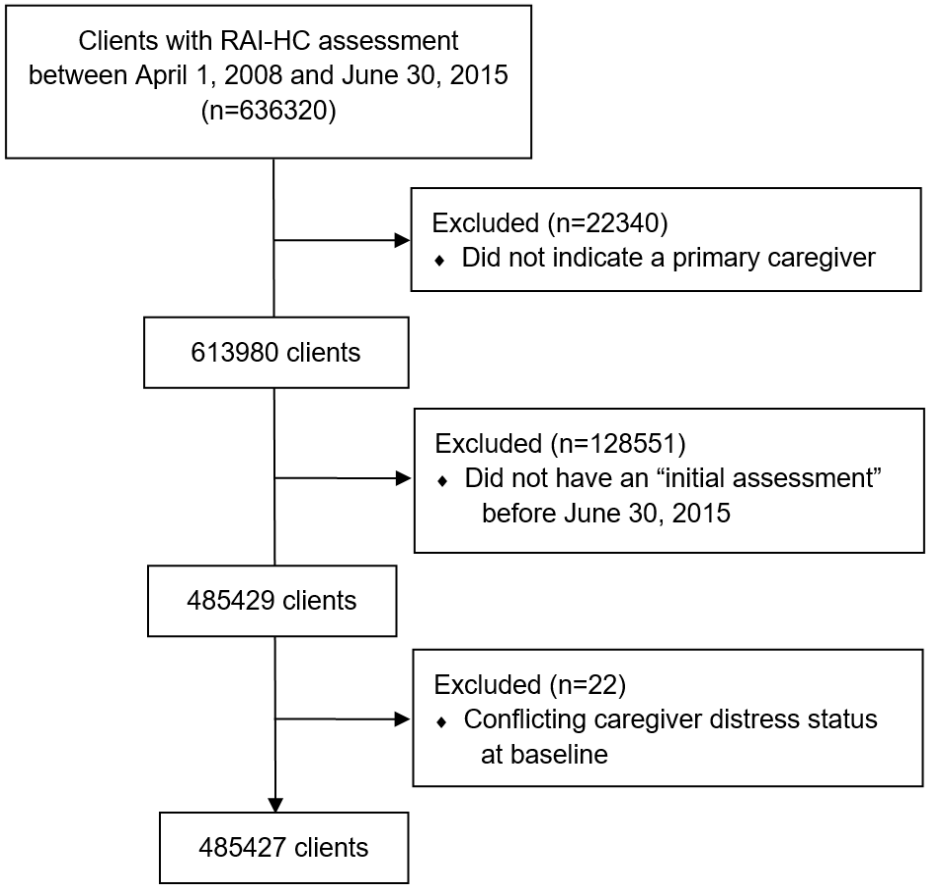
Data source

This study used population-based data in Ontario, a multicultural and the most populous province in Canada. Since 2002, the Resident Assessment Instrument-Home Care (RAI-HC) has been used by case managers and care coordinators in Ontario to determine the needs of persons expected to be, or currently are, long-term recipients of home care or those applying for admission into a long-term care facility[150]. This standardized, well-validated[127–129], and highly reliable[127–129] assessment is routinely administered to record information on the client's physical, cognitive, and social functions, service use, and their caregivers' characteristics and caregiving profile[17]. While all persons assessed by the RAI-HC have additional care needs, not everyone receives home care as some may decline home care or are admitted to other care settings while waiting for home care. Some receive multiple RAI-HC assessments, as existing policies requires a reassessment at least every 6 months or when significant changes in care needs occur[150]. Individual-level RAI-HC data is held and analyzed at ICES, a non-profit research institute funded by the Ontario Ministry of Health and Long-term Care. Its legal status under Ontario's health information privacy law allows it to collect and analyze personal health data, without consent, for research and health system evaluation.

Study Sample

Our study population comprised of adults aged over 50 years and residing in Ontario who have received a RAI-HC "initial assessment" (indicative of a first assessment since opening of a care case) between April 1st, 2008 and June 30th, 2015. Since RAI-HC data was only available up to June 30, 2016 and to ensure that everyone had at least one-year of follow-up, we only included initial assessments that occurred before June 30, 2015. Clients who did not have a primary caregiver were excluded (see Figure 5.1 for a CONSORT diagram of cohort creation). Although the caregivers themselves were not followed longitudinally, the clients (i.e., care-recipients) often received multiple assessments, allowing us to track their caregivers' distress status over time.

Figure 5.1. CONSORT flow diagram of the cohort creation



Defining Caregiver Distress

The primary caregiver is defined as distressed when one or both of the following items on the RAI-HC is checked:

1) A caregiver is unable to continue in caring activities.

2) The primary caregiver expresses feelings of distress, anger or depression.

Both items are coded by assessors based on clinical judgment informed by their observations of the client and their caregivers[28], hence limiting self-report bias. Jointly developed by interRAI and the Canadian Institute for Health Information, this distress indicator measures both feelings of distress and the caregiving situation in distress[151] and has been used by previous studies[17,28,38].

Each person's initial RAI-HC assessment was used to determine their primary caregiver's baseline distress status. Some did not have another assessment within one year of their initial assessment and were excluded in trajectory analyses. For those with additional assessments, their caregivers followed one of four possible distress trajectories: 1) initially non-distressed caregivers who remained non-distressed in all subsequent assessments; 2) initially non-distressed caregivers who became distressed in a subsequent assessment; 3) initially distressed caregivers who remained distressed in all subsequent assessments; or 4) initially distressed caregivers who became non-distressed in a subsequent assessment.

The Health, Care Needs, and Caregivers of Men and Women

Most of the differences in men and women's care needs and their caregivers' experience of distress likely pertain to differences in socially constructed roles, behaviours, experiences, and identities (i.e., gender-based) rather than to biological, physical, or physiological reasons (i.e., sex-based)[152]. However, as gender is not collected by the RAI-HC assessment, we used care-recipient's sex (male or female) as a proxy. While all analyses were performed using care-recipient's sex,

terms of gender (e.g., men, women) were used throughout the paper, which is consistent with other studies examining gender using health administrative data[147,153].

We examined the following factors of older men and women at their initial (i.e., baseline) RAI-HC assessment: demographic characteristics (age, marital status, place of residence, co-residence status); functional status indicated by their self-performance in activities of daily living (ADLs), difficulties in independent activities of daily living (IADL), and continence; cognitive performance and presence of delirium; mood and behavioural issues such as disruptive behaviours and depressive symptoms; and presence of the comorbidities such as dementia and cardiovascular diseases (CVD). We also described their primary caregiver's relationship to them ("kinship"), whether caregivers co-resided, provided ADL/IADL care and emotional support, and the hours of care provided on an average week.

Statistical Analyses:

Gender Differences in Health, Care Needs, and Caregiver Profiles

Descriptive analyses (calculations of mean, standard deviations, and proportions) were performed on the socio-demographics, health, care needs, and caregivers of men and women separately, along with tests of statistical significance (t-test, chi-square test) for differences between men and women.

Gender Differences in Caregiver Distress

To examine caregivers' distress trajectories, we calculated the proportions of caregivers who were distressed at baseline, proportions of initially non-distressed caregivers who became distressed, and proportions of initially distressed caregivers who remained distressed. These calculations are performed for men and women separately, and further stratified by type of kinship. We also performed three logistic regressions with baseline caregiver distress as the outcome:

Model 1 examined the unadjusted effect of care-recipient's gender; Model 2 adjusted for well-known predictors of caregiver distress: care-recipient's age, marital status, place of residence, and caregiver's kinship and co-residence status[17,38,52]; Model 3, in addition to covariates in Model 2, adjusted for the care-recipients' diagnosis of Alzheimer's disease or dementia, functional status, behavioural issues, and hours of care provided by their primary caregiver, all of which have also previously been identified as predictors of caregiver distress[17,23,38,43,52,59]. All covariates included in regressions were pre-specified, and checked for potential collinearity by examining the correlation matrices and cross-tabulation of frequencies as well as the regression parameters for large standard errors. Since no collinearity issues were detected, all were kept in the models.

Since we hypothesized that gender difference in caregiver distress is at least partially due to men having more health and behavioural issues and requiring more care, we expected the effect of sex to decrease after controlling for these factors. Since models 2 and 3 included variables with missing data (with "hours of care" having the highest proportion of missingness at 12.2%), multiple imputation for missing data was performed (number of imputations = 15) using the fully conditional specification method, which uses a separate conditional distribution for each variable and is more appropriate if the imputation involves binary variables[154]. All analyses were performed in SAS Enterprise Guide (V.6.1)[155].

5.3 Results

The RAI-HC assessments of 485,407 older adults, 60.5% of whom women, were included in this study. Table 4 shows the characteristics of these men and women, who their primary caregivers were, and the type and amount of care received as indicated on their baseline assessment. The mean and median age of men were two years less than the age of women. Men were more likely to be married and residing in private homes with their spouse, while women were more often divorced or

widowed and living alone or in group setting. Caregivers of men were often their spouses (52.0%), while women were mostly cared by their child/child-in-law (60.1%). Caregivers of men were also more likely to co-reside, provide ADL care, and provide more hours of care.

Table 5.2 shows the health and functioning of older men and women. In general, men receiving care had poorer health and greater care needs. Though the performance of men and women in ADL tasks were similar, more men had great difficulty in two or all three IADLs. While more women had possible depression (18.3% vs 15.0% of men), incontinence (43.8% vs. 34.1% of men), and fractures (15.3% vs. 8.4% of men), men had slightly greater cognitive impairment (indicated by higher Cognitive Performance Scale (CPS) scores), were more likely to exhibit behavioural issues and delirium, and were more likely to have cardiovascular diseases, Parkinson's disease, and cancer. The prevalence of Alzheimer's/dementia were similar between men and women.

Table 5.1. Characteristics of older men and women receiving care and their caregivers

Care-recipient's demographic and assessment-related characteristics		Women Receiving Care (n=293721) % (n) [4]	Men Receiving Care (n=191686) % (n)
Age	Mean ± SD	79.0 (10.4)	77.1 (10.5)
	Median (IQR[5])	81.0 (13.0)	79.0 (15.0)
	50 to 64 years	11.7 (34210)	14.8 (28403)
	65 to 79 years	28.5 (83712)	32.6 (62572)
	Over 80 years	59.9 (175799)	52.5 (100711)
Marital status	Married	31.1 (91494)	61.7 (118353)
	Never Married	4.9 (14393)	6.5 (12526)
	Widowed/separated/divorced	62.8 (184325)	30.2 (57903)
	Other	1.2 (3509)	1.5 (2904)
Place of residence at time of referral (missing: <0.1%)	Private home with home care	75.3 (221038)	78.0 (149457)
	Private home without home care	13.9 (40916)	14.1 (27027)
	Non-private home	10.8 (31728)	7.9 (15182)
Who care-recipient lived with at the time of referral (missing: <0.1%)	Lived alone	39.9 (117196)	23.6 (45133)
	Lived with spouse only	24.0 (70456)	48.2 (92358)
	Lived with spouse and others	5.5 (16265)	11.2 (21376)
	Lived with child (not spouse)	17.7 (51896)	6.9 (13240)
	Lived with others/in group setting	12.9 (37869)	10.2 (19559)
Characteristics of the primary caregiver and care provided			
Caregiver lived with care-recipient	Yes	47.4 (139338)	65.6 (125735)
Caregiver's relationship to care-recipient	Child/child-in-law	60.1 (176380)	32.3 (62000)
	Spouse	23.5 (69080)	52.0 (99654)
	Other relatives	10.2 (29812)	9.1 (17514)
	Friend/neighbor	6.3 (18449)	6.5 (12518)
Caregiver provides emotional support[6]	Yes	97.4 (286209)	97.3 (186545)
Caregiver provides care for instrumental activities of daily living (IADL)[7]	Yes	89.6 (263090)	89.3 (171202)
Caregiver provides care for activities of daily living (ADL)	Yes	38.0 (111568)	47.5 (91125)
Hours of care provided for ADL and IADL activities in the last 7 days (missing: <0.1%)	10 or fewer hours	42.7 (125475)	33.0 (63243)
	11-20 hours	19.4 (56955)	19.5 (37440)
	21+ hours	26.2 (76848)	34.6 (66297)

[4] All p-values for differences between women and men care-recipients are <0.0001 unless otherwise specified
[5] IQR: inter-quartile range
[6] Difference between women and men care-recipients are significant at p = 0.0078
[7] Difference between women and men care-recipients are significant at p = 0.0043

Table 5.2. Health, functional status, and behavioural symptoms of men and women care-recipients

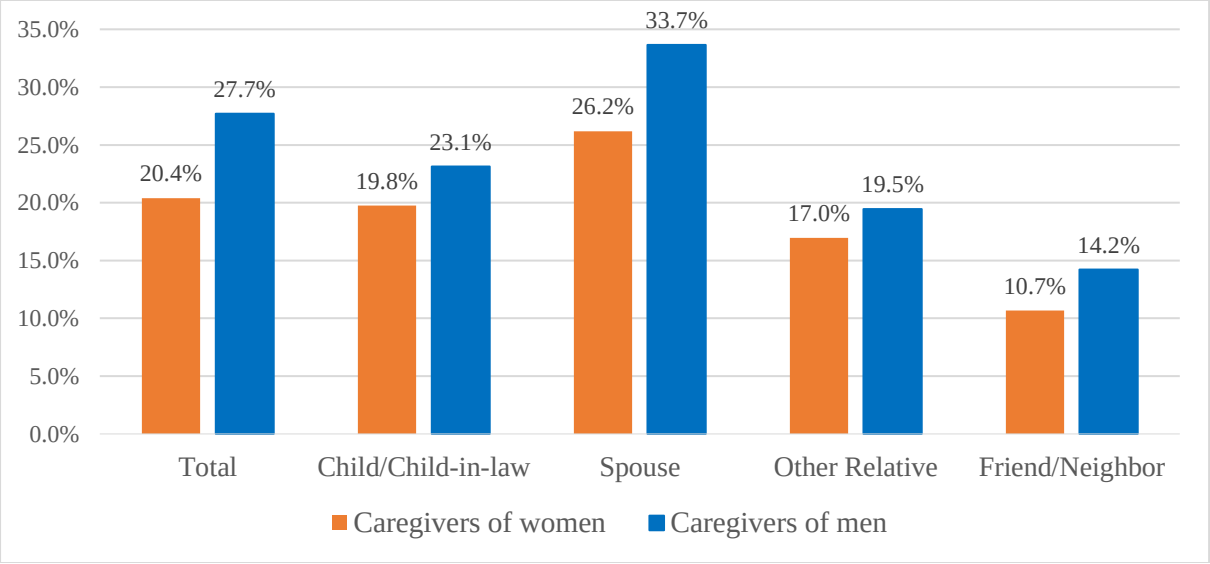
		Women Receiving Care (n=293721)	Men Receiving Care (n=191686)
Functional status		**% (n)[8]**	**% (n)**
ADL self-performance hierarchy	0: Independent	61.7 (181175)	57.1 (109518)
	1: Supervision required	10.6 (31051)	11.9 (22843)
	2: Limited impairment	13.2 (38809)	14.4 (27628)
	3: Extensive assistance required (I)	5.2 (15153)	6.9 (13256)
	4: Extensive assistance required (II)	5.0 (14594)	5.1 (9805)
	5: Dependent	3.6 (10441)	3.6 (6829)
	6: Total Dependence	0.8 (2498)	0.9 (1807)
IADL difficulty scale	0: No difficulty in any IADLs	5.1 (14908)	5.8 (11207)
	1: Some difficulty in one IADL	7.7 (22591)	5.4 (10328)
	2: Some difficulty in two IADLs	14.3 (41888)	11.7 (22484)
	3: Some difficulty in all three IADLs	2.1 (6102)	2.0 (3803)
	4: Great difficulty in one IADL	20.7 (60673)	17.2 (33024)
	5: Great difficulty in two IADLs	37.0 (108645)	40.4 (77526)
	6: Great difficulty in all three IADLs	13.2 (38914)	17.4 (33314)
Bladder/bowel incontinence	Incontinence present in last 7 days	43.8 (128695)	34.1 (65409)
Pain intensity	Mild or no pain	49.3 (144917)	59.1 (113302)
	Moderate	36.2 (106253)	30.1 (57703)
	Severe	11.3 (33100)	8.4 (16151)
	Pain is horrible	3.2 (9451)	2.4 (4530)
Cognitive abilities			
Cognitive Performance Scale	0: Intact	44.4 (130370)	41.0 (78515)
	1: Borderline intact	17.0 (48145)	16.4 (31435)
	2: Mild impairment	16.2 (47686)	16.9 (32374)
	3: Moderate impairment	18.5 (54266)	20.2 (38756)
	4: Moderately severe impairment	1.4 (4107)	2.0 (3914)
	5: Severe impairment	2.5 (7300)	2.8 (5447)
	6: Very severe impairment	0.6 (1847)	0.7 (1245)
Had delirium in the last 90 days	Yes	5.8 (17005)	7.3 (13919)
Mood and behavior			
Wandering behavior	Yes	2.4 (7143)	3.2 (6101)
Verbally and/or physically abusive	Yes	2.8 (8180)	4.6 (8738)
Socially inappropriate/disruptive	Yes	1.5 (4400)	2.1 (3992)
Depression rating scale (categorized)	Possible depression	18.3 (53651)	15.0 (28786)
Comorbidities			
Has Alzheimer's or dementia	Yes	21.0 (61716)	21.7 (41534)

[8] All p-values for differences between women and men care-recipients are <0.0001

Has any cardiovascular diseases[9]	Yes	36.6 (107448)	47.0 (90140)
Has Parkinson's disease	Yes	2.4 (6978)	5.1 (9726)
Has any fractures	Yes	15.3 (45009)	8.4 (16059)
Has cancer (excluding skin cancer)	Yes	14.5 (42625)	21.9 (41900)

Figure 5.2 shows the proportions of caregivers of men and women, stratified by kinships, who were distressed at baseline. Spousal caregivers were most likely to be distressed, followed by child/child-in-law, while friends or neighbors providing care were least likely to be distressed. More caregivers of men were distressed at baseline (27.7% of all versus 20.4% caregivers of women). This gender difference is present across all types of kinships, but is especially prominent for spouses (33.7% of spousal caregivers of men vs. 26.2% of spousal caregivers of women).

Figure 5.2. Proportions of caregivers of men and women who were distressed at baseline, by kinship to care-recipients

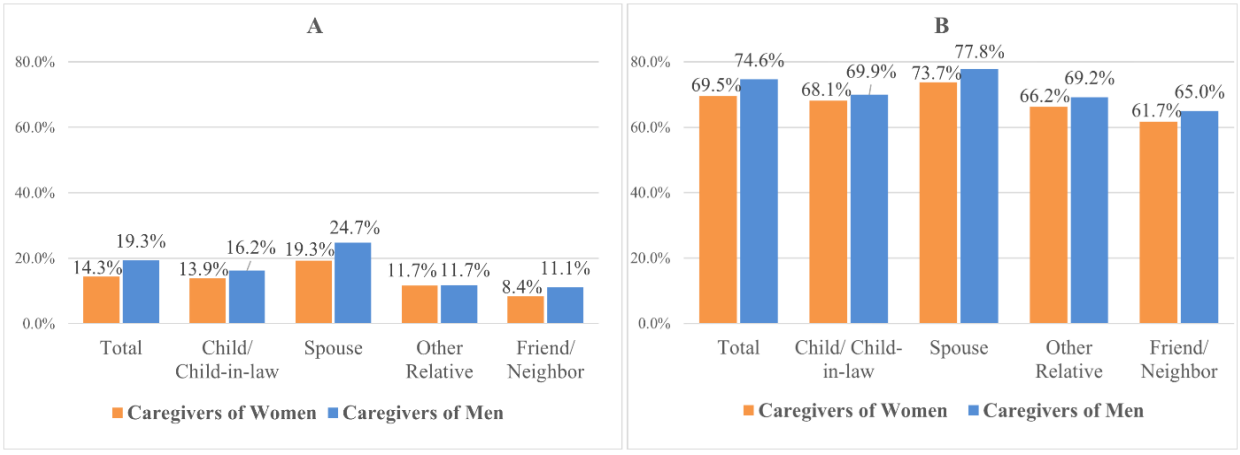


Note: all differences between caregivers of men and women were statistically significant at p<0.0001

[9] Includes stroke, coronary heart diseases, congestive heart failure, or peripheral vascular disease

Most older women (53.7%) and men (56.0%) did not have another RAI-HC assessment within one-year of their initial assessment, hence excluding them from distress trajectory analyses. Among those with multiple assessments, 22.6% and 31.7% of caregivers of women and men, respectively, were distressed at baseline. In addition, figures 5.3A and 5.3B show that initially non-distressed caregivers of men were more likely to become distressed (19.3% versus 14.3% of initially non-distressed caregivers of women), and initially distressed caregivers of men were also more likely to remain distressed (74.6 % versus 69.5% of initially distressed caregivers of women). These gender differences were present across almost all types of kinship, except for distant relatives where there were no sex differences in the one-year incidence of becoming distressed. The gender difference is more prominent among spousal caregivers, who also had the highest proportions of becoming or remaining distressed.

Figure 5.3. (A) Proportions of initially non-distressed caregivers who became distressed; (B) initially distressed caregivers who remained distressed, by care-recipient's gender and caregiver's kinship



Note: all differences between caregivers of men and women were statistically significant at $p<0.0001$, except for caregivers who were other relatives in figure 5.3A

Table 5.3 shows the odds ratios (ORs) and 95% confidence intervals (CIs) of the three logistic regression models. Looking at the unadjusted effect of care-recipient's gender in Model 1, caregivers of men had 1.49 (CI: 1.47-1.51) times the odds of being distressed at baseline than caregivers of women. The OR of gender decreased to 1.26 (CI: 1.24-1.28) after controlling for care-recipient's characteristics and caregiver's kinship and co-residence status in Model 2, and further decreased to 1.17 (CI: 1.15-1.19) in Model 3 after also controlling for care-recipient's health, functional status, behavioural issues, and the hours of care their caregivers provided. Though the effect of gender remains significant in Model 3, other factors have much larger independent effects on caregiver distress. Care-recipient's IADL and CPS scores had the largest impacts, more than doubling the odds of caregiver distress if the care-recipient had some IADL difficulty or moderate to very severe cognitive impairment (indicated by scores above three). Caregivers who provided more than 20 hours of care per week also doubled their odds of being distressed (OR=2.23, CI: 2.18-2.28). In contrast, they were half as likely to be distressed if their care-recipients resided in a congregate setting instead of a private home. In addition, caregivers who were spouses, children, or relatives of their care-recipients were slightly more distressed than if they were a friend or neighbor. Co-residence also increased the odds of distress, but its OR decreased from 1.75 in Model 2 to a range of 1.17 in Model 3 after controlling for hours of care provided and care-recipient's health and behavioural issues.

Table 5.3. Results of logistic regression models with baseline caregiver distress as outcome.

		Model 1	Model 2	Model 3
		OR (95% CI)		
Care-recipient's gender	Men vs. Women	1.49 (1.47-1.51)	1.26 (1.24 1.28)	1.17 (1.15-1.19)
Care-recipient's age	65 to 79		1.52 (1.48-1.56)	1.15 (1.12-1.19)
(reference: 50 to 64)	Over 80		1.95 (1.91-2.00)	1.20 (1.17-1.23)
Marital status	Married		1.14 (1.10-1.19)	1.36 (1.30-1.42)
(reference: never married)	Widowed/separated/divorced		0.79 (0.76-0.83)	0.89 (0.86-0.93)
Place of residence	Board care, assisted living, or group home		0.80 (0.78-0.83)	0.54 (0.58-0.56)
(reference: private home)	Residential care facilities		0.74 (0.70-0.78)	0.46 (0.44-0.49)
Caregiver co-resides	Yes vs. No		1.75 (1.72-1.78)	1.17 (1.15-1.20)
Caregiver's relationship	Spouse		1.53 (1.46-1.60)	1.30 (1.24-1.36)
to care-recipient	Child/child-in-law		1.61 (1.55-1.67)	1.33 (1.27-1.38)
(reference: friend/neighbor)	Other relative		1.55 (1.48-1.61)	1.36 (1.30-1.43)
ADL self-performance hierarchy scale (reference: 0)	1			1.30 (1.28-1.33)
	2			1.28 (1.26-1.30)
	3			1.38 (1.34-1.41)
	4			1.33 (1.29-1.38)
	5			1.26 (1.21-1.32)
	6			1.14 (1.11-1.17)
IADL difficulty scale (reference: 0)	1			1.25 (1.17-1.34)
	2			1.70 (1.61-1.79)
	3			2.23 (2.20-2.23)
	4			2.20 (1.90-2.21)
	5			2.45 (2.20-2.50)
	6			2.56 (2.33-2.79)
Cognitive performance scale (reference: 0)	1			1.68 (1.66-1.71)
	2			1.94 (1.90-1.98)
	3			2.43 (2.37-2.48)
	4			2.40 (2.29-2.51)
	5			2.38 (2.29-2.47)
	6			2.53 (2.28-2.82)
Wandering	Yes vs. No			1.42 (1.37-1.48)
Verbally/physically abusive	Yes vs. No			1.42 (1.28-1.47)

Socially inappropriate or disruptive behaviour	Yes vs. No		1.27 (1.21-1.33)
Resists care	Yes vs. No		1.37 (1.33-1.41)
Bladder/bowel incontinence	Incontinent vs Continent		1.25 (1.23-1.27)
Has Alzheimer's/dementia	Yes vs. No		1.35 (1.30-1.40)
Pain intensity (reference: mild or no pain)	Moderate		1.02 (0.99-1.04)
	Severe		1.20 (1.18-1.22)
	Pain is horrible		1.48 (1.43-1.54)
Hours of care per week (reference: fewer than 10)	10 to 20 hours		1.66 (1.63-1.69)
	21 hours or more		2.23 (2.18-2.28)

5.4 Discussion

Our study showed that older men and women receiving care in Ontario differed in demographic characteristics, health, care needs, and caregiver profiles. We also showed that caregiver distress is substantial, regardless of who the caregiver or care-recipient is. Not only were approximately one quarter of caregivers distressed at baseline, more than 70% of these initially distressed caregivers also remained distressed throughout the year. Among initially non-distressed caregivers, about 16% subsequently became distressed within one year.

As hypothesized, caregivers of men and women had different levels of distress: across all types of kinship, caregivers of men were more likely to be distressed, remain distressed, or become distressed. This is partly because of differences in their demographic profiles and levels of disability and need. Similar to findings from other studies in Canada[104,144,147], men had more functional and cognitive impairments, behavioural issues and required more care, all of which significantly increased the odds of caregiver distressed as shown in our regression analyses and in past findings[17,38,41,52]. The effect of care-recipient's gender on caregiver distress also decreased after these factors were controlled for, further confirming that the effect of gender is largely attributed to differences in health and care profiles. This explanation also aligns with past studies which have consistently shown that having

complex health conditions increases caregiving burden and financial strain, leading to greater caregiver stress[5,47,156]. Additionally, more women than men lived in congregate settings which greatly reduced the odds of caregiver distress. This factor is often neglected in past studies, but there is evidence that the social and professional supports provided through congregate settings could reduce caregivers' stress and burnout[157–159].

Caregivers of older men and women also differed in kinship and co-residence status. Women were mostly (60%) cared for by their children or children-in-laws while men were mostly (52%) cared by their spouses. This is likely because, as shown in Table 1, women were more likely widowed and older, and therefore had no spouses or frail or institutionalized spouses. Spousal caregivers, being older themselves and often feeling obligated to undertake caregiving responsibilities[30], have been shown to experience more depression symptoms and greater financial and physical strain[5,30,160]. Spouses of men are also mostly women since most men are in heterosexual relationships, and women caregivers often experience more negative consequences of caregiving such as employment/financial repercussions[161–163], difficulty juggling child-rearing and caregiving responsibilities[164], and social isolation[165]. In addition, men were more likely to live with their caregivers, and co-residence has been associated with higher distress, strain, and negative health consequences[30,41,52] as the constant caregiving burden can be emotionally and physically draining. In our regression analyses, co-residence indeed increased the odds of caregiver distress, but the magnitude of its effect decreased substantially after adjusting for hours of care provided and care-recipients' health and behavioural issues. This is unsurprising as the decision to co-reside is often driven by care-recipients having complex health issues and greater care needs[160].

It is interesting to note that the OR of gender was substantially, but only partially, reduced after controlling for other factors. The remainder of its effect on caregiver distress may be due to residual confounding, the principal ones being caregiver's age and gender, which we do not have

data on. There may also be multi-way interactions between types of kinship, caregiver's gender, and care-recipient's gender, which we also could not test due to the lack of data. For example, Lott (1991) found that women caregivers were more burdened if they cared for a mother or mother-in-law than a father or father-in-law, while men caregivers were more burdened caring for a parent than for a parent-in-law[166]. Obtaining data on all the multitude of contributors of caregiver distress for modelling has always been challenging for researchers. Care-recipient's gender, however, can be easily measured or estimated from population distribution. By highlighting how men and women differ in their health, behaviour, and caregiving/caregiver profiles and providing the unadjusted and partially-adjusted effects of care-recipient's gender on caregiver distress, we demonstrate the importance of including care-recipient's gender when modelling caregiver distress, especially when information on factors such as functioning and behaviours are not available.

This study has several strengths. First, using routinely collected population-level data results in better generalizability and less selection bias. Unlike other studies that only examined caregiver distress cross-sectionally, we followed care-recipients longitudinally for their caregivers' distress trajectories. Finally, we not only described but also investigated reasons for gender differences caregiver distress by looking at changes in the OR of care-recipient's gender when health, care needs, and caregiving factors are added to the regression model.

Limitations

Our research is constrained by several limitations commonly associated with using health administrative data. First, the RAI-HC is limited in variable availability. Due to the lack of gender variables, we resorted to using care-recipient's sex as a proxy for gender. This ignores other gender identities such as being transgendered or gender-fluid, and prevents us from identifying or separating gender-based versus sex-based differences. Other confounders or determinants of caregiver distress, such as caregiver's gender and age, were also unavailable. Furthermore, caregiver distress was

defined as a binary variable since information on the degree or nuanced aspects of distress were unavailable.

Another limitation is that we could only follow the trajectories of caregivers through their care-recipients' assessments, as the RAI-HC does not collect identification information of the caregivers. Thus, we could not ensure that each care-recipient had the same caregiver throughout their multiple assessments. This is partially mitigated by limiting the follow-up period to one year, during which a change of the primary caregiver is expected to be infrequent. We verified this assumption by showing that the caregiver's kinship to the care-recipient changed for only 2.8% of our cohort. This assumption is also supported by a national survey in the U.S. which found that 85% of surveyed caregivers had provided care for more than one year[9], as well as an AARP report stating that caregivers of adults provided on average 4.5 years of care[5].

Finally, more than half of our cohort did not have the requisite multiple assessments within one year to measure distress trajectory. This might result in selection bias, as those with multiple assessments are more likely to have change in their health status, and thus our trajectory findings may describe more unstable care-recipients. Selection bias may also have occurred as certain disadvantaged groups (e.g., immigrants with language barriers) have less access to or awareness of health care resources, and thus are both less likely to receive RAI-HC assessments (i.e., less represented in our cohort) and more likely to have distressed caregivers.

Past studies on sex differences in distress have often been challenged on the possibility that women caregivers simply report more distress while men are reluctant to do so despite being similarly distressed. This is unlikely in our study since the two items used to define caregiver distress were evaluated by assessors based on reports from the caregivers and clients as well as the assessors' observations and clinical judgement of the client's situation, including projection of future needs[133].

5.5 Conclusion

Our study showed that, across all types of kinship, caregivers of men were more likely to be distressed, remain distressed or become distressed within one year. This is partly because older men had more health, functional, and behaviour issues which required more care, and partly because their caregivers are more likely to be spouses and co-residing. Policy makers and health systems planners should account for the different care needs of men and women and the different profiles of their caregivers to provide adequate and appropriate resources and support. Our study also highlights the need to examine trajectories of caregiver distress longitudinally and on a population level, as consequences of prolonged or changes in distress on caregivers, care-recipients, and the healthcare system remains unclear.

Chapter 6

THE ASSOCIATION BETWEEN CAREGIVER DISTRESS AND DYING IN NON-PALLIATIVE ACUTE CARE – A RETROSPECTIVE COHORT STUDY.

6.1 Introduction

People at the end of life generally prefer to die at home[167–169] – defined as their regular place of living, including retirement and long-term care homes [168,170,171]. Dying in acute care, on the other hand, is often undesirable to patients and their family and friend caregivers (henceforth referred to as "caregivers"), ineffective in providing end-of-life or palliative care, and costly to the health care system[167,172]. Canada has one of the highest proportions of hospital deaths among developed countries[173], with much of the hospital deaths considered avoidable[174]. Policy-makers are thus interested in improving access to home and palliative care services, both of which have been shown to enable individuals to spend more time at home and avoid hospital deaths[136,167,175].

As individuals decline physically and mentally, they often rely on caregivers to make end-of-life decisions[167,176]. This is especially true for individuals who are unable to communicate (e.g., due to dementia or stroke)[177]. Anecdotally, experts in palliative and end-of-life care have expressed that distressed caregivers are less capable of helping their care-recipients die in an appropriate or preferred location[167]. Evidence from past research also indirectly supports this conjecture. A study of individuals in hospice palliative care in Ontario by Salam et al. has found that being cared for by distressed caregivers increased the likelihood of acute care admissions at the end-of-life[119]. Additionally, common barriers that prevent individuals from dying in their preferred place include communication difficulties, sudden and drastic worsening of functioning, and lack of professional support[168,177], all of which are also associated with caregiver distress. Distressed caregivers, often having been less-supported in care planning, are also less capable of

managing unexpected end-of-life situations[167] and less willing to or capable of undertaking the emotional, physical, and financial strains of arranging an out-of-hospital death[178]. Finally, distressed caregivers are more likely to stop caregiving altogether or reduce the amount of care provision. This is problematic as having a caregiver is near-essential for home death[167,176].

We therefore hypothesized that individuals cared for by a distressed caregiver would be more likely to die in acute care than individuals cared for by a non-distressed caregiver. The only study on this topic, to our knowledge, was conducted by Fukui et al. which found that Japanese patients with advanced-stage malignant disease who were cared for by distressed caregivers had greater odds of dying in hospital[122]. However, the generalizability of their findings is limited due to their restricted cohort and small sample sizes as well as regional and cultural differences. Therefore, we aimed to use large, population-based data to determine whether being cared for by a distressed caregiver, compared to being cared for by a non-distressed caregiver, is associated with a greater likelihood of dying in acute care. As a secondary aim, we also examined whether caregiver distress is associated with longer length-of-stay in acute care or alternative levels of care (ALC) in the last month of life.

6.2 Methods

Context

This study used health administrative data in Ontario, Canada. From 2002 to March 2018, the Resident Assessment Instrument-Home Care (RAI-HC) has been used in Ontario by care coordinators and case managers to systematically determine the needs of persons applying for or receiving home care as well as those in need of placement into a long-term care facility[150]. This standardized, validated[127–130], and reliable[127–129] assessment is routinely administered to record information on individuals' physical, cognitive, and social functions, service use, and their caregivers' characteristics and caregiving profile[17]. On April 27, 2018, the RAI-HC was replaced

by its updated version, the interRAI-HC assessment[131,132]. While the interRAI-HC assessment provides opportunities to measure additional and improved outcomes, most of its assessment items are identical or comparable to those in the RAI-HC[131,133]. All persons assessed by the RAI-HC or interRAI-HC have additional care needs, and many receive multiple assessments as existing policies requires a re-assessment at least every six months or when significant changes in health and care needs occur[150].

Study Design and Data Sources

We conducted a retrospective cohort study of Ontario decedents aged over 18 years at time of death, who died between July 1, 2015 and June 30, 2020. Decedents were included if they were eligible for government-funded health care, received a RAI-HC (pre-March 2018) or interRAI-HC (post-March 2018) assessment within one year of death, and indicated the presence of a primary caregiver on the assessment closest to death. Individuals were excluded if they had resided in a long-term care home within one year of death. For the secondary analyses of examining lengths-of-stay in acute care and ALC in the last month of life, decedents were only included in the analyses if they received a RAI-HC or interRAI-HC assessment within the last year but prior to the last month of life. This is to ensure that caregiver's distress status was established before the outcomes of lengths-of-stay in acute care and ALC.

Using uniquely encoded identifiers, we linked and analyzed multiple health administrative databases held at ICES, an independent, non-profit research institute funded by the Ontario Ministry of Health and Long-term Care. Its legal status under Ontario's health information privacy law allows it to collect and analyze health and demographic data, without consent, for health system evaluation and improvement. Information was obtained from the following datasets: 1) the Registered Persons Database (RPDB), which captures demographic information including sex, age, and dates of birth and death; 2) the RAI-HC and interRAI-HC,

which contains individuals' health and functional status, cognition, behavioural issues, comorbidities, formal care received, and caregiver characteristics; 3) Ontario Health Insurance Plan (OHIP) Claims database, capturing claims for physician services in inpatient and outpatient settings; 4) Discharge Abstract Database (DAD), containing information of all acute care admissions and discharges; 5) National Ambulatory Care Reporting System (NACRS), containing information for all hospital- and community-based ambulatory care; 6) Same Day Surgery (SDS), records information on same-day surgery or procedure stay; 7) Home Care Database (HCD), which captures all publicly-funded home care services in Ontario; 8) Statistics Canada Census Data, linked to individuals' postal codes to identify their neighborhood's income quintile, rurality, and its associated Local Health Integration Networks (LHINs) which, from 2007 to 2021, were the health authorities in Ontario responsible for regional administration of public healthcare services, including home and community care[179].

Outcomes

We defined location of death as a binary outcome of dying in *non-palliative* acute care versus elsewhere (i.e., dying in palliative care units or outside of acute care). Palliative care unit is considered appropriate for those at the end-of-life, therefore qualitatively different than dying in non-palliative acute care. We first used a previously derived method[180–182] that uses the discharge date and discharge disposition of each record of acute care admission (from DAD, NACRS, and SDS) to determine if death occurred while in acute care. Among these, deaths that occurred in palliative care units, defined as occurring during an admission in which palliative care was the most responsible diagnosis and most responsible service provider (a method used in previous studies[183–185]), were categorized as dying "elsewhere" while the remaining are identified as dying in non-palliative acute care. Deaths in any other setting were also categorized as dying "elsewhere".

We examined two outcomes in our secondary objectives: length-of-stay (in days) in *non-palliative* acute care and in ALC in the last month of life. We used a previously derived method[180,186] that uses the admission and discharge dates of hospitalization records to identify the number of days spent in acute care and ALC within one month of death. We identified records during which palliative care was the most responsible diagnosis and most responsible service provider and subtracted them from the total number of days in acute care to obtain length-of-stay in non-palliative acute care. Details of the derivation of all outcomes are provided in Supplementary Materials 3.

Exposure and covariates:

The main exposure, caregiver distress, was obtained from the RAI-HC or interRAIHC assessment closest to death. The primary caregiver was defined as distressed if one or both of the following was answered "yes":

1) Caregiver is unable to continue in caring activities; or

2) Primary caregiver expresses feelings of distress, anger, or depression.

Both items were coded by assessors based on clinical judgment informed by their observations of the client and their caregivers[28], hence limiting self-report bias. Jointly developed by interRAI and the Canadian Institute for Health Information, this distress indicator measures both feelings of distress and the caregiving situation in distress[151] and has been used by previous studies[17,28,38].

Covariates were selected from items present in both the RAI-HC and interRAI-HC assessments and based on a literature review of factors associated with caregiver distress and/or death. All were measured at the RAI-HC or interRAI-HC assessment closest to death unless otherwise specified: decedents' demographic characteristics (age at death and sex from RPDB, and marital status); functional and cognitive status as indicated by several validated composite

measures: self-performance in activities of daily living (ADL)[127], the Changes in Health, End-Stage Disease, Signs, and Symptoms Scale (CHESS)[187], and the Cognitive Performance Scale (CPS)[188]; behavioural issues (wandering and others); the presence of comorbidities (e.g., stroke, Alzheimer's disease or dementia); receipt of formal care services (home health aide, visiting nurses, and homemaking services); and receipt of publicly-funded palliative home care within one year of death, identified using a method that identifies individuals with a record in the HCD with an end-of-life designation[189]. We also described decedents' place of residence in terms of neighborhood income quintile, rurality, and its associated Local Health Integration Networks (LHIN) by linking postal codes from RPDB to census data. From 2007 to 2021, Ontario's 14 LHINs were responsible for the funding and administration of all hospital- and community-based health services provided to all residents within their geographic boundaries[179]. Finally, we described the primary caregiver's relationship to decedents ("kinship") and whether they co-resided with their care-recipients.

Statistical Analyses:

Descriptive analyses (calculations of mean, standard deviations, and proportions) were performed on the socio-demographic characteristics, health and functioning, and caregiver characteristics of decedents who died in acute care versus elsewhere. We also compared decedents cared for by distressed versus non-distressed caregivers in terms of their location of death, mean length-of-stay in non-palliative acute care and in ALC, and the proportion who spent any number of days ALC in the last month of life.

To examine the effects of caregiver distress on the location of death, we performed four pre-specified and increasingly-adjusted logistic regressions (the rationale for choosing this method and the hypothesized directed acyclic graph of the potential pathways between caregiver distress, location of death, and covariates are provided in Supplementary Materials 4). Model 1

examined the unadjusted association between caregiver distress and location of death. Model 2 adjusted for decedents' socio-demographic characteristics of age, sex, marital status, neighborhood rurality status, income quintile, and associated LHIN, as well as their caregivers' kinship and co-residence status. Model 3, in addition to covariates in Model 2, further adjusted for decedents' functioning (i.e., ADL, CPS, and CHESS scores), behavioural issues, and disease diagnoses of Alzheimer's and/or dementia, cancer, stroke, coronary heart failure (CHF), congestive heart failure (CHD), pneumonia, and whether the patient is receiving dialysis (as a proxy for renal failure). Model 4, in addition to covariates in Model 3, further adjusted for receipt of receipt of formal home care services (i.e., home health aide, visiting nurses, homemaking services) and palliative home care. We modelled age using restricted cubic splines with five knots at the 5th, 27.5th, 50th, 72.5th and 95th percentiles of the distribution of age. All covariates were assessed for potential collinearity and kept as no collinearity issues were detected. Multiple imputation for missing data was performed (number of imputations=5) with all aforementioned variables and using the fully conditional specification method, which uses a separate conditional distribution for each variable and is more appropriate if the imputation involves binary variables[154].

Upon post-hoc consultation with clinical experts, we recognized potential interactions between CHESS scores and caregiver distress as well as receipt of palliative home care and caregiver distress. Therefore, sensitivity analyses were performed to test whether these interactions were significant and improved model fit. All analyses were performed in SAS Enterprise Guide (V.6.1)[155].

6.3 Results

Our study included 127,472 decedents (85,258 and 42,214 decedents received a RAI-HC and interRAI-HC, respectively, as their last assessment), of whom 61,158 (48.0%) died in non-

palliative acute care (see Figure 6.1 for a CONSORT diagram of cohort creation). Table 6.1 compares the characteristics of decedents and their caregivers according to the location of death. Decedents were 81.3 years on average, mostly married (44.8%) or widowed (41.7%), and cared for by caregivers who were their child or a spouse (48.8% and 36.3%, respectively), co-residing (59.9%), and distressed (43.2%) - these characteristics were comparable between those who died in non-palliative acute care versus elsewhere. Decedents in non-palliative acute care were less likely female (50.7% versus 53.4% of those who died elsewhere) and more likely to have resided in rural settings (15.3% versus 11.3% of those who died elsewhere). They also had less functional and cognitive impairments (indicated by lower proportions in the highest ADL and CPS score categories), less health instabilities (indicated by lower proportions in the highest CHESS score categories), and higher prevalence of stroke, CHD, CHF, pneumonia, and dialysis. In contrast, those who died elsewhere had higher prevalences of Alzheimer's or dementia and cancer and notably were much more likely to have received palliative home care and visiting nurses (48.6% and 45.5%, respectively, compared to 12.1% and 37.5% of decedents in non-palliative acute care).

Figure 6.1. CONSORT flow diagram of cohort creation

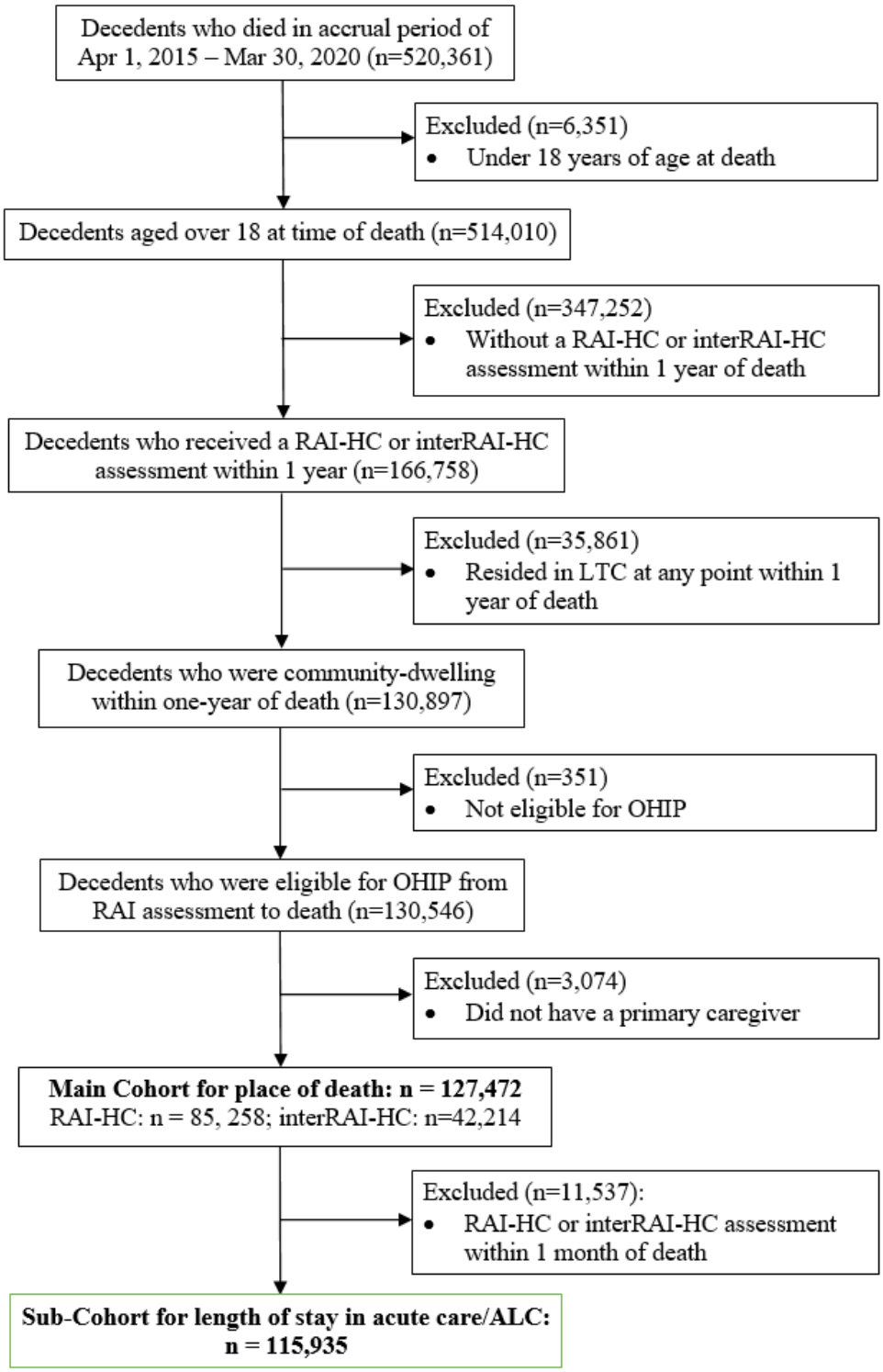


Table 6.1. Characteristics of decedents by location of death

Decedent's socio-demographic characteristics		**Died in acute care** (n=61158) **% (n)**	**Died elsewhere** (n=66314) **% (n)**	**Total** (n=127472)
Age	Mean (SD)	80.9 (11.8)	81.6 (12.0)	81.3 (11.9)
Number of days from last assessment to death	Mean (SD)	112.7 (91.6)	116.2 (93.2)	114.5 (92.5)
Sex	Female	50.7 (26435)	53.4 (35422)	52.1 (66456)
Marital status	Never Married	5.5 (3366)	5.1 (3368)	5.3 (6734)
	Married or partnered	45.5 (27815)	44.1 (29260)	44.8 (57075)
	Widowed	40.5 (24762)	42.8 (28386)	41.7 (53148)
	Separated or divorced	8.5 (5215)	8.0 (5300)	8.3 (10515)
Rurality	Rural	15.3 (9375)	11.3 (7500)	13.2 (16875)
	Missing	0.3 (188)	0.4 (231)	0.3 (389)
Income quintile	Lowest quintile	26.3 (16056)	24.4 (16164)	25.3 (32220)
	Quintile 2	22.7 (13911)	22.2 (14708)	22.5 (28619)
	Quintile 3	19.4 (11883)	19.5 (12905)	19.4 (24788)
	Quintile 4	16.4 (9997)	17.0 (11305)	16.7 (21302)
	Highest quintile	14.9 (9123)	16.6 (10977)	15.8 (20100)
	Missing	0.3 (188)	0.4 (255)	0.4 (443)
Local Health Integration Networks (LHIN) (missing <0.1%)	Erie St. Clair	6.5 (21585)	5.5 (16685)	6.0 (38270)
	South West	7.5 (24925)	8.0 (24245)	7.7 (49170)
	Waterloo Wellington	5.3 (17760)	4.2 (12830)	4.8 (30590)
	Hamilton Niagara Haldimand Brant	11.9 (39765)	12.8 (38665)	12.3 (78430)
	Central West	4.4 (14525	4.2 (12650)	4.3 (27175)
	Mississauga Halton	6.1 (20240)	6.6 (19885)	6.3 (40125)
	Toronto Central	7.5 (25010)	7.0 (21235)	7.3 (46245)
	Central	11.6 (38790)	10.8 (32645)	11.2 (71435)
	Central East	15.6 (52145)	12.8 (38715)	14.3 (90860)
	South East	6.2 (20800)	6.5 (19655)	6.4 (40455)
	Champlain	7.2 (23980)	8.7 (26290)	7.9 (50270)
	North Simcoe Muskoka	4.6 (15255)	3.63 (11020)	4.1 (26270)
	North East	3.9 (12995)	6.9 (20895)	5.3 (33890)
	North West	1.9 (6240)	2.6 (7875)	2.2 (14115)
Decedents' functional status				
ADL self-performance hierarchy	0: Independent	31.4 (19190)	28.6 (18993)	30.0 (38183)
	1: Supervision required	11.9 (7291)	10.3 (6829)	11.1 (14120)
	2: Limited impairment	19.2 (11762)	17.5 (11586)	18.3 (23348)
	3: Extensive assistance required (I)	14.6 (8897)	13.3 (8804)	13.9 (17701)

	4: Extensive assistance required (II)	10.0 (6087)	11.6 (7699)	10.8 (13786)
	5: Dependent	9.8 (5971)	13.2 (8727)	11.5 (14698)
	6: Total Dependence	3.2 (1960)	5.5 (3676)	4.4 (5636)
Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) Scale (missing <0.1%)	0: No health instability	9.7 (5921)	8.9 (5908)	9.3 (11829)
	1: Minimal health instability	20.2 (12330)	18.3 (12152)	19.2 (24482)
	2: Low health instability	28.8 (17623)	26.1 (17313)	27.4 (34936)
	3: Moderate health instability	27.1 (16554)	25.7 (17058)	26.4 (33612)
	4: High health instability	12.8 (7811)	16.3 (10773)	14.6 (18584)
	5: Very high health instability	1.5 (913)	4.6 (3069)	3.1 (3982)
Cognitive Performance Scale (missing <0.1%)	0: Intact	19.9 (12188)	20.4 (13521)	20.2 (25709)
	1: Borderline intact	15.8 (9672)	14.2 (9420)	15.0 (19092)
	2: Mild impairment	43.2 (26422)	39.1 (25928)	41.1 (52350)
	3: Moderate impairment	10.5 (6431)	11.3 (7516)	10.9 (13947)
	4: Moderately severe impairment	1.9 (1148)	2.4 (1569)	2.1 (2717)
	5: Severe impairment	6.1 (3711)	8.1 (5339)	7.1 (9050)
	6: Very severe impairment	2.6 (1586)	4.6 (3020)	3.6 (4606)
Decedents' behavioral issues				
Had wandering behavior (missing <0.1%)	Yes	2.1 (1297)	2.1 (1366)	2.1 (2663)
Had other behavioral issues[10] (missing <0.1%)	Yes	10.5 (6410)	10.9 (7247)	10.7 (13657)
Decedents' comorbidities				
Has cerebrovascular accidents (stroke)	Yes	17.3 (10589)	16.2 (10743)	16.7 (21332)
Has coronary heart disease	Yes	33.9 (20737)	28.5 (18926)	31.1 (39663)
Has congestive heart failure	Yes	25.3 (15449)	19.6 (13011)	22.3 (28460)
Has Alzheimer's or dementia	Yes	24.6 (15051)	26.8 (17778)	25.8 (32829)
Has Parkinson's disease	Yes	4.0 (15051)	4.2 (2767)	4.1 (5208)
Has pneumonia	Yes	5.8 (3571)	4.8 (3206)	5.3 (6777)
Has cancer	Yes	23.4 (14291)	36.2 (24002)	30.0 (38293)
Requires dialysis	Yes	4.2 (2554)	2.1 (1366)	3.1 (3920)
Services received by decedents				
Received home health aides	Yes	57.3 (35019)	57.4 (38093)	57.4 (73112)
Had visiting nurses	Yes	37.5 (22957)	45.5 (30161)	41.7 (53118)
Received homemaking services	Yes	26.7 (16306)	28.3 (13760)	27.5 (35066)
Received palliative home care	Yes	12.1 (7392)	48.6 (32244)	31.1 (39636)
Characteristics of decedents' primary caregiver				

[10] Was verbally or physically abusive, exhibited socially inappropriate behaviours, or resisted care

Caregiver lived with decedent (missing <0.1%)	Yes	60.7 (37093)	59.3 (39320)	59.9 (76413)
Caregiver's relationship to care-receiver	Child/child-in-law	47.7 (29169)	49.8 (33019)	48.8 (62188)
	Spouse	36.8 (22532)	35.7 (23689)	36.3 (46221)
	Other relatives	9.4 (5770)	8.9 (5932)	9.2 (11702)
	Friend/neighbor	5.5 (3335)	5.0 (3328)	5.2 (6663)
	Missing	0.6 (352)	0.5 (346)	0.6 (698)
Whether caregiver is distressed	Distressed	43.2 (26435)	43.2 (28660)	43.2 (55095)

Table 6.2 shows the number of days decedents spent in non-palliative acute care and ALC in their last month of life according to their caregivers' distress status. Those cared for by distressed caregivers spent, on average, one more day in non-palliative acute care and ALC than individuals cared for by non-distressed caregivers. In addition, 18.2% of decedents cared for by distressed caregivers spent time in ALC, compared to only 13.9% of those cared for by non-distressed caregivers.

Table 6.2. Decedents' length of stay in non-palliative acute care and ALC in the last month of life, by their caregivers' distress status.

	Non-distressed	**Distressed**	**p-value**
Mean (SD) length of stay (in days) in acute care	8.0 (9.7)	9.0 (10.6)	<0.0001
Mean (SD) length of stay (in days) in ALC	1.6 (5.4)	2.7 (7.6)	<0.0001
% who spent any number of days in ALC	13.9%	18.2%	<0.0001

Table 6.3 shows results from the four logistic regressions. Without adjustments or adjusting only for the characteristic of decedents and caregivers, caregiver distress had no impact on location of death, with odds ratios (ORs) of 1.00 and 95% confidence intervals (CI) of 0.98-1.02 and 0.98-1.03 for models 1 and 2, respectively. After adjusting for decedents' functional and cognitive status, behavioural issues, and comorbidities in Model 3, caregiver distress significantly increased the odds of dying in non-palliative acute care (OR=1.10, CI: 1.07-1.13). Its effect remained (OR=1.09, CI: 1.06-1.12) after further adjusting for receipt of home and palliative home care services in Model 4.

Table 6.3. Results of the four logistic regressions modelling death in non-palliative acute care.

		Model 1	Model 2	Model 3	Model 4
		Odds Ratio (95% Confidence Interval)			
Caregiver distress	Distressed vs. non-distressed	1.00 (0.98-1.02)	1.00 (0.98-1.03)	1.10 (1.07-1.13)	1.09 (1.06-1.12)
Care-receiver's age (restricted cubic splined [RCS])	1st segment: 5th to 27.5th percentile		1.00 (1.00-1.00)	0.99 (0.99-1.00)	0.99 (0.99-0.99)
	2nd segment: 27.5th to 50th percentile		1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
	3rd segment: 50th to 72.5th percentile		1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
	4th segment: 72.5th to 95th percentile		1.00 (1.00-1.00)	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Care-receiver's gender	Men vs. Women		1.08 (1.06-1.11)	1.06 (1.04-1.09)	1.02 (0.99-1.05)
Rurality	Rural vs. Urban		1.36 (1.31-1.41)	1.42 (1.37-1.48)	1.51 (1.45-1.57)
Income quintile	1 vs. 3		1.10 (1.06-1.14)	1.07 (1.03-1.11)	1.02 (0.98-1.06)
	2 vs. 3		1.04 (1.01-1.08)	1.03 (0.99-1.07)	1.01 (0.97-1.02)
	4 vs. 3		0.96 (0.93-1.01)	0.97 (0.93-1.01)	0.97 (0.93-1.01)
	5 vs. 3		0.91 (0.87-0.94)	0.93 (0.89-0.96)	0.95 (0.91-0.99)
Marital status (reference: never married)	Married/partnered		0.99 (0.93-1.06)	1.05 (0.98-1.13)	1.13 (1.04-1.21)
	Separated/divorced		1.01 (0.94-1.08)	1.00 (0.93-1.07)	1.01 (0.94-1.09)
	Widowed		0.98 (0.92-1.04)	0.99 (0.93-1.06)	1.06 (0.98-1.13)
Local Health Integration Networks (LHIN) (reference: Eerie St. Clair)	South West		1.16 (1.09-1.23)	1.13 (1.06-1.20)	1.06 (0.99-1.14)
	Waterloo Wellington		0.94 (0.88-1.01)	0.87 (0.81-0.93)	0.93 (0.86-1.01)
	Hamilton Niagara Haldimand Brant		1.28 (1.21-1.36)	1.24 (1.17-1.31)	1.34 (1.26-1.43)
	Central West		1.14 (1.06-1.22)	1.20 (1.12-1.30)	1.06 (0.98-1.15)
	Mississauga Halton		1.34 (1.26-1.43)	1.33 (1.24-1.41)	1.08 (1.00-1.16)
	Toronto Central		1.16 (1.09-1.23)	1.14 (1.07-1.21)	0.90 (0.84-0.96)
	Central		1.14 (1.08-1.20)	1.10 (1.04-1.17)	0.83 (0.78-0.88)
	Central East		0.96 (0.91-1.01)	0.99 (0.93-1.04)	0.74 (0.70-0.79)
	South East		1.11 (1.04-1.18)	1.22 (1.15-1.31)	0.89 (0.83-0.96)
	Champlain		1.43 (1.35-1.52)	1.36 (1.28-1.45)	1.20 (1.12-1.28)
	North Simcoe Muskoka		0.87 (0.80-0.93)	0.84 (0.78-0.91)	0.90 (0.83-0.97)
	North East		1.87 (1.75-2.00)	1.79 (1.67-1.91)	1.61 (1.50-1.74)
	North West		1.52 (1.39-1.67)	1.54 (1.40-1.68)	1.11 (1.01-1.22)
Caregiver co-resides	Yes vs. No		1.07 (1.04-1.11)	1.11 (1.07-1.14)	1.20 (1.16-1.23)
Caregiver's relationship	Child/child-in-law		0.93 (0.88-0.99)	0.96 (0.91-1.01)	1.00 (0.95-1.07)

to care-receiver	Other relative		0.98 (0.92-1.04)	0.98 (0.92-1.05)	0.98 (0.91-1.04)
(reference: friend/neighbor)	Spouse/partner		0.88 (0.83-0.94)	0.91 (0.85-0.97)	0.96 (0.89-1.03)
ADL self-performance hierarchy scale (reference: 0)	1			1.04 (0.99-1.08)	1.03 (0.99-1.08)
	2			0.99 (0.96-1.03)	0.99 (0.96-1.04)
	3			0.99 (0.95-1.03)	0.98 (0.94-1.02)
	4			0.82 (0.78-0.86)	0.84 (0.80-0.88)
	5			0.72 (0.69-0.75)	0.73 (0.70-0.77)
	6			0.59 (0.54-0.65)	0.66 (0.60-0.73)
Cognitive performance scale (reference: 0)	1			1.10 (1.05-1.14)	1.03 (0.99-1.08)
	2			1.11 (1.07-1.15)	1.00 (0.96-1.04)
	3			1.01 (0.96-1.06)	0.90 (0.85-0.95)
	4			0.91 (0.83-0.99)	0.81 (0.72-0.86)
	5			0.84 (0.79-0.90)	0.75 (0.71-0.81)
	6			0.88 (0.79-0.98)	0.80 (0.72-0.90)
CHESS (reference: 0)	1			0.97 (0.92-1.01)	0.99 (0.94-1.04)
	2			0.95 (0.91-0.99)	1.01 (0.97-1.06)
	3			0.90 (0.86-0.94)	1.03 (0.98-1.08)
	4			0.72 (0.68-0.75)	0.97 (0.92-1.02)
	5			0.34 (0.31-0.37)	0.75 (0.69-0.83)
Wandering	Yes vs. No			1.04 (0.96-1.13)	0.96 (0.88-1.05)
Other behavioural issues	Yes vs. No			1.03 (0.99-1.07)	0.97 (0.93-1.01)
Had cerebrovascular accident	Yes vs. No			1.05 (1.02-1.08)	1.01 (0.98-1.04)
Has coronary heart disease	Yes vs. No			1.13 (1.11-1.16)	1.08 (1.05-1.11)
Has congestive heart failure	Yes vs. No			1.24 (1.20-1.27)	1.20 (1.17-1.24)
Has Alzheimer's disease or dementia	Yes vs. No			0.96 (0.93-0.99)	0.92 (0.89-0.95)
Has pneumonia	Yes vs. No			1.20 (1.14-1.27)	1.16 (1.10-1.23)
Has cancer	Yes vs. No			0.51 (0.50-0.53)	0.81 (0.79-0.83)
Received dialysis	Yes vs. No			1.62 (1.51-1.74)	1.36 (1.27-1.47)
Received home health aides	Yes vs. No				1.01 (0.98-1.03)
Had visiting nurses	Yes vs. No				0.93 (0.90-0.95)
Received homemaking services	Yes vs. No				0.95 (0.92-0.98)
Received palliative services	Yes vs. No				0.14 (0.14-0.14)

Other factors associated with increased odds of dying in non-palliative acute care in Model 4 include living in a rural setting (OR=1.51, CI: 1.45-1.57), being married/partnered compared to being single (OR=1.13, CI: 1.04-1.21), having a caregiver who co-resided (OR=1.20, CI: 1.16-1.23), having CHD (OR=1.08, CI: 1.05-1.11), CHF (OR=1.20, CI: 1.17-1.24), and pneumonia (OR=1.16, CI: 1.10-1.23), and receiving dialysis (OR=1.36, CI: 1.27-1.47). In contrast, having greater functional and cognitive impairments and health instabilities substantially reduced the odds of dying in non-palliative acute care, as indicated by decreasing ORs as ADL, CPS, and CHESS scores increase. ORs for those at the highest levels of ADL, CPS, and CHESS scores were 0.66 (0.60-0.73), 0.80 (0.72-0.90), and 0.75 (0.69-0.83), respectively. Having Alzheimer's disease or dementia (OR=0.92, CI: 0.89-0.95) and cancer (OR=0.81, CI: 0.79-0.83) as well as receiving visiting nurses (OR=0.93, CI: 0.90-0.95) and homemaking services (OR=0.95, CI: 0.92-0.98) also reduced the odds of dying in non-palliative acute care. Most notably, having received palliative home care greatly reduced the odds of dying in non-palliative acute care (OR = 0.14, CI: 0.14-0.14). Finally, there were geographic variations in the odds of dying in non-palliative care. Compared to those residing in the Eerie St. Clair LHIN, individuals in the North East (OR = 1.61, CI: 1.50-1.74) and Hamilton Niagara Haldimand Brant (OR = 1.34, CI: 1.26-1.43) LHINs had the highest odds of dying in non-palliative acute care, while those residing in the Central (OR = 0.83, CI: 0.78-0.88) and Central East (OR = 0.74, CI: 0.70-0.79) LHINs had the lowest odds. Sensitivity analyses with inclusions of the interaction terms of CHESS score with caregiver distress and receipt of palliative home care and caregiver distress in the modelling, separately or together, were not statistically significant, nor did they improve model fit or substantially change parameter estimates of other variables.

6.4 Discussion

In this retrospective cohort study using large health administrative data, we found that nearly half of decedents in Ontario died in non-palliative acute care and 43.2% had distressed caregivers. Those cared for by distressed caregivers spent more time in non-palliative acute care and ALC in their last month of life, and were more likely to die in non-palliative acute care. We also found that having greater functional and cognitive impairments, greater health instabilities, and receiving home care and especially palliative home care were associated with greatly reduced odds of dying in non-palliative acute care. The high proportions of distress among caregivers in our study concur with existing end-of-life literature – in Quebec, for example, 41%-62% of caregivers providing palliative care experienced high levels of distress[190]. Other studies have found that many caregivers have anxiety and depression levels in the clinical range, even higher than that of their care-recipients at the end-of-life[65,191]. Such high rates of distress are alarming since caregivers are near-essential for individuals wishing to remain at home at the end-of-life[167].

Our finding that individuals cared for by distressed caregivers had higher odds of dying in non-palliative acute care complements literature on the negative impacts of caregiver distress on health outcomes and service use. For example, a study by Maggio et al. (2010) of individuals with Alzheimer's disease found that caregiver distress was associated with future falls[21], a leading cause of hospitalization among seniors in Canada[192]. Caregiver distress has also been associated with increased likelihood of hospitalization among dementia patients in France[25] and individuals in hospice palliative care in Ontario[119]. It is thus unsurprising that caregiver distress would be associated with place of death. Aside from sudden deaths (e.g., accidents and suicides), individuals often experience substantial health deteriorations in the months before death, which can place added emotional, physical, and financial burden on caregivers[65,193,194]. As caregivers' level of distress and anxiety increase, they are more likely to seek relief by entrusting their care-

recipients to healthcare professionals in acute care, especially if they are uninformed or unprepared to manage the complex care needs of their care-recipients[178,195]. Therefore, provision of information and training as well as improved accessibility to respite and financial supports may effectively reduce caregiver distress and enable home deaths.

Interestingly, the association between caregiver distress and location of death was only significant after controlling for decedents' health and functional status. Similar to past findings[196–199], decedents in our study with chronic, mortal conditions (e.g., cancer), severe functional impairments, and health instabilities were less likely to die in hospital. This is likely because it is easier to anticipate their end-of-life prognosis – for example, individuals with cancer generally have more predictable health trajectories and prognosis than those with other conditions[200]. Their caregivers would thus be more likely to anticipate death and initiate end-of-life care planning. Notably, these same health conditions are well-established risk factors for caregiver distress[17,38,52,68], which explains their confounding effects on the association between caregiver distress and place of death - distressed caregivers were more likely to have been caring for individuals with greater health issues, while the predictability of these individuals' end-of-life status and resulting advanced care planning helped them avoid hospital deaths. We demonstrated that caregiver distress was indeed independently associated with a greater likelihood of dying in non-palliative acute care.

Some researchers have challenged the argument that acute care is an inappropriate location of death since some conditions can only be adequately treated in acute care[195,201,202]. While this is true, many individuals with such conditions would receive palliative acute care[195,201,202], which we have recognized to be appropriate for individuals at the end-of-life. Thus, only non-palliative acute care was identified as the undesired outcome in our study. It is also well-established that receipt of palliative home care reduces hospitalizations and hospital

deaths[175,203,204] as it provides a comprehensive system of support to individuals and their caregivers, including (but not limited to) medical support for symptom and pain management, psychological and spiritual support, information and training, and advanced care planning[175]. This concurs with our finding, as the receipt of palliative home care drastically reduced the odds of dying in non-palliative acute care. Despite estimates that 62% to 89% of decedents could benefit from palliative care[205,206] and it being a priority in many Canadian jurisdictions[175], fewer than 15% of individuals who died in 2016–2017 received publicly funded palliative home care[175]. Our study reinforces the importance of palliative home care in reducing hospital deaths.

It is noteworthy that the associations between caregiver distress and location of death persisted even after adjusting for decedents' receipt of home and palliative care. While these services - which mostly focus on alleviating caregiving burden by addressing the care needs of care recipients - are effective in enabling home deaths, additional support for caregivers themselves are needed. Past studies have identified modifiable risk factors for caregiver distress to target, such as lack of care-coordination[101], the burdens of navigating multiple health care systems[100], lack of information and training[102], and negative occupational and financial consequences[65,194]. Therefore, distress may be reduced or eliminated by better care-coordination between caregivers and healthcare providers and having greater access (with less stringent eligibility criteria and less burdensome application processes) to training, counselling services, respite, and financial supports. A few intervention studies have also shown that psycho-educational programs aimed at improving caregivers' competence and preparedness for care-provision[207] and increasing caregivers' sense of hope[208] could reduce distress.

Limitations

Our study has several strengths, including the capacity to leverage comprehensive, population-level data and the ability to tease out palliative acute care from other types of acute

care admissions. However, our study is not without limitations. Firstly, inaccurate health administrative data could result in misclassifications of the place of death or miscalculations of length of stay. Secondly, to account for individuals' health, functioning, and service use, we included only decedents who received a RAI-HC or interRAI-HC assessment within one year of death, thus limiting the generalizability of our findings. We also did not have information on individuals' and caregivers' preferences for the location of death and assumed that dying in non-palliative acute care is not desired. However, we believe this assumption is justified since past studies showed overwhelming preference in avoiding hospital deaths[167–169], and likely even more so if palliative acute care was excluded. Finally, we were not able to account for cultural or religious factors, which are associated with both caregiver distress[95,139] and preferences for location of death[209,210].

6.5 Conclusion

As many countries face an increasingly aging population, supporting individuals at the end-of-life and reducing avoidable hospital deaths have become a priority. Our study showed that caregiver distress was significantly and independently associated with increased likelihood of dying in non-palliative acute care. We also found that receiving palliative home care in the last year of life drastically reduced the likelihood of dying in non-palliative acute care. Thus, our study re-affirms the importance of improving access to home and palliative care services in enabling an appropriate and dignified dying experience. We also highlighted the need to support caregivers in ways beyond merely helping them take care of their loved ones. To effectively reduce caregiver distress and its impact on care-recipients' and caregivers' health, more targeted, holistic, and flexible services and policies should be available to caregivers and their families.

Chapter 7

USING EXPLORATORY STRUCTURAL EQUATION MODELLING TO EXAMINE CAREGIVER DISTRESS AND ITS CONTRIBUTORS

7.1 Introduction

Family and friend caregivers (henceforth referred to as "caregivers") are individuals who provide ongoing care and assistance, without pay, for family members and friends in need of support for physical, cognitive, mental, or aging-related conditions[2]. Like many countries in the world, Canada – the site of this study – relies heavily on caregivers, with nearly one in four Canadians aged over 15 years (or 7.8 million people in 2018) having provided care to a family or friend[3]; the proportion is similar in the United states (21.3%, or 53.0 million people in 2020)[8]. Caregivers undertake a wide range of emotionally and physically demanding tasks, with one-third of Canadian caregivers spending over 10 hours a week on caregiving[3]. These responsibilities, along with the accompanying financial burden and the negative impacts to personal relationships, often leads to caregiver distress[26,27] – commonly defined as having experienced physical, mental and/or emotional exhaustion[45–47] as well as symptoms of depression, anger, and/or anxiety[17,21,48]. This affects not only caregivers' own health but also their caregiving capacity and the quality of care provided, which in turn jeopardizes their care-recipients' health and increases their health care use and institutionalization[25,211]. Identifying factors associated with caregiver distress is crucial for informing policy and developing strategies to support caregivers.

Caregiver distress has been studied widely in the past, though many studies focused on patients with a specific illness (e.g., dementia)[54,59,212,213], resulting in small sample sizes and reduced generalizability. Past studies using large, population-level data often lacked comprehensive information on caregiver/caregiving. Specifically, many used simple definitions

of caregiver distress or overlooked important factors such as caregiving history and positive aspects of caregiving. Meanwhile, studies with greater details on caregiving or those that produced more complex conceptual models of caregiver distress were mostly qualitative or had small, non-representative samples[33,74,214–216]. To date, no studies to our knowledge have used nationally-representative data to examine a comprehensive model of the contributors of caregiver distress.

Therefore, we addressed these limitations by using data from a national survey focused on caregiving to develop and test the relationships between caregiver distress and its many contributing factors and covariates. To measure caregiver distress and its contributing factors with less bias and errors, we examined them as latent (i.e., unobserved) variables – each measured by multiple survey items - using exploratory structural equation modelling.

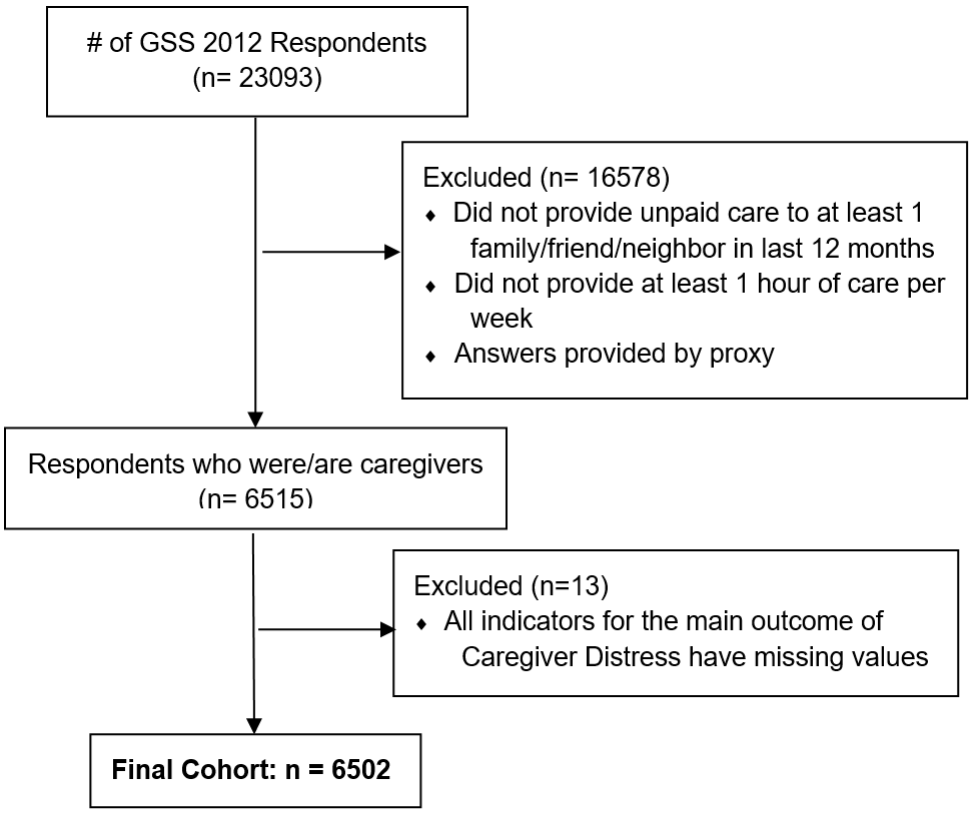
7.2 Methods

Data and study population

This study used cross-sectional data from the General Social Survey cycle 26 (GSS2012), conducted from March to December 2012[217]. The GSS2012 used a two-stage sampling design to survey non-institutionalized Canadians residing in the ten provinces, over 15 years of age, who have received care for health or aging-related issues and/or provided unpaid care to friends and families. In addition to socio-demographic and health-related characteristics, respondents were surveyed on details of their caregiving and/or care-receiving activities, needs, and support.

Our cohort consisted of respondents of the GSS2012 aged over 15 years at the time of survey and have self-identified as caregivers (i.e., had provided unpaid care in the last 12 months). We excluded 13 respondents who had missing responses for all items that comprise caregiver distress (our main outcome). Our final study sample consisted of 6502 respondents (see Figure 7.1 for the CONSORT flow diagram of cohort creation).

Figure 7.1. CONSORT flow diagram of cohort creation



Caregiver distress

Current literature on caregiver distress does not follow a standard definition or measurement of this concept. Generally, caregivers are considered distressed if they experience physical, mental, and emotional exhaustion[45–47] as well as symptoms of depression, anger, and/or anxiety[17,21,48]. Popular operationalizations of caregiver distress, used independently or in combination, include the Beck Depression Inventory[49], the Zarit Burden Interview[51], and various mental health questionnaires. As such, we examined caregiver distress as a latent factor (i.e., a construct that is not directly observed, but inferred through mathematical modelling of measured items), hypothesized to be represented by seven measured items on the GSS2012: six dichotomous items asking respondents whether caregiving caused them to feel worried or anxious,

overwhelmed, lonely or isolated, short-tempered or irritable, resentful, and depressed; and respondents' rating (a score of 0 to 3) of how stressful caregiving had been. These items were selected as they were used in past research to measure caregiver distress and depression[74,151,213,218–221].

Contributors of caregiver distress

Through a scoping review of literature on the risk factors and predictors of caregiver distress, we identified five groups of factors that contribute, negatively or positively, to caregiver distress (henceforth called "contributing factors"): 1) **caregiving burden**, comprised of the types and amount of care respondents have provided and the expenses incurred from caregiving[17,33,41]; 2) **caregiving network and support**, which captures help provided by caregivers' family, friends, the community and any professional or financial support received[141,222]; 3) **disruptions of family and social life**, which captures the negative impacts of caregiving responsibilities on respondents' family, social, and personal life[223,224]; 4) **positive emotional experiences** from caregiving, including feelings of agency, reward, and strengthened bond to care-recipients[216,224,225]; and 5) **caregiving history**, comprised of the number of years and people respondents have provided care for other than their primary care-recipient, as well as whether they have provided end-of-life care[96,212,226]. While many studies have identified variables characterizing the context of caregiving (e.g., demographic characteristics of the caregiver and care-recipient) as important contributors of caregiver distress, most (e.g., sex and kinship) are nominal categorical, and thus cannot together form a latent factor that is quantitative in nature. Thus, they are separately entered as covariates in the model.

Survey items hypothesized to measure each latent contributing factor were selected based on the following criteria: i) they were asked of all respondents in our cohort; ii) they were hypothesized to strongly measure one of the latent factors and no others (i.e., no substantial cross-

loading to multiple factors); and iii) there was sufficient variation to achieve enough explanatory power, with less than 95% of the study sample having the same value for an item[227]. As shown in Table 7.2, a total of 31 survey items were mapped to the five hypothesized latent factors.

Covariates

Through literature review, we identified twelve characteristics of the respondents and their primary care-recipients that are hypothesized to directly contribute to caregiver distress and may also be associated with the latent contributing factors. These include respondents' age, sex, education level, marital status, immigrant status, relationship to primary care-recipient, employment status, and self-reported physical health as well as their primary care-recipient's sex, age, dwelling type, and main health condition requiring care.

Statistical analysis

Descriptive analyses were performed for all items included in the modelling. Descriptive analyses (means and standard deviations for continuous item, frequencies for categorical items) were performed for all measured items to assess their completeness and distributions. Pearson and Spearman's rho correlations were run for continuous and categorical variables, respectively, to ensure that correlations between items did not exceed 0.95[228]. To account for missing values (constituting less than 5% of each item), we performed 10 multiple imputations using the Fully Conditional Specification with 100 burn-ins (see Supplementary Materials 5 for details of the multiple imputations). All descriptive analyses and multiple imputations were conducted using SAS® software, version 9.4[229]. The imputed dataset was exported to the Mplus statistical software Version 8 for subsequent analyses.

We used exploratory structural equation modelling (ESEM) to estimate the linear relationships between caregiver distress and its contributors. Structural equation modelling (SEM) is a statistical approach used to make causal inferences by testing the linear relations

(direct and indirect) among measured items and latent factors[230]. It is comprised of two steps: first, the identification of the measurement model (i.e., the model specifying how well measured items represent each latent factor) through factor analysis; then the modelling of the proposed relationships between the latent factors identified. We chose SEM instead of regression methods for two main reasons: 1) caregiver distress and its contributing factors are multi-dimensional and cannot be directly and accurately measured using single items. SEM is able to model them as latent factors composed of multiple measured items; 2) traditional regression methods cannot accommodate the large number of items (i.e., degrees of freedom) used to measure caregiver distress, its contributing factors, and covariates, nor model the complexity of their direct and indirect relationships.

We also chose to perform ESEM rather than traditional SEM. Traditional SEM first employs confirmatory (rather than exploratory) factor analysis, which restricts factor loadings of measured items on factors not intended to measure to zero – this practice is not only unrealistic in the real-world, but also leads to inflations of factor correlations and biased estimates[231]. ESEM, in contrast, employs exploratory factor analysis (EFA) which allows the measured items to (minimally) cross-load onto multiple factors, thus preventing factor loading inflations and distortions of structural relations[231,232]. ESEM is also more appropriate when a well-established measurement model does not exist[232].

Exploratory factor analysis

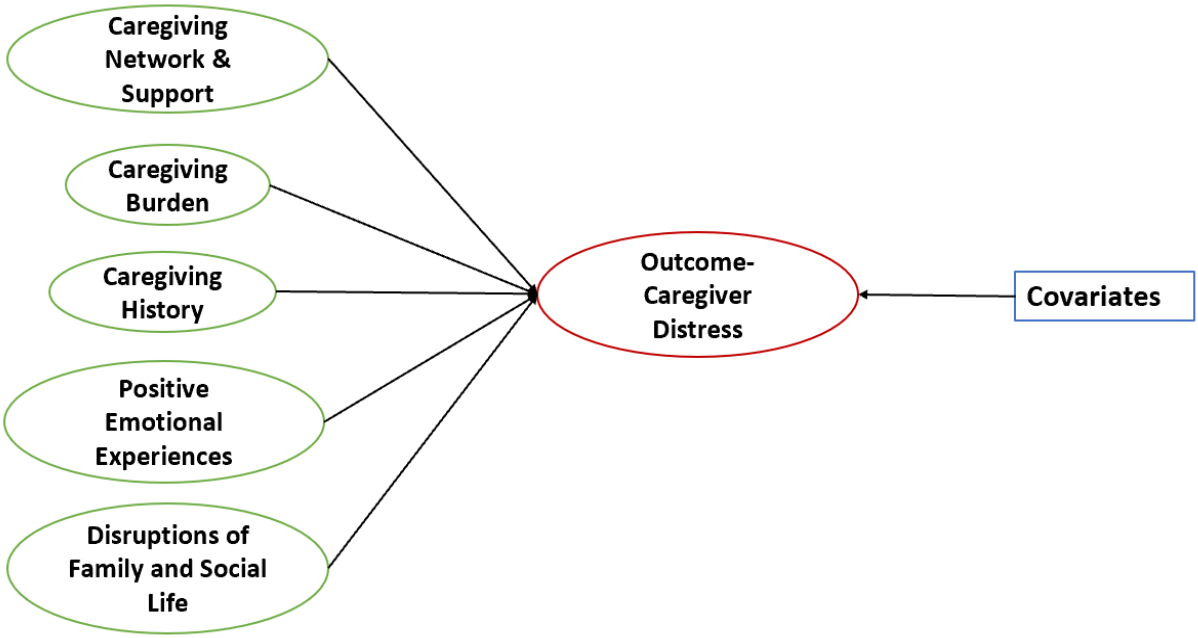
We performed EFA on the selected survey items to test their fit to the hypothesized six-factor model (one latent factor of caregiver distress and five latent contributing factors). We also tested if the items mapped better to a four-, five-, seven-, or eight-factor model. Weighted least squares means and variances-adjusted estimator and Geomin (oblique) rotation were applied. Selection of the number of factors was based on interpretability, model fit indices (with Root Mean

Square Error of Approximation [RMSEA] <0.06, Comparative Fit Index [CFI] >0.95, Tucker-Lewis Index [TLI] >0.95, and Standardized Root Mean Square Residual [SRMR] <0.08 indicating excellent fit), and visual inspection of the scree plot (eigenvalues >1)[233]. Once we established that a six-factor measurement model had the best fit, we inspected the factor loadings – correlation coefficients between each measured item and latent factor - and retained items whose primary factor loading was above 0.40[234], did not load substantially (above 0.30) onto other factors[234], and did not create Heywood cases (as indicated by negative residuals)[235].

Structural equation modelling

Our hypothesized structural model is shown in 7.2. Using items retained in the final EFA model, we first modelled the linear relationships between caregiver distress and its five contributing factors without adjusting for covariates. To account for the complex sampling frame of GSS2012[217], we included sample weights and respondents' province of residence as strata in the modelling. Then, covariates were added and retained regardless of their statistical significance. Finally, modification indices were examined to identify missing paths (i.e., linear relationships between latent variables, measured items, and covariates) that, if added, may improve model fit. Paths with sufficiently large index values and that were theoretically justified were then added to the model. At each stage, model fit indices were re-assessed, and factor structure and loadings re-examined to evaluate model stability. Additional information on the EFA and SEM analyses are provided in Supplementary Materials 5.

Figure 7.2. Theoretical structural model of caregiver distress and its contributing factors.



7.3 Results

Sample characteristics

Table 7.1 presents the characteristics of caregivers (i.e., survey respondents) and their primary care-recipients. Of the 6502 caregivers, the majority were between 45 to 64 years of age (53.0%), female (62.0%), married (63.0%), employed (59.2%), and reported having very good (34.0%) or excellent (18.9%) health. Most care-recipients were female, between 65 to 79 (28.5%) or over 80 (42.0%) years old, and lived in a private home (82.1%). Care-recipients were mostly a parent of the respondents (48.9%) and required care for aging and frailty (25.4%) or other health conditions (36.7%).

Table 7.1. Characteristics of respondents and their primary care-recipients

	% (n)
Respondent's age (categorized)	
Under 25	6.6 (426)
25 to 44 years	21.3 (1386)
45 to 64 years	53.0 (3447)
65 to 79 years	16.9 (1100)
80+	2.2 (143)
Respondent's sex	
Female	62.0 (4028)
Male	38.0 (2474)
Respondent's marital status	
Single, never married	17.7 (1153)
Divorced or separated	11.7 (761)
Widowed	7.3 (477)
Married or common-law	63.0 (4097)
(missing: n=14)	
Respondent is an immigrant	
Yes	11.1 (720)
(missing: n=77)	
Respondent's education level	
High school or below	42.4 (2758)
Trade or college diploma	33.3 (2166)
Bachelor's degree or beyond	23.8 (1548)
(missing: n=30)	
Respondent's employment status	
Employed/self-employed	59.2 (3850)
(missing: n=4)	
Respondent's self-rated physical health	
Poor	3.3 (212)
Fair	10.8 (703)
Good	31.9 (2075)
Very good	34.0 (2212)
Excellent	18.9 (1232)
(missing: n=68)	
Primary care-recipient's (PCR) sex	
Female	65.4 (4255)
Male	34.5 (2243)
(missing: n=4)	
PCR's age	
Under 25	5.8 (376)
25 to 44 years	6.4 (419)
45 to 64 years	17.3 (1123)
65 to 79 years	28.5 (1851)
80+	42.0 (2733)
(missing: n=70)	

PCR's type of dwelling	
Private home	82.1 (5337)
Long-term care homes, supportive housing, or others	17.9 (1161)
(missing: n=4)	
Main health condition PCR is receiving care for	
CVD	10.3 (668)
Cancer	12.4 (805)
Mental illness or addiction	7.0 (457)
Alzheimer's or dementia	7.3 (476)
Aging or frailty	25.4 (1650)
All other health conditions	36.7 (2389)
(missing: n=57)	
Respondent's relationship to PCR	
Spouse/partner or ex-spouse	11.4 (740)
Parent (-in-law)	6.3 (409)
Grandparent	0.5 (30)
Child (-in-law)	48.9 (3176)
Grandchild	6.2 (401)
Sibling	5.3 (346)
Other relative	4.6 (300)
Friend, neighbor, or co-worker	16.6 (1077)
(missing: n=23)	

Measures of caregiver distress and its contributing factors

As shown in Table 7.2, 18.9% to 57.3% of caregivers reported having experienced distressing emotions due to caregiving. Most caregivers helped with transportation (84.6%) and household errands (63.2%) and 63.4% had out-of-pocket expenses. Many spent less time with family (41.8%), friends (45.2%), on social activities (50.1%), and for self-care (53.6%) due to caregiving. Families of 57.3% of caregivers accommodated their caregiving responsibilities, but only 5.3% to 18.6% of caregivers received financial or respite support from friends, family, or the government. In terms of caregiving history, 32.4% of caregivers have provided end-of-life care, and 30.0% have cared for someone other than their primary care-recipients. Finally, almost all caregivers reported that the caregiving experience was somewhat to very rewarding, and 67.2% stated that the relationship with their care-recipients have strengthened.

Table 7.2. Frequencies of survey items and their primary factor loadings in the final exploratory factor analysis model.

Measured Survey Item	Coding	%	N (%) missing	Final EFA factor loading
Outcome - Caregiver Distress				
Caregiving caused respondent to feel worried or anxious	1: yes 0: no	yes: 57.3%	10 (0.1)	0.699
Caregiving caused respondent to feel overwhelmed	1: yes 0: no	yes: 34.8%	13 (0.2)	0.674
Caregiving caused respondent to feel lonely or isolated	1: yes 0: no	yes: 19.6	15 (0.2)	0.775
Caregiving caused respondent to feel short tempered or irritable	1: yes 0: no	yes: 36.6	20 (0.3)	0.589
Caregiving caused respondent to feel resentful	1: yes 0: no	yes: 18.9	16 (0.3)	0.642
Caregiving caused respondent to feel depressed	1: yes 0: no	yes: 21.4	15 (0.2)	0.915
How stressful has caregiving been?	0: Not at all stressful 1: Somewhat stressful 2: Stressful 3: Very stressful	33.5% 38.2% 15.1% 13.0%	15 (0.2)	0.638
Caregiving burden				
In past year, had various out-of-pocket expenses for caregiving	1: yes 0: no	yes: 63.4%	24 (0.4)	Eliminated*
Respondent provided emotional support in last year	1: yes 0: no	yes: 92.0%	18 (0.3)	Eliminated*
Respondent helped with transportation to do errands, get to appointments or social events	1: yes 0: no	yes: 84.6%	0	Eliminated*
Respondent helped with meal preparation/clean-up, house cleaning, laundry, or sewing	1: yes 0: no	yes: 63.2%	1 (0.0)	0.489
Respondent helped with house maintenance or outdoor work	1: yes 0: no	yes: 51.2%	1 (0.0)	Eliminated*
Respondent helped with personal care (e.g., bathing, toileting)	1: yes 0: no	yes: 32.0%	1 (0.0)	0.711
Respondent helped with medical treatments	1: yes 0: no	yes: 33.7%	0	0.750
Respondent helped with scheduling or care-coordination	1: yes 0: no	yes: 45.0%	2 (0.0)	0.655

Respondent helped with banking, bill paying or managing finances	1: yes 0: no	yes: 39.9%	1 (0.0)	0.558
# of hours respondent provided help in an average week	1: <10 hours 2: 11 to 20 hours 3: 21 to 30 hours 4: 31 to 40 hours 5: 41+ hours	70.4% 12.6% 5.7% 2.9% 8.5%	0	0.618
Disruptions of family and social life				
Respondent spent less time with spouse, children, or other family due to caregiving responsibilities	1: yes 0: no	yes: 41.8%	33 (0.5)	0.765
Respondent spent less time with friends	1: yes 0: no	yes: 45.2%	15 (0.2)	0.860
Respondent spent less time on social activities or hobbies	1: yes 0: no	yes: 50.1%	15 (0.2)	0.889
Respondent spent less time on relaxing or self care	1: yes 0: no	yes: 53.6%	22 (0.3)	0.693
Respondent spent less time volunteering	1: yes 0: no	yes: 33.5%	24 (0.4)	0.912
Respondent spent less time participating in political, social or cultural groups	1: yes 0: no	yes: 25.6%	16 (0.2)	0.916
Caregiving caused strain in respondent's relationship with family or friends	1: yes 0: no	yes: 25.6%	18 (0.3)	Eliminated*
Caregiving network and support				
To accommodate caregiving, spouse/partner, children, or extended family modified their life/work	1: yes 0: no	yes: 57.3%	20 (0.3)	0.577
To accommodate caregiving, close friends or neighbours provided help	1: yes 0: no	yes: 29.6%	8 (0.1)	0.697
To accommodate caregiving, spiritual community or cultural/ ethnic groups provided help	1: yes 0: no	yes: 18.6%	17 (0.3)	0.638
To help with caregiving, respondent had occasional relief or respite care	1: yes 0: no	yes: 16.0%	23 (0.3)	0.405
Family or friends provided financial support	1: yes 0: no	yes: 10.0%	8 (0.1)	0.464
Respondent received money from government programs	1: yes 0: no	yes: 6.3%	13 (0.2)	0.410

Respondent received federal tax credits	1: yes 0: no	yes: 5.3%	81 (1.2)	Eliminated*
PCR received help from professionals (paid workers or organizations) in the past year	1: yes 0: no	yes: 61.8%	20 (0.3)	Eliminated*
Caregiving history				
Respondent have provided end-of-life care	1: yes 0: no	yes: 32.4%	7 (0.1)	Eliminated
Number of people respondent cared for other than their PCR	Continuous	Mean (SD): 0.55 (1.13)	82 (1.2)	0.907
Number of years respondent provided care to people other than their PCR	0: 0 years 1: 1 to 9 years 2: 10+ years	70.0% 20.1% 9.9%	0	1.000
Positive emotional experiences				
Respondent felt they had a choice in taking on caregiving duties	1: yes 0: no	yes: 53.4%	44 (0.7)	0.403
Relationship with care-recipients strengthened	1: yes 0: no	yes: 67.2%	60 (0.9)	0.611
Respondent felt that the caregiving experience was rewarding	0: Not at all rewarding 1: Somewhat rewarding 2: Rewarding 3: Very rewarding	6.0% 21.6% 33.1% 37.5%	121 (1.9)	0.636

Note: Primary factor loadings are the correlation coefficients between each measured item and the latent factor they measure most strongly, with larger values representing stronger correlations.

*See Supplementary Materials 5 for the reason of elimination for each eliminated item.

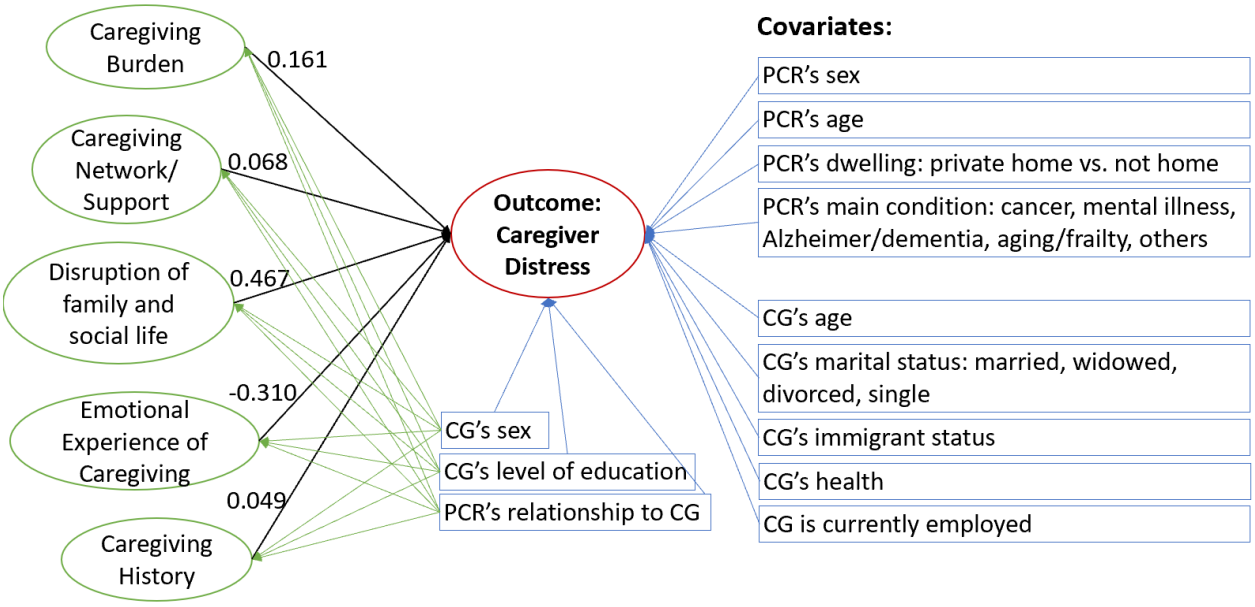
Exploratory factor analysis

EFA model established a well-fit (RMSEA = 0.036, CFI = 0.984, TLI = 0.973, SRMR = 0.029) 6-factor model as hypothesized, comprised of caregiver distress and its five contributing factors: caregiving burden, caregiving network and support, disruption of family and social life, caregiving history, and positive emotional experiences. Table 7.2 shows the factor loadings of survey items to the contributing factors they measure (see Table S6.1 for their factor loadings to all contributing factors). Eight survey items were eliminated because they had low factor loadings to their hypothesized factors, cross-loaded to other factors, and/or resulted in negative residuals (see Supplementary Materials 5 for reasons for their elimination).

Structural equation model

The final model consisted of caregiver distress regressed on its five contributing factors and covariates. Based on a review of modification indices, additional linear paths were added from three covariates - caregiver's sex, education level, and relationship to their primary care-recipient - to each of the five contributor factors. The final model (shown in Figure 7.3) achieved an excellent fit (RMSEA = 0.018, CFI = 0.951, SRMR = 0.064) except for a TLI value of 0.942 - slightly lower than excellent but still well above the acceptable value of 0.90[236]. Correlations between five contributing factors of caregiver distress were not statistically significant.

Figure 7.3. Diagrammatic representation of the final structural equation model.



Note: The final model adjusts for covariates and has paths (based on modification indices) from caregiver's sex, education, and kinship to primary care-recipients to each of the five contributing factors. Oval outline indicates latent factors; rectangular outline indicates measured items. Coefficients of the five contributing factors on caregiver distress are standardized and significant at $p<0.01$.

PCR: primary care-recipient of the respondent
CG: caregiver (i.e., respondent)

Standardized path coefficients (β) representing the relative magnitude of the effects of contributing factors and covariates on caregiver distress are presented in Table 7.2. All five contributing factors had significant ($p<0.05$) effects on caregiver distress, with disruption of family and social life contributing the most (β=0.462), almost three times that of caregiving burden (β=0.161). Positive emotional experiences also had a large, protective effect on caregiver distress (β=-0.310). In comparison, caregiving history and caregiving network and support had relatively small, positive effects on caregiver distress (β=0.049 and 0.068, respectively).

Covariates with significant associations with caregiver distress include the caregiver being female, having less than excellent health, and caring for someone with cancer and mental illness or addiction (β: 0.104 to 0.247). Caregivers being divorced (versus single) or caring for individuals not residing in private homes also had small, positive associations with caregiver distress (β=0.052 and 0.038, respectively). In contrast, caregivers having a bachelor's degree or beyond (compared to high school or below) and their care-recipients being between 65 to 79 years of age (compared to under 25 years) were protective against caregiver distress (β = -0.036 and -0.131, respectively). Caregiver's age, relationship to primary care-recipient, immigrant status, and employment status were not significantly associated with caregiver distress.

Table 7.3. Standardized* path coefficients (β) of contributing factors and covariates on caregiver distress.

	β (95% confidence interval)	p-value
CF1: Caregiving burden	**0.161 (0.111 - 0.211)**	**0.000**
CF2: Disruption of family and social life	**0.467 (0.410 - 0.524)**	**0.000**
CF3: Caregiving network and support	**0.068 (0.020 - 0.117)**	**0.006**
CF4: Caregiving history	**0.049 (0.018 - 0.080)**	**0.002**
CF5: Positive emotional experiences	**-0.310 (-0.364 - -0.257)**	**0.000**
PCR's age (ref: under 25)		
25 to 44	-0.038 (-0.090 – 0.014)	0.155
45 to 64	-0.087 (-0.179 - 0.005)	0.064
65 to 79	**-0.131 (-0.241 - -0.021)**	**0.020**
80 +	-0.109 (-0.234 - 0.017)	0.090
PCR's sex (ref: female)		
Male	**0.040 (0.006 – 0.074)**	**0.023**
PCR's dwelling (ref: private home)		
LTC, supportive house, others	**0.038 (0.005 - 0.070)**	**0.023**
PCR's main health condition (ref: other conditions)		
CVD	0.031 (-0.001 - 0.064)	0.061
Cancer	**0.114 (0.079 - 0.149)**	**0.000**
Mental illness or addiction	**0.118 (0.081 - 0.156)**	**0.000**
Alzheimer's or dementia	**0.105 (0.071 - 0.140)**	**0.000**
Aging or frailty	**-0.087 (-0.130 - -0.044)**	**0.000**
Respondent's age (in 5 years)	0.027 (-0.031 - 0.086)	0.363
Respondent's sex (ref: female)		
Male	**-0.135 (-0.168 - -0.103)**	**0.000**
Respondent's marital status (ref: single, never married)		
Married	0.022 (-0.028 - 0.072)	0.383
Widowed	-0.009 (-0.037 - 0.019)	0.532
Divorced	**0.052 (0.018 - 0.086)**	**0.003**
Respondent is an immigrant (ref: no)		
Yes	0.030 (-0.005 - 0.065)	0.093
Respondent's self-reported health (ref: excellent)		
Very good	**0.104 (0.058 - 0.150)**	**0.000**
Good	**0.211 (0.166 - 0.257)**	**0.000**
Fair	**0.247 (0.208 - 0.286)**	**0.000**
Poor	**0.125 (0.094 - 0.155)**	**0.000**
Respondent's education level (ref: high school or below)		
Trade or college diploma	0.016 (-0.015 - 0.048)	0.306
Bachelor's degree or beyond	**-0.036 (-0.070 - -0.003)**	**0.031**
Respondent's relationship to primary care-recipient (ref: friend, neighbor, or co-worker)		
Spouse/partner or ex-spouse	0.022 (-0.017 - 0.061)	0.274
Parent (-in-law)	0.027 (-0.017 – 0.070)	0.233

Grandparent	-0.010 (-0.034 - 0.014)	0.424
Child (-in-law)	0.011 (-0.041 - 0.063)	0.684
Grandchild	-0.025 (-0.079 - 0.048)	0.359
Sibling	0.016 (-0.016 - 0.048)	0.323
Other relative	-0.004 (-0.033 - 0.025)	0.781
Respondent is currently employed (ref: no)		
Yes	0.028 (-0.008 - 0.064)	0.131

*****β represent the relative magnitude of the effects of contributing factors and covariates on caregiver distress. All β are standardized using the variances of contributing factors, covariates, and the outcome of caregiver distress (i.e., StdXY standardization in Mplus).

Note: Bolded coefficients indicate statistical significance at $p < 0.05$.

As shown in Table 7.4, caregiver's sex, education level, and relationship to primary care-recipient were significantly associated with most contributing factors of caregiver distress. Compared to female caregivers, male caregivers experienced less caregiving burden (β=-0.234), less disruption to family and social life (β=-0.131), and had less caregiving history (β=-0.060). Caregivers with a bachelor's degree or beyond (versus high school or less) had more burden, disruptions to family and social life, and caregiving history but less caregiving network and support and positive emotional experiences. Furthermore, respondents caring for a spouse, child, or parent (versus a friend/neighbor) had more burden, disruptions to family and social life, and network and support but also less caregiving history and positive emotional experiences.

Table 7.4. Standardized***** path coefficients (β) of caregiver's sex, education, and kinship on each contributing factors of caregiver distress.

	Caregiving burden	**Disruption of family and social life**	**Caregiving network/ support**	**Caregiving history**	**Positive emotional experiences**
Respondent's sex (ref: female):					
Male	**-0.234 (-0.273 - -0.195)**	**-0.131 (-0.169 - -0.093)**	0.043 (-0.006 - 0.092)	**-0.060 (-0.100 - -0.019)**	-0.025 (-0.075 - 0.025)
Respondent's education level (ref: high school or less):					
Trade or college diploma	0.030 (-0.012 - 0.072)	**0.069 (0.027 - 0.111)**	-0.002 (-0.054 - 0.050)	**0.073 (0.028 - 0.117)**	-0.043 (-0.093 - 0.007)
Bachelor's degree or beyond	**0.066 (0.022 - 0.111)**	**0.152 (0.111 - 0.193)**	**-0.065 (-0.116 - -0.014)**	**0.118 (0.073 - 0.163)**	**-0.118 (-0.171 - -0.066)**
Respondent's relationship to primary care-recipient (ref: friend, neighbor, or co-worker):					
Spouse/partner/ex-spouse	**0.425 (0.382 - 0.468)**	**0.208 (0.164 - 0.252)**	**0.114 (0.056 - 0.173)**	**-0.091 (-0.132 - -0.050)**	**-0.309 (-0.365 - -0.253)**
Parent (-in-law)	**0.259 (0.205 - 0.313)**	**0.190 (0.137 - 0.243)**	**0.136 (0.064 - 0.208)**	**-0.047 (-0.093 - -0.001)**	**-0.211 (-0.281 - -0.142)**
Grandparent	-0.001 (-0.043 - 0.041)	**-0.046 (-0.087 - -0.004)**	**0.056 (0.002 - 0.111)**	-0.016 (-0.068 - 0.036)	0.005 (-0.041 - 0.052)
Child (-in-law)	**0.350 (0.281 - 0.419)**	**0.254 (0.190 – 0.318)**	**0.121 (0.038 – 0.204)**	**-0.130 (-0.189 - -0.071)**	**-0.455 (-0.532 - -0.378)**
Grandchild	**0.109 (0.038 - 0.180)**	0.026 (-0.044 – 0.096)	0.078 (-0.007 - 0.162)	-0.074 (-0.155 - 0.007)	**-0.121 (-0.210 - -0.033)**
Sibling	**0.078 (0.037 - 0.119)**	**0.085 (0.047 – 0.124)**	0.021 (-0.029 - 0.071)	**-0.053 (-0.094 - -0.012)**	**-0.125 (-0.174 - -0.077)**
Other relative	**0.074 (0.024 - 0.123)**	**0.068 (0.025 – 0.111)**	0.027 (-0.023 - 0.077)	-0.027 (-0.069 - 0.016)	**-0.091 (-0.148 - -0.034)**

*****All β are standardized using the variances of sex, education level, relationship, and the five contributing factors (i.e., StdXY standardization in Mplus).

Note: Bolded coefficients indicate statistical significance at $p < 0.05$

7.4 Discussion

To our knowledge, this is the first study to use exploratory structural equation modelling and nationally-representative data to construct and test a model of caregiver distress. We established a well-fit measurement model for caregiver distress and its five groups of contributing factors. We found that disruption of family and social life and positive emotional experiences from caregiving had the largest effects on caregiver distress, while caregiver burden contributed only moderately to distress. Caregiving network/support and history, in comparison, had significant but relatively minor effects.

Past literature has identified both caregiving burden and disruptions of family or social life as contributors of distress[26,27,237,238], though none to our knowledge have compared their relative contributions. Most services provided by the government (e.g., home and respite care) focus on providing the same, uniform services that address immediate health care needs such as nursing and personal care. Though important and often essential, our findings suggest that these services might not be sufficient or the most effective in reducing caregiver distress. Instead, support for caregivers and care-recipients should be expanded to cover both health and social needs in a holistic, flexible, and personalized manner. Services and resources, especially training and counselling, could also be extended to family members of caregivers to reduce distress and disruptions to their lives[102]. Employment policies that provide accommodations and flexibility have also been shown to minimize negative impacts on caregivers' family and social life[237].

Studies have shown that the lack of choice about caregiving increases caregiver distress[156], while positive aspects of caregiving, such as personal growth, gratitude, and deeper bonds with the care-recipient, can improve caregivers' well-being[239,240]. Results from our study further highlight the importance of fostering agency and positive caregiving experiences, possibly by providing flexible and personalized support that allow caregivers to spend time on tasks they

find meaningful and rewarding. Experts have recommended reimbursement systems that allow caregivers to choose services that suit their specific needs[241] and preferences, as those vary drastically according to factors such as culture, conditions requiring care, and family structure[5,156]. Additionally, a report by the AARP (formerly the American Association of Retired Persons) showed that 20% of caregivers wanted information on ways to engage with their care-recipients[5]. Providing more training on how to better communicate and engage with care-recipients may make the caregiving experience more positive and reduce distress, especially for those caring for individuals with limited cognitive or communicative capacities (e.g., Alzheimer's, stroke).

Similar to past findings[47,96,226], we showed that having greater caregiving history (i.e., providing care for many years and/or to multiple people) leads to greater distress, though its effect is minor relative to other factors. A consideration is that caregivers may build resilience and experience over time, thus enabling them to better manage caregiving tasks and minimize distress[242]. We also found that, perhaps counterintuitively, having greater caregiving network and support contributed to distress. This could be because receiving help from multiple sources reflects a more complex caregiving case – complexity that is not captured through the survey items. For example, caregivers of individuals with dementia or greater ADL impairments tend to seek more sources of help and are more likely distressed[5,67]. Furthermore, navigating multiple health care systems and coordinating multiple services could generate additional distress[100,101]. This highlights the importance of making services and resources more transparent, more accessible, and less burdensome to coordinate.

Finally, our findings on covariates generally concur with past studies – notably that caregivers being female[30,31], having poorer health[92], and caring for someone who is male[147] and has cancer[66,68], mental illness or addiction[74,76,77], or Alzheimer's or dementia[5,17,67] were associated

with greater distress. We also highlight the importance of examining both direct and indirect effects of these covariates in future studies. For example, past studies have reported that spousal and children caregivers are more likely to be distressed[17,30]. We however found that kinship had no direct association with caregiver distress, but instead significantly impacted all contributing factors of distress. In other words, kinship indirectly contributes to distress as close family members experience more caregiving burden and disruptions to family and social life.

Limitations:

Our study has several limitations. Firstly, we used data collected ten years ago since data from the latest GSS-Caregiving and Care-receiving, Cycle 32 (collected in 2018) has not been released by Statistics Canada at the time of our study. Additionally, our effort to produce a comprehensive model of caregiver distress is limited by the data source. We did not include caregiver's income, religion, and ethnicity since they had large proportions of non-random missingness. In addition, the GSS2012 contained very few survey items on caregiving history, which resulted in a latent factor comprised of only two measured items. While acceptable when factor loadings of both items are high, such a latent factor may be less stable[230]. Future studies should aim to collect more measurements of caregiving history. Nevertheless, our study includes the most comprehensive set of contributors of distress in a nationally-representative sample.

7.5 Conclusion

Our study showed that understanding the multi-facetted nature of caregiver distress is crucial for developing effective strategies to support caregivers. Rather than focusing solely on reducing caregiving burden, we highlight the importance of reducing disruptions on family and social life and enabling caregivers to obtain positive experiences from caregiving. To better support caregivers, policies and services should be more flexible and holistic, and training and counselling extended to their family members.

Chapter 8

GENERAL DISCUSSION AND CONCLUSIONS

There is a paucity of caregiving studies using population-based data and a near-complete lack of examination of changes in caregiver distress over time in existing literature. There were also inconsistencies on the identification of risk and protective factors for distress, as well as a lack of investigation of the effect of caregiver distress on care-recipients' location of death. This thesis research filled these gaps by using large, health administrative data to identify the overall burden and trajectories of distress among caregivers of older adults in Ontario, how they changed over time, and how they differed according to care-recipients' level of care needs. The care profiles of older men and women were compared, and differences in their caregivers' distress status and trajectories described. While measurements of caregiver distress using data from RAI assessments is crude, its population-level coverage and linkage to other health administrative datasets allowed for the adjustment of a greater number of variables on care-recipients' health, functional status, and receipt of home and palliative services. It also allowed us to show that individuals cared by a distressed caregiver were more likely to spend more time/die in acute care.

To counter the lack of depth and nuance in the measurement of distress and caregiving factors in the analyses for Chapters 4-6, data from a national survey on caregiving and care-receiving was used in Chapter 7 to obtain a refined definition of distress and develop in-depth understandings of the different domains of contributors of distress. Using exploratory structural equation modeling, we identified five domains of contributors for caregiver distress and quantified the relative magnitudes of their associations to distress.

Findings from the three objectives showed that a substantial proportion of caregivers in Ontario and across the nation are distressed. In Ontario, the proportion of distressed caregivers are

increasing over the years, especially among caregivers of individuals with lower care needs at initial application for home and community support. Findings using both health administrative data and survey data showed that caregivers of men are more likely to be distressed, with an in-depth examination in Chapter 5 showing that older men tended to be sicker/frailer and required more care. Findings from both data sources also showed consistently that high caregiving burden as well as care-recipients having mental health issues, cancer, or Alzheimer's/dementia are associated with greater likelihood of caregiver distress. Chapter 5 showed that spousal and child caregivers are more likely to be distressed, though Chapter 7 showed that this association is likely indirect through child and spousal caregivers having greater caregiving burden and experiencing greater disruptions to family and social life. While analyses using RAI assessments identified many aspects of the care-recipients' health profiles and care needs that contribute to caregivers being distressed, analyses using GSS data demonstrated, from the caregivers' perspective, which factors contributed the most to their distress levels – while caregiver burden is an expected contributor, disruptions to their family and social life as a result of caregiving as well as obtaining positive experiences from caregiving played much more substantial role in their distress levels.

8.1 Implications for policy and practice

The general policy and practical implications of the findings for each objective have been discussed in their respective papers. As such, this section focuses on tangible ways that the health systems, policies, and practices can change to support caregivers in the Ontario and Canadian context. In 2017, the federal and provincial governments identified the shared health priority of improving access to home and community care, and dedicated to investing $11 billion to over 10 years[136]. Ontario, in particular, invested $80 million to enhance home care and $20 million for caregiver respite. This translated to 350,000 additional hours of nursing care, 1.3 million additional hours of personal support, 600,000 additional hours of respite services for caregivers, and 100,000

additional hours of rehabilitation[243]. While these investments provide much-needed relief, we propose additional steps based on the findings of this thesis research that could further improve the well-being of both care-recipients and caregivers.

Firstly, it is imperative for all healthcare sectors to recognize the current burden of caregiver distress and its anticipated increase. The increase is particularly prominent among caregivers of individuals with lower care needs, who are less prioritized to receive support and may benefit less from standard home and community services. The increase in caregiver distress may also be further exacerbated by the COVID-19 pandemic, during which caregivers and care-recipients have experienced prolonged periods of social isolation, significant delays in treatments, reduction in healthcare services, and financial turmoil[244,245]. Since efforts to expand service capacity may not be effective or possible in the face of limited government resources, restructuring and reforms in home and community care to focus on improving performance and sustainability in care delivery are needed.

Currently in Ontario and many other provinces, home and community care focus primarily on providing home care, respite care, and financial assistance. While these undoubtedly reduce caregiving burden and distress, other contributors of distress are left unaddressed. Thus, reforms to home and community care should aim to be more holistic and personalized – a sentiment shared in the recent AARP report on caregivers[5]. For example, instead of limiting caregivers to choose from a standard set of home care services, caregivers should have the flexibility to choose services that suit their needs so that they can focus on caregiving duties they find meaningful and rewarding. Furthermore, care planning could involve a greater variety of professionals (e.g., social worker, personal support worker, mental health professionals) who, in addition to helping caregivers understand and manage their care-recipients' needs, could also address caregivers' psychological and social needs. Access to mental health professionals, training, and peer support should also be

extended to family members of caregivers whose lives are often disrupted by their loved one's caregiving duties.

Much of the supplementary supports (e.g., peer support groups, counselling, helplines) are provided by regional community support agencies. However, the specific types of service offered as well as their eligibility criteria and application process vary greatly depending on the region and agency. Additionally, healthcare providers are not always aware of these agencies and the services offered. As such, it falls onto the caregivers themselves to discover and apply for services, which not only results in services and/or resources being overlooked but also adds significant burden and distress onto caregivers[246,247]. To improve access to support and resources, we recommend greater standardization and transparency of the services offered by community support agencies across regions and simplification of their application processes – a sentiment shared by many past findings[5,167].

Improving communication and coordination between community support agencies and healthcare providers is also crucial. The Ontario government has recently introduced Ontario Health Teams (OHT) to be responsible for the majority of healthcare delivery in the province. The goals of this reform is to build connected and patient-centered health care system, with emphasis on bringing equitable and sustainable value for patients and family caregivers[248]. Being platforms of direct contact between healthcare providers and patients and caregivers, OHTs have the greatest potential to both recognize distress and support caregivers to reduce distress. For example, front line providers should be informed of the risk factors of caregiver distress and trained to recognize distress in a timely manner. Caregivers identified to be experiencing or at risk of distress should then be directed to appropriate resources and assisted in navigating the healthcare systems. Provision of psychoeducational and psychosocial supports could also help caregivers gain a greater sense of agency, thus reducing distress. Additionally, OHTs should pay particular attention to

caregivers of individuals with challenging behavioural, medical, or communication issues and provide training for not only management of care needs but also enabling greater connection with care-recipients. Such training could help caregivers bond with their care-recipients and find greater meaning and reward from their caregiving experience[216,224,225], which we have shown to be most strongly associated with reduced distress.

Identification of caregiver distress and caregiving needs could also be incorporated into routine clinical assessments and clinical decision tools. One example of such effort is the Caregiver Risk Evaluation algorithm – developed using items from the RAI-HC assessment (including caregiver distress, kinship, and hours of care provided as well as care-recipients' CPS score and symptoms of depression) and validated against the ZBI, it categorizes home care clients into three levels of risk for caregiver burden[249]. If incorporated into routine clinical assessment, it can help flag caregivers at high risk of being over-burdened and in need of additional support, education and training, and respite. Similarly, a flag for caregiver distress could be created for LTC residents who, in Ontario and other provinces, receive a Resident Assessment Instrument – Minimum Data Set (RAI-MDS) assessment at least every three months. The RAI-MDS has many of the same items as the RAI-HC except that it does not contain items measuring caregiver's characteristics, distress, or caregiving burden. Fortunately, this thesis research as well as other past studies have identified many factors that are strongly associated with caregiver distress, all of which can be used to develop algorithms to identify caregiver distress to be embedded in routine assessments.

8.2 Implications for future studies

Findings from this thesis research provides several insights for future research directions. As previously stated, literature on the trajectories of caregiver distress over time is scarce, and even more so using population-level data. While we have provided an initial description of distress trajectories of caregivers of older, community-dwelling adults in Ontario, longitudinal studies using

more finite measures of distress are needed, especially for high-risk populations. While a plethora of risk and protective factors of caregiver distress have been identified, studies have rarely accounted for the time-varying nature of these factors. Thus, future studies should examine how changes in these factors affect distress trajectories over time to better understand their causal relationships. Similarly, studies on the effect of caregiver distress on care-recipients' or caregivers' health outcomes and healthcare use could also examine distress in a time-varying manner.

A primary cause of these gaps in literature is limitations in data availability. The RAI-HC and the interRAI-HC were designed to assess individuals requiring care rather than their caregivers. Therefore, these data sources only contain crude information about caregivers and does not allow for examinations of changes in levels or aspects of distress. In addition, identifying information (e.g., health care number) of the caregivers are not collected at these routine assessments, which prevents researchers from tracking caregivers over time for their healthcare use and health outcomes. The ability to longitudinally examine the effects of burden and distress on caregivers' downstream service use and health outcomes would provide invaluable insight on the true burden of distress on the healthcare system – in other words, whether "offloading" care to caregivers may actually increase the burden on the healthcare system over time. If collecting caregivers' identifying information on routine clinical assessments is challenging to implement, linkage of national surveys (e.g., the GSS and the Canadian Longitudinal Study on Aging) to health administrative databases is another option. These surveys conduct primary data collection on caregivers and care-recipients and collects more detailed, nuanced, and targeted information than could be obtained through routine assessments. They are also longitudinal in design or conducted at regular intervals, thus allowing for examinations of time trends in caregiver distress and burden. Linkage of these surveys to health administrative data would allow us to follow caregivers and care-recipients over time for their health outcomes and service use.

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Supplementary Materials 1

DESCRIPTIONS OF ICES DATASETS

Table S1.1. Descriptions of ICES datasets and the information each dataset contains

Database	Description	Information obtained
1. Registered Persons Database (RPDB)	Captures demographic information on persons registered under the Ontario Health Insurance Plan (OHIP) and who are eligible for the Ontario Drug Program.	Sex, postal code, date of birth, and date of death
2. OHIP Claims database	Captures all claims data for physician services in inpatient and outpatient settings	OHIP eligibility
3. Discharge Abstract Database (DAD), from the Canadian Institute for Health Information (CIHI)	Contains administrative, clinical, and demographic information of all acute care admissions and discharges.	Admission and discharge dates, discharge disposition, main service provided, main diagnosis type
4. National Ambulatory Care Reporting System (NACRS)	Captures information for all hospital- and community-based ambulatory care	Dates of arrival and departure, whether death occurred during visit
5. Same Day Surgery (SDS)	Records information on all same-day surgery or procedure stay	Dates of arrival and departure, whether death occurred during visit
6. Continuing Care Reporting System (CCRS)	Captures administrative, clinical, and care-related information in publicly-funded long-term care facility and in complex continuing care (CCC; equivalent to sub-acute care)	Admission and discharge dates, whether death occurred during visit
7. Vital Statistics Database: Office of the Registrar General—Deaths (ORGD)	Captures mortality information from death certificates of decedents in Ontario, including cause of death.	Date of death
8. Statistics Canada Census Data	Provides demographic information about the population and neighborhoods.	Neighborhood income quintile and rurality, derived from postal code

Supplementary Materials 2

ADDITIONAL RESULTS FOR OBJECTIVE 1-I

Table S2.1. Time trends of one-year change in caregiver distress, stratified by MAPle score

MAPLe = 1

	Became distressed	Remained distressed	Became non-distressed	Remained non-distressed	Total
2008	4.7 (150)	3.1 (100)	2.4 (76	89.9 (2903)	3229
2009	4.6 (197)	2.9 (122)	1.7 (74)	90.1 (3866)	4259
2010	6.6 (226)	3.4 (118)	1.9 (64)	88.1 (3025)	3433
2011	10.3 (293)	3.7 (105)	2.1 (60)	83.9 (2378)	2836
2012	11.6 (433)	5.6 (207)	2.2 (82)	80.6 (3002)	3724
2013	14.3 (384)	6.4 (172)	2.6 (70)	76.7 (2059)	2685
2014	17.1 (368)	6.8 (146)	2.6 (56)	73.4 (1576)	2146
2015	17.0 (191)	7.4 (83)	2.4 (27)	73.2 (821)	1122

MAPLe = 2

	Became distressed	Remained distressed	Became non-distressed	Remained non-distressed	Total
2008	5.1 (247)	4.3 (207)	3.0 (145)	87.7 (4257)	4856
2009	5.7 (352)	4.2 (263)	3.1 (192)	87.0 (5393)	6200
2010	7.7 (391)	5.1 (256)	3.5 (176)	83.7 (4228)	5051
2011	11.3 (400)	6.2 (220)	3.3 (115)	79.2 (2805)	3540
2012	11.8 (282)	7.3 (175)	3.9 (92)	77.0 (1841)	2390
2013	13.8 (257)	10.7 (200)	4.6 (85)	70.9 (1318)	1860
2014	15.3 (239)	11.3 (176)	4.2 (65)	69.2 (1080)	1560
2015	15.5 (123)	11.0 (87)	2.7 (21)	70.1 (561)	792

MAPLe = 3

	Became distressed	Remained distressed	Became non-distressed	Remained non-distressed	Total
2008	7.6 (627)	9.6 (793)	6.9 (568)	75.9 (6260)	8248
2009	7.8 (800)	9.9 (1018)	6.4 (656)	75.9 (7807)	10281
2010	9.9 (856)	10.8 (936)	6.3 (544)	73.0 (6317)	8653
2011	12.9 (1094)	14.7 (1249)	6.8 (580)	65.5 (5555)	8478
2012	13.1 (1285)	17.7 (1733)	8.0 (786)	61.2 (5993)	9797
2013	14.0 (1250)	20.1 (1790)	7.8 (700)	58.1 (5185)	8925
2014	14.7 (1321)	21.4 (1924)	7.8 (701)	56.1 (5042)	8988
2015	14.9 (741)	23.0 (1149)	6.9 (342)	55.3 (2757)	4989

MAPLe = 4

	Became distressed	Remained distressed	Became non-distressed	Remained non-distressed	Total
2008	10.1 (803)	16.4 (1306)	8.5 (643)	65.0 (5173)	7955
2009	10.6 (1041)	16.5 (1619)	8.0 (782)	65.1 (6402)	9834
2010	12.7 (1138)	17.8 (1596)	8.7 (776)	60.9 (5464)	8974
2011	15.4 (1448)	22.3 (2100)	8.7 (816)	53.7 (5034)	9428
2012	15.3 (1471)	25.7 (2478)	8.9 (856)	50.1 (4833)	9648
2013	16.1 (1593)	27.9 (2759)	9.2 (905)	46.9 (4636)	9893
2014	16.6 (1709)	28.9 (2987)	8.9 (920)	45.5 (4694)	10320
2015	17.2 (953)	29.3 (1627)	8.5 (471)	45.0 (2500)	5551

MAPLe = 5

	Became distressed	Remained distressed	Became non-distressed	Remained non-distressed	Total
2008	10.3 (311)	28.1 (873)	11.8 (368)	49.7 (1546)	3108
2009	10.8 (419)	29.8 (1161)	11.0 (427)	48.4 (1888)	3895
2010	12.3 (444)	31.1 (1117)	10.9 (392)	45.7 (1644)	3597
2011	12.3 (508)	37.2 (1535)	10.7 (441)	39.5 (1631)	4125
2012	12.9 (531)	40.7 (1671)	11.9 (489)	34.5 (1415)	4106
2013	13.0 (585)	43.7 (1971)	11.1 (500)	32.3 (1458)	4514
2014	13.3 (651)	45.2 (2210)	10.7 (521)	30.6 (1494)	4886
2015	13.9 (356)	46.3 (1184)	10.2 (260)	29.6 (756)	2556

Figure S2.1. Proportion of initially non-distressed caregivers who became distressed (i.e., incident distress), stratified by MAPLe levels

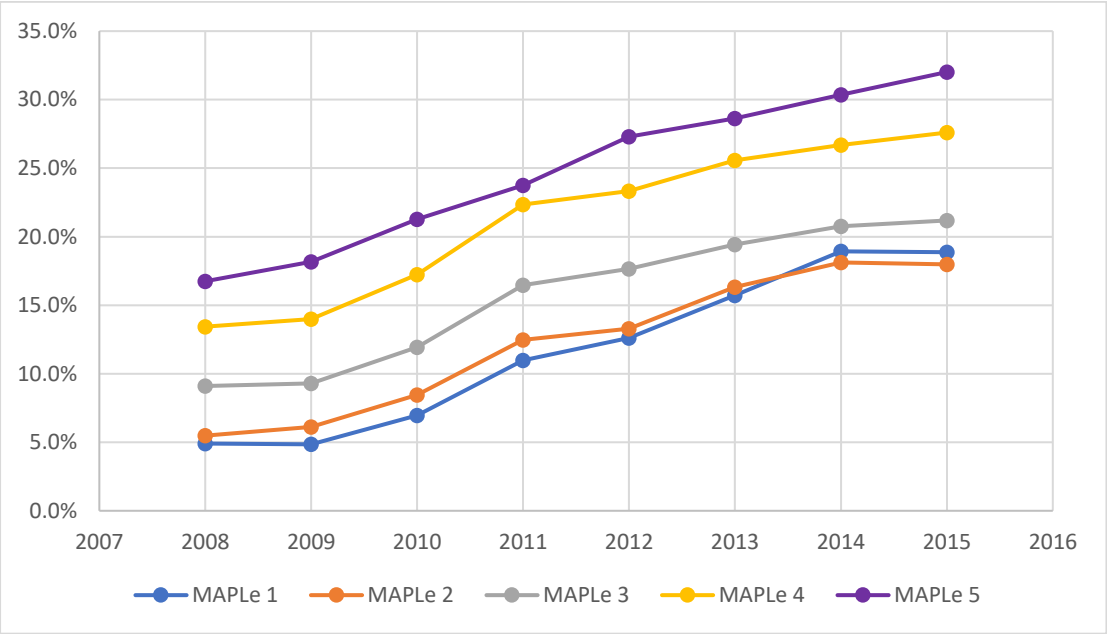
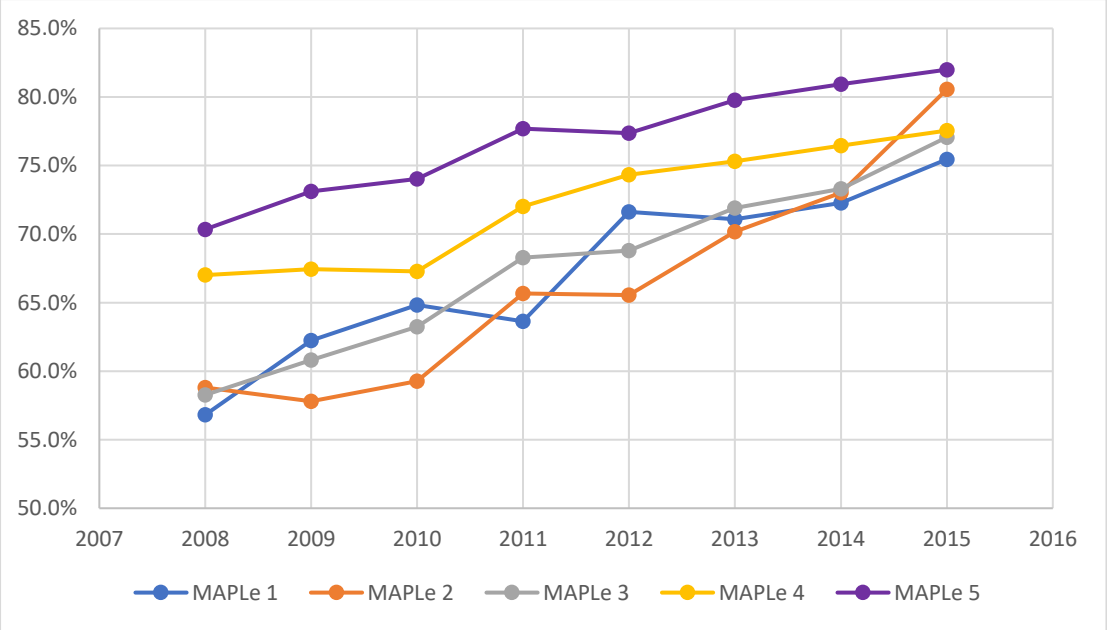


Figure S2.2. Proportion of initially distressed caregivers who remained distressed (i.e., sustained distress), stratified by MAPLe levels.



Supplementary Materials 3

ALGORITHMS TO DETERMINE PLACE OF DEATH AND PLACE OF CARE

To determine individuals' place of care, defined as the number of days spent in each care setting within a defined period, we identified individuals' records of admission or contact with each healthcare system associated with that setting, then used the admission and discharge dates of each record to calculate the number of days spent in that setting. Data sources for the healthcare systems associated with each setting are as follows:

- ***Acute care***: hospitalizations (CIHI-DAD), same day surgery (SDS), and ambulatory care (NACRS).
- ***Palliative acute care***: acute care admissions during which palliative care was the most responsible diagnosis (DxType M, Dx10Code: Z515) and the most responsible service provider (PATSERV: 58) (CIHI-DAD).
- ***Elsewhere:*** *all other settings*

If an individual had records in multiple care settings on the same day, the following hierarchy was used to categorize the care setting for that day:

- Palliative care units > acute care > sub-acute care > long-term care homes > community

For example, if an individual was admitted to a hospital through a LTC facility, they would have a record in CCRS-LTC and DAD databases on the same day. The hierarchy we specified would count that day as having been spent in acute care.

To determine decedents' place of death, we identified individuals' record with a care setting where the discharge disposition indicates death and the discharge date concur with their death date recorded on the Registered Persons Database, thus indicating that the individual died in

that care setting. As dates on health administrative records are sometimes recorded with a few days of delays, we allowed for plus or minus three days of discrepancies between the death date and the discharge date.

Supplementary Materials 4

RATIONALE FOR MODELLING METHODS AND SENSITIVITY ANALYSIS FOR OBJECTIVE 2

Figure S4.1. Hypothesized directed acyclic graph (DAG) of the potential direct and indirect pathways between place of death, caregiver distress, and other factors.

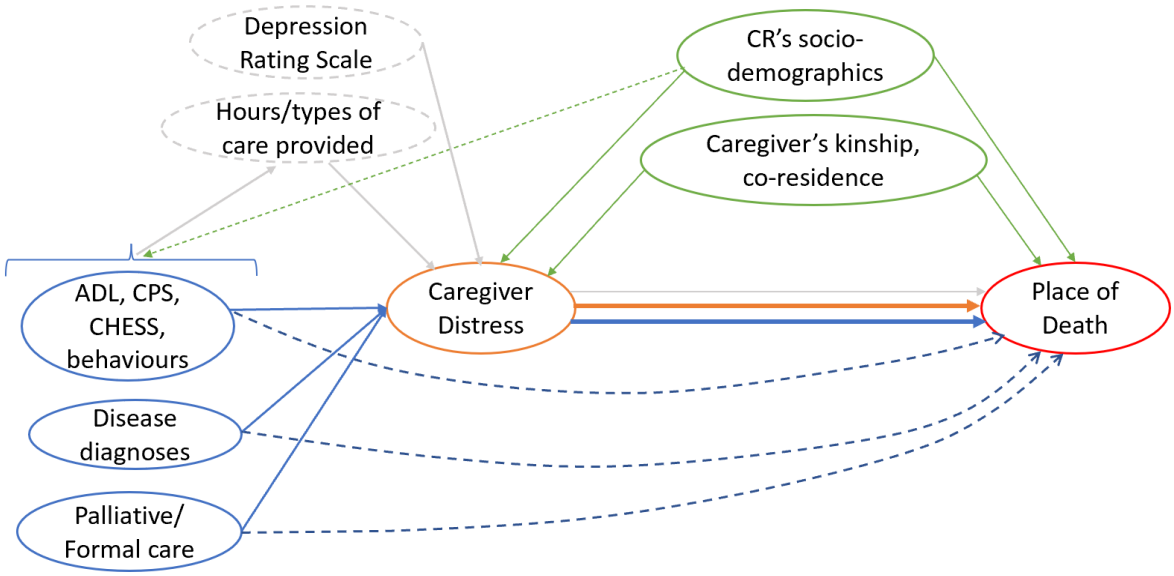


Figure S4.1 shows a hypothesized DAG of the potential direct and indirect relationships between the outcome of place of death, the exposure of caregiver distress, and other factors:

- Caregiver distress: as the main exposure, it was hypothesized to directly contribute to place of death (orange arrow)
- Care-recipient's socio-demographics of age, sex, marital status, and neighborhood income; caregiver's kinship and co-residence: hypothesized to be associated with caregiver distress and place of death (solid green arrow). They may also be associated with other covariates (dotted green arrow). They are regular confounders.
- Care-recipient's functional status, comorbidities, and service use: they may have both direct

effects (dotted blue arrow) on place of death and indirect effects (solid blue arrow) through caregiver distress on place of death.

- Hours/types of care; Care-recipient's Depression Rating Scale (DRS): hypothesized to contribute to place of death only indirectly through caregiver distress. Past literature has also shown that caregiving burden is a mediator for the associations between function and health impairments and/or service use and caregiver distress.

Based on the hypothesized DAG, care-recipient's socio-demographic characteristics and their caregiver's kinship and co-residence status are confounders and were adjusted for. Hours/types of care and care-recipients' DRS were **not included** in the modelling since they have no direct effects on the outcome and could be mediators for other pathways in the model. However, decisions involving care-recipient's health and service use were more complex since they may have both *direct and indirect effects* on place of death. Their indirect effects through caregiver distress would make caregiver distress a mediator. In typical regression analyses, we would either eliminate these care-recipient's health and service use or caregiver distress. Neither would be wise for our analyses, however, since caregiver distress is our main exposure of interest and since health/service use variables also have direct effects on the outcome of place of death.

We then considered performing formal mediation analyses for the pathways of

care-recipient's health/service use → caregiver distress → place of death

However, mediation analyses were also not possible nor appropriate for several reasons:

1) Our model has 16 variables related to care-recipient's health/service use: ADL, CPS, CHESS, wandering, other behavioural issues, 7 comorbidities, and receipts of 4 types of home and palliative services. Thus, there are potentially 16 mediating pathways from each of these variables to caregiver distress then to the outcome of place of death. Mediation analyses performed in SAS, R and other statistical programs can only test one pathway at a time, rather than 16 simultaneously.

2) Two assumptions of mediation analyses cannot be met:

i. Temporal ordering[250,251]: for caregiver distress to be a mediator in these paths, care-recipient's health/service use must have occurred before caregivers became distressed. Since all variables in the model were obtained from the same RAI assessment, this temporal ordering cannot be established. Given that about half of individuals in our cohort received multiple RAI assessments, an alternative approach is to obtain care-recipients' health/service use from the RAI assessment prior to the one used to obtain caregiver distress. This would, however, eliminate anyone with only one assessment, thereby cutting over half of the cohort and creating biases.

ii. Teasing out the direct and indirect effects requires full identification of the mediating pathway and its covariates, *without any unmeasured confounding*[250,251]. This assumption cannot be met given the limitations of using routine-collected assessment data. Residual confounding exists since we do not have information on patient's and caregiver's preferences and the availability of hospital beds, to name a few.

3) Arguments could be made that care-recipients' health, functioning and service use may have reciprocal effects with each other and with caregiver distress, which cannot be easily untangled. For example, greater functional impairments may lead to both greater caregiver distress and greater receipt of formal care, with the receipt of formal care then reducing distress. Since temporality cannot be established and we do not have nuanced information on the levels of distress or frequency of service use, it is impossible to identify the precise timing and relationships between these factors. We also cannot remove any of these variables since all of them are hypothesized to have direct effects on place of death.

Additionally, we considered, but ultimately decided against, running structural equation modelling (SEM) to test the hypothesized direct and indirect associations (see Chapter 7 for a detailed

explanation of SEM). This is because the main advantage of using SEM is its ability to model latent factors, which are constructs that are not directly observed, but inferred through mathematical modelling of measured variable. For this study, as an example, service use could form a latent construct measured by whether care-recipients received home health aide, visiting nurses, home-making services, and palliative care. Doing so, however, prevents us from obtaining parameter estimates for each measured variable. In the case of service use, for example, it would not be possible to identify receipt of which service was more or less effective in reducing distress.

Since pursuing a clean model via mediation analyses or SEM is not possible, we instead focused on yielding results that would be meaningful on a clinical or policy level. We chose to run four increasingly-adjusted regressions where groups of pre-specified variables were added sequentially. This allows us to examine how the strength of association between caregiver distress and place of death changes as variables are added in order to identify their confounding effects. To further determine if caregiver distress could be a mediator for the associations between care-recipient's functional status, comorbidities, and service use and the outcome of place of death, we conducted a sensitivity analysis by running a model (Model S) with the same variables as Model 4 except without caregiver distress. If caregiver distress is indeed a mediator for the association between a variable and place of death, incorrectly adjusting for caregiver distress in Model 4 would have masked this true association. Thus, we would expect to see a drastic increase in the odds ratio of this variable in Model S once caregiver distress is no longer adjusted for.

Table S4.1 shows the odds ratios of variables in Model S and in Model 4 (same as those shown in Chapter 6, shown again here for comparison). It is evident that the odds ratios of variables in Model S (without the adjustment of caregiver distress) did not differ much compared to those in Model 4. Thus, it is probable that caregiver distress is not a mediator on the pathways between care-recipient's functional status, comorbidities, and service use and the outcome of place of death.

Table S4.1. Odds ratios of variables in Models 4 and Model S

		Model 4	Model S
		Odds Ratio (95% Confidence Interval)	
Caregiver distress	Distressed vs. non-distressed	1.09 (1.06-1.12)	
Care-receiver's age (restricted cubic splined [RCS])	1st segment – 5th to 27.5th percentile	0.99 (0.99-0.99)	0.99 (0.99-1.00)
	2nd segment – 27.5th to 50th percentile	1.00 (1.00-1.00)	1.00 (1.00-1.00)
	3rd segment – 50th to 72.5th percentile	1.00 (1.00-1.00)	1.00 (1.00-1.00)
	4th segment – 72.5th to 95th percentile	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Care-receiver's gender	Men vs. Women	1.02 (0.99-1.05)	1.04 (0.99-1.07)
Rurality	Rural vs. Urban	1.51 (1.45-1.57)	1.50 (1.45-1.56)
Income quintile	1 vs. 3	1.02 (0.98-1.06)	1.02 (0.98-1.05)
	2 vs. 3	1.01 (0.97-1.02)	1.01 (0.96-1.03)
	4 vs. 3	0.97 (0.93-1.01)	0.97 (0.93-1.01)
	5 vs. 3	0.95 (0.91-0.99)	0.94 (0.90-0.99)
Marital status (reference: never married)	Married/partnered	1.13 (1.04-1.21)	1.15 (1.06-1.23)
	Separated/divorced	1.01 (0.94-1.09)	1.02 (0.94-1.09)
	Widowed	1.06 (0.98-1.13)	1.07 (0.99-1.14)
Local Health Integration Networks (LHIN) (reference: Eerie St. Clair)	South West	1.06 (0.99-1.14)	1.01 (0.94-1.07)
	Waterloo Wellington	0.93 (0.86-1.01)	0.93 (0.86-1.02)
	Hamilton Niagara Haldimand Brant	1.34 (1.26-1.43)	1.31 (1.23-1.40)
	Central West	1.06 (0.98-1.15)	1.06 (0.98-1.15)
	Mississauga Halton	1.08 (1.00-1.16)	1.10 (1.03-1.17)
	Toronto Central	0.90 (0.84-0.96)	0.88 (0.82-0.94)
	Central	0.83 (0.78-0.88)	0.84 (0.77-0.88)
	Central East	0.74 (0.70-0.79)	0.74 (0.70-0.78)
	South East	0.89 (0.83-0.96)	0.88 (0.82-0.96)
	Champlain	1.20 (1.12-1.28)	1.17 (1.10-1.25)
	North Simcoe Muskoka	0.90 (0.83-0.97)	0.88 (0.81-0.96)
	North East	1.61 (1.50-1.74)	1.60 (1.50-1.74)
	North West	1.11 (1.01-1.22)	1.14 (1.03-1.23)
Caregiver co-resides	Yes vs. No	1.20 (1.16-1.23)	1.22 (1.18-1.26)
Caregiver's relationship to care-receiver (reference: friend/neighbor)	Child/child-in-law	1.00 (0.95-1.07)	1.00 (0.94-1.07)
	Other relative	0.98 (0.91-1.04)	0.97 (0.91-1.03)
	Spouse/partner	0.96 (0.89-1.03)	0.92 (0.86-0.99)
ADL self-performance hierarchy scale (reference: 0)	1	1.03 (0.99-1.08)	1.04 (1.00-1.09)
	2	0.99 (0.96-1.04)	0.99 (0.96-1.03)
	3	0.98 (0.94-1.02)	0.98 (0.94-1.02)
	4	0.84 (0.80-0.88)	0.81 (0.77-0.85)

	5	0.73 (0.70-0.77)	0.70 (0.66-0.74)
	6	0.66 (0.60-0.73)	0.64 (0.59-0.68)
Cognitive performance scale (reference: 0)	1	1.03 (0.99-1.08)	1.02 (0.99-1.06)
	2	1.00 (0.96-1.04)	1.01 (0.96-1.05)
	3	0.90 (0.85-0.95)	0.89 (0.85-0.93)
	4	0.81 (0.72-0.86)	0.80 (0.71-0.88)
	5	0.75 (0.71-0.81)	0.72 (0.69-0.76)
	6	0.80 (0.72-0.90)	0.76 (0.70-0.82)
CHESS (reference: 0)	1	0.99 (0.94-1.04)	0.97 (0.93-1.02)
	2	1.01 (0.97-1.06)	1.01 (0.97-1.06)
	3	1.03 (0.98-1.08)	1.04 (0.99-1.09)
	4	0.97 (0.92-1.02)	0.93 (0.87-1.00)
	5	0.75 (0.69-0.83)	0.74 (0.70-0.80)
Wandering	Yes vs. No	0.96 (0.88-1.05)	0.94 (0.88-1.02)
Other behavioural issues	Yes vs. No	0.97 (0.93-1.01)	0.95 (0.90-0.99)
Had cerebrovascular accident	Yes vs. No	1.01 (0.98-1.04)	1.02 (0.98-1.06)
Has coronary heart disease	Yes vs. No	1.08 (1.05-1.11)	1.08 (1.05-1.10)
Has congestive heart failure	Yes vs. No	1.20 (1.17-1.24)	1.18 (1.14-1.22)
Has Alzheimer's disease or dementia	Yes vs. No	0.92 (0.89-0.95)	0.86 (0.80-0.91)
Has pneumonia	Yes vs. No	1.16 (1.10-1.23)	1.15 (1.10-1.21)
Has cancer	Yes vs. No	0.81 (0.79-0.83)	0.81 (0.79-0.83)
Received dialysis	Yes vs. No	1.36 (1.27-1.47)	1.36 (1.28-1.46)
Received home health aides	Yes vs. No	1.01 (0.98-1.03)	1.00 (0.98-1.02)
Had visiting nurses	Yes vs. No	0.93 (0.90-0.95)	0.90 (0.87-0.94)
Received homemaking services	Yes vs. No	0.95 (0.92-0.98)	0.93 (0.90-0.96)
Received palliative services	Yes vs. No	0.14 (0.14-0.14)	0.14 (0.14-0.14)

Supplementary Materials 5

ADDITIONAL INFORMATION ON METHODS FOR OBJECTIVE 3

Multiple Imputation

All analyses related to multiple imputation was performed in SAS 9.4[229]. All variables included in the ESEM modelling (i.e., all items listed in Tables 1 and 2 as well as respondents' province of residence) are included in the imputation process. We also included auxiliary variables as they have been shown to improve the quality of imputed values and make the assumption of Missing at Random more plausible[252]. These variables were selected if they are related to variables with missingness or are believed to be associated with missingness. There are ongoing debates on whether to include a variable as an auxiliary if it does not achieve a correlation of r>0.4 with any of the variables to be imputed. Some believe that including these are unnecessary[253], while others believe that a variable may be selected if it was conceptually justified[254]. We decided to follow the latter and included the following auxiliary variables:

- At the time of caregiving, respondent was tired
- Number of family, friends or neighbours respondent helped in the past year
- Household size of respondent
- Respondent was also receiving care for health or aging problems
- Respondent's overall health suffered in the last 12 months due to caregiving
- Respondent suffered injuries while performing caregiving responsibilities
- How physically strenuous caregiving responsibilities were in last 12 months
- Caregiving caused respondent to experience disturbed sleep
- Distance between dwellings of respondent and their primary care-recipient
- Respondent's self-rated mental health

- Whether respondent's primary care-recipient was employed when respondent was caring for them
- Respondent has child/children living at home at the time of caregiving
- Respondent was in school at the time of caregiving

Imputation Methods:

Multiple imputation was performed using the Fully Conditional Specification (FCS) method, which uses a separate conditional distribution for each variable and is appropriate for binary and categorical outcomes[154] (the alternative is to use multivariate normal method which assumes linearity and normality for all variables and is considered inappropriate for categorical variables). For continuous variables, we used predictive mean matching as it draws from existing (i.e., possible) values, creates less bias, and works better for discrete values. For nominal and ordinal categorical variables, the discriminant and logistic methods were used, respectively.

We first examined the missing data patterns to confirm that the assumptions of Missing at Random (MAR) or Missing Completely at Random (MCAR) were satisfied for imputation. For each variable with missingness, we compared, for those with versus without missingness, the distribution of values of all other variables and found no systematic differences. The variables with the most missingness only had 5% missing. Thus, we performed 10 multiple imputations, with 100 burn-in iterations before each imputation.

Imputation Diagnostics:

We examined the trace plots of continuous variables and found good convergence. For each variable, we also compared the imputed and non-imputed values in terms of their frequencies (for categorical variables) and mean, standard deviations, and ranges (for continuous variables), and

found them to be comparable. No outliers or extreme values were identified. Given the small proportion of missingness, the relative increases in variance for all imputed variables were less than 1%.

Exploratory Factor Analysis and Structural Equation Modelling

Structural equation modelling (SEM) is used for causal inference that tests linear relations among measured items and latent variables (also known as factors)[228]. A combination of factor analysis and multiple regressions, it is appropriate for research questions involving multifaceted constructs measured with error and complex systems of relationships with direct and indirect effects[230]. SEM analyzes of the covariance of the data inputted, which represents the strength of the linear associations between variables, and identifies the extent of the variance explained by the specified model[228]. Exploratory structural equation modelling (ESEM) is the integration of exploratory factor analysis (EFA) and SEM, which allows for measured variables to cross-load onto more than one factor, thus preventing the inflation of factor correlations and biased estimates[231].

Using the 10 imputed datasets, we first conducted EFA, using MPlus Version 8, starting with 38 indicators hypothesized to represent 6 latent factors – caregiver distress and its five contributing factors. A series of four- to eight-factor models were run using the Mean- and Variance-Adjusted Weighted Least Squares (WLSMV) estimator and applying an oblique (Geomin) rotation. The following criteria were assessed to determine model fit and the number of factors to extract:

- Fit statistics, with Model fit Root Mean Square Error of Approximation (RMSEA) < 0.06), Standardized Root Mean Square Residual (SRMR) < 0.08), the Tucker-Lewis Index (TLI) > 0.95, and the Comparative Fit Index (CFI) > 0.95 indicating excellent

model fit[230].

- Scree plot inspection and Eigenvalue > 1
- Factor interpretability
- Parsimony

We did not report the Chi-square statistics of model fit as it is biased to both sample and model size[255,256]. Instead, we reported four fit indices: the RMSEA, SRMR, CFI, and TLI. The RMSEA is an absolute fit index that quantifies the difference (per degree of freedom) between the observed covariance matrix and the hypothesized covariance matrix denoting the specified model with its optimally chosen parameter estimates[257]. It ranges from 0 to 1, with smaller values indicating better fit and a value of 0.06 indicative of good model fit[233]. It is not sensitive to sample size, but tends to decrease when the number of observed variables is high (i.e., over 30)[256]. The SRMR, another absolute fit index, is an index of the average standardized residuals between the observed and hypothesized covariance matrices[258]. A value less than 0.08 indicates good model fit[233]. The CFI and TLI, in contrast, are incremental fit indices. The CFI measures the improvement in fit between the baseline model and the hypothesized model, while the TLI measures the relative reduction in misfit between the baseline and hypothesized models[256,259]. Both adjust for samples size and degrees of freedom[256,259], and values greater than 0.95 indicate excellent fit[233].

We iteratively examined the EFA results for each of the four- to eight-factor models. If the fit and interpretability for a particular model was reasonable, we examined the measured variables and retained those with a primary factor loading above 0.40, did not cross-load substantially (above 0.30) onto other factors, and did not result in Heywood cases (shown as negative residuals)[234]. Those that did not meet these criteria were removed and the EFA was run and assessed again until

only items meeting all criteria were retained. Factor quality was assessed by examining the number of items that loaded onto each factor and the correlation between the estimated factor score and the factor[230].

Through this process, we established that a six-factor model, with caregiver distress and its five contributing factors as hypothesized, had the best fit. Eight survey items were eliminated for the reasons listed in below. The order of their elimination did not change the final EFA model established. All results reported for the final EFA model in the main text and supplementary materials were the pooled results from analyses of the 10 imputed datasets.

Table S5.1. Reasons for elimination of each survey item not included in the final EFA model.

Survey Item	**Reason for Elimination**
Respondent helped with house maintenance or outdoor work	Very low factor loadings (FL) for all factors
Caregiving caused strain in respondent's relationship with family or friends	Did not meet the cut-off for Disruption to Family and Social Life (FL=0.310), and cross-loaded somewhat to Caregiver Distress (FL=0.245)
In past year, had various out-of-pocket expenses for caregiving	Did not meet cut-off for Caregiving Burden (FL=0.295), and cross-loaded somewhat to Disruption to Family and Social Life (FL=0.234)
PCR received help from professionals (paid workers/organizations) in the past year	Very low factor loadings (FL) for all factors
Respondent helped with transportation to do errands, get to appointments/social events	Very low factor loadings (FL) for all factors
Respondent provided emotional support in last year	Did not meet cut-off for Caregiving Burden (FL=0.338), and cross-loaded somewhat to Caregiver Distress (FL=0.296)
Respondent received federal tax credits	Did not meet cut-off for Caregiving Network/ Support (FL=0.312), and cross-loaded somewhat to Caregiver Distress (FL=0.263)
Respondent have provided end-of-life care	Very low factor loadings (FL) onto all factors and resulted in negative residuals.

Once we established a stable and well-fitted final EFA model, we proceeded to test the structural model. Complex survey design was accounted for using TYPE=COMPLEX in the Analysis command and incorporating respondents' sample weights and province of residence as strata. We first modelled the linear effects of the five contributing factors on caregiver distress (i.e., the outcome), without adjusting for covariates. Model fit, factor structure, and factor loadings were

re-assessed to confirm model stability. We then added the pre-selected covariates and conducted the aforementioned assessments again. Covariates were retained regardless of their statistical significance.

Finally, we examined modification indices to identify missing paths that could improve model fit. In Mplus, modification indices are produced for analysis on a single dataset, but for the pooled results of imputed datasets. Therefore, we ran the SEM model with covariates separately for each of the 10 imputed datasets and examined the modification indices produced for each. As the proportion of missingness (and therefore imputed data) is low, results were very similar across the 10 datasets and the modification indices were unanimously very high (>100) for paths regressing the five contributing factors on caregiver's sex, education, and relationship to primary care-recipients. Upon re-running the model with these additional paths, we found that modification indices for all other paths were low, suggesting that the addition of other paths would not improve model fit. Therefore, we arrived at the final structural model as shown in Figure 1 in the main text.

Supplementary Materials 6

ADDITIONAL RESULTS – OBJECTIVE 3

Table S6.1. Factor loadings of measured items to latent factors in the final exploratory factor analysis model.

Measured Variables	Outcome: Caregiver distress	CF 1: Caregiving burden	CF 2: Disruption of family & social life	CF 3: Caregiving network & support	CF 4: Caregiving history	CF 5: Positive emotional experiences
Caregiving respondent to feel worried or anxious	**0.699**	0.071	0.092	0.012	0.029	-0.011
Caregiving caused respondent to feel overwhelmed	**0.674**	0.052	0.138	0.068	-0.039	-0.041
Caregiving caused respondent to feel lonely or isolated	**0.775**	0.094	0.024	-0.062	0.011	0.039
Caregiving caused respondent to feel short tempered or irritable	**0.589**	-0.009	0.085	0.103	0.019	-0.218
Caregiving caused respondent to feel resentful	**0.642**	-0.041	-0.014	-0.003	0.002	-0.239
Caregiving caused respondent to feel depressed	**0.915**	-0.031	-0.044	-0.056	0.022	0.053
How stressful caregiving has been	**0.638**	0.112	0.127	0.037	0.014	-0.127
Respondent helped with meal preparation, cleaning, laundry, or sewing	0.072	**0.489**	0.024	0.064	-0.036	0.020
Respondent helped with personal care	0.065	**0.711**	-0.004	-0.018	0.017	0.023
Respondent helped with medical treatments	0.048	**0.750**	-0.025	0.059	0.012	-0.055
Respondent helped with scheduling or care-coordination	-0.017	**0.655**	0.055	0.056	0.054	-0.203
Respondent helped with banking, bill paying or managing finances	-0.044	**0.558**	0.050	-0.029	0.016	-0.185
Number of hours of help provided in an average week	0.192	**0.618**	-0.010	-0.029	-0.050	0.073
Respondent spent less time with family due to caregiving responsibilities	0.046	-0.046	**0.765**	0.085	0.007	-0.110
Respondent spent less time with friends due to caregiving responsibilities	0.059	-0.011	**0.860**	0.125	-0.007	-0.015
Respondent spent less time on social activities or hobbies due to caregiving responsibilities	0.060	-0.024	**0.889**	0.052	-0.012	-0.021

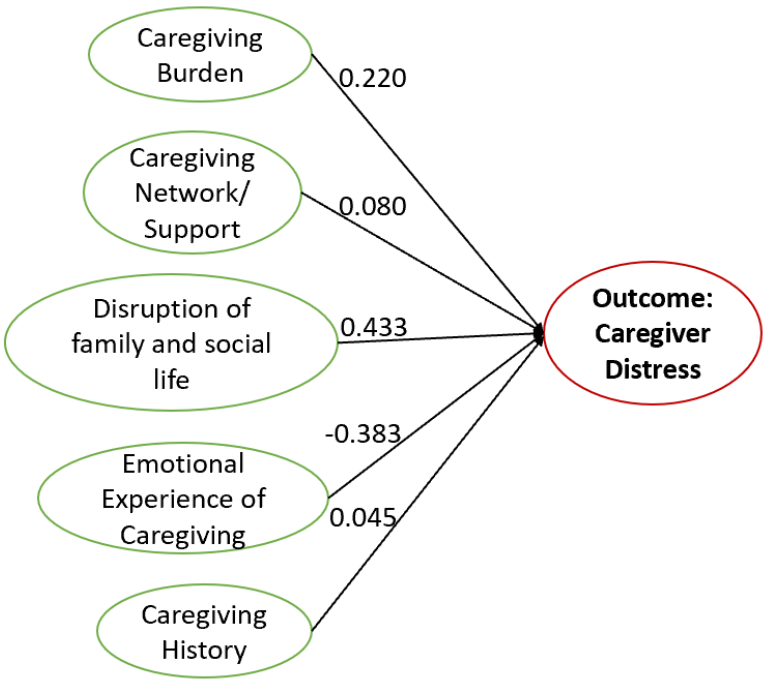
Respondent spent less time on self care due to caregiving responsibilities	0.221	-0.047	**0.693**	0.004	0.013	-0.074
Respondent spent less time volunteering due to caregiving responsibilities	-0.016	0.095	**0.912**	-0.119	0.001	0.159
Respondent spent less time participating in political, social or cultural groups due to caregiving responsibilities	-0.004	0.110	**0.916**	-0.131	-0.002	0.178
To accommodate caregiving, family modified their life or work	-0.114	0.053	0.230	**0.577**	0.001	-0.119
To accommodate caregiving, close friends or neighbours provided help	0.062	0.018	0.006	**0.697**	0.034	0.048
To accommodate caregiving, spiritual community or cultural/ethnic groups provided help	-0.016	0.018	0.006	**0.638**	0.089	0.070
Respondent had occasional relief or respite care	-0.033	0.241	0.034	**0.405**	-0.036	0.001
Family or friends provided financial support	0.180	-0.054	-0.043	**0.464**	-0.058	0.204
Respondent received money from government programs	0.176	0.237	-0.087	**0.410**	-0.052	0.044
Respondent felt they had a choice in taking on caregiving duties	-0.268	-0.154	-0.085	0.045	0.002	**0.403**
Relationship with care-recipients strengthened	-0.031	-0.040	0.201	0.105	0.035	**0.611**
Caregiving experience was rewarding	-0.112	0.077	0.039	0.044	0.040	**0.636**
Number of people respondent cared for other than their PCR	0.007	0.011	0.003	0.000	**0.907**	0.044
Number of years respondent provided care to people other than their PCR	0.012	-0.006	-0.010	-0.002	**1.000**	-0.020

CF: contributing factor of caregiver distress
PCR: primary care-recipient

Table S6.2. Model fit indices of the exploratory factor analysis and structural equation modelling.

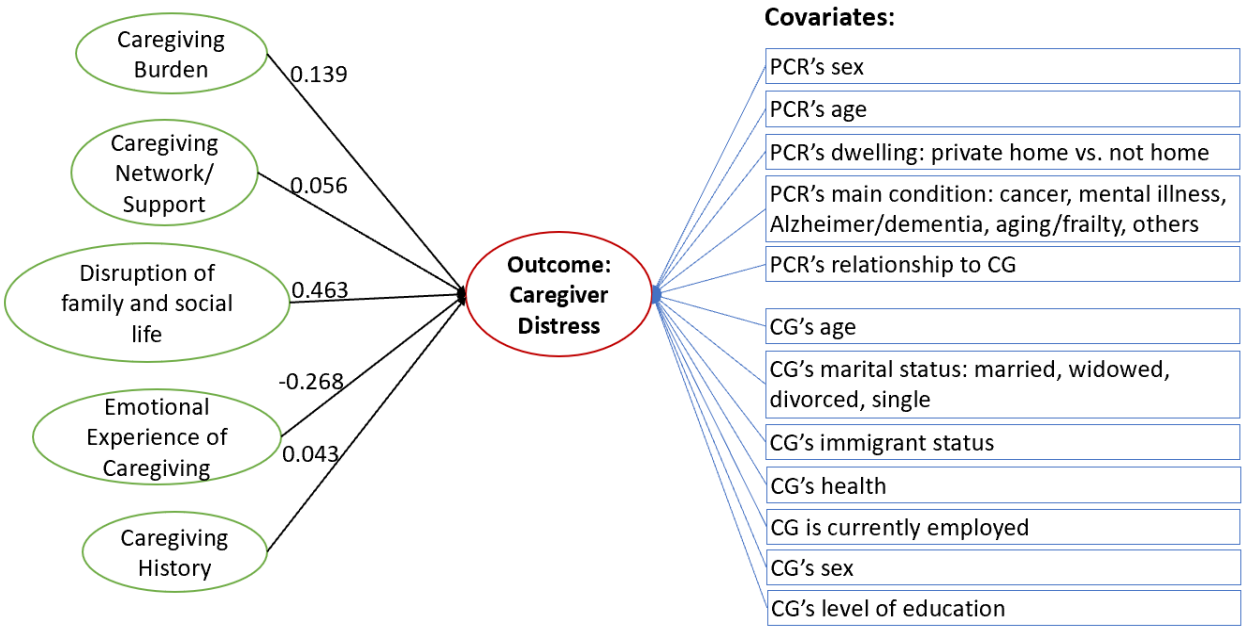
	Number of Free Parameters (df)	**RMSEA**	**CFI**	**TLI**	**SRMR**
Cut-offs for good model fit	N/A	<0.06	>0.95	>0.95	<0.08
Final EFA model	204 (270)	0.036	0.984	0.973	0.029
Unadjusted SEM	156 (318)	0.026	0.979	0.972	0.043
SEM – Adjusted for covariates, without additional paths based on modification indices	187 (1217)	0.023	0.914	0.903	0.084
Final SEM	237 (1167)	0.018	0.951	0.942	0.064

Figure S6.1. Diagrammatic representation of the unadjusted structural equation model.



Note: Path coefficients of the five contributing factors on caregiver distress are standardized, and p-values of all five factors are <0.01.

Figure S6.2. Diagrammatic representation of the structural equation model, adjusting for covariates, without additional paths suggested by the modification indices.



PCR: primary care-recipient of the respondent
CG: caregiver (i.e., respondent)
Note: Path coefficients of the five contributing factors on caregiver distress are standardized and significant at $p<0.01$.