

UNDERSTANDING CAREGIVER BURDEN AND HOSPITAL USE AMONG
OLDER HOME CARE RECIPIENTS IN NOVA SCOTIA

by

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ABSTRACT

Background and rationale: There has been a shift in health care resource allocation from long-term care (LTC) facilities to home care, aiming to provide better care for older adults with multi-morbidities and alleviate burdens on health care systems. Home care is often fragmented and requires support from family and friend caregivers. Caregivers' experiences and situations can vary resulting in differing levels of caregiver burden. Caregivers who experience burden are sometimes unable to continue caregiving, and care recipients are prematurely admitted to institutions. Previous literature primarily focuses on associations between caregiver burden and older care recipients' LTC use, and it is unclear whether or not caregiver burden influences utilization of acute care services, such as hospitals. Hospital use could indicate problems in primary health care that are essential to coordinate complex needs of older care recipients and are costly to the health care system. **Research questions:** (1) Do older home care recipients who have caregivers experiencing distress, burnout, or dissatisfaction have higher hospital use than those who have a caregiver with none of these experiences? (2) If not, what other factors explain higher hospital use of the older home care recipient? **Methods:** This is a secondary analysis of the Nova Scotia Residential Assessment Instrument-Home Care (RAI-HC) collected from 2009 to 2012. Data were collected to assess the health of home care recipients and their caregivers as well as the quality of home care services provided by Nova Scotia Continuing Care. Hospitalization was measured in a follow-up RAI-HC. Caregiver burden was measured by three indicators available in the RAI-HC: (1) caregiver distress, (2) caregiver burnout, and (3) caregiver dissatisfaction. The study used logistic regression to investigate the relationships between older care recipient hospitalization and each indicator of caregiver burden, controlling for older home care recipient predisposing, enabling, and need characteristics variables using the Andersen model of health service utilization. **Findings:** Out of the 4,235 older home care recipients who received home support services from Nova Scotia Continuing Care, 21.75% were hospitalized. In the unadjusted analyses, out of the three indicators of caregiver burden, only caregiver burnout was statistically significantly associated with hospitalization (odds ratio: 1.31; 95% confidence intervals: 1.03-1.67). After adjusting for older home care recipient predisposing, enabling, and need characteristics, none of the three indicators of caregiver burden were associated with hospitalization at the 95% confidence level. However, two older home care recipient factors were statistically significantly associated with an increased likelihood of hospitalization across all three models, including requiring assistance with Activities of Daily Living (ADL) and being diagnosed with a respiratory disorder. Older home care recipients diagnosed with Alzheimer's disease were statistically significantly less likely to be hospitalized across all three models. **Conclusions:** While caregiver burden was not statistically significantly associated with hospitalization, it should not undermine the burden that caregivers experience. These results should be understood with caution as caregiver burden is difficult to measure. The RAI-HC has a promise to contribute to the caregiver burden literature with its focus on a general population, as opposed to clinical population. Future research should validate further the three indicators of caregiver burden in the RAI-HC.

LIST OF ABBREVIATIONS USED

LTC	Long-term care
RAI-HC	Residential Assessment Instrument- Home Care
ADL	Activities of Daily Living
CIHI	Canadian Institute of Health Information
CHCA	Canadian Home Care Association
DHW	Department of Health and Wellness
ZBI	Zarit Burden Interview
COPD	Chronic Obstructive Pulmonary Disease
CES-D	Centre for Epidemiologic Studies Depression Scale
CBI	Caregiver Burden Inventory
PSS	Perceived Stress Scale
CDS	Caregiving Distress Scale
SMD	Standardized Mean Difference
CHESS	Changes in Health End Stage Disease Symptoms and Signs
DRS	Depression Rating Scale
MAPLe	Method for Assigning Priority Levels
HCRS	Home Care Reporting System
CI	Confidence interval
OR	Odds ratio

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CHAPTER 1 – INTRODUCTION

Home care is a health policy priority in Nova Scotia as a growing number of adults are living longer with multi-morbidity and functional decline, warranting an increase in demand of health care (1–4). The past two decades have seen a shift in health care resource allocation from long-term care (LTC) to home care (5–7). In Canada, the utilization of home care increased from 1.2 million in 2010 to 2.2 million in 2012 (8,9). There are a number of population-level changes that contribute to this shift towards increased home care provisions. First, Canada is aging since the proportion of older adults in the population is increasing. The 2016 Canadian census reported that Nova Scotia has the highest proportion of individuals over the age of sixty-five, at 19.9% of the provinces population. Statistics Canada projects that Nova Scotia’s aging population, those over sixty-five years, will increase to one fourth of the province’s population by 2031 (4). In addition to increasing chronological age being a factor related to requiring health care services, there are other determining factors that also play a role in a prospective demand in health care services. These factors are related to multi-morbidity and functional decline, which often culminate in later life. For instance, low physical activity and suboptimal nutrition profiles demonstrated within Canadian and Nova Scotian populations, observed at most ages and contribute to accumulated deficits over time, also increase the likelihood of needing health care services in later life (10-11). With these details in mind, it is important to note that although health care services are often utilized by older adult groups more so than relatively younger groups of the population, this increased need for care is not entirely attributed to or caused by the aging process, as lifestyle and other factors also play a role.

Studies have shown that the majority (87%) of older adults who have complex care needs prefer to stay in the home, even if they have chronic health conditions that limit their autonomy (12). There is government support for home care, as it is believed to be a cost-effective alternative to LTC (12). The delivery of publicly-funded home care is coordinated at provincial and territorial levels of government through contracted medical and non-medical services (9). Nursing and home support services are part of the delivery

of all provincial and territorial home care across Canada, although the content of these services differ across provinces (e.g., homemaking and therapies) (9).

Home care relies heavily on family and friend caregivers as they provide necessary care outside of the structure and hours of provincial and territorial home care services. Nearly six million Canadians are primary caregivers for friends or family members (13). The experience of caregivers is highly variable and influenced by a range of factors, such as the care need of care recipients, social support for caregivers, and how socially disadvantaged a caregiver might be (14). While caregiving can be a rewarding experience, it is common for family and friend caregivers to experience caregiver burden (14,15).

Caregiver burden is understood as a multidimensional concept encompassing the impact of the physical, psychosocial, social, and financial domains of caregiving (14). Caregiver burden can also be differentiated between objective (e.g., events, undertakings, and activities) and subjective burden (i.e., the caregiver's perception of how caregiving influences their life) (16). Even though caregiver burden has been studied for over three decades, there is still no standardization in the concept and the measurement of caregiver burden. Over 74 instruments are available to assess caregiver burden. The large number of instruments available coupled with no standardization in measurement has resulted in problems in measuring caregiver burden in research and in clinical practice (17,18). Accordingly, it is challenging for researchers to draw conclusions from the literature on caregiver burden, although assessing caregiver burden is critical in understanding the caregiver needs and preferences influenced by the provision of care.

When family or friend caregivers become too burdened to handle home care responsibilities, care recipients often prematurely face institutionalization (17). Previous studies on caregiver burden have focused on examining causes and influence of caregiver burden on caregiver health (14). Much less attention is paid to the impact of caregiver burden on the health of the care recipient (17). Of the studies that do focus on the association between caregiver burden and adverse health outcomes of care recipients, the majority of studies focus on LTC admission (17,19). It is still relatively unclear whether or not caregiver burden influences utilization of acute care services, such as hospitals (20). Hospital admissions could indicate problems in primary health care that are costly

to the health care system and essential to coordinate complex needs of older patients requiring care. Hereafter older adults receiving home care will be referred to as older care recipients (21).

The studies that do examine the association between caregiver burden and care recipient hospital use highlight three major gaps in the literature. Firstly, the majority of studies in this area focus on specific older care recipient populations with homogeneous diagnostic groups, such as dementia or cardiovascular disease, limiting generalizability of the studies to older care recipients with multi-morbidity and functional decline within a general population. Secondly, no known studies have examined the association between caregiver burden and older care recipient hospitalization in Canada. Thirdly, no known studies in Nova Scotia use administrative data from a provincial database to assess caregiver burden and hospital use to inform provincial policies (14,17).

To address these limitations, this study examined the relationship between caregiver burden and older home care recipient hospital use among 4,235 home care recipients and their primary caregivers using provincial administrative data, the Resident Assessment Instrument– Home Care (RAI-HC). The Nova Scotia RAI-HC collects information on home care recipients and their caregivers from everyone receiving home care services through Continuing Care in Nova Scotia (22). Caregiver burden is measured within the RAI-HC through three questions assessing subjective caregiver burden. This dataset allows for a population-based analysis of caregivers and care recipients who receive home care in Nova Scotia.

CHAPTER 2 – BACKGROUND

A home care strategy is critical as more Canadians are living with multiple complex chronic conditions largely secondary to an increased life expectancy, resulting in several broader social and economic implications (1,5). The 2016 Canadian census reported that Nova Scotia has the highest proportion of individuals over the age of sixty-five, encompassing 19.9% of the provinces population (4). Not only is Nova Scotia's population expected to continue to have the highest provincial proportion of adults over the age of sixty-five, this proportion is projected to increase to 28.6% of the provinces population by the year 2031 (4). Along with increased life expectancy, aging of the “baby-boomers” is thought to be, in part, responsible for this demographic shift (2,3). While living longer, the older adult segment of the population on average has an increased number and severity of secondary aging-related chronic conditions (e.g., dementia, heart disease, and diabetes) that can lead to frailty (1,23–25). Frailty is a state of increased susceptibility to adverse health outcomes for individuals of the same chronological age (26). Frailty presents a major challenge in the provision of care of some older adults, as people who are frail have longer hospitalizations, worse health outcomes, and higher mortality than people who are not frail (27).

Many older adults have more complex care needs than the general population and require specialized assistance with care (25). On average, older adults have more physician visits, longer hospital stays, and utilize more health services overall when compared to the general population (1,25). Over the past thirty years the advancement of health technologies and medicine (e.g., medical diagnostic imaging and surgical tools) have changed the way people interact with the healthcare system (24,28). Adults eighty years and older are twice as likely to have cataract surgery, knee arthroplasty, poly-pharmacy, medical imaging, and coronary bypass compared to the same group thirty years ago, and has led to the creation of specialized geriatric medicine (24). Although some of these health services are high cost, they allow older care recipients to sustain their quality of life, avoid high-cost institutionalization, and remain living in their own homes (24,29).

There has been a recent shift in health service resource allocation from LTC to home care (25,28). Less than twenty years ago, it was common for older care recipients to move into LTC facilities and hospitals when they could no longer care for themselves at home (29,30). HealthCareCAN, formerly named the Canadian Healthcare Association, suggests there are four main reasons for a shift towards care in the home, including: the preference to remain at home, an increase in Canadians living longer with more chronic conditions, advances in technology that allow for more care at home, and the belief that home care is a more cost-effective alternative to LTC (31). In fact, in 2007, the Special Senate Committee on Aging reported that 87% of older adults prefer to remain at home for as long as possible (12). Home care provides an avenue for older care recipients to receive care at home, while maintaining independence and dignity (31). LTC is expensive for both care recipients and the healthcare system (24,30). Additionally, as the demand for care increases, the admission criteria to LTC have become increasingly stringent. For instance, in Nova Scotia, all home and community-based care services must be explored before the Health Authority determines that placement in a LTC facility is the most appropriate (32). Recent health policy has reflected these concerns by working to improve access to home care for older care recipients in Canada (1,23).

The preference to stay at home comes with the additional demand for care in the home (1,29,33). Home care services are intended to supplement the ongoing work of family and friend caregivers, hereafter referred to as caregivers (29,33). Caregivers provide unpaid care, often around the clock, to ensure their friend or family member living with physical or mental health conditions of varying acuteness are able to live at home (29). While the majority of caregiving research focuses on the negative health and financial outcomes attributed to the experience, there are also positive aspects that caring for a close family member or friend can have on the caregiver. A qualitative study on positive aspects of caregiving found that caring for an older family member who requires care enhances personal fulfillment, time-management skills, family bonds, empathy towards others, and motivates caregivers to promote the rights and dignities for older care recipients (35). Caregiving can be emotionally rewarding as it can honour past care from family members and save family financial resources. In addition to saving household

financial costs, caregivers providing care in the home save the health care system costs (29,31).

Preventable hospitalizations among older home care recipients further contribute to existing health service use problems. Patient flow through the health care system is a common health services issue as a result of an increasing number of individuals within the population who have complex care needs. Older care recipients, on average, have longer stays in hospitals than their younger counterparts and often remain in hospital even after improvement in their condition (29). Many older care recipients who have long lengths of stay are waiting for adequate care conditions at home or an opening at a LTC facility (29). Furthermore, the Canadian Institute for Health Information's (CIHI) 2011 report on seniors and aging found that every day an older care recipient is hospitalized they can lose up to 5% of their function (29), meaning that the longer the hospital stay the less likely the individual will go on to live independently in the community. As provincial health care systems work toward addressing the issues of navigating older care recipients through hospital services, the reasons for hospitalization will likely come into question (29).

2.1 HOME CARE

In 1990, Health and Welfare Canada, a former federal department, described home care by its three pillars of function: (1) acute care substitution, (2) LTC substitution, and (3) prevention and maintenance of health conditions that enable a person, regardless of age, to live independently (12,29). The definition of home care has continuously evolved over time to reflect the wide variety of health and social services provided in the home in order to meet the needs of a growing population with complex care needs (29). Today, the Canadian Home Care Association (CHCA) defines home care as “an array of services offered in the home and community setting that encompass health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for the informal (family) caregiver” (29). In 2016, the CHCA reported that more than 1.8 million Canadians use

publicly funded home care services and the majority of these services were provided to older care recipients (9).

Home care has two core components: medical and non-medical care (35). In addition to medical management and assistance with instrumental activities of daily living (IADLs) provided by caregivers, paid home care and medical professionals are involved in the delivery of specialized care in the home (29,31). Medical care, for instance, pain management and catheter maintenance, is care provided by licensed medical professionals like nurses and physicians (13,9). Non-medical care, also known as home support services, assist home care clients with personal care and homemaking (13). Home support workers assist with the home care recipients' housekeeping, laundry, meal preparation, hygiene, medication management and other activities of daily living (ADLs) (13). Furthermore, additional community support services may provide help to support ongoing services in the home, such as adult day care programs to provide relief to caregivers (3,25,29,31,36).

Medical and non-medical services are essential for individuals receiving care to live independently in their homes, but financing these services may become complicated. Home care is not an insured service under the Canada Health Act, which provides a national standard for the delivery of the insured health care services (35,37). Physician and hospital services are governed by the Canada Health Act and publicly funded through federal and provincial tax revenue, without patients being billed at the point of service. The delivery of these services is the responsibility of provincial and territorial governments (11,37). In Nova Scotia, the costs for home care are split privately (i.e., out of pocket and private insurance) and publicly (i.e., government tax revenue). The provincial government's health sector, the Department of Health and Wellness (DHW), operates home medical services with public funds; however, non-medical services such as housekeeping and medication management are not fully paid for under DHW. Costs for non-medical services are based on income and family size (3,13). For example, one person with an annual income between \$47,006 and \$57,006 have a maximum out-of-pocket monthly fee of \$363 while someone in the same income bracket with a family size of three or more would have a maximum monthly fee of \$121 per month (35,38). Paying for non-medical home care services can therefore be costly for home care recipients and

their caregivers. In a complex system with fragmented delivery of services, family and friend caregivers play a vital role in the provision of home care, and as a result, can become overworked and experience a phenomenon known as “caregiver burden” (3,14,17).

2.2 CAREGIVER BURDEN

The concept of caregiver burden was initially studied to understand the negative implications of caregiving of family members who take on a caregiving role. The earliest attempt to clarify the concept of caregiver burden was by Steven Zarit while developing the Zarit Burden Interview (ZBI) to measure caregiver burden on relatives of patients with dementia. Zarit and colleagues considered problems frequently mentioned by caregivers, including the caregiver’s health, psychological well-being, finances, social life, and the relationship between the caregiver and the care recipient (41). Throughout the 1980s, the concept of caregiver burden was further studied and the definition evolved to how it is defined today: the extent to which caregivers perceive that caregiving has an adverse effect on their emotional, psychological, social, financial, and physical functioning (42–44). These five areas are often referred to as the domains of caregiver burden. The definition of caregiver burden is broad and multidimensional (14,15,42), and caregiver burden is commonly studied and measured as a function of the five domains (43,44).

Caregiver burden can be further differentiated between objective and subjective burden (44). Objective burden includes the directly observable consequences caregiving has on a caregiver’s life (e.g., events, undertakings, and activities). Subjective burden is the caregiver’s perception of the strain of caring and perception of the objective burden on the caregiver’s life. Objective and subjective burden have different effects on physical and mental health of caregivers, thus, are both important (16,18,44).

2.3 MEASURING CAREGIVER BURDEN

Measuring caregiver burden is critical in understanding caregiver health and well-being in relation to the care that they are providing. For these five domains, numerous caregiver burden instruments have been developed since the measurement of caregiver burden was first explored in the 1980s (16-18).

A systematic review conducted by Whalen with an objective of quantitatively measuring the psychometric properties and feasibility of caregiver burden instruments found over 74 different instruments existing in the literature. Inclusion criteria for the systematic review included international quantitative research papers that addressed the psychometric properties and feasibility of caregiver burden screening instruments. Out of the 74 instruments that met the studies inclusion criteria, the ZBI, Caregiver Reaction Assessment, and the Caregiver Burden Inventory (CBI) were the most commonly used (18). The review found many of the instruments were developed to assess one of the five domains of caregiver burden and were developed for a disease specific population (e.g., caregiver's psychological health outcomes and care recipients with dementia). As a result, many of the instruments that assess caregiver burden do so within a specific care recipient population. For example, the original ZBI was designed for caregivers caring for care recipients with dementia in a small study population (n=29). The Caregiver Quality of Life Index-Cancer assesses caregiver burden among (n=263) caregivers caring for care recipients with cancer. Convenience sampling was used to develop these instruments, which limits the generalizability of both the instrument and study outcomes across various health care settings and patient populations (16). It is difficult to know how these instruments compare or contrast to one another, given their variability.

Arguably, the most popular instrument to measure caregiver burden is the ZBI that measures caregivers' emotional, psychological, social, financial, and physical functioning as a result of taking care of their family member or friend (18). Despite using a convenience sample to develop this instrument (i.e., caregivers of dementia patients in a small study), the ZBI is now used broadly across patient populations and care settings around the world. Moreover, the ZBI is translated into several languages, including Portuguese, Spanish, and Japanese, and there are various versions used in research (45). The original version consisted of twenty-nine items whereas the one that is currently used in research is shorter with twenty-two items (18).

Many researchers claim that the ZBI is well-validated across a variety of patient populations, care settings and countries (15,17). However, there are other studies that show discrepancies in the validation, including external validity of the ZBI, especially in populations outside of care recipients with dementia (18). Because the ZBI is the most popular instrument used in literature assessing caregiver burden, it is speculated that some researchers make an assumption that the reliability of the instrument is validated for any population (16). This assumption results in the application of the ZBI across a variety of populations and care settings where it is not known if the ZBI will give an accurate measure of caregiver burden. More broadly, the ZBI is commonly referred to as the gold standard for measuring caregiver burden in the caregiver burden literature. Other instruments use the ZBI as a reference in the validation of their instrument. This practice warrants caution to researchers and clinicians studying caregiver burden as the ZBI is not validated across all care settings and care recipient populations, further questioning the validation of other caregiver burden instruments (16,46). Overall, in the caregiver burden literature, there is a lack of external validity for instruments designed to measure caregiver burden (18). In addition to the limited validation of caregiver burden instruments, other problems include instruments not clarifying the differences between objective and subjective burden, the large number of terms used to express caregiver burden, and the disconnect between research and the practical application of caregiver burden instruments (16–18,48).

The sub-categories of objective and subjective burden within caregiver burden instruments may result in different caregiver health outcomes (18). As mentioned earlier, objective and subjective burden have different effects on physical and mental health (44). For example, a caregiver's perception of burden may be substantially different than the actual intensity or number of tasks, differentiating subjective and objective types of burden. However, instruments measuring objective burden are not necessarily *better* than instruments measuring subjective burden, they are just *different* assessments (16). The differentiation between objective and subjective burden is important in the understanding of caregiver burden and planning interventions to alleviate (18).

Caregiver burden is expressed in the literature using many different terms (17). For example, many instruments that measure burden include other constructs such as

strain, hassles, impact, quality of life, or stress within the name of the instrument. However, the items within the instrument may actually measure burden comprehensively and not the domains its name suggests (18). Ambiguity in the domains captured by the instrument may lead to incorrect reporting of results. Researchers suggest that it is important for clinicians and future researchers to understand the domains captured within the selected instrument rather than relying on the name or explanation of the instrument (17,18). Acknowledging the inconsistencies in the caregiver burden literature is critical when drawing conclusions on outcomes (17).

Furthermore, there is a disconnect between research and the practical application of caregiver burden instruments. Some work has been done in shortening existing instruments to effectively measure caregiver burden in settings where lengthier instruments are not practical (14,16). This is especially important as the provision of care is shifting from acute care settings to home and community care (9). For example, instruments that were designed to be administered in an acute care setting by a physician may not be appropriate in screening caregiver burden across a large population receiving home care (16). There are few known instruments that are designed to measure caregiver burden at a broad population level.

2.4 MEASURING CAREGIVER BURDEN USING THE RAI-HC

A systemic review and meta-analysis assessing caregiver stress and care recipient institutionalization found that improved study methodologies over time, including larger sample sizes, has decreased the study effect of caregiver stress on institutionalization due to the increased power in recent studies. With care transitioning from institutions into the community, measuring caregiver burden from a population level is becoming increasingly important in understanding caregiver health (17). The RAI-HC collects administrative information on care recipients and their caregivers from everyone receiving publicly funded home care services in several provinces in Canada, including Nova Scotia (22). Caregiver burden is measured within the RAI-HC through three indicators of caregiver burden: (1) the caregiver was unable to continue in caring activities due to declines in his/her own health (caregiver distress), (2) the caregiver

expressed feelings of distress, anger, or depression (caregiver burnout), and (3) the caregiver was dissatisfied with the support received from family and friends (caregiver dissatisfaction). While these three indicators are not as extensive as composite instruments that incorporate a greater number of data items, the RAI-HC allows for population-based measurement of caregiver burden. The indicators within the RAI-HC were designed to gather information on all home care recipients and their caregivers and are not limited to specific sub-populations (e.g., care recipients with dementia). Although the indicators are not meant to be comprehensive measures of caregiver burden, such as the ZBI, they do allow for an analysis of caregiver health (49).

The three indicators of caregiver burden are previously used in population-based research, but not extensively. The use and description of the RAI-HC caregiver questions vary in the published literature. For example, a secondary analysis evaluating the relationship between caregiver burden and the risk of hospitalization utilized the three indicators of caregiver burden within the RAI-HC. The author described the three indicators as perceptions of caregiver burden. On the other hand, CIHI and interRAI Canada (Canada's research, education, and knowledge exchange cluster specializing in interRAI suite of instruments including the RAI-HC) label burnout and distress measures as indicators of caregiver distress and do not include the third measure of caregiver dissatisfaction. The description of the caregiver distress indicator in the RAI-HC by CIHI and interRAI Canada is the most common in the literature (16). Despite the slight differences in each of the three caregiver burden variables in the RAI-HC, all three caregiving items are measures of subjective caregiver burden, meaning that they are perceptions of the burden involved in the actual caregiving duties (16,49,50).

The aforementioned systematic review by Whalen does not include the indicators of caregiver burden from the RAI-HC as it did not meet its inclusion criteria as a validated caregiver burden screening instrument. Unlike the clinical assessments for the home care recipient within the RAI-HC (e.g., depression rating scale [DRS]), the caregiver burden questions in the RAI-HC have not been studied in terms of reliability and validity, and the research literature may not consider them as screening instruments for caregiver burden. However, the strength of the indicators in RAI-HC is that they allow for a population based assessment of caregiver health and can be linked to detailed

information on the home care recipient. Additionally, the dichotomous nature of the indicators, as opposed to a lengthy scale, makes it easier for the caregiver or care coordinator to respond to the assessment (18). Moreover, there are no known population-based instruments that collect information on caregiver health equivalent to the breadth of the RAI-HC. The RAI-HC also includes home care recipient information that is considered to be risk factors for caregiver burden.

2.5 RISK FACTORS FOR CAREGIVER BURDEN

It is known that family and friend caregivers have poorer physical and psychological outcomes compared to non-caregivers (14,51). A review of cohort studies assessing risk factors for caregiver burden found low education, sleep deprivation, amount of caregiving time, lack of choice in assuming caregiving role and responsibilities, depression, social isolation, and weight loss to be independent risk factors of caregiver burden (14). Other risk factors of caregiver burden include female sex, fewer coping strategies (e.g., advice seeking and exercising), cohabitation with the care recipient, financial stress, the caregiver's perceived stress of the care recipient, and transfers in care (e.g., hospital to home) (17,52,53). Caregivers providing over twenty-one hours of care per week were more than four times as likely to experience burden than unpaid caregivers providing less than ten hours of care per week (52). In addition, caregiver burden is more prominent in caregivers who care for individuals with symptoms of depression, with moderate to severe cognitive impairment (e.g., Alzheimer's disease and dementia), and those displaying aggressive behaviours (53).

Consequences of caregiver burden can lead to inability to continue employment, suicide, and increased mortality (14). In fact, a four-year follow-up study found that highly distressed caregivers had a 63% increased risk of mortality compared to a non-caregiving control group (relative risk [RR], 1.63; 95% confidence interval [CI], 1.00-2.65) (53). Furthermore, employed caregivers have the responsibility of managing their paid employment in addition to their caregiving duties, experiencing additional burden (54,55). Of caregivers experiencing burden, 55% of women and 45% of men have reported interference at work including change of work hours and turning down

promotions (37). It is known that some groups of caregivers such as those with low income may be more vulnerable to caregiver burden and may face additional barriers to accessing needed supports, thus experiencing poorer psychological health outcomes (52,56,57).

The social determinants of health influence health whereby those who are of lower socioeconomic status have poorer overall health. Similarly, caregivers who are of lower income and education have a more difficult time coping with caregiving than those in similar caregiving circumstances with higher socioeconomic status (3,15,53,58,59). Authors of another systematic review assessing caregiver stress and care recipient institutionalization found it difficult to draw conclusions between the two because of the inconsistencies in measuring caregiver burden across studies in the literature, limiting the ability to compare findings on caregiver burden (17).

Previous studies on caregiver burden focus on examining its causes and its influence on caregiver health (52). Much less attention has been paid to the impact of caregiver burden on the health of the care recipient (17). While the association between caregiver burden and LTC admission is well-demonstrated in the literature (17,19), it is still relatively unclear whether caregiver burden influences utilization of acute care services, such as hospitalization (19).

2.6 CAREGIVER BURDEN AND HEALTH SERVICE UTILIZATION

Over the past two decades, health service and policy researchers have become increasingly interested in the relationship between caregiver burden and care recipient health service use, especially in terms of premature use of LTC facilities and acute care services (e.g., emergency department visits and hospital stays) (17,19). To date, the majority of the research on this topic examines admission to LTC facilities, yet utilization of LTC facilities are on a decline (17,29). Donnelly et al. conducted a systematic review and meta-analysis on the effect of psychological domains of caregiver burden on institutionalization among older home care recipients (17).

The review consisted of fifty-four studies measuring caregiver stress and health service use at baseline. As a result of inconsistencies in measuring caregiver stress, the

review included studies with a broad array of variables that assessed aspects of caregiver stress such as burden, depression, or distress. The outcome variable, institutionalization, included utilization of acute care services (i.e., emergency department visits and hospital admissions) and admissions to nursing homes. The majority of the studies in the review had an outcome variable of admission to LTC, while acute care services accounted for seven of the included studies (20,61–65). Donnelly and colleagues did report a statistically significant effect of caregiver stress on institutionalization, however, the effect size is negligible (standardized mean difference [SMD]: 0.05; 95% CI: 0.04-0.07). After a sensitivity analysis for measurements of caregiver stress, a small effect size was again reported (SMD: 0.23; 95% CI: 0.09-0.38) (17). Although this study reports only a small effect size, the relationship between caregiver stress and acute health service use is still not fully understood in the literature due to the small proportion of studies analyzing acute care utilization as an outcome.

While the review did not assess hospital use independently from LTC individual studies, it did include several studies assessing the relationship between caregiver stress and hospital use (17). In Japan, Kuzuya and colleagues conducted a study to determine if caregiver burden (measured by ZBI) was associated with all-cause mortality and hospitalization of older care recipients. The study found older care recipients with caregivers exhibiting higher burden were more likely to be hospitalized. This relationship remained even after controlling for characteristics such as age, gender, number of community-based services used, older care recipient ADL status, and comorbidities (e.g., diabetes, pain, chronic obstructive pulmonary disease [COPD]). Furthermore, those who used community-based services, such as respite care, were less likely to be admitted to hospital (20). The Andersen model of health service utilization, a tool composed of three pillars (i.e., predisposing factors, enabling characteristics, and need characteristics) to predict health service use, was used to control for known factors for hospitalization. The study found that caregiver dissatisfaction (measured by RAI-HC) was strongly associated with hospitalization in the past ninety days among a cohort of home care recipients in Michigan (50). Caregiver stress (measured by Perceived Stress Scale [PSS]) was also statistically significantly associated with hospitalization among care recipients with heart failure in Ohio (62). A two-year prospective study among Alzheimer's disease patients in

France found caregiver burden (measured by ZBI) as a predictive factor for hospitalization of home care recipients (64). Conversely, a study of older veterans with dementia in the US (measured by Centre for Epidemiologic Studies Depression Scale [CES-D]), a study of stroke patients in Taipei (measured by CBI), and a study of older home care recipients in Japan did not find caregiver burden (measured by ZBI) as a risk factor for hospitalization of older home care recipients (60,63,66).

Additional studies report inconclusive findings. Two studies assessing the relationship between caregiver burden and hospital use found no statistically significant associations between high caregiver burden (measured by CBI; PSS) and health care utilization. However, both studies had small sample sizes (n=214 and n=284) (67,68). Miller and colleagues examined this relationship from a different perspective by examining caregiver distress (measured by the Caregiver Distress Scale [CDS]) as a mediating variable between care recipients' health status and hospitalization. The study found that caregiver distress weakens the inverse relationship between care recipient health and hospital use. That is, if a care recipient has good health, they are less likely to be institutionalized. If their caregiver is experiencing high levels of distress, the given relationship becomes weak and it is more likely that the care recipient will be institutionalized (69).

2.7 OTHER FACTORS INFLUENCING HOSPITALIZATION

The Andersen model of health service utilization model is a conceptual model aimed at demonstrating the factors that lead to the use of health services. According to the model, health service use is determined by three pillars, including: predisposing factors, enabling characteristics, and need characteristics. The model was further adapted and by Bass and colleagues and the modification takes into account a fourth characteristic: the influence of the family caregiver. Bass's adaptation of the Andersen model of health service utilization demonstrates the importance of caregivers in determining the use of health services (50,70).

Factors outside of caregiver burden are also known to influence hospitalization of home care recipients. In dementia populations, a prospective cohort study found

dependency with ADLs, polypharmacy, and neurological conditions as predictive factors for hospitalization (64). In addition, an Australian study of home care recipients with dementia found previous hospital admissions and cognitive impairment to be statistically significant predictive factors for hospitalization (68). A population-based study of home care recipients in Michigan found patient characteristics that included the presence of cancer, COPD, pain, flare-up of a chronic condition, poor food intake, and prior hospitalization, all to be statistically significantly attributed to hospitalization (50). A Japanese study found that older care recipients enrolled in home care who have friends, in addition to a primary caregiver, were more likely to continue home care and prevent hospitalization than those without friends or who lived alone (66). Other known protective factors that prevent hospitalization include the use of community-based services, such as respite care, although community-based services may only be a temporary protective factor (nine months or less) (20,68). Thresholds of caregiver stress may also be higher for caregivers who have higher emotional capacity in their role as a caregiver (14).

2.8 GAPS IN KNOWLEDGE

Only seven studies examined the relationship between caregiver stress and hospital use (17,19,20,50,60,62–64). Among these studies, most used homogeneous diagnostic groups (e.g., people with dementia), limiting generalizability of the studies to a smaller segment of the population with particular types of multi-morbidity and functional decline. Five studies from the Donnelly review examined this association among people with dementia (60,64,68–71). Three other studies also investigated the same association among other populations such as stroke patients, heart failure, homebound, and end of life (62,63,67).

Caregiver burden instruments were not consistent across the seven studies in the review. Six different instruments were used across the seven studies including the ZBI, RAI-HC, PSS, CES-D, CBI, and the CDS. Out of the four studies with statistically significant findings, the RAI-HC, PSS, and ZBI were used to measure caregiver burden (20,50,62,64). Of the studies that did not have statistically significant findings, the CES-

D, CBI, and ZBI were used for measurement instruments (60,63,66). The review further delved into the impact of the particular measures of caregiver burden by comparing studies that utilized the ZBI (SMD: 0.06; 95% CI: 0.04-0.09) to those that utilized any other measure of burden (SMD: 0.19; 95% CI: 0.04–0.35). While the SMD between the ZBI instrument and the other instruments appear different, the effect sizes were still small (17). Thus, the review further highlights the minor impact that the instrument used to measure caregiver burden has on the overall relationship between caregiver stress and institutionalization.

While population-specific research indicates high-risk groups of caregiver burden, further population-based research is warranted so that it can be applied to understand the larger segment of the population (14). Additional population-based research can enhance generalizability of study results and increase implementation of population-based home care interventions to reduce hospitalizations among older home care recipients. Although several studies examine associations between caregiver burden and hospitalization, there are no known studies examining this association in Canada. Two studies report descriptive statistics on caregiver burden and hospital use among home care recipients, however the studies do not provide enough information to show a correlation between the two. Additionally, all Canadian studies were conducted in Ontario and therefore may not be generalizable to other areas of Canada that differ demographically (e.g., higher proportion of older care recipients), such as Nova Scotia (65,72). In addition, as mentioned earlier, home care in Canada is not publicly insured and is delivered differently across provinces and territories. Thus, generalizing results from one province to others requires a caution. This generalizability concern applies to cross-country comparisons. For example, in countries where hospitalization requires an out-of-pocket cost, hospitalization for the care recipient may not be a likely alternative when a caregiver is experiencing burden (35).

CHAPTER 3 – OBJECTIVES

The overall goal of this study was to examine the association between caregiver health and hospital use among older home care recipients in Nova Scotia.

To meet this overall goal, the following questions were asked:

1. Do older home care recipients who have caregivers experiencing distress, dissatisfaction, and burnout have higher hospital use than those who have caregivers with none of these experiences?
2. If not, what other factors explain higher hospital use of the older home care recipient?

CHAPTER 4 – METHODS

4.1 DATA

Data for this study came from the RAI-HC (Appendix A). The RAI-HC is used internationally, part of a larger series of assessments *inteRAI*, that aims to support care-planning strategies across various health care settings. The RAI-HC assesses the care preferences, needs, and strengths of long-term (i.e., a minimum of ninety days) home care recipients and their primary caregivers. The RAI-HC is designed to inform and guide care planning and delivery of home care, highlighting home care recipient function and quality of life (73). The RAI-HC is shown to have good reliability and validity across home care settings around the world (74). The RAI-HC includes valid scales such as the Method for Assigning Priority Levels (MAPLe), the Changes in Health End Stage Disease Symptoms and Signs (CHESS) scale, the Cognitive Performance Scale (CPS), DRS, and the ADL hierarchy scale (75). The RAI-HC is used in home care research to assess health service utilization among home care recipients such as hospitalization (50).

In Canada, the RAI-HC is the standard for collecting home care data for the Home Care Reporting System (HCRS). The HCRS, held by CIHI, is a national database that includes information on demographics, clinical function, and resource utilization of home care clients whom use publicly funded home care services in several provinces in Canada (22). In Nova Scotia, the assessment has been made mandatory for those who use home care services provided through the provincial government. The data collected through the RAI-HC provides population-based information to assist in the development of home care policies and delivery of home care in Nova Scotia. Information is collected in the Nova Scotia RAI-HC by a trained Continuing Care Coordinator (38).

For this study, data from the RAI-HC conducted in Nova Scotia from July 1, 2009 to December 31, 2012 were used, which includes 72,077 home care recipients. The population represents home care clients in Nova Scotia who have been receiving home care for a minimum of ninety days. The Nova Scotia DHW Continuing Care obtains RAI-HC assessments from the same respondents every year as long as they remain home care clients. The RAI-HC data belong to Continuing Care, which is held by Nova Scotia

DHW. These data are previously cleaned by researchers at the Nova Scotia DHW and reviewed for errors. Errors due to data entry were corrected where possible. If data entry errors could not be corrected, each individual assessment was deleted. For example, assessments that had missing values preventing calculations of the CHESS, CPS, and ADL hierarchy scale variables were deleted case-wise. Home care recipients were excluded if they did not have income information at last assessment and who received care services that did not include home support or home support with nursing (e.g., nursing only, oxygen services). For this study, home care recipients were also excluded if they were under sixty years of age to have a sample that represents a segment of Nova Scotia's older population with complex care needs. Finally, for this study, home care recipients were excluded if they did not have subsequent RAI-HC assessments as they will not have a measure for the dependent variable, hospitalization. These exclusions resulted in reducing the sample size for analysis of $n=4,235$ (Figure 1).

4.2 VARIABLES

4.2.1 Dependent variable: Hospital use

The dependent variable is hospital use by older home care recipients. Hospital use was determined by a survey question asking about the “number of times admitted to hospital with an overnight stay” in the past ninety days or since last assessment. The variable hospital use was created to be dichotomous because older home care recipients are more likely to be readmitted to hospital after being admitted once. This variable is in the form of “hospital use yes” and “hospital use no” and was self-reported by the older home care recipient. A response of one or more indicates “hospital use yes.” Due to the likelihood of the dependent variable, hospitalization (reference period of the past ninety days), occurring before the independent variable, caregiver burden (reference period of the past three days), the hospitalization variable was captured from the care recipient's follow-up RAI-HC (hereafter referred to as the subsequent RAI-HC assessment) to minimize issues of temporality. The Nova Scotia DHW obtains subsequent RAI-HC assessments at least every year after the care recipient original RAI-HC assessment to

inform and guide care planning. A subsequent RAI-HC may have been obtained sooner, if the care recipient required changes within their provision of care from Nova Scotia DHW.

4.2.2 Independent variables of main interest: Indicators of caregiver burden

This study used three indicators of caregiver burden available in the RAI-HC: (1) caregiver distress, (2) caregiver burnout, and (3) caregiver dissatisfaction. All three indicators of caregiver burden are based on caregiver self-report or observation by the Continuing Care Coordinator in the past three days. All three indicators of caregiver burden have previously been used in research to assess the relationships between caregiver burden and health service use in both acute and long-term settings (50).

4.2.3 Caregiver distress

The first indicator of caregiver burden, caregiver distress, is a dichotomous variable (yes or no). Caregiver distress is captured by the presence of the following question within the RAI-HC: is the primary caregiver expresses feelings of distress, anger, or depression?

4.2.4 Caregiver burnout

The second indicator of caregiver burden, caregiver burnout is a dichotomous variable (yes or no). Caregiver burnout is captured in the RAI-HC by the following question: is the caregiver is unable to continue in caring activities (e.g., decline in caregiver health)?

4.2.5 Caregiver dissatisfaction

The third indicator of caregiver burden is caregiver dissatisfaction. Caregiver dissatisfaction is a dichotomous variable (yes or no). Caregiver dissatisfaction is captured

in the RAI-HC through the following question: the primary caregiver is not satisfied with support received from family and friends (e.g., other children of client)?

4.2.6 Other independent variables

This study included as other independent variables factors that have been previously used in research as predictor variables for hospitalization of older home care recipients (50,70,76) and that are available in the RAI-HC (Table 4). Bass et al.'s adaptation of the Andersen model of health service utilization was used to guide the selection of these variables.

Variables using the Bass et al.'s adaptation fell under the four pillars of the model and include: (1) predisposing (sex, age);, (2) enabling (lives with caregiver, income category), (3) need (ADLs, CPS, DRS, respiratory disorder (COPD/emphysema/asthma), dementia, Alzheimer's disease, cancer, behavioral problems, daily pain, congestive heart failure, CHESS), and (4) caregiver burden indicators (caregiver burnout, caregiver dissatisfaction) (50,70,76). Correlations were tested between these independent variables to avoid the problem of collinearity in regression analysis. No variables were highly correlated, therefore, none were removed.

Predisposing characteristic variables of the care recipient are sex and age. Care recipient age was the care recipient age on the day of the assessment. The variable care recipient sex was dichotomous (male or female) and has a reference of the point in time of the assessment.

Enabling characteristic variables include care recipient lives with helper (e.g., caregiver) and care recipient income category. The former variable is captured in the RAI-HC through the following question: does the care recipient live with their helper? This variable is dichotomous (yes or no) and has a reference period of the point in time of the assessment. Household income was used as an indicator of socioeconomic status. Income information came from the last assessment (i.e., at the time of the subsequent RAI-HC assessment) used to determine home care fee. The home care fee structure (Appendix B) is categorized into six levels based on self-reported income and family size. This six-level income information was linked to the RAI-HC by the Nova Scotia

DHW prior to this study. For all analyses, the six levels were divided into three groups based on the distribution of the sample high (categories C, D, E F), medium (category B), and low (category A). This provided three categories of socioeconomic status (high, medium, and low).

Care recipient need variables include ADL impairment, CPS, DRS, respiratory disorder, dementia, Alzheimer's disease, cancer, behavioral problems, daily pain, congestive heart failure, and CHESS score. Most care recipient need variables were taken from a single RAI-HC item, however, measures of ADL impairment, cognitive impairment, behavioral problems, pain, and CHESS were composites of several RAI-HC questions calculated in the Nova Scotia RAI-HC by Nova Scotia DHW. All items composed of a series of RAI-HC questions have been previously used in research and proven to have high validity across diverse care settings (22). Care recipient need variables from a single RAI-HC item were captured within the disease diagnoses category that individually asks the care recipient for the presence of the following diagnoses: respiratory disorder (presence of emphysema, COPD, asthma), dementia (dementia other than Alzheimer's disease), Alzheimer's disease, cancer, and congestive heart failure. The aforementioned disease diagnoses need variables are taken from a single item and are dichotomous (yes or no). Care recipient need variables have a reference period of three days with the exception of ADL impairment and daily pain having reference periods of the past seven days.

4.3 ANALYSIS

Descriptive analyses examined differences in each care recipient characteristic between caregiver distress, caregiver dissatisfaction, and caregiver burnout using Chi-square tests. Statistical significance was considered at $p < 0.05$.

Research question 1: do older home care recipients who have caregivers experiencing distress, dissatisfaction, and burnout have higher hospital use than those who have caregivers with none of these experiences?

(1) The association between caregiver distress and hospital use were examined using the logistic regression model in the following form:

$$hosp_i = \beta_0 + \beta_1 distress_j + \gamma X_i + \varepsilon_i \quad [1]$$

Where $hosp_i$ is whether care recipient i was hospitalized or not, $distress_j$ is the caregiver distress of care recipient i 's caregiver j , X_i is a vector of control variables (sex, age, income, marital status, ADLs, CPS, congestive heart failure, DRS, respiratory disorder, dementia, Alzheimer's disease, cancer, behavioral problems, daily pain, and CHESS), and ε_i is an error term for care recipient i .

(2) The association between caregiver burnout and hospital use were examined using the logistic regression model in the following form:

$$hosp_i = \beta_0 + \beta_1 burnout_j + \gamma X_i + \varepsilon_i \quad [2]$$

Where $hosp_i$ is whether care recipient i was hospitalized or not, $burnout_j$ is the caregiver burnout of care recipient i 's caregiver j , X_i is a vector of control variables (sex, age, income, marital status, ADLs, CPS, congestive heart failure, DRS, respiratory disorder, dementia, Alzheimer's disease, cancer, behavioral problems, daily pain, and CHESS), and ε_i is an error term for care recipient i .

(3) The association between caregiver dissatisfaction and hospital use were examined using the logistic regression model in the following form:

$$hosp_i = \beta_0 + \beta_1 dissatisfaction_j + \gamma X_i + \varepsilon_i \quad [3]$$

Where $hosp_i$ is whether care recipient i was hospitalized or not, $dissatisfaction_j$ is the caregiver dissatisfaction of care recipient i 's caregiver j , X_i is a vector of control variables (sex, age, income, marital status, ADLs, CPS, congestive heart failure, DRS, respiratory disorder, dementia, Alzheimer's disease, cancer, behavioral problems, daily pain, and CHESS), and ε_i is an error term for care recipient i .

The Hosmer Lemeshow goodness-of-fit test was used to test the fit of all logistic regression models. Statistical significance was considered at $p < 0.05$.

Research question 2: if not, what other factors explain higher hospital use of the older home care recipient?

For each of the three logistic regression models above (as per equation [1], [2], and [3]) for research question one, variables other than distress, burnout, or dissatisfaction were examined for association with higher hospital use. These variables included: sex, age, income, marital status, ADLs, CPS, congestive heart failure, DRS, respiratory disorder, dementia, Alzheimer's disease, cancer, behavioral problems, daily pain, and CHESS. The Hosmer Lemeshow goodness-of-fit test was used to test the fit of all logistic regression models. Statistical significance was considered at $p < 0.05$.

Stata 13 was used for all analyses. This research was reviewed by the Dalhousie University Health Sciences Research Ethics Board (REB# 2016-3841) (Appendix C).

CHAPTER 5 – RESULTS

5.1 CHARACTERISTICS OF STUDY SAMPLE BY HOSPITALIZATION

Out of the 4,235 older home care recipients who have received home support services from Nova Scotia Continuing Care, 21.75% were hospitalized at least once in the past ninety days in their subsequent RAI-HC assessment (Table 1). Of those who were hospitalized, 6.73% had a caregiver that had caregiver distress, 10.3% had a caregiver that was experiencing burnout, and 1.63% that were experiencing dissatisfaction. Compared to older home care recipients not hospitalized, those hospitalized had statistically significantly higher proportions of caregiver burnout, ADL impairment, CHESS instability, CPS rating of not intact, congestive heart failure, respiratory disorder; but, had statistically significantly lower proportions of females and those living with Alzheimer's disease ($p < 0.05$).

5.2 CHARACTERISTICS OF THOSE WITH CAREGIVER BURDEN

Characteristics in caregivers experiencing distress, burnout, or dissatisfaction are shown in Tables 2, 3, and 4. Common older home care recipient characteristics whose caregivers were experiencing distress, burnout, or dissatisfaction include having a live-in helper, ADL impairment, CPS rating of not intact, depression, and not being female. Similarities between caregivers experiencing distress and caregivers experiencing burnout (Tables 2 and 3) included statistically significantly higher proportions of CHESS instability and being of high income (Categories c, d, e, f, and g). Similarities between caregiver distress and dissatisfaction included being eighty-five and above. The only indicator of caregiver burden that had statistically significantly higher proportions of hospitalization was caregiver burnout (Table 4) ($p < 0.05$).

A Spearman correlation was run on caregiver burden indicators, caregiver distress, caregiver burnout, and caregiver dissatisfaction, to test the correlation of the caregiver burden indicators (Table 5). Results of the Spearman correlation between each caregiver burden indicator were not highly correlated: caregiver burnout and caregiver

distress $r_s = 0.06$, caregiver burnout and caregiver dissatisfaction $r_s = 0.05$, and caregiver distress and caregiver dissatisfaction $r_s = 0.14$. Thus, each indicator of caregiver burden was examined separately in hospitalization.

5.3 ASSOCIATIONS BETWEEN INDICATORS OF CAREGIVER BURDEN AND HOSPITALIZATION

Unadjusted analysis (Tables 6, 7, and 8) showed caregiver burnout, ADL impairment, health instability, congestive heart failure, and respiratory disorder were statistically significantly associated with hospitalization ($p < 0.05$). Older home care recipients with caregivers experiencing burnout were 1.31 times more likely to be hospitalized in comparison to older home care recipients with caregivers who are not experiencing burnout (95% [CI]: 1.03-1.67). Older home care recipients with ADL impairment were 1.37 times more likely to be admitted to a hospital (95% CI: 1.16-1.62) in comparison to those without ADL impairment. Similarly, those with health instability (CHESS score of one or greater) were 1.45 times more likely to be admitted to a hospital (95% CI: 1.22-1.71) in comparison to those with stable health. Those with congestive heart failure were 1.29 times more likely to be hospitalized (95% CI: 1.03-1.61) in comparison to those without congestive heart failure. Finally, those with a respiratory disorder were 1.61 times more likely to be hospitalized than those who do not have a respiratory of disorder (95% CI: 1.37-1.90).

A series of models were run to adjust for the older home care recipients' predisposing, enabling, and need characteristics (Appendix E). After running each caregiver burden indicator separately, the full models (caregiver variable, predisposing, enabling, and need characteristics) were the most parsimonious for each of the three indicators. After running the Hosmer-Lemeshow goodness-of-fit test for each indicator of caregiver burden, results showed that the models were not statistically significant, indicating that the data fit the model well: caregiver distress ($p = 0.41$), burnout ($p = 0.54$), and dissatisfaction ($p = 0.64$).

5.3.1 Caregiver distress and hospitalization

After adjusting for predisposing, enabling, and need characteristics, having a caregiver experiencing distress was not statistically significantly associated with hospitalization ($p < 0.05$). While caregiver distress was not statistically significantly associated with hospitalization, those with ADL impairment were 1.37 times more likely to be hospitalized (95% CI: 1.15-1.65) in comparison to those without ADL impairment. Similarly, those who had a respiratory disorder were 1.58 times more likely to be hospitalized (95% CI: 1.34-1.88) in comparison to those without a respiratory disorder.

5.3.2 Caregiver burnout and hospitalization

In the caregiver burnout model adjusting for predisposing, enabling, and need characteristics, caregiver burnout was not statistically significantly associated with hospitalization. While caregiver burnout was not statistically significantly associated with hospitalization, those with an ADL impairment were 1.37 times more likely to be hospitalized (95% CI: 1.14-1.64) in comparison to those without an ADL impairment. Similarly, those with health instability were 1.25 times more likely (95% CI: 1.04-1.49) and those who had a respiratory disorder were 1.58 times more likely (95% CI: 1.33-1.87) to be hospitalized in comparison to those with stable health and those without a respiratory disorder.

5.3.3 Caregiver dissatisfaction and hospitalization

In the caregiver dissatisfaction model adjusting for predisposing, enabling, and need characteristics, caregiver burnout was not statistically significantly associated with hospitalization. While caregiver burnout was not statistically significantly associated with hospitalization, those with an ADL impairment were 1.38 times more likely to be hospitalized (95% CI: 1.15-1.65) in comparison to those without an ADL impairment. Similarly, those with health instability were 1.26 times more likely (95% CI: 1.05-1.50) and those who have a respiratory disorder were 1.58 times more likely (95% CI: 1.33-

1.87) to be hospitalized in comparison to those with stable health and those without respiratory disorders.

5.3.4 Other factors associated with hospitalization

Although caregiver distress, caregiver burnout, and caregiver dissatisfaction were not statistically significantly associated with older home care recipient hospitalization in the adjusted models, other variables in the three models were statistically significantly associated with hospitalization. While across all three models, experiencing pain once daily was statistically significantly different from never experiencing pain, pain was not a variable statistically significantly associated with caregiver distress, caregiver burnout, or caregiver dissatisfaction. Across all three models (Tables 6, 7, and 8), older home care recipients with ADL impairment and older home care recipients diagnosed with a respiratory disorder were more likely to be hospitalized than those without. Additionally, in the caregiver burnout model and in the caregiver dissatisfaction model, those with health instability (CHESS score of one or more) were 1.25 (95% CI: 1.04-1.49) times and 1.26 (95% CI: 1.05-1.50) times more likely to be hospitalized in comparison to those with stable health. Conversely, older home care recipients that had a diagnoses of Alzheimer's disease had a statistically significantly decreased likelihood of hospitalization across all three models: (1) odds ratio (OR): 0.49 (95% CI: 0.30-0.80); (2) OR: 0.49 (95% CI: 0.30-0.81); and (3) OR: 0.49 (95% CI: 0.30-0.80) in comparison to those without Alzheimer's disease. In addition, in the caregiver burnout OR: 0.80 (95% CI: 0.68-0.95) and caregiver dissatisfaction OR: 0.80 (95% CI: 0.68-0.95) models, being female decreased likelihood of hospitalization ($p < 0.05$).

CHAPTER 6 – DISCUSSION

Using the population-based Nova Scotia RAI-HC in 2009-2012, this study identified that 21.75% of older home care recipients were admitted to hospital with an overnight stay at least once in the past ninety days in a subsequent RAI-HC assessment. In the unadjusted analyses among the three indicators of caregiver burden, only caregiver burnout was significantly associated with hospitalization. After adjusting for predisposing, enabling, need characteristics, this study found that indicators of caregiver burden (i.e., caregiver distress, caregiver burnout, and caregiver dissatisfaction) were not statistically significantly associated with hospitalization.

These results differ from a similar 2002 study in Michigan that assessed caregiver burden and risk of hospitalization using the RAI-HC. While this population-based cross-sectional study did not find caregiver distress or caregiver burnout to be associated with hospitalization, the study found a statistically significant, positive association between caregiver dissatisfaction and hospitalization (OR: 2.99; 90% CI: 1.38-6.46) (50). The authors' explanation for this result is that caregiver dissatisfaction is an indicator that the home care recipient's needs exceed the ability of the caregiver to provide them, warranting a higher level of care. Unlike the methods in the present study (i.e., hospitalization measured in a subsequent RAI-HC assessment from caregiver burden), the Michigan study did not look at caregiver burden before hospitalization (50). Consequently, it is unknown if caregiver dissatisfaction was present before hospitalization or if the caregiver experienced dissatisfaction after the care recipient's discharge from the hospital (e.g., the caregiver may be anticipating greater care need for the care recipient based on the reason for hospitalization). The RAI-HC does not report the exact timing of hospitalization (i.e., past ninety days); therefore, it is not possible to know if caregiver dissatisfaction occurred before or after hospitalization in the 2002 study, unlike the present study where it is known that hospitalization occurred after caregiver burden is present.

Results of this study are consistent with findings from some previous studies that used other measurement instruments to assess caregiver burden. These studies include an analysis of older veterans with dementia in the US, measured by Centers for

Epidemiological Depression Scale, a study of stroke patients in Taipei, measured by Caregiver Burden Inventory, and a study of older care recipients in Japan where caregiver burden measured by ZBI found no association with the hospitalization of home care recipients (60,63,66). While not finding an association in the Japanese study, the prospective cohort study excluded caregivers who hoped that the care recipient would soon be placed in LTC, further indicating that they excluded a portion of caregivers who knew they could no longer care for their family member or friend. Measurement instruments of caregiver burden across the aforementioned studies show statistically significant results with care recipients that are hospitalized and not hospitalized, thus providing inconclusive support for a specific measurement instrument that may influence the relationship between caregiver burden and hospitalization. Similarly, a systematic review found that there is no relationship between the instrument used to assess caregiver burden and the relationship between caregiver burden and hospitalization (17).

Conversely, this study's overall results differ from three other studies assessing the relationship between caregiver burden and hospitalization. In Japan, Kuzuya and colleagues conducted a study to determine if caregiver burden, measured by ZBI, was associated with all-cause mortality and hospitalization of older care recipients. The study found older care recipients with caregivers exhibiting higher burden were at higher risk of hospitalization (19). In another study, caregiver stress, measured by the PSS, was also statistically significantly associated with hospitalization among care recipients with heart failure in Ohio (62). Furthermore, a two-year prospective study among Alzheimer's disease patients in France found caregiver burden, measured by ZBI, as a predictive factor for hospitalization of home care recipients (64).

There is a common assumption among policy-makers that caregiver burden is related to hospitalization (Sankarsingh, 2015, personal communication, 4th March). In the caregiving literature, there is a recurring theme that caregivers are a critical component of home care and if the level of burden on a caregiver is too much then home care may be threatened (17). It is discussed in the literature that caregiver burden is related to the hospitalization of older home care recipients as hospitals provide a temporary relief in care for their caregivers (17,66). However, a systemic review measuring this relationship found that overtime, as study sample sizes have increased, the effect sizes have

decreased. This means that earlier studies assessing this relationship support the assumption that caregiver burden jeopardizes the continuity of homecare while more recent studies are suggesting otherwise (17). This observation aligns with one of the findings from the present study (n=4,235) where the indicators of caregiver burden were not statistically significantly associated with hospitalization in comparison to other studies with smaller sample sizes where caregiver burden was statistically significantly associated to care recipient hospitalization (55,63,66). The results should raise caution for policy-makers when drawing conclusions from the literature where studies are underpowered. A systematic review recommends that policy-makers use population-based data sets to better inform decisions for home care policies (17). These recommendations reinforce the need to have better population-based home care indicators throughout the province, especially for caregivers.

While the results of the first objective of this study are not statistically significant, the importance of burden on caregivers should not be undermined. The level of burden experienced by caregivers is important to recognize as it has adverse effects on caregivers emotional, psychological, social, financial, and physical functioning (14,17). It is well cited in the literature that caregivers have poorer health outcomes than individuals who are not caregivers (14). While caregiver burden did not have a statistically significant influence on hospitalization in this study, it is important for future research to consistently measure caregiver burden and understand other determinants of hospitalization among older home care recipients.

Among older home care recipients, common characteristics that were statistically significantly associated with hospitalization included having an ADL impairment, health instability (measured by the CHESS scale), and being diagnosed with a respiratory disorder. These results are consistent with the existing literature highlighting common characteristics of hospitalizations among older home care recipients (50,75). Older home care recipients with instability of health status (e.g., flare-up of chronic disease) are more likely to be hospitalized, while those with a progressive disease (e.g., dementia) are less likely to be hospitalized. Older home care recipients with a progressive disease are also more likely to be admitted to LTC in the early stages of the disease because the care demand is predicted to become higher (50,75). For example, in a population based study

it was found that care recipients with a flare up of chronic condition were 1.98 times more likely to be hospitalized than those that did not have a flare up chronic condition (90% CI: 1.17-3.33) (50). This is primarily due to the increasing number of people who are living with multiple chronic conditions at home with conditions that are not severe enough to warrant a higher level of care such as LTC (37,38). Home care has been described in the literature as a volatile environment due to the growing number of older people with complex chronic conditions living at home (20,60,64,67,68).

Older home care recipients who are experiencing impairment with their ADLs and those who have a respiratory disorder were statistically significantly associated with increased hospital use. These results are not surprising given that ADL impairment and respiratory disorders are well known causes of hospitalization among older adults with care need (77,78). Additionally, it is not surprising that care recipients with respiratory disorders have an increased likelihood of hospitalization across all three models in the analyses. COPD is the number one reason for hospital admissions and readmissions across Canada (78). Future study should investigate the interaction between common predictors of hospitalization such as ADL impairment with caregiver burden, as the interaction between the two may increase the effect of caregiver burden on hospitalization. Results of such an investigation may shed light on a relationship that increases hospital use, warranting a targeted home care intervention. In response to known high hospital use of Canadians with respiratory disorders, a multi-faceted approach the INSPIRED model was piloted in 2010 in Halifax, Nova Scotia's largest city. INSPIRED is the acronym for implementing a novel and supportive program of individualized care for patients and families living with respiratory disease. The model addresses the multi-dimensional toll COPD has on those living with the disorder, their families, and communities through education, coordination of community resources, and advance care planning. During its six-month pilot the program saw a 63% reduction in hospital admission rates (78). These results may encourage other researchers to further examine associations of older home care recipient need characteristics with hospitalization outside of Nova Scotia. These results could catalyze more home care planning to implement support for older home care recipients with ADL impairment and respiratory disorders to reduce hospitalizations.

Characteristics of older home care recipients that were statistically significantly less likely to be admitted to a hospital include having Alzheimer's disease and being female. These findings are consistent with previous studies investigating hospitalization among older home care recipients (50,64,65). While it is well-noted in the literature that older home care recipients living with Alzheimer's disease have a high care demand, it is not unusual for people with Alzheimer's disease to have fewer hospitalizations than those without Alzheimer's disease. This phenomenon is explained as a result of the progressive manifestation of the disease. The decision may be made by caregivers of people living with Alzheimer's disease to admit the person they are caring for to LTC as the anticipation of the progression of care need exceeds the resources of the caregiver in the home (75). Therefore, it is more common to have people in home care diagnosed with early staged Alzheimer's disease whereas people with advanced stage Alzheimer's disease are typically already admitted to LTC.

Understanding factors that are determinant of hospitalization will assist in implementing planning and interventions to reduce hospitalization. Additionally, this evidence will provide policy-makers with information to improve home care and health systems in Nova Scotia to meet the needs of the province's aging population that, without prevention efforts, will include an increasing number of individuals in later life who will have complex care needs.

This study has at least the following five important limitations: (1) recall bias, (2) generalizability to an older home care population, (3) the measurement of caregiver burden, (4) inconsistent reference periods for exposure and outcome variable, and (5) self-reported hospital use. Due to the retrospective nature of this study design there is risk of recall bias, defined as the accuracy of the research participants' responses due to their ability to recall information. The response from the study participant may not accurately represent what actually happened, for example, the classification of the outcome variable (hospitalization) could be incorrect for some responses in the data due to a ninety-day recall period. Additionally, if a care recipient is experiencing cognitive impairment the care recipient may not be able to accurately recall if they have been hospitalized in the past ninety days. This may lead to an under-representation or overrepresentation of the study effect. Also, this study only accounts for older home care recipients receiving

formal home care service through Continuing Care in Nova Scotia and their primary caregivers. This study does not reflect those who are receiving home care from a private home care service, those who are waiting for home care, those who are only relying on care from family and friend caregivers, and those who may require home care but are not receiving any care at home. Therefore, study results are not generalizable to older home care recipients who fall outside of formal home care from Nova Scotia Continuing Care.

The measurement of caregiver burden has some limitations. The measurement of caregiver burden is based on caregiver self-report or observation by the Continuing Care Coordinator. Accurate responses for the caregiver variable are based on the assumption that the Continuing Care Coordinator interacted and understood the primary caregiver's feelings or observed behavior and that the primary caregiver reported their feelings to the Continuing Care Coordinator. In contrast to the gold standard measure of caregiver burden, the ZBI, the measure in this study is limited to three questions eliciting information on three indicators of caregiver burden while the ZBI contains twenty-two items on a five-point scale (15). Additional caregiver demographics (e.g., age, sex, relationship to care recipient) may shed light onto further understanding of caregivers experiencing burden or situations that may promote caregiver resilience. The indicators of caregiver burden within the RAI-HC did not undergo validation and it is unknown how the three indicators relate to other scales such as the ZBI. With this in mind, it is possible that this study may have underestimated the effect of caregiver burden on hospitalization. Thus, the measurement of caregiver burden is limited by the questions, Care Coordinator observation, primary caregiver self-report, and its lack of validation.

The outcome variable, hospitalization, does not indicate information on why the older home care recipient was admitted with an overnight stay at a hospital or the length of stay. Older home care recipients are more likely to have repeated hospitalizations after being admitted once to a hospital. Therefore, the variable hospital use is dichotomous in the form of, "hospital use yes" and "hospital use no." While this study is able to show the number of older home care recipients who are hospitalized, it is unable to fully understand caregivers' influence on the older home care recipients' total number of hospitalizations. Also, this study is without a consistent reference period. For instance, the outcome variable, hospitalization, is measured in the past ninety days in the care

recipient's subsequent RAI-HC assessment, while the exposure variable caregiver distress is based on the past three days. This difference in reference periods may result in an underestimation or an overestimation of the exposure variable during time of the older home care recipients' hospitalization. Finally, hospital use and other independent variables rely on self-report of older home care recipients. Self-reporting behaviors are shown to vary by age and socioeconomic status. For example, adults eighty years and older and those of lower income and education are more optimistic about their health (79). In contrast, those who have healthier lifestyles are more pessimistic about their health (79). Self-reported data may underestimate or overestimate study results.

Despite having limitations, the major strengths of this study are: (1) the use of the RAI-HC, (2) the use of a population-based dataset of a reasonable sample size (n=4,235), (3) considering a timeline of events for the exposure and outcome variables, and (4) addressing health service and policy issues of a growing concern;

The research instrument used in this study, is the RAI-HC is the standard for collecting data on home care recipients across Canada. Data includes information on home care need, strengths, and health service use for home care recipients. The survey provides complete and comprehensive information on home care recipients, including caregiver information that is otherwise unattainable in administrative datasets. The RAI-HC can further be strengthened with additional research focusing on validation the caregiver burden indicators within the RAI-HC as it is unknown if they accurately measure caregiver burden. Validation of caregiver the caregiver burden indicators will strengthen the understanding of caregiver health across a large population. Additionally, performing this study with an instrument widely used across Canada will make the research easy to replicate in other provinces.

The use of a population-based dataset (n=4,235) allows for a large sample size of older home care recipients in Nova Scotia for analysis. The nature of a large sample size provides greater precision in estimates, allows stratified subgroups, and permits an understanding of older Nova Scotians receiving home care.

This study makes a consideration for the reference period times between the exposure and outcome variables. The reference period of the exposure variable, caregiver burden is in the past three days while the reference period of the outcome variable is the

past 90 days. The reference period of the outcome variable goes back further in time than the exposure variable. For this reason, the outcome variable was taken from the next subsequent RAI-HC assessment, conducted within a year of the initial assessment. This consideration for time was made to minimize issues of temporality to make certain that the exposure variable, caregiver burden was present before the outcome variable, hospitalization.

The goal to address health policy issues of growing need and concern are reflected in this study. As more adults in Nova Scotia are living with multi-morbidity and functional decline, the need for a home care strategy is critical. The literature suggests that use of acute care facilities such as hospitals are costly and are often inappropriate for the complex care needs of older adults (11, 17). Previous research in this field has primarily focused on individual causes of hospitalization while few looked at the caregivers' influence (17). Results of this study are timely and assist health policy makers who make care decisions for Continuing Care in the Nova Scotia DHW which include strategies that promote the continuation of home care for older home care recipients and programming to alleviate caregiver burden.

CHAPTER 7 – CONCLUSION

This study found that the three indicators of caregiver burden were not associated with older home care recipient hospitalization among those receiving care through Nova Scotia Continuing Care, after adjusting for risk factors for hospitalization through the Andersen model of health service utilization. Other characteristics of older home care recipients that were at higher risk of hospitalization included those with health instability, ADL impairment, and respiratory disorders. Although this study shows that indicators of caregiver burden are not statistically significantly associated with hospitalization, it should not undermine the implications caregiving has on caregiver health. Although the indicators of caregiver burden are not statistically significant, it is unknown if the indicators accurately measure caregiver burden. Future research should focus on validity testing of the indicators of caregiver burden within the RAI-HC to have a more accurate understanding of caregiver health at the population level.

While study results provide a snapshot on older home care recipients and their caregivers receiving care through Nova Scotia Continuing Care, study results are not generalizable to all older home care recipients and caregivers in Nova Scotia. Moreover, the RAI-HC does collect home care information on a population of older home care recipients and their caregivers, study results may not represent those who are receiving home care from a private home care service, those who are waiting for home care and those who are only relying on care from family and friend caregivers, and those who may require home care but are not receiving any care at home. It is recommended that policy makers implement a standardized approach to home care data collection across public and privately funded home care services to have better population health indicators for health policy and services improvement.

The results caution policy makers when drawing conclusions from the literature where studies previously relied on smaller sample size. It is recommended that policy makers perform further validation of the caregiver indicators in the RAI-HC to further understand the constructs that they indeed represent and their association with more composite measures of caregiver burden and other assessments. It is also recommended for policy makers to use population-based data sets to inform decisions for home care

policies. These recommendations reinforce the need to have better population-based home care indicators throughout the province, especially for caregivers. This information will be useful in the development of a home care strategy by the DHW in Nova Scotia and future development of the HCRS in Canada.

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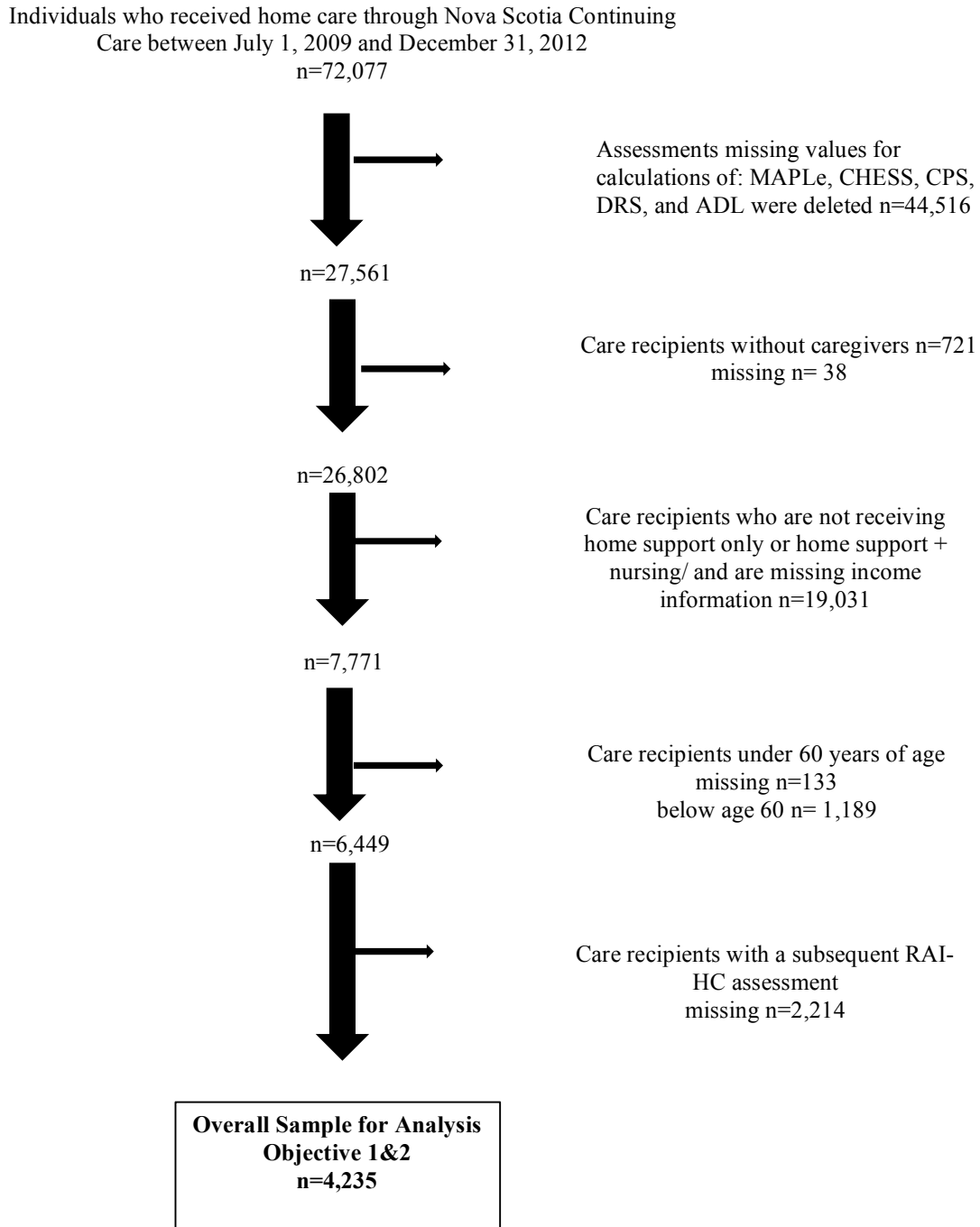
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Figure 1: Exclusion Criteria



Objectives

- (1) Do home care recipients who have caregivers experiencing distress, burnout, or dissatisfaction have higher hospital use than those who have caregivers with none of these experiences?
- (2) If not, what other factors explain higher hospital use of the older home care recipient?

Table 1. Baseline characteristics of study sample by hospitalization

	Total sample (%)	Hospitalization (%)	No hospitalization (%)	P value†
Total	4,235 (100)	921 (21.75)	3,314 (78.25)	
Caregiver characteristics				
Distress				
Yes	231 (5.45)	62 (6.73)	169 (5.10)	0.054
No	4,004 (94.45)	859 (93.26)	3,145 (94.90)	0.054
Burnout				
Yes	362 (8.54)	95 (10.31)	267 (8.05)	0.030
No	3,873 (92.45)	826 (89.68)	3,047(91.94)	
Dissatisfaction				
Yes	66 (1.56)	15 (1.63)	55 (1.66)	0.846
No	4,169 (98.44)	906 (98.37)	3,263 (98.46)	0.846
Recipient predisposing characteristics				
Female	3,169 (74.82)	659 (71.55)	2,510 (75.74)	0.010
Age				
60-64 years	278 (6.56)	55 (5.97)	223 (6.73)	0.233
65-74 years	914 (21.58)	190 (20.63)	724 (21.84)	
75-84 years	1,611 (38.04)	339 (36.81)	1,272 (38.38)	
85 years or older	1,432 (33.81)	337 (36.59)	1,095 (33.04)	
Recipient enabling characteristics				
Lives with caregiver	1,886 (44.53)	419 (45.49)	1,467 (44.27)	0.507
Income Category‡				
A	3,359 (79.32)	713 (77.41)	2,646 (79.84)	0.083
B	534 (12.61)	136 (14.77)	398 (12.01)	
C, D, E, F, or G	342 (8.08)	72 (7.82)	270 (8.15)	
Need characteristics				
ADL impairment				
Independent	3,212 (75.84)	655 (71.11)	2,557 (77.16)	0.002
Impairment	1,023 (24.15)	266 (28.88)	757 (22.84)	
Alzheimer's disease	152 (3.59)	20 (2.17)	132 (3.98)	0.009
Cancer	479 (11.31)	109 (11.83)	370 (11.16)	0.570
Changes in Health, End-Stage Disease, Signs, and Symptoms Scale (CHESS)				
No health instability	1,239 (29.26)	217 (19.72)	1,022 (30.84)	0.000
Instability	2,996 (70.75)	883 (80.27)	2,292 (69.16)	

Cognitive Performance Scale (CPS)				0.003
Intact	2,281 (53.86)	476 (51.68)	1,805 (54.47)	
	Total sample (%)	Hospitalization (%)	No hospitalization (%)	P value†
Not intact	1,954 (46.14)	445 (48.31)	1509 (45.53)	
Dementia	231 (5.45)	45 (4.89)	186 (5.61)	0.390
Depression Rating Scale(DRS) [§]				0.873
0	2,841 (67.08)	611 (66.34)	2,230 (67.29)	
1	519 (12.26)	112 (12.16)	407 (12.28)	
2	383 (9.04)	84 (9.12)	299 (9.02)	
3	492 (11.62)	114 (12.37)	378 (11.41)	
Congestive heart failure	452 (10.67)	117 (12.70)	335 (10.11)	0.024
Pain				0.094
Never	1,013 (23.92)	228 (24.75)	785 (23.69)	
Less than daily	693 (16.36)	144 (15.64)	549 (16.57)	
Once daily	330 (7.79)	55 (5.97)	275 (8.30)	
2 or more times daily	2,199 (51.92)	494 (53.64)	1,705 (51.45)	
Respiratory disorder	985 (23.26)	280 (30.40)	705 (21.27)	0.000

†Differences in each characteristic between those hospitalized and not hospitalized were assessed using chi square tests: statistical significance is at $p < 0.05$

‡Income categories are based on annual income and family size. Category A represents the lowest income category and Category G represents the highest income category. See Appendix B for full reference.

§DRS categories are defined by the number of mood symptoms in the past 3 days. A score of 3 or more represents a major or minor depressive disorder.

Table 2. Baseline characteristics of study sample by caregiver distress

	Total sample (%)	Distressed (%)	No distress (%)	P value†
Total	4,235 (100)	231 (5.45)	4,004 (94.55)	
Caregiver characteristics				
Burnout				
Yes	362 (8.54)	37 (16.01)	325 (8.12)	0.000
No	3,873 (91.45)	194 (83.98)	3,679 (91.88)	
Dissatisfaction				
Yes	66 (1.56)	20 (8.66)	46 (1.15)	0.000
No	4169 (98.44)	211 (91.34)	3,958 (98.85)	
Hospitalized				
Yes	921 (21.75)	62 (26.83)	859 (21.45)	0.054
No	3,314 (78.25)	169 (73.16)	3,145 (78.55)	
Recipient predisposing characteristics				
Female	3,169 (74.83)	154 (66.66)	3,015 (75.30)	0.003
Age				0.003
60-64 years	278 (6.56)	12 (5.19)	266 (6.64)	
65-74 years	914 (21.58)	39 (16.88)	875 (21.85)	
75-84 years	1,611 (38.04)	76 (32.90)	1,535 (38.34)	
85 years or older	1,432 (33.81)	104 (45.02)	1,328 (33.16)	
Recipient enabling characteristics				
Lives with helper	1,886 (44.53)	155 (67.10)	1,731 (43.23)	0.000
Income Category‡				0.000
A	3,359 (79.32)	159 (68.83)	3,200 (79.92)	
B	936 (13.46)	39 (16.88)	495 (12.36)	
C, D, E, F, or G	591 (8.50)	33 (14.29)	309 (7.71)	
Need characteristics				
ADL impairment				0.000
Independent	3,212 (75.84)	122 (33.15)	3,090 (77.17)	
Impairment	1,023 (24.15)	246 (66.84)	914 (22.83)	
Alzheimer's disease	152 (3.59)	24 (10.39)	128 (3.20)	0.000
Cancer	479 (11.31)	25 (10.82)	454 (11.34)	0.810
Changes in Health, End-Stage Disease, Signs, and Symptoms Scale (CHESS)				0.000
No health instability	1,239 (29.26)	36 (15.58)	1,203 (30.04)	
Health instability	2,996 (70.75)	195 (84.4)	2801 (69.95)	
Cognitive Performance Scale (CPS)				0.000

Intact	2,281 (53.86)	49 (21.21)	2,232 (55.74)	
	Total sample (%)	Distressed (%)	No distress (%)	P value†
Not intact	1,954 (46.14)	182 (78.78)	1772 (44.28)	
Dementia	231 (5.45)	45 (19.48)	185 (4.62)	0.000
Depression Rating Scale(DRS) [§]				0.000
0	2,841 (67.08)	80 (34.63)	2,761 (68.95)	
1	519 (12.26)	40 (17.32)	479 (11.96)	
2	383 (9.04)	35 (15.15)	348 (8.69)	
3	492 (11.62)	76 (32.90)	416 (10.39)	
Congestive heart failure	452 (10.67)	33 (14.28)	419 (10.46)	0.067
Pain				0.012
Never	1,013 (23.92)	74 (32.03)	939 (23.45)	
Less than daily	693 (16.36)	38 (16.45)	655 (16.36)	
Once daily	330 (7.79)	11 (4.76)	319 (7.96)	
2 or more times daily	2,199 (51.92)	108 (4.67)	2,091 (52.22)	
Respiratory disorder	985 (23.26)	43 (18.61)	942 (23.53)	0.086

†Differences in each characteristic between those distressed and those not distressed were assessed using chi square tests: statistical significance is at $p < 0.05$

‡Income categories are based on annual income and family size. Category A represents the lowest income category and Category G represents the highest income category. See Appendix B for full reference.

§DRS categories are defined by the number of mood symptoms in the past 3 days. A score of 3 or more represents a major or minor depressive disorder.

Table 3. Baseline characteristics of study sample by caregiver burnout

	Total sample (%)	Burnout (%)	No burnout (%)	P value†
Total	4,235 (100)	362 (8.54)	3,873 (91.45)	
Caregiver characteristics				
Distressed				
Yes	231 (5.45)	37 (10.22)	194 (5.00)	0.000
No	4,004 (94.54)	325 (89.78)	3,679 (94.99)	
Dissatisfaction				
Yes	66 (1.56)	13 (3.59)	53 (1.37)	0.001
No	4,169 (98.44)	349 (96.41)	3,820 (98.48)	
Hospitalized				
Yes	921 (21.75)	95 (25.41)	826 (21.33)	0.030
No	3,314 (78.25)	267 (73.76)	3,047 (78.67)	
Recipient predisposing characteristics				
Female	3,169 (74.83)	253 (69.88)	2,916 (75.29)	0.024
Age				0.127
60-64 years	278 (6.56)	15 (4.14)	263 (6.79)	
65-74 years	914 (21.58)	90 (24.86)	824 (21.28)	
75-84 years	1,611 (38.04)	133 (36.74)	1,478 (38.16)	
85 years or older	1,432 (33.81)	124 (34.25)	1,308 (33.64)	
Recipient enabling characteristics				
Lives with helper	1,886 (44.53)	250 (69.06)	1,636 (42.24)	0.000
Income Category‡				0.007
A	3,359 (79.32)	275 (75.96)	3,084 (79.63)	
B	936 (13.46)	45 (12.43)	489 (12.63)	
C, D, E, F, or G	591 (8.50)	42 (11.60)	300 (7.74)	
Need characteristics				
ADL impairment				
Independent	3,212 (75.84)	219 (60.50)	2,993 (77.28)	0.000
Impaired	1,023 (24.16)	143 (39.50)	880 (22.72)	
Alzheimer's disease	152 (3.59)	16 (4.42)	36 (0.93)	0.374
Cancer	479 (11.31)	43 (11.88)	436 (11.26)	0.721
Changes in Health, End-Stage Disease, Signs, and Symptoms Scale (CHESS)				
No health instability	1,239 (29.26)	63 (17.40)	1,176 (30.36)	0.000
Health instability	2,996 (70.75)	300 (82.60)	2,697 (69.63)	
Cognitive Performance Scale (CPS)				
				0.001

Intact	2,281 (53.86)	166 (45.85)	2,115 (54.61)	
	Total sample (%)	Burnout (%)	No burnout (%)	P value†
Not intact	1,954 (46.14)	196 (54.13)	1,758 (45.39)	
Dementia	231 (5.45)	17 (4.70)	214 (5.52)	0.506
Depression Rating Scale(DRS) [§]				0.000
0	2,841 (67.08)	189 (52.21)	2,652 (68.47)	
1	519 (12.26)	57 (15.75)	462 (11.93)	
2	383 (9.04)	43 (11.79)	340 (8.78)	
3	492 (11.62)	73 (20.16)	419 (10.81)	
Congestive heart failure	452 (10.67)	44 (12.15)	408 (10.53)	0.340
Pain				0.000
Never	1,013 (23.92)	54 (14.92)	959 (24.67)	
Less than daily	693 (16.36)	55 (15.19)	638 (16.47)	
Once daily	330 (7.79)	22 (6.10)	308 (7.95)	
2 or more times daily	2,199 (51.92)	231 (63.81)	1,968 (50.81)	
Respiratory disorder	985 (23.26)	86 (23.76)	899(23.21)	0.814

†Differences in each characteristic between those burned out and not burned out were assessed using chi square tests: statistical significance is at $p < 0.05$

‡Income categories are based on annual income and family size. Category A represents the lowest income category and Category G represents the highest income category. See Appendix B for full reference.

§DRS categories are defined by the number of mood symptoms in the past 3 days. A score of 3 or more represents a major or minor depressive disorder.

Table 4. Baseline characteristics of study sample by caregiver dissatisfaction

	Total sample (%)	Dissatisfied (%)	Not dissatisfied(%)	P value†
Total	4,235 (100)	66 (1.55)	4,169 (98.44)	
Caregiver characteristics				
Distressed				
Yes	231 (5.45)	20 (30.30)	211 (5.06)	0.000
No	4,004 (94.54)	46 (69.70)	3,958 (94.93)	
Burnout				
Yes	362 (8.54)	13 (19.70)	349 (8.37)	0.001
No	3,873 (91.45)	53 (80.30)	3,820 (91.63)	
Hospitalized				
Yes	921 (21.75)	15 (22.72)	906 (21.73)	0.846
No	3,314 (78.25)	51(77.27)	3,263 (78.27)	
Recipient predisposing characteristics				
Female	3,169 (74.83)	40 (60.60)	3,235 (77.60)	0.007
Age				
60-64 years	278 (6.56)	3 (4.54)	275 (6.60)	0.046
65-74 years	914 (21.58)	12 (18.18)	902 (21.64)	
75-84 years	1,611 (38.04)	18 (27.27)	1,593 (38.21)	
85 years or older	1,432 (33.81)	33 (50.00)	1,399 (33.56)	
Recipient enabling characteristics				
Lives with helper	1,886 (44.53)	42 (63.63)	1,844 (44.23)	0.002
Income Category‡				
A	3,359 (79.32)	53 (80.30)	3,306 (79.30)	0.979
B	936 (13.46)	8 (12.12)	526 (12.62)	
C, D, E, F, or G	591 (8.50)	5 (7.57)	337 (8.08)	
Need characteristics				
ADL impairment				
Independent	3,212 (75.84)	36 (54.54)	3,176 (76.18)	0.000
Impairment	1,023 (24.16)	30 (45.46)	993 (23.82)	
Alzheimer's disease				
Cancer	152 (3.59)	1 (1.51)	151 (3.62)	0.361
	479 (11.31)	7 (10.61)	472 (11.32)	0.855
Changes in Health, End-Stage Disease, Signs, and Symptoms Scale (CHESS)				
No health instability	1,239 (29.26)	17 (25.76)	1,222 (29.31)	0.529
Health instability	2,996 (70.75)	49 (74.24)	2,947 (70.69)	
Cognitive Performance Scale (CPS)				
				0.009

Intact	2,281 (53.86)	25 (37.88)	2,256 (54.11)	
	Total sample (%)	Dissatisfied (%)	Not dissatisfied(%)	P value†
Not intact	1,954 (46.14)	41 (62.12)	1,913 (45.89)	
Dementia	231 (5.45)	7 (10.61)	224 (5.37)	0.063
Depression Rating Scale(DRS) [§]				0.000
0	2,841 (67.08)	25 (37.88)	2,816 (67.55)	
1	519 (12.26)	16 (24.24)	503 (12.06)	
2	383 (9.04)	9 (13.63)	374 (8.97)	
3	492 (11.62)	16 (24.24)	476 (11.42)	
Congestive heart failure	452 (10.67)	7 (10.60)	445 (10.67)	0.986
Pain				0.864
Never	1,013 (23.92)	13 (19.70)	1,000 (23.99)	
Less than daily	693 (16.36)	11 (16.67)	682 (16.36)	
Once daily	330 (7.79)	6 (9.09)	324 (7.77)	
2 or more times daily	2,199 (51.92)	36 (54.54)	2,163 (51.88)	
Respiratory disorder	985 (23.26)	16 (24.24)	969 (23.24)	0.849

†Differences in each characteristic between those dissatisfied and not dissatisfied were assessed using chi square tests: statistical significance is at $p < 0.05$

‡Income categories are based on annual income and family size. Category A represents the lowest income category and Category G represents the highest income category. See Appendix B for full reference.

§DRS categories are defined by the number of mood symptoms in the past 3 days. A score of 3 or more represents a major or minor depressive disorder.

Table 5. Spearman correlation of indicators of caregiver burden

	Caregiver burnout	Caregiver distress	Caregiver dissatisfied
Caregiver burnout	1.00		
Caregiver distress	0.06	1.00	
Caregiver dissatisfaction	0.05	0.14	1.00

Table 6. Associations between caregiver distress and hospitalization among home care recipients in Nova Scotia (n= 4,235)

Variable	OR (95 %CI) for hospitalization	
	Unadjusted	Adjusted
Caregiver characteristics		
Distressed	1.34 (0.99-1.81)	1.25 (0.91-1.73)
Recipient predisposing characteristics		
Female	0.81 (0.68-0.94) [†]	0.81 (0.68-0.96)
Age		
60-64 years	1.00	1.00
65-74 years	1.06 (0.76-1.49)	1.07 (0.76-1.51)
75-84 years	1.08 (0.78-1.48)	1.11 (0.80-1.54)
85 years or older	1.25 (0.91-1.71)	1.31 (0.94-1.82)
Recipient enabling characteristics		
Lives with helper	1.05 (0.91-1.21)	0.97 (0.82-1.13)
Income Category [‡]		
A	1.00	1.00
B	1.27 (1.03-1.57)	1.23 (0.99-1.53)
C, D, E, F, or G	0.99 (0.75-1.30)	0.90 (0.68-1.19)
Need characteristics		
ADL impairment	1.37 (1.16-1.62) [‡]	1.37 (1.15-1.65) [†]
Alzheimer's disease	0.53 (0.33-0.86) [†]	0.49 (0.30-0.80) [*]
Cancer	1.07 (0.85-1.34)	1.03 (0.82-1.31)
CHESS (rating of minimal or greater)	1.45 (1.22-1.71) [‡]	1.25 (1.04-1.49)
CPS (rating other than intact)	1.12 (0.97-1.29)	1.09 (0.93-1.28)
dementia	0.86 (0.61-1.21)	0.73 (0.51-1.04)
Depression Rating Scale(DRS) [§]		
0	1.00	1.00
1	1.00 (0.80-1.26)	0.95 (0.76-1.20)
2	1.02 (0.79-1.32)	0.98 (0.75-1.28)
3	1.10 (0.88-1.38)	0.98 (0.77-1.25)
Congestive heart failure	1.29 (1.03-1.61) [*]	1.11 (0.88-1.40)
Pain		
Never	1.00	1.00
Less than daily	0.90 (0.71-1.14)	0.89 (0.71-1.14)
Once daily	0.69 (0.49-0.95)	0.68 (0.49-0.95) [*]
2 or more times daily	1.00 (0.83-1.19)	0.97 (0.81-1.16)
Respiratory disorder	1.61 (1.37-1.90) [‡]	1.58 (1.34-1.88) [‡]
Goodness-of-fit test	0.90 (0.71-1.14)	0.4088

†Differences in each characteristic between those dissatisfied and not dissatisfied were assessed using chi square tests: statistical significance is at $p < 0.05$

‡Income categories are based on annual income and family size. Category A represents the lowest income category and Category G represents the highest income category. See Appendix B for full reference.

§DRS categories are defined by the number of mood symptoms in the past 3 days. A score of 3 or more represents a major or minor depressive disorder.

* $p < 0.05$; † $p < 0.01$; ‡ $p < 0.001$

OR: Odds Ratios CI: Confidence Intervals

Full models (best fit) were used for all indicators of caregiver burden: Caregiver burden indicator + demographic variables + need characteristics (collapsed) + enabling characteristics

Table 7. Association between caregiver burnout and hospitalization among home care recipients receiving care through Nova Scotia Continuing Care (n=4,235)

Variable	OR (95 %CI) for hospitalization	
	Unadjusted	Adjusted
Caregiver characteristics		
Burnout	1.31 (1.03-1.67)*	1.21 (0.93-1.55)
Recipient predisposing characteristics		
Female	0.81 (0.68-0.94)†	0.80 (0.68-0.95)*
Age		
60-64 years	1.00	1.00
65-74 years	1.06 (0.76-1.49)	1.06 (0.76-1.49)
75-84 years	1.08 (0.78-1.48)	1.10 (0.79-1.52)
85 years or older	1.25 (0.91-1.71)	1.30 (0.94-1.81)
Recipient enabling characteristics		
Lives with helper	1.05 (0.91-1.21)	0.96 (0.81-1.13)
Income Category‡		
A	1.00	1.00
B	1.27 (1.03-1.57)	1.23 (0.99-1.53)
C, D, E, F, or G	0.99 (0.75-1.30)	0.90 (0.68-1.19)
Need characteristics		
ADL impairment	1.37 (1.16-1.62)‡	1.37 (1.14-1.64)†
Alzheimer's disease	0.53 (0.33-0.86)†	0.49 (0.30-0.81)†
Cancer	1.07 (0.85-1.34)	1.04 (0.82-1.31)
CHESS (rating of minimal or greater)	1.45 (1.22-1.71)‡	1.25 (1.04-1.49)*
CPS (rating other than intact)	1.12 (0.97-1.29)	1.10 (0.94-1.29)
dementia	0.86 (0.61-1.21)	0.76 (0.53-1.07)
Depression Rating Scale(DRS)§		
0	1.00	1.00
1	1.00 (0.80-1.26)	0.96 (0.76-1.21)
2	1.02 (0.79-1.32)	0.99 (0.76-1.29)
3	1.10 (0.88-1.38)	0.99 (0.78-1.26)
Congestive heart failure	1.29 (1.03-1.61)*	1.11 (0.88-1.40)
Pain		
Never	1.00	1.00
Less than daily	0.90 (0.71-1.14)	0.89 (0.70-1.13)
Once daily	0.69 (0.49-0.95)	0.67 (0.49-0.93)*
2 or more times daily	1.00 (0.83-1.19)	0.96 (0.79-1.15)
Respiratory disorder	1.61 (1.37-1.90)‡	1.58 (1.33-1.87)‡
Goodness-of-fit test	0.90 (0.71-1.14)	0.5397

†Differences in each characteristic between those dissatisfied and not dissatisfied were assessed using chi square tests: statistical significance is at $p < 0.05$

‡Income categories are based on annual income and family size. Category A represents the lowest income category and Category G represents the highest income category. See Appendix B for full reference.

§DRS categories are defined by the number of mood symptoms in the past 3 days. A score of 3 or more represents a major or minor depressive disorder.

* $p < 0.05$; † $p < 0.01$; ‡ $p < 0.001$

OR: Odds Ratios CI: Confidence Intervals

Full models (best fit) were used for all indicators of caregiver burden: Caregiver burden indicator + demographic variables + need characteristics (collapsed) + enabling characteristics

Table 8. Associations between caregiver dissatisfaction and hospitalization among home care recipients receiving care through Nova Scotia Continuing Care (n=4,235)

Variable	OR (95 %CI) for hospitalization	
	Unadjusted	Adjusted
Caregiver characteristics		
Dissatisfaction	1.06 (0.59-1.89)	0.91 (0.50-1.65)
Recipient predisposing characteristics		
Female	0.81 (0.68-0.94) [†]	0.80 (0.68-0.95)*
Age		
60-64 years	1.00	1.00
65-74 years	1.06 (0.76-1.49)	0.97 (0.83-1.14)
75-84 years	1.08 (0.78-1.48)	0.97 (0.83-1.14)
85 years or older	1.25 (0.91-1.71)	0.97 (0.83-1.14)
Recipient enabling characteristics		
Lives with helper	1.05 (0.91-1.21)	0.97 (0.83-1.14)
Income Category [‡]		
A	1.00	1.00
B	1.27 (1.03-1.57)	1.23 (0.99-1.54)
C, D, E, F, or G	0.99 (0.75-1.30)	0.90 (0.68-1.19)
Need characteristics		
ADL impairment	1.37 (1.16-1.62) [‡]	1.38 (1.15-1.66) [‡]
Alzheimer's disease	0.53 (0.33-0.86) [†]	0.49 (0.30-0.80)*
Cancer	1.07 (0.85-1.34)	1.04 (0.82-1.31)
CHESS (rating of minimal or greater)	1.45 (1.22-1.71) [‡]	1.26 (1.05-1.50)*
CPS (rating other than intact)	1.12 (0.97-1.29)	1.10 (0.94-1.29)
dementia	0.86 (0.61-1.21)	0.75 (0.53-1.07)
Depression Rating Scale(DRS) [§]		
0	1.00	1.00
1	1.00 (0.80-1.26)	0.96 (0.76-1.22)
2	1.02 (0.79-1.32)	0.99 (0.76-1.30)
3	1.10 (0.88-1.38)	1.00 (0.79-1.28)
Congestive heart failure	1.29 (1.03-1.61)*	1.11 (0.88-1.40)
Pain		
Never	1.00	1.00
Less than daily	0.90 (0.71-1.14)	0.89 (0.70-1.14)
Once daily	0.69 (0.49-0.95)	0.68 (0.49-0.94)*
2 or more times daily	1.00 (0.83-1.19)	0.97 (0.80-1.16)
Respiratory disorder	1.61 (1.37-1.90) [‡]	1.58 (1.33-1.87) [‡]
Goodness-of-fit test	0.90 (0.71-1.14)	0.6394

†Differences in each characteristic between those dissatisfied and not dissatisfied were assessed using chi square tests: statistical significance is at $p < 0.05$

‡Income categories are based on annual income and family size. Category A represents the lowest income category and Category G represents the highest income category. See Appendix B for full reference.

§DRS categories are defined by the number of mood symptoms in the past 3 days. A score of 3 or more represents a major or minor depressive disorder.

* $p < 0.05$; † $p < 0.01$; ‡ $p < 0.001$

OR: Odds Ratios CI: Confidence Intervals

Full models (best fit) were used for all indicators of caregiver burden: Caregiver burden indicator + demographic variables + need characteristics (collapsed) + enabling characteristics

Appendix A: RAI-HC

Minimum Data Set Home Care (MDS-HC)[®] Canadian Version

- Unless otherwise noted, score for last 3 days
- Examples of exceptions include IADLs/Continence/ Services/Treatments where status scored over last 7 days

Addressograph

SECTION AA: NAME AND IDENTIFICATION INFORMATION											
1	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 20%;">NAME OF CLIENT</td> <td> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 100%;">a. Last/Family Name</td> </tr> <tr> <td style="width: 100%;">b. First Name</td> </tr> <tr> <td style="width: 100%;">c. Middle Name/Initial</td> </tr> </table> </td> </tr> </table>	NAME OF CLIENT	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 100%;">a. Last/Family Name</td> </tr> <tr> <td style="width: 100%;">b. First Name</td> </tr> <tr> <td style="width: 100%;">c. Middle Name/Initial</td> </tr> </table>	a. Last/Family Name	b. First Name	c. Middle Name/Initial					
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2	CASE RECORD NUMBER <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td> </tr> </table>										
3a	HEALTH CARD NUMBER <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td> </tr> </table>										
3b	PROVINCE/TERRITORY ISSUING HEALTH CARD NO. <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td> </tr> </table>										
4	POSTAL CODE OF RESIDENCE <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td> </tr> </table>										

SECTION BB: PERSONAL ITEMS													
1	SEX <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 100%;">M. Male F. Female</td> </tr> </table>	M. Male F. Female											
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2a	BIRTH DATE <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td> </tr> <tr> <td style="width: 10%;">Year</td><td style="width: 10%;">Month</td><td style="width: 10%;">Day</td><td colspan="3"></td> </tr> </table>							Year	Month	Day			
Year	Month	Day											
2b	ESTIMATED BIRTH DATE Birth date is estimated? 0. No 1. Yes												
3	ABORIGINAL ORIGIN Client's origin is Inuit, Métis or North American Indian 0. No 1. Yes												
4	MARITAL STATUS <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 100%;"> 1. Never married 2. Married 3. Widowed 4. Separated 5. Divorced 6. Other </td> </tr> </table>	1. Never married 2. Married 3. Widowed 4. Separated 5. Divorced 6. Other											
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b. Interpreter needed 0. No 1. Yes													
6	EDUCATION (Highest Level Completed) <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 100%;"> 1. No schooling 2. 8th grade/less 3. 9-11 grades 4. High school 5. Technical or trade school 6. Some college/university 7. Diploma/Bachelor's degree 8. Graduate degree 9. Unknown </td> </tr> </table>	1. No schooling 2. 8th grade/less 3. 9-11 grades 4. High school 5. Technical or trade school 6. Some college/university 7. Diploma/Bachelor's degree 8. Graduate degree 9. Unknown											
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7	RESPONSIBILITY/ADVANCED DIRECTIVES <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 100%;">(Code for responsibility/advanced directives) 0. No 1. Yes</td> </tr> <tr> <td style="width: 100%;">a. Client has a legal guardian/substitute decision-maker</td> </tr> <tr> <td style="width: 100%;">b. Client has advanced medical directives in place (for example, a do not hospitalize order)</td> </tr> </table>	(Code for responsibility/advanced directives) 0. No 1. Yes	a. Client has a legal guardian/substitute decision-maker	b. Client has advanced medical directives in place (for example, a do not hospitalize order)									
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8	RESPONSIBILITY FOR PAYMENT <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 100%;">(Check all that apply)</td> </tr> <tr> <td style="width: 100%;">a. Provincial/territorial government plan</td> </tr> <tr> <td style="width: 100%;">b. Other province/territory</td> </tr> <tr> <td style="width: 100%;">c. Federal government—Veteran Affairs Canada</td> </tr> <tr> <td style="width: 100%;">d. Federal government—First Nations and Inuit Health Branch (FNIHB)</td> </tr> <tr> <td style="width: 100%;">e. Federal government—other (RCMP, Canadian Armed Forces federal penitentiary inmate, refugee)</td> </tr> <tr> <td style="width: 100%;">f. Worker's Compensation Board (WCB/WSIB)</td> </tr> <tr> <td style="width: 100%;">g. Canadian resident—private insurance pay</td> </tr> <tr> <td style="width: 100%;">h. Canadian resident—public trustee pay</td> </tr> <tr> <td style="width: 100%;">i. Canadian resident—self pay</td> </tr> <tr> <td style="width: 100%;">j. Other country resident—self pay</td> </tr> <tr> <td style="width: 100%;">k. Responsibility for payment unknown/unavailable</td> </tr> </table>	(Check all that apply)	a. Provincial/territorial government plan	b. Other province/territory	c. Federal government—Veteran Affairs Canada	d. Federal government—First Nations and Inuit Health Branch (FNIHB)	e. Federal government—other (RCMP, Canadian Armed Forces federal penitentiary inmate, refugee)	f. Worker's Compensation Board (WCB/WSIB)	g. Canadian resident—private insurance pay	h. Canadian resident—public trustee pay	i. Canadian resident—self pay	j. Other country resident—self pay	k. Responsibility for payment unknown/unavailable
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SECTION CC: REFERRAL ITEMS (Complete at Intake Only)													
1	DATE CASE OPENED/REOPENED <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td><td style="width: 10%;"> </td> </tr> <tr> <td style="width: 10%;">Year</td><td style="width: 10%;">Month</td><td style="width: 10%;">Day</td><td colspan="3"></td> </tr> </table>							Year	Month	Day			
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2	REASON FOR REFERRAL <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 100%;"> 1. Post hospital care 2. Community chronic care 3. Home placement screen 4. Eligibility for home care 5. Day care 6. Other </td> </tr> </table>	1. Post hospital care 2. Community chronic care 3. Home placement screen 4. Eligibility for home care 5. Day care 6. Other											
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3	UNDERSTANDING OF GOALS OF CARE <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 100%;">(Code for client/family understanding of goals of care) 0. No 1. Yes</td> </tr> <tr> <td style="width: 100%;">a. Skilled nursing treatments</td> </tr> <tr> <td style="width: 100%;">b. Monitoring to avoid clinical complications</td> </tr> <tr> <td style="width: 100%;">c. Rehabilitation</td> </tr> <tr> <td style="width: 100%;">d. Client/family education</td> </tr> <tr> <td style="width: 100%;">e. Family respite</td> </tr> <tr> <td style="width: 100%;">f. Palliative care</td> </tr> </table>	(Code for client/family understanding of goals of care) 0. No 1. Yes	a. Skilled nursing treatments	b. Monitoring to avoid clinical complications	c. Rehabilitation	d. Client/family education	e. Family respite	f. Palliative care					
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Name of Client _____

Case Record # _____

4	TIME SINCE LAST HOSPITAL STAY	Time since discharge from last inpatient setting (Code for most recent instance in LAST 180 DAYS) 0. Presently in hospital 1. No hospitalization within 180 days 2. Within last week 3. Within 8 to 14 days 4. Within 15 to 30 days 5. More than 30 days ago	<input type="checkbox"/>
5	WHERE LIVED AT TIME OF REFERRAL	1. Private home/apt. with no home care services 2. Private home/apt. with home care services 3. Board and care/assisted living/group home 4. Residential care facility 5. Other	<input type="checkbox"/>
6	WHO LIVED WITH AT REFERRAL	1. Lived alone 2. Lived with spouse only 3. Lived with spouse and other(s) 4. Lived with child (not spouse) 5. Lived with other(s) (not spouse or children) 6. Lived in group setting with non-relative(s)	<input type="checkbox"/>
7	PRIOR RESIDENTIAL CARE FACILITY PLACEMENT	Resided in a residential care facility at anytime during 5 YEARS prior to case opening 0. No 1. Yes	<input type="checkbox"/>
8	RESIDENTIAL HISTORY	Moved to current residence within last two years. 0. No 1. Yes	<input type="checkbox"/>

SECTION A. ASSESSMENT INFORMATION

1	ASSESSMENT REFERENCE DATE	Date of assessment <table border="1"> <tr> <td><input type="text"/></td> <td><input type="text"/></td> <td><input type="text"/></td> </tr> <tr> <td>Year</td> <td>Month</td> <td>Day</td> </tr> </table>	<input type="text"/>	<input type="text"/>	<input type="text"/>	Year	Month	Day	
<input type="text"/>	<input type="text"/>	<input type="text"/>							
Year	Month	Day							
2	REASON FOR ASSESSMENT	Type of assessment 1. Initial assessment 2. Follow-up assessment 3. Routine assessment at fixed intervals 4. Review within 30-day period prior to discharge from the program 5. Review at return from hospital 6. Change in status 7. Other	<input checked="" type="checkbox"/>						

SECTION B. COGNITIVE PATTERNS

1	MEMORY RECALL ABILITY	(Code for recall of what was learned or known) 0. Memory OK 1. Memory problem a. Short-term memory OK—seems/appears to recall after 5 minutes b. Procedural memory OK—can perform all or almost all steps in a multitask sequence without cues for initiation	<input type="checkbox"/> <input type="checkbox"/>
2	COGNITIVE SKILLS FOR DAILY DECISION-MAKING	a. How well client made decisions about organizing the day (e.g. when to get up or have meals, which clothes to wear or activities to do) 0. INDEPENDENT—Decisions consistent/reasonable/safe 1. MODIFIED INDEPENDENCE—Some difficulty in new situations only 2. MINIMALLY IMPAIRED—In specific situations, decisions become poor or unsafe and cues/supervision necessary at those times 3. MODERATELY IMPAIRED—Decisions consistently poor or unsafe, cues/supervision required at all times 4. SEVERELY IMPAIRED—Never/rarely made decisions	<input type="checkbox"/>

		b. Worsening of decision making as compared to status of 90 DAYS AGO (or since last assessment if less than 90 days) 0. No 1. Yes	<input type="checkbox"/>
3	INDICATORS OF DELIRIUM	a. Sudden or new onset/change in mental function over LAST 7 DAYS (including ability to pay attention, awareness of surroundings, being coherent, unpredictable variation over course of day) 0. No 1. Yes b. In the LAST 90 DAYS (or since last assessment if less than 90 days), client has become agitated or disoriented such that his or her safety is endangered or client requires protection by others 0. No 1. Yes	<input type="checkbox"/> <input type="checkbox"/>

SECTION C. COMMUNICATION/HEARING PATTERNS

1	HEARING	(With hearing appliance if used) 0. HEARS ADEQUATELY—Normal talk, TV, phone, doorbell 1. MINIMAL DIFFICULTY—When not in quiet setting 2. HEARS IN SPECIAL SITUATIONS ONLY—Speaker has to adjust tonal quality and speak distinctly 3. HIGHLY IMPAIRED—Absence of useful hearing	<input type="checkbox"/>
2	MAKING SELF UNDERSTOOD (Expression)	(Expressing information content—however able) 0. UNDERSTOOD—Expresses ideas without difficulty 1. USUALLY UNDERSTOOD—Difficulty finding words or finishing thoughts BUT if given time, little or no prompting required 2. OFTEN UNDERSTOOD—Difficulty finding words or finishing thoughts, prompting usually required 3. SOMETIMES UNDERSTOOD—Ability is limited to making concrete requests 4. RARELY/NEVER UNDERSTOOD	<input type="checkbox"/>
3	ABILITY TO UNDERSTAND OTHERS (Comprehension)	(Understands verbal information—however able) 0. UNDERSTANDS—Clear comprehension 1. USUALLY UNDERSTANDS—Misses some part/intent of message, BUT comprehends most conversation with little or no prompting 2. OFTEN UNDERSTANDS—Misses some part/intent of message; with prompting can often comprehend conversation 3. SOMETIMES UNDERSTANDS—Responds adequately to simple, direct communication 4. RARELY/NEVER UNDERSTANDS	<input type="checkbox"/>
4	COMMUNICATION DECLINE	Worsening in communication (making self understood or understanding others) as compared to status of 90 DAYS AGO (or since last assessment if less than 90 days) 0. No 1. Yes	<input type="checkbox"/>

Name of Client _____

Case Record # _____

4	TIME SINCE LAST HOSPITAL STAY	Time since discharge from last inpatient setting <i>(Code for most recent instance in LAST 180 DAYS)</i> 0. Presently in hospital 1. No hospitalization within 180 days 2. Within last week 3. Within 8 to 14 days 4. Within 15 to 30 days 5. More than 30 days ago	<input type="checkbox"/>
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	b. Worsening of decision making as compared to status of 90 DAYS AGO (or since last assessment if less than 90 days) 0. No 1. Yes	<input type="checkbox"/>
3	INDICATORS OF DELIRIUM a. Sudden or new onset/change in mental function over LAST 7 DAYS (including ability to pay attention, awareness of surroundings, being coherent, unpredictable variation over course of day) 0. No 1. Yes b. In the LAST 90 DAYS (or since last assessment if less than 90 days), client has become agitated or disoriented such that his or her safety is endangered or client requires protection by others 0. No 1. Yes	<input type="checkbox"/>

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Name of Client _____

Case Record # _____

	<p>Areas of help: 0. Yes 1. No</p> <p>g. Advice or emotional support <input type="checkbox"/> <input type="checkbox"/></p> <p>h. IADL care <input type="checkbox"/> <input type="checkbox"/></p> <p>i. ADL care <input type="checkbox"/> <input type="checkbox"/></p> <p>If needed, willingness (with ability) to increase help: 0. More than 2 hours per day 1. 1-2 hours per day 2. No</p> <p>j. Emotional support <input type="checkbox"/> <input type="checkbox"/></p> <p>k. IADL care <input type="checkbox"/> <input type="checkbox"/></p> <p>l. ADL care <input type="checkbox"/> <input type="checkbox"/></p>
2	<p>CAREGIVER STATUS</p> <p>(Check all that apply)</p> <p>A caregiver is unable to continue in caring activities—e.g. decline in the health of the caregiver makes it difficult to continue <input type="checkbox"/> a.</p> <p>Primary caregiver is not satisfied with support received from family and friends (e.g. other children of client) <input type="checkbox"/> b.</p> <p>Primary caregiver expresses feelings of distress, anger or depression <input type="checkbox"/> c.</p> <p>NONE OF ABOVE <input type="checkbox"/> d.</p>
3	<p>EXTENT OF INFORMAL HELP (HOURS OF CARE, ROUNDED)</p> <p>For instrumental and personal activities of daily living received over the LAST 7 DAYS, indicate extent of help from family, friends, and neighbours</p> <p style="text-align: right;">HOURS</p> <p>a. Sum of time across five weekdays <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/></p> <p>b. Sum of time across two weekend days <input type="text"/> <input type="text"/> <input type="text"/></p>

SECTION H. PHYSICAL FUNCTIONING: • IADL PERFORMANCE IN 7 DAYS • ADL PERFORMANCE IN 3 DAYS		
1	<p>IADL SELF-PERFORMANCE—Code for functioning in routine activities around the home or in the community during the LAST 7 DAYS.</p> <p>(A) IADL SELF-PERFORMANCE CODE (Code for client's performance during LAST 7 DAYS)</p> <p>0. INDEPENDENT—did on own</p> <p>1. SOME HELP—help some of the time</p> <p>2. FULL HELP—performed with help all of the time</p> <p>3. BY OTHERS—performed by others</p> <p>8. ACTIVITY DID NOT OCCUR</p>	
	<p>(B) IADL DIFFICULTY CODE How difficult it is (or would it be) for client to do activity on own</p> <p>0. NO DIFFICULTY</p> <p>1. SOME DIFFICULTY—e.g. needs some help, is very slow, or fatigued</p> <p>2. GREAT DIFFICULTY—e.g. little or no involvement in the activity is possible</p>	<p>(A) Performance <input type="checkbox"/></p> <p>(B) Difficulty <input type="checkbox"/></p>
	a. MEAL PREPARATION—How meals are prepared (e.g. planning meals, cooking, assembling ingredients, setting out food and utensils)	<input type="checkbox"/> <input type="checkbox"/>
	b. ORDINARY HOUSEWORK—How ordinary work around the house is performed (e.g. doing dishes, dusting, making bed, tidying up, laundry)	<input type="checkbox"/> <input type="checkbox"/>
	c. MANAGING FINANCES—How bills are paid, cheque book is balanced, household expenses are balanced	<input type="checkbox"/> <input type="checkbox"/>
	d. MANAGING MEDICATIONS—How medications are managed (e.g. remembering to take medicines, opening bottles, taking correct drug dosages, giving injections, applying ointments)	<input type="checkbox"/> <input type="checkbox"/>

	e. PHONE USE—How telephone calls are made or received (with assistive devices such as large numbers on telephone, amplification as needed)	<input type="checkbox"/> <input type="checkbox"/>
	f. SHOPPING—How shopping is performed for food and household items (e.g. selecting items, managing money)	<input type="checkbox"/> <input type="checkbox"/>
	g. TRANSPORTATION—How client travels by vehicle (e.g. gets to places beyond walking distance)	<input type="checkbox"/> <input type="checkbox"/>
2	<p>ADL SELF-PERFORMANCE—The following address the client's physical functioning in routine personal activities of daily life, for example, dressing, eating, etc. during the LAST 3 DAYS, considering all episodes of these activities. For clients who performed an activity independently, be sure to determine and record whether others encouraged the activity or were present to supervise or oversee the activity (Note—For bathing, code for most dependent single episode in LAST 7 DAYS.)</p> <p>0. INDEPENDENT—No help, setup, or oversight—OR—Help, setup, oversight provided only 1 or 2 times (with any task or subtask)</p> <p>1. SETUP HELP ONLY—Article or device provided within reach of client 3 or more times</p> <p>2. SUPERVISION—Oversight, encouragement or cueing provided 3 or more times during last 3 days—OR—Supervision (1 or more times) plus physical assistance provided only 1 or 2 times (for a total of 3 or more episodes of help or supervision)</p> <p>3. LIMITED ASSISTANCE—Client highly involved in activity; received physical help in guided manoeuvring of limbs or other non-weight bearing assistance 3 or more times—OR—Combination of non-weight bearing help with more help provided only 1 or 2 times during period (for a total of 3 or more episodes of physical help)</p> <p>4. EXTENSIVE ASSISTANCE—Client performed part of activity on own (50% or more of subtasks), but help of following type(s) were provided 3 or more times: — Weight-bearing support—OR— — Full performance by another during part (but not all) of last 3 days</p> <p>5. MAXIMAL ASSISTANCE—Client involved and completed less than 50% of subtasks on own (Includes 2+ person assist), received weight bearing help or full performance of certain subtasks 3 or more times</p> <p>6. TOTAL DEPENDENCE—Full performance of activity by another</p> <p>8. ACTIVITY DID NOT OCCUR (regardless of ability)</p>	
	a. MOBILITY IN BED—Including moving to and from lying position, turning side to side, and positioning body while in bed	<input type="checkbox"/>
	b. TRANSFER—Including moving to and between surfaces—to/from bed, chair, wheelchair, standing position. (Note—Excludes to/from bath/toilet)	<input type="checkbox"/>
	c. LOCOMOTION IN HOME—(Note—If in wheelchair, self-sufficiency once in chair.)	<input type="checkbox"/>
	d. LOCOMOTION OUTSIDE OF HOME—(Note—If in wheelchair, self-sufficiency once in chair.)	<input type="checkbox"/>
	e. DRESSING UPPER BODY—How client dresses and undresses (street clothes, underwear) above the waist, includes prostheses, orthotics, fasteners, pullovers, etc.	<input type="checkbox"/>
	f. DRESSING LOWER BODY—How client dresses and undresses (street clothes, underwear) from the waist down, includes prostheses, orthotics, belts, pants, skirts, shoes, and fasteners.	<input type="checkbox"/>
	g. EATING—Including taking in food by any method, including tube feedings.	<input type="checkbox"/>
	h. TOILET USE—Including using the toilet room or commode, bedpan, urinal, transferring on/off toilet, cleaning self after toilet use or incontinent episode, changing pad, managing any special devices required (ostomy or catheter), and adjusting clothes.	<input type="checkbox"/>
	i. PERSONAL HYGIENE—Including combing hair, brushing teeth, shaving, applying makeup, washing/drying face and hands (EXCLUDE baths and showers).	<input type="checkbox"/>

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	j. BATHING —How client takes full-body bath/shower or sponge bath (EXCLUDE washing of back and hair). Includes how each part of body is bathed: arms, upper and lower legs, chest/abdomen, perineal area. Code for most dependent episode in LAST 7 DAYS.	<input type="checkbox"/>
3	ADL DECLINE ADL status has become worse (i.e. now more impaired in self-performance) as compared to status 90 days ago (or since last assessment if less than 90 days) 0. No 1. Yes	<input type="checkbox"/>
4	PRIMARY MODES OF LOCOMOTION 0. No assistive device 1. Cane 2. Walker/crutch 3. Scooter (e.g. Amigo) 4. Wheelchair 8. ACTIVITY DID NOT OCCUR	<input type="checkbox"/>
	a. Indoors	<input type="checkbox"/>
	b. Outdoors	<input type="checkbox"/>
5	STAIR CLIMBING In the last 3 days , how client went up and down stairs (e.g. single or multiple steps, using handrail as needed). 0. Up and down stairs without help 1. Up and down stairs with help 2. Not go up and down stairs	<input type="checkbox"/>
6	STAMINA a. In a typical week, during the LAST 30 DAYS (or since last assessment), code the number of days client usually went out of the house or building in which client lives (no matter how short a time period) 0. Every day 1. 2-6 days a week 2. 1 day a week 3. No days b. Hours of physical activities in the last 3 days (e.g. walking, cleaning house, exercise) 0. Two or more hours 1. Less than two hours	<input type="checkbox"/>
7	FUNCTIONAL POTENTIAL (Check all that apply) Client believes he/she capable of increased functional independence (ADL, IADL, mobility) Caregivers believe client is capable of increased functional independence (ADL, IADL, mobility) Good prospects of recovery from current disease or conditions, improved health status expected NONE OF ABOVE	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

SECTION I. CONTINENCE IN LAST 7 DAYS

1	BLADDER CONTINENCE a. In LAST 7 DAYS (or since last assessment if less than 7 days) control of urinary bladder function (with appliances such as catheters or incontinence program employed) (Note—If dribbles, volume insufficient to soak through underpants) 0. CONTINENT—Complete control; DOES NOT USE any type of catheter or other urinary collection device 1. CONTINENT WITH CATHETER—Complete control with use of any type of catheter or urinary collection device that does not leak urine 2. USUALLY CONTINENT—Incontinent episodes once a week or less 3. OCCASIONALLY INCONTINENT—Incontinent episodes 2 or more times a week but not daily 4. FREQUENTLY INCONTINENT—Tends to be incontinent daily, but some control present 5. INCONTINENT—Inadequate control, multiple daily episodes 8. DID NOT OCCUR—No urine output from bladder	<input type="checkbox"/>
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	b. Worsening of bladder incontinence as compared to status 90 days ago (or since last assessment if less than 90 days) 0. No 1. Yes	<input type="checkbox"/>
2	BLADDER DEVICES (Check all that apply in LAST 7 DAYS —or since last assessment if less than 7 days) Use of pads or briefs to protect against wetness Use of an indwelling urinary catheter NONE OF ABOVE	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
3	BOWEL CONTINENCE In LAST 7 DAYS (or since last assessment if less than 7 days), control of bowel movement (with appliance or bowel continence program if employed) 0. CONTINENT—Complete control; DOES NOT USE ostomy device 1. CONTINENT WITH OSTOMY—Complete control with use of ostomy device that does not leak stool 2. USUALLY CONTINENT—Bowel incontinent episodes less than weekly 3. OCCASIONALLY INCONTINENT—Bowel incontinent episodes once a week 4. FREQUENTLY INCONTINENT—Bowel incontinent episodes 2-3 times a week 5. INCONTINENT—Bowel incontinent all (or almost all) of the time 8. DID NOT OCCUR—No bowel movement during entire 7 day assessment period	<input type="checkbox"/>

SECTION J. DISEASE DIAGNOSES

1	DISEASES Disease/infection that doctor has indicated is present and affects client's status, requires treatment, or symptom management. Also include if disease is monitored by a home care professional or is the reason for a hospitalization in LAST 90 DAYS (or since last assessment if less than 90 days). (blank) Not present 1. Present—not subject to focused treatment or monitoring by home care professional 2. Present—monitored or treated by home care professional (If no disease in list, check 11ac , None of Above)	<input type="checkbox"/>
	HEART/CIRCULATION a. Cerebrovascular accident (stroke) b. Congestive heart failure c. Coronary artery disease d. Hypertension e. Irregularly Irregular pulse f. Peripheral vascular disease	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
	SENSES g. Cataract h. Glaucoma	<input type="checkbox"/> <input type="checkbox"/>
	PSYCHIATRIC/MOOD i. Any psychiatric diagnosis	<input type="checkbox"/>
	INFECTIONS j. HIV infection k. Pneumonia l. Tuberculosis	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
	NEUROLOGICAL m. Alzheimer's n. Dementia other than Alzheimer's disease o. Head trauma p. Hemiplegia/hemiparesis q. Multiple sclerosis	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
	OTHER DISEASES r. Cancer (in past 5 years) not including skin cancer s. Diabetes	<input type="checkbox"/> <input type="checkbox"/>

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	l. Parkinsonism	<input type="checkbox"/>	z. Emphysema/ COPD/ asthma	<input type="checkbox"/>
	MUSCULO-SKELETAL		aa. Renal Failure	<input type="checkbox"/>
	m. Arthritis	<input type="checkbox"/>	ab. Thyroid disease (hyper or hypo)	<input type="checkbox"/>
	n. Hip fracture	<input type="checkbox"/>		
	o. Other fractures (e.g. wrist, vertebral)	<input type="checkbox"/>	ac. NONE OF ABOVE	<input type="checkbox"/>
	p. Osteoporosis	<input type="checkbox"/>		
2	OTHER CURRENT OR MORE DETAILED DIAGNOSES AND ICD-10- CA CODES	a.	<input type="checkbox"/>	<input type="checkbox"/>
	b.	<input type="checkbox"/>	<input type="checkbox"/>	
	c.	<input type="checkbox"/>	<input type="checkbox"/>	
	d.	<input type="checkbox"/>	<input type="checkbox"/>	

SECTION K. HEALTH CONDITIONS AND PREVENTIVE HEALTH MEASURES					
1	PREVENTIVE HEALTH (PAST TWO YEARS)	(Check all that apply—in PAST 2 YEARS)			
		Blood pressure measured	a.	IF FEMALE: Received breast examination	d.
		Received Influenza vaccination	b.	or mammography	
		Test for blood in stool or screening endoscopy	c.	NONE OF ABOVE	e.
2	PROBLEM CONDITIONS PRESENT ON 2 OR MORE DAYS	(Check all that were present on at least 2 of the last 3 days)			
		Diarrhea	a.	Loss of appetite	d.
		Difficulty urinating or urinating 3 or more times at night	b.	Vomiting	e.
		Fever	c.	NONE OF ABOVE	f.
3	PROBLEM CONDITIONS	(Check all present at any point during last 3 days)			
		PHYSICAL HEALTH		MENTAL HEALTH	
		Chest pain/pressure at rest or on exertion	a.	Delusions	f.
		No bowel movement in 3 days	b.	Hallucinations	g.
		Dizziness or lightheadedness	c.	NONE OF ABOVE	h.
		Edema	d.		
		Shortness of breath	e.		
4	PAIN	a. Frequency with which client complains or shows evidence of pain			
		0. No pain (score b-e as 0) 1. Less than daily 2. Daily—one period 3. Daily—multiple periods (e.g. morning and evening)			
		b. Intensity of pain			
			0. No pain 1. Mild 2. Moderate 3. Severe 4. Times when pain is horrible or excruciating		
c. From client's point of view, pain intensity disrupts usual activities			0. No 1. Yes		

	d. Character of pain	<input type="checkbox"/>			
	0. No pain				
	1. Localized—single site				
	2. Multiple sites				
	e. From client's point of view, medications adequately control pain	<input type="checkbox"/>			
	0. Yes or no pain				
	1. Medications do not adequately control pain				
	2. Pain present, medication not taken				
5	FALLS FREQUENCY	Number of times fell in LAST 90 DAYS (or since last assessment if less than 90 days). If none, code "0", if more than 9, code "9".			
6	DANGER OF FALL	(Code for danger of falling)			
		0. No 1. Yes			
		a. Unsteady gait	<input type="checkbox"/>		
		b. Client limits going outdoors due to fear of falling (e.g. stopped using bus, goes out only with others)	<input type="checkbox"/>		
7	LIFESTYLE (Drinking/Smoking)	(Code for drinking or smoking)			
		0. No 1. Yes			
		a. In the LAST 90 DAYS (or since last assessment if less than 90 days), client felt the need or was told by others to cut down on drinking, or others were concerned with client's drinking			
		b. In the LAST 90 DAYS (or since last assessment if less than 90 days), client had to have a drink first thing in the morning to steady nerves (i.e. an "eye opener") or has been in trouble because of drinking			
		c. Smoked or chewed tobacco daily	<input type="checkbox"/>		
8	HEALTH STATUS INDICATORS	(Check all that apply)			
		Client feels he/she is poor health (when asked)	a.	Treatments changed in LAST 30 DAYS (or since last assessment if less than 30 days) because of a new acute episode or condition	d.
		Has conditions or diseases that make cognition, ADL, mood, or behaviour patterns unstable (fluctuations, precarious, or deteriorating)	b.	Prognosis of less than six months to live—e.g. physician has told client or client's family that client has end-stage disease	e.
		Experiencing a flare-up of a recurrent or chronic problem	c.	NONE OF ABOVE	f.
9	OTHER STATUS INDICATORS	(Check all that apply)			
		Fearful of a family member or caregiver	a.	Physically restrained (e.g. limbs restrained, used bed rails, constrained to chair when sitting)	e.
		Unusually poor hygiene	b.	NONE OF ABOVE	f.
		Unexplained injuries, broken bones, or burns	c.		
		d. Neglected, abused, or mistreated			

SECTION L. NUTRITION/HYDRATION STATUS			
1	WEIGHT	(Code for weight items)	
		0. No 1. Yes	
		a. Unintended weight loss of 5% or more in the LAST 30 DAYS (or 10% or more in the LAST 180 DAYS)	
		b. Severe malnutrition (cachexia)	<input type="checkbox"/>
		c. Morbid obesity	<input type="checkbox"/>

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2	CONSUMPTION	(Code for consumption) 0. No 1. Yes	
		a. In at least 2 of the last 3 days, ate one or fewer meals a day	<input type="checkbox"/>
		b. In last 3 days, noticeable decrease in the amount of food client usually eats or fluids usually consumes	<input type="checkbox"/>
		c. Insufficient fluid—did not consume all/almost all fluids during last 3 days	<input type="checkbox"/>
		d. Enteral tube feeding	<input type="checkbox"/>
3	SWALLOWING	0. NORMAL—Safe and efficient swallowing of all diet consistencies 1. REQUIRES DIET MODIFICATION TO SWALLOW SOLID FOODS (mechanical diet or able to ingest specific foods only) 2. REQUIRES MODIFICATION TO SWALLOW SOLID FOODS AND LIQUIDS (puree, thickened liquids) 3. COMBINED ORAL AND TUBE FEEDING 4. NO ORAL INTAKE (NPO)	<input type="checkbox"/>

SECTION M. DENTAL STATUS (ORAL HEALTH)			
1	ORAL STATUS	(Check all that apply)	
		Problem chewing (e.g. poor mastication, immobile jaw, surgical resection, decreased sensation/motor control, pain while eating)	<input type="checkbox"/>
		Mouth is "dry" when eating a meal	<input type="checkbox"/>
		Problem brushing teeth or dentures	<input type="checkbox"/>
		NONE OF ABOVE	<input type="checkbox"/>

SECTION N. SKIN CONDITION			
1	SKIN PROBLEMS	Any troubling conditions or changes in skin condition (e.g. burns, bruises, rashes, itchiness, body lice, scabies)	<input type="checkbox"/>
			0. No 1. Yes
2	ULCERS (Pressure/Stasis)	Presence of an ulcer anywhere on the body. Ulcers include any area of persistent skin redness (Stage 1); partial loss of skin layers (Stage 2); deep craters in the skin (Stage 3); breaks in skin exposing muscle or bone (Stage 4). [Code 0 if no ulcer, otherwise record the highest ulcer stage (Stage 1-4).]	
		a. Pressure ulcer—any lesion caused by pressure, shear forces, resulting in damage of underlying tissues	<input type="checkbox"/>
		b. Stasis ulcer—open lesion caused by poor circulation in the lower extremities	<input type="checkbox"/>
3	OTHER SKIN PROBLEMS REQUIRING TREATMENT	(Check all that apply)	
		Burns (second or third degree)	<input type="checkbox"/>
		Open lesions other than ulcers, rashes, cuts (e.g. cancer)	<input type="checkbox"/>
		Skin tears or cuts	<input type="checkbox"/>
		Surgical wound	<input type="checkbox"/>
		Corns, calluses, structural problems, infections, fungi	<input type="checkbox"/>
		NONE OF ABOVE	<input type="checkbox"/>
4	HISTORY OF RESOLVED PRESSURE ULCERS	Client previously had (at any time) or has an ulcer anywhere on the body.	<input type="checkbox"/>
			0. No 1. Yes
5	WOUND/ ULCER CARE	(Check for formal care in LAST 7 DAYS)	
		Antibiotics, systemic or topical	<input type="checkbox"/>
		Dressings	<input type="checkbox"/>

	Surgical wound care	<input type="checkbox"/>
	Other wound/ulcer care (e.g. pressure relieving device, nutrition, turning, debridement)	<input type="checkbox"/>
	NONE OF ABOVE	<input type="checkbox"/>

SECTION O. ENVIRONMENTAL ASSESSMENT			
1	HOME ENVIRONMENT	[Check any of following that make home environment hazardous or uninhabitable (If none apply, check NONE OF ABOVE, if temporarily in institution, base assessment on home visit)]	
		Lighting in evening (including inadequate or no lighting in living room, sleeping room, kitchen, toilet, corridors)	<input type="checkbox"/>
		Flooring and carpeting (e.g. holes in floor, electric wires where client walks, scatter rugs)	<input type="checkbox"/>
		Bathroom and toilet room (e.g. non-operating toilet, leaking pipes, no rails though needed, slippery bathtub, outside toilet)	<input type="checkbox"/>
		Kitchen (e.g. dangerous stove, inoperative refrigerator, infestation by rats or bugs)	<input type="checkbox"/>
		Heating and cooling (e.g. too hot in summer, too cold in winter, wood stove in a home with an asthmatic)	<input type="checkbox"/>
		Personal safety (e.g. fear of violence, safety problem in going to mailbox or visiting neighbours, heavy traffic in street)	<input type="checkbox"/>
		Access to home (e.g. difficulty entering/leaving home)	<input type="checkbox"/>
		Access to rooms in house (e.g. unable to climb stairs)	<input type="checkbox"/>
		NONE OF ABOVE	<input type="checkbox"/>
2	LIVING ARRANGEMENT	a. As compared to 90 DAYS AGO (or since last assessment), client now lives with other persons—e.g. moved in with another person, other moved in with client	<input type="checkbox"/>
		b. Client or primary caregiver feels that client would be better off in another living environment	<input type="checkbox"/>
			0. No 1. Yes
			1. Client only
			2. Caregiver only
			3. Client and caregiver

SECTION P. SERVICE UTILIZATION (IN LAST 7 DAYS)						
1	FORMAL CARE (Minutes rounded to even 10 minutes)	Extent of care or care management in LAST 7 DAYS (or since last assessment if less than 7 days) since involving				
			#of:	(A) Days	(B) Hours	(C) Mins
		a. Home health aides	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		b. Visiting nurses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		c. Homemaking services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		d. Meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		e. Volunteer services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		f. Physical therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		g. Occupational therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		h. Speech therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		i. Day care or day hospital	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		j. Social worker in home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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2	SPECIAL TREATMENTS, THERAPIES, PROGRAMS	Special treatments, therapies, and programs received or scheduled during the LAST 7 DAYS (or since last assessment if less than 7 days) and adherence to the required schedule. Includes services received in the home or on an outpatient basis. (Blank) Not applicable 1. Scheduled, full adherence as prescribed 2. Scheduled, partial adherence 3. Scheduled, not received (If no treatments provided, check NONE OF ABOVE P2aa)																																	
		<table border="1"> <thead> <tr> <th>RESPIRATORY TREATMENTS</th> <th>THERAPIES</th> </tr> </thead> <tbody> <tr> <td>a. Oxygen</td> <td>n. Exercise therapy</td> </tr> <tr> <td>b. Respirator for assistive breathing</td> <td>o. Occupational therapy</td> </tr> <tr> <td>c. All other respiratory treatments</td> <td>p. Physical therapy</td> </tr> <tr> <th>OTHER TREATMENTS</th> <th>PROGRAMS</th> </tr> <tr> <td>d. Alcohol/drug treatment program</td> <td>q. Day centre</td> </tr> <tr> <td>e. Blood transfusion(s)</td> <td>r. Day hospital</td> </tr> <tr> <td>f. Chemotherapy</td> <td>s. Hospice care</td> </tr> <tr> <td>g. Dialysis</td> <td>t. Physician or clinic visit</td> </tr> <tr> <td>h. IV infusion—central</td> <td>u. Respite care</td> </tr> <tr> <td>i. IV infusion—peripheral</td> <th>SPECIAL PROCEDURES DONE IN HOME</th> </tr> <tr> <td>j. Medication by injection</td> <td>v. Daily nurse monitoring (e.g. EKG, urinary output)</td> </tr> <tr> <td>k. Ostomy care</td> <td>w. Nurse monitoring less than daily</td> </tr> <tr> <td>l. Radiation</td> <td>x. Medical alert bracelet or electronic security alert</td> </tr> <tr> <td>m. Tracheostomy care</td> <td>y. Skin treatment</td> </tr> <tr> <td></td> <td>z. Special diet</td> </tr> <tr> <td></td> <td>aa. NONE OF ABOVE</td> </tr> </tbody> </table>	RESPIRATORY TREATMENTS	THERAPIES	a. Oxygen	n. Exercise therapy	b. Respirator for assistive breathing	o. Occupational therapy	c. All other respiratory treatments	p. Physical therapy	OTHER TREATMENTS	PROGRAMS	d. Alcohol/drug treatment program	q. Day centre	e. Blood transfusion(s)	r. Day hospital	f. Chemotherapy	s. Hospice care	g. Dialysis	t. Physician or clinic visit	h. IV infusion—central	u. Respite care	i. IV infusion—peripheral	SPECIAL PROCEDURES DONE IN HOME	j. Medication by injection	v. Daily nurse monitoring (e.g. EKG, urinary output)	k. Ostomy care	w. Nurse monitoring less than daily	l. Radiation	x. Medical alert bracelet or electronic security alert	m. Tracheostomy care	y. Skin treatment		z. Special diet	
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3	MANAGEMENT OF EQUIPMENT (In Last 3 Days)	Management codes: 0. Not used 1. Managed on own 2. Managed on own if laid out or with verbal reminders 3. Partially performed by others 4. Fully performed by others a. Oxygen b. IV c. Catheter d. Ostomy																																	

4	VISITS IN LAST 90 DAYS OR SINCE LAST ASSESSMENT	Enter "0" if none, if more than 9, code "9"	
		a. Number of times ADMITTED TO HOSPITAL with an overnight stay	
		b. Number of times VISITED EMERGENCY ROOM without an overnight stay	
5	TREATMENT GOALS	Any treatment goals that have been met in the LAST 90 DAYS (or since last assessment if less than 90 days)? 0. No 1. Yes	
6	OVERALL CHANGE IN CARE NEEDS	Overall self-sufficiency has changed significantly as compared to status of 90 DAYS AGO (or since last assessment if less than 90 days) 0. No change 1. Improved—receives fewer supports 2. Deteriorated—receives more support	
7	TRADE OFFS	Because of limited funds, during the last month, client made trade-offs among purchasing any of the following: prescribed medications, sufficient home heat, necessary physician care, adequate food, home care 0. No 1. Yes	

SECTION Q. MEDICATIONS			
1	NUMBER OF MEDICATIONS	Record the number of different medicines (prescriptions and over the counter), including eye drops, taken regularly or on an occasional basis in the LAST 7 DAYS (or since last assessment) (If none, code "0", if more than 9, code "9".)	
2	RECEIPT OF PSYCHOTROPIC MEDICATION	Psychotropic medications taken in the LAST 7 DAYS (or since last assessment) [Note—Review client's medications with the list that applies to the following categories.] 0. No 1. Yes	
		a. Antipsychotic/neuroleptic	
		b. Anxiolytic	
		c. Antidepressant	
		d. Hypnotic	
3	MEDICAL OVERSIGHT	Physician reviewed client's medications as a whole in LAST 180 DAYS (or since last assessment) 0. Discussed with at least one physician (or no medication taken) 1. No single physician reviewed all medications	
4	COMPLIANCE/ADHERENCE WITH MEDICATIONS	Compliant all or most of time with medications prescribed by physician (both during and between therapy visits) in LAST 7 DAYS 0. Always compliant 1. Compliant 80% of time or more 2. Compliant less than 80% of time, including failure to purchase prescribed medications 3. NO MEDICATIONS PRESCRIBED	

Name of Client _____

Case Record # _____

5	LIST OF ALL MEDICATIONS	<p>List prescribed and nonprescribed medications taken in LAST 7 DAYS (or since last assessment)</p> <p>a. Name: Record the name of the medication.</p> <p>b. Dose: Record the dosage.</p> <p>c. Form: Code the route of Administration using the following list:</p> <table style="width: 100%; border: none;"> <tr> <td>1. By mouth (PO)</td> <td>6. Rectal (R)</td> </tr> <tr> <td>2. Sub lingual (SL)</td> <td>7. Topical</td> </tr> <tr> <td>3. Intramuscular (IM)</td> <td>8. Inhalation</td> </tr> <tr> <td>4. Intravenous (IV)</td> <td>9. Enteral tube</td> </tr> <tr> <td>5. Subcutaneous (SQ)</td> <td>10. Other</td> </tr> </table> <p>d. Freq: Code the number of times per day, week, or month the medication is administered using the following list:</p> <table style="width: 100%; border: none;"> <tr> <td>PRN. As necessary</td> <td>QOD. Every other day</td> </tr> <tr> <td>QH. Every hour</td> <td>QW. Once each week</td> </tr> <tr> <td>Q2H. Every two hours</td> <td>2W. Two times every week</td> </tr> <tr> <td>Q3H. Every three hours</td> <td>3W. Three times every week</td> </tr> <tr> <td>Q4H. Every four hours</td> <td>4W. Four times every week</td> </tr> <tr> <td>Q6H. Every six hours</td> <td>5W. Five times every week</td> </tr> <tr> <td>Q8H. Every eight hours</td> <td>6W. Six times every week</td> </tr> <tr> <td>QD. Once daily</td> <td>1M. Once every month</td> </tr> <tr> <td>HS. Bedtime</td> <td>2M. Twice every month</td> </tr> <tr> <td>BID. Two times daily (Includes every 12 hrs)</td> <td>C. Continuous daily</td> </tr> <tr> <td>TID. Three times daily</td> <td>O. Other</td> </tr> <tr> <td>QID. Four times daily</td> <td></td> </tr> <tr> <td>SD. Five times daily</td> <td></td> </tr> </table> <p>e. IF PRN: record number of doses taken in last 7 days.</p>	1. By mouth (PO)	6. Rectal (R)	2. Sub lingual (SL)	7. Topical	3. Intramuscular (IM)	8. Inhalation	4. Intravenous (IV)	9. Enteral tube	5. Subcutaneous (SQ)	10. Other	PRN. As necessary	QOD. Every other day	QH. Every hour	QW. Once each week	Q2H. Every two hours	2W. Two times every week	Q3H. Every three hours	3W. Three times every week	Q4H. Every four hours	4W. Four times every week	Q6H. Every six hours	5W. Five times every week	Q8H. Every eight hours	6W. Six times every week	QD. Once daily	1M. Once every month	HS. Bedtime	2M. Twice every month	BID. Two times daily (Includes every 12 hrs)	C. Continuous daily	TID. Three times daily	O. Other	QID. Four times daily		SD. Five times daily	
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a.	b.	c.	d.	e.																																		
Name	Dose	Form	Freq	IF PRN # of times taken in last 7 days																																		
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SECTION 8. ASSESSMENT INFORMATION											
1 SIGNATURES OF PERSONS COMPLETING THE ASSESSMENT											
a. Signature of Assessment Coordinator											
b. Title of Assessment Coordinator											
c. Date Assessment Coordinator signed as complete											
<table style="display: inline-table; border: none;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td style="text-align: center; font-size: 8px;">Year</td> <td style="text-align: center; font-size: 8px;">Month</td> <td style="text-align: center; font-size: 8px;">Day</td> <td></td> </tr> </table>					Year	Month	Day				
Year	Month	Day									
Other Signatures	Title	Sections	Date								
d.											
e.											
f.											
g.											
h.											
i.											

Note: Permission was obtained from CIHI to include this information in this thesis.

Appendix B: Income information for co-payment (income variable)

Income Range	Income			Family Size		
	Annual	Monthly Equivalent from	Monthly Equivalent to	1	2	3 or more
01	\$0 to \$22,003	\$ 0.00	\$1,834	A	A	A
02	\$22,004 to \$37,004	\$1,834	\$3,084	B	A	A
03	\$37,005 to \$47,005	\$3,084	\$3,917	C	B	A
04	\$47,006 to \$57,006	\$3,917	\$4,751	D	C	B
05	\$57,007 to \$67,007	\$4,751	\$5,584	E	D	C
06	\$67,008 or more	\$5,584	\$5,584+	F	E	D

Home Care Client Income Category	Charge per Hour Client Fees	Maximum Monthly Client Fee Charge	Monthly Home Oxygen Services Fee
A	---	---	---
B	\$12.10	\$121.00	\$72.60
C	\$12.10	\$242.00	\$145.20
D	\$12.10	\$363.00	\$217.80
E	\$12.10	\$484.00	\$290.40
F	\$12.10	\$605.00	\$363.00

Note: Fee paying clients who are receiving both home support and home oxygen services are assessed the home oxygen fee first and any applicable hourly home support fees second. In no case, shall the combined total of the home support and the home oxygen services client fees exceed the maximum Monthly Client Fee Charge for the client's income category.

Nursing Home	\$102.50 per day
Residential Care Facility	\$61.50 per day
Respite Care	\$34 per day

Note: Permission was obtained from Nova Scotia DHW Continuing Care to include this information in this thesis.

Appendix C: Dalhousie Research Ethics Board Approval



Health Sciences Research Ethics Board Letter of Approval

November 16, 2016

Ashley Chisholm
Medicine\Community Health & Epidemiology

Dear Ashley,

REB #: 2016-3841

Project Title: Understanding caregiver distress and hospitalization among home care recipients in Nova Scotia from perspectives of social disadvantage

Effective Date: November 16, 2016

Expiry Date: November 16, 2017

The Health Sciences Research Ethics Board has reviewed your application for research involving humans and found the proposed research to be in accordance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans*. This approval will be in effect for 12 months as indicated above. This approval is subject to the conditions listed below which constitute your on-going responsibilities with respect to the ethical conduct of this research.

Sincerely,

Dr. Tannis Jurgens, Chair

Appendix D: Variable Identifications

Variable	Variable Category	Survey Question	Reference Period	Variable ID	Reference
Primary Interest Variables					
Caregiver distress	yes no	Caregiver feeling of distress, anger, or depression	Past 3 days	cgdistress	Shugarman (2002)
Caregiver dissatisfaction	yes no	Primary caregiver is not satisfied with support received from other family or friends	Past 3 days	cgdissatisfaction	Shugarman (2002)
Caregiver burnout	yes no	A caregiver is unable to continue in caring activities—e.g. decline in the health of the caregiver makes it difficult to continue	Past 3 days	cgburnout	Shugarman (2002)
Hospitalization	yes no	Hospital admissions*Past 90 days	Past 90 days in subsequent RAI-HC assessment	hospstay	Shugarman (2002)
Controlling Variables					
(1) Predisposing Characteristics					
Sex	yes no	Sex	Date of assessment	clientsex	Shugarman (2002); Goncalves (2014)

Variable	Variable Category	Survey Question	Reference Period	Variable ID	Reference
Age		Date of birth	Date of assessment	age_group	Shugarman (2002); Morris (2014)
(2) Enabling Characteristics					
Lives with helper	Yes no	Does the care recipient live with helper	Date of assessment	livewithhelp	Shugarman (2002)
Income	A, B, C, D, E, F, G Divided into low (A), medium (B), high (C,D,E,F,G)	Annual Income and family size	Past year	Income level	Bass (1987); Goncalves (2014)
(3) Need Characteristics					
ADL impairment	Independent=0 Need assistance with ADLs =1	ADL self-performance	Past 7 days	adlsp	Shugarman (2002); Morris (2014); Goncalves (2014); Rosali (2003)
COPD/emphysema/asthma	yes no	Emphysema/copd/asthma?	Past 3 days	emphcopdasthma_yn	Shugarman (2002); Morris (2014)
Dementia	yes no	Presence of dementia that is not Alzheimer's Disease	Past 3 days	dementia_yn	Shugarman (2002); Morris (2014); Rosali (2003)
Alzheimer's Disease	yes no	Presence of Alzheimer's Disease	Past 3 days	alzheimers_yn	Shugarman (2002); Morris (2014); Rosali (2003)
Cancer	yes no	cancer	Past 3 days	cancer_yn	Shugarman (2002) Morris (2014)

Variable	Variable Category	Survey Question	Reference Period	Variable ID	Reference
Behavioral Problems	yes no	beavioural problems: wandering, verbally abusive, physically abusive, socially inappropriate, resists care	Past 3 days	behavprob	Shugarman (2002)
Congestive heart failure	yes no	Congenitive heart failure	Past 3 days	congestive	Shugarman (2002); Morris (2014); Rosali (2003)
Daily Pain	0=no pain 1=less than daily 2=daily once 3=daily multiple periods	Frequency with which client complains or shows evidence of pain	Past 7 days	k4a2-3 pain	Shugarman (2002)
Changes in health, End-Stage Disease, Signs and Symptoms Scale (CHESS)	(0=No Health instability, 1= Health instability (1-5))	Calculated Scale of 12 Survey questions	Past 3 days	chess	Hirdes (2003) Morris (2014)
Depression (DRS)	0–14 A score of 3 or more may indicate a potential or actual problem with depression.	Depression Rating Scale	Past 3 days	drs	Shugarman (2002)
(4) Caregiver Variables					
Variable	Variable Category	Survey Question	Reference Period	Variable ID	Reference

Caregiver dissatisfaction	yes no	Primary caregiver is not satisfied with support received from other family or friends	Past 3 days	g2b cgdissatisfaction	Shugarman (2002)
Discontinuation of care	yes no	A caregiver is unable to continue in caring activities—e.g. decline in the health of the caregiver makes it difficult to continue	Past 3 days	cghealth	Shugarman (2002)
Caregiver distress	yes no	Caregiver feeling of distress, anger, or depression	Past 3 days	distress1	Shugarman (2002)

Appendix E

Associations between indicators of caregiver burden and hospitalization among Nova Scotia Continuing Care home care recipients (n=4,235)

Variable	OR (95% CI) for hospitalization				
	Model 1	Model 2	Model 3	Model 4	Model 5
Caregiver characteristics					
Distressed	1.34 (0.90-1.82)	1.29 (0.95-1.75)	1.24 (0.90-1.72)	1.25 (0.906-1.72)	1.34 (0.99-1.81)
Burned out					1.31 (1.03-1.67)*
Dissatisfaction					1.06 (0.59-1.89)
Recipient predisposing characteristics					
Female		0.79 (0.67-0.93)‡	0.79 (0.78-0.95)‡	0.79 (0.74-1.47)‡	0.81 (0.68-0.94)†
Age					
60-64 years		1.00	1.00	1.00	1.00
65-74 years		1.06 (0.76-1.49)	1.04 (0.74-1.46)	1.04 (0.74-1.46)	1.06 (0.76-1.49)
75-84 years		1.10 (0.80-1.52)	1.09 (0.78-1.51)	1.07 (0.77-1.49)	1.08 (0.78-1.48)
85 years or older		1.28 (0.92-1.76)	1.28 (0.92-1.78)	1.27 (0.91-1.76)	1.25 (0.91-1.71)
Recipient enabling characteristics					
Lives with helper				0.97 (0.83-1.14)	1.05 (0.91-1.21)
Income Category‡					
A				1.00	1.00
B				1.23 (0.98-1.52)‡	1.27 (1.03-1.57)
C, D, E, F, or G				1.00 (0.68-1.21)	0.99 (0.75-1.30)
Need characteristics					
ADL impairment					
Independent			1.00	1.00	1.00

Supervision			1.53 (1.14-2.04)‡	1.54 (1.15-2.07)†	1.40 (1.07-1.84)*
Limited			1.37 (0.79-1.66)‡	1.38 (1.11-1.73)†	1.41 (1.14-1.78)*
Extensive or more			1.15 (0.79-1.66)	1.17 (0.80-1.70)‡	1.19 (0.83-1.71)*
Alzheimer's disease			0.60 (0.36-1.01)	0.60 (0.36-1.02)	0.53 (0.33-0.86)†
Cancer			1.00 (0.80-1.26)	1.01 (0.80-1.26)	1.07 (0.85-1.34)
CHES (rating of minimal or greater)					
No health instability			1.00		1.00
Minimal			1.15 (0.95-1.40)	1.15 (0.95-1.40)	1.26 (1.04-1.52)‡
Low			1.36 (1.09-1.68)†	1.34 (1.08-1.57)†	1.54 (1.26-1.89)‡
Moderate or high			1.61 (1.22-2.13)‡	1.59 (1.21-2.10)‡	1.94 (1.51-2.51)‡
CPS (rating other than intact)					
Intact			1.00	1.00	1.00
Border intact			1.10 (0.99-1.42)	1.19 (0.99-1.43)	1.27 (1.07-1.52)†
Mild impairment			0.98 (0.78-1.23)	0.98 (0.78-1.23)	1.09 (0.88-1.35)†
Moderate impairment			0.69 (0.48-0.99)*	0.69 (0.48-0.99)*	0.74 (0.55-1.01)†
Dementia			0.86 (0.59-1.24)	0.85 (0.58-1.24)	0.86 (0.61-1.21)
Depression Rating Scale(DRS)§					
0			1.00	1.00	1.00
1			0.95 (0.75-1.20)	0.95 (0.75-1.20)	1.00 (0.80-1.26)
2			0.98 (0.75-1.28)	0.98 (0.75-1.28)	1.02 (0.79-1.32)
3			0.95 (0.75-1.22)	0.96 (0.75-1.22)	1.10 (0.88-1.38)
Congestive heart failure			1.07 (0.85-1.35)	1.06 (0.84-1.35)	1.29 (1.03-1.61)*
Pain					
Never			1.00	1.00	1.00
Less than daily			0.89 (0.70-1.13)	0.89 (0.70-1.13)	0.90 (0.71-1.14)
Once daily			0.67 (0.48-0.93)*	0.67 (0.47-0.93)*	0.69 (0.49-0.95)
2 or more times daily			0.94 (0.78-1.13)	0.94 (0.78-1.13)	1.00 (0.83-1.19)
Respiratory disorder			1.51 (1.27-1.80)‡	1.52 (1.28-1.83)‡	1.61 (1.37-1.90)‡
Goodness-of-fit test	0.0008	0.0033	0.39	0.0928	

Variable	OR (95% CI) for hospitalization				
	Model 6	Model 7	Model 8	Model 9	Model 10
Caregiver characteristics					
Distressed	1.26 (0.91-1.74)	1.26 (0.91-1.74)			
Burned out	1.38 (0.91-1.52)	1.20 (0.93-1.55)			
Dissatisfaction	0.85 (0.46-1.55)	0.85 (0.46-1.55)			
Recipient predisposing characteristics					
Female	0.79 (0.67-0.94) [†]	0.85 (0.68-96)*			
Age					
60-64 years	1.00	1.00			
65-74 years	1.04 (0.74-1.45)	1.07 (0.75-1.50)			
75-84 years	1.07 (0.77-1.48)	1.10 (0.80-1.53)			
85 years or older	1.26 (0.90-1.75)	1.30 (0.93-1.81)			
Recipient enabling characteristics					
Lives with helper	0.96 (0.82-1.13)	0.95 (0.81-1.12)			
Income Category [‡]					
A	1.00	1.00			
B	1.23 (0.99-1.52)	1.23 (0.99-1.53)			
C, D, E, F, or G	0.91 (0.68-1.21)	0.89 (0.67-1.18)			
Need characteristics					
ADL impairment		1.36 (1.13-1.64)	1.37 (1.16-1.62) [‡]	3.02 (2.31-3.95) [‡]	2.22 (1.78-2.78)
Independent	1.00				
Supervision	1.53 (1.14-2.06) [†]				
Limited	1.38 (1.11-1.73) [†]				
Extensive or more	1.16 (0.80-1.70)				
Alzheimer's disease	0.60 (0.35-1.01)	0.48 (0.29-0.79) [†]			
Cancer	1.00 (0.80-1.01)	1.63 (0.82-1.31)			

CHESS (rating of minimal or greater)		1.24 (1.04-1.49)*	1.45 (1.22-1.71)‡	2.33 (1.62-3.34)‡	2.07 (1.56-2.74)‡
No health instability	1.00				
Minimal	1.14 (0.94-1.39)				
Low	1.34 (1.09-1.67)†				
Moderate or high	1.57 (1.19-2.08)†				
CPS		1.09 (0.93-1.28)	1.12 (0.97-1.29)	4.67 (3.39-6.45) ‡	1.42 (1.14-1.76)†
Intact	1.00				
Border intact	1.19 (0.99-1.43)				
Mild impairment	0.98 (0.77-1.24)				
Moderate impairment	0.69 (0.48-1.00)*				
Dementia	0.86 (0.59-1.24)	0.74 (0.52-1.05)			
Depression Rating Scale(DRS) [§]					
0	1.00	1.00			
1	0.95 (0.75-1.20)	0.95 (0.75-1.19)			
2	0.98 (0.75-1.28)	0.97 (0.75-1.27)			
3	0.95 (0.74-1.21)	0.97 (0.76-1.24)			
Congestive heart failure	1.07 (0.85-1.35)	1.11 (0.88-1.39)			
Pain					
Never	1.00	1.00			
Less than daily	0.89 (0.70-1.13)	0.89 (0.70-1.13)			
Once daily	0.67 (0.48-0.93)*	0.68 (0.49-0.94)*			
2 or more times daily	0.93 (0.77-1.12)	0.96 (0.80-1.16)			
Respiratory disorder	1.02 (0.90-1.16)	1.58 (1.34-1.88)‡			
Goodness-of-fit test	0.219	0.2843			

Variable	OR (95% CI) for hospitalization		
	Model 11	Model 12	Model 13
Caregiver characteristics			
Distressed			
Burned out			
Dissatisfaction	1.29 (1.01-1.65)*	1.19 (0.92-1.54)	1.21 (0.93-1.55)
Recipient predisposing characteristics			
Female	0.79 (0.67-0.93)†	0.81 (0.69-0.96)*	0.81 (0.68-0.95)*
Age			
60-64 years	1.00	1.00	1.00
65-74 years	1.05 (0.75-1.47)	1.06 (0.76-1.49)	1.06 (0.76-1.49)
75-84 years	1.09 (0.79-1.50)	1.12 (0.81-1.54)	1.10 (0.79-1.52)
85 years or older	1.28 (0.93-1.76)	1.32 (0.95-1.84)	1.30 (0.94-1.81)
Recipient enabling characteristics			
Lives with helper			0.96 (0.82-1.12)
Income Category‡			
A	1.00	1.00	
B			
C, D, E, F, or G			
Need characteristics			
ADL impairment		1.35 (1.13-1.60)†	1.37 (1.14-1.64)†
Alzheimer's disease		0.49 (0.29-0.80)†	0.49 (0.30-0.80)†
Cancer		1.04 (0.82-1.30)	1.04 (0.82-1.31)
CHESS (rating of minimal or greater)		1.26 (1.05-1.50)*	1.25 (1.04-1.49)*
CPS (rating other than intact)		1.10 (0.94-1.29)	1.10 (0.94-1.29)
Dementia			
Depression Rating Scale(DRS)§			
0	1.00	1.00	1.00

1		0.96 (0.76-1.21)	0.98 (0.76-1.21)
2		0.99 (0.76-1.28)	0.99 (0.76-1.28)
3		0.99 (0.78-1.26)	0.99 (0.78-1.26)
Congestive heart failure		1.11 (0.88-1.41)	1.11 (0.88-1.40)
Pain			
Never	1.00	1.00	
Less than daily		0.89 (0.70-1.13)	0.88 (0.69-1.12)
Once daily		0.68 (0.48-0.94)	0.67 (0.49-0.94)*
2 or more times daily		0.96 (0.79-1.15)	0.95 (0.79-1.15)
Respiratory disorder		1.57 (1.32-1.86)	1.58 (1.33-1.87)‡
Goodness-of-fit test		0.2809	0.5397

*p< 0.05; † p < 0.01; ‡p<0.001

+Income categories are based on annual income and family size. Category A represents the lowest income category and Category G represents the highest income category.

OR: Odds Ratios CI: Confidence Intervals

§ Odds ratio is adjusted