ASSOCIATIONS BETWEEN CARE PROVIDED IN THE HOME AND HOME DEATH

by

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ABSTRACT

Context: It is projected that the number of annual deaths in Canada will increase from 259,000 in 2011 to 425,000 by 2036. Most Canadians prefer to die at home. Currently, the proportion of individuals receiving formal and informal care is not known in Canada. Formal medical care at home has been associated with home deaths in other countries, but we know little about this association nor the association of formal home support and a home death in Canada. The objectives of this thesis were to examine (1) the proportion of individuals at the end of life receiving formal and informal care in their home in Nova Scotia, (2) the association between receiving formal care at home and having a home death, and (3) the association between the type of formal care at home (medical only or home support with or without medical care) and having a home death. **Methods**: Data came from the population-based mortality follow-back survey conducted in Nova Scotia between 2010-2012. Surrogate respondents, the next-of-kin listed on the death certificate, of Nova Scotians who died in this period answered a survey. This follow-back survey provides a snapshot of the experience of end of life care among adults in Nova Scotia with an emphasis on unmet needs, preferences, and satisfaction with the end of life care that the decedents received. This thesis included the decedents who spent at least one day at home during the last 30 days of life (n=694 for Objective 1 and n=662 for Objective 2) and the decedents who received formal care at home during the last 30 days of life (n=518 for Objective 3). The dependent variable (having a home death) was measured dichotomously. Care at home was measured as receiving formal care at home and receiving informal care at home. Formal care at home included medical care at home as well as home support with or without medical care at home. Through descriptive analysis, I identified the proportion of the decedents receiving care at home at the end of life. Using logistic regression, I examined whether receiving formal care at home is associated with having a home death, after adjustment for demographic, medical, and socioeconomic factors and informant characteristics. Using logistic regression, I examined which type of formal care (medical care at home or home support with or without medical care at home) had a stronger association with a home death, adjusting for the aforementioned variables. **Findings**: In 2010-2012, among those who spent at least one day at home in the last 30 days of life, 92.94% of decedents had care at home and 33.96% of the decedents had died at home. Decedents who received care at home had a higher proportion of individuals who received the majority of care at home. As for the type of care at home among those received care at home, 80.98% of decedents had informal care at home and 78.67% of decedents had formal care at home. Compared to those who did not receive formal care at home, those received formal care at home were 3.38 times more likely to die at home (95% Confidence Intervals [CI]: 1.96-5.85), after adjustment for the decedents' demographic factors, medical factors, socioeconomic factors, and informant characteristics. Among those with good symptom management, after adjustment for the decedents' demographic factors, medical factors, socioeconomic factors, and informant characteristics, receiving home support with or without medical care was 2.76 times (95% CI: 1.57-4.87) more likely to die at home compared to receiving medical care only. **Conclusions**: This study showed that receiving formal care at home was positively associated with a home death. Among those decedents with well-managed symptoms, receiving formal home support with or without medical care at home had a stronger positive association with a home death compared to receiving medical care only at home. This implies that individuals at the end of life need to firstly have their symptoms well managed to be able to die at home. With well-managed symptoms, formal home support had a positive association with a home death.

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CHAPTER 1 – INTRODUCTION

With the aging demographic, it is projected that the number of annual deaths in Canada will increase from 259,000 in 2011 to 425,000 by 2036 (1,2). Most of these deaths will not be sudden, but occur slowly, in old age or at the end of a quality-limiting or chronic illness (3). Today, 58% of Canadians die from cancer and heart disease, and another 16% succumb to stroke, chronic obstructive pulmonary disease and other chronic diseases (4,5). Studies have shown that the majority of the dying prefer that their care and death occur in their home, for example, among those with terminal cancer, 80% prefer to die at home (6). However, there is a discrepancy between preferred and actual location of death as the number of home deaths has increased to only 30% of all deaths in the past twenty years (6-10). Studies show that persons with certain characteristics, such as living with a caregiver and receiving services provided in the home, are more likely to die at home (49, 50).

Among the Canadian population, the utilization of formal care in the home has increased by 7% between 2007 and 2010 (11). Formal care provided in the home not only includes health care services from health professionals (hereafter referred to as medical care), but also housekeeping, meal preparation and assistance with activities of daily living provided by volunteers or agencies outside of friends and family (hereafter referred to as home support). Each province and territory delivers formal care in the home either through public sector employees or through private sector contracts. All provinces deliver formal care but vary widely in the provision of medical care and home support for those who are dying (11).

Those receiving formal care in the home are more likely to die at home (12,13) with either fewer (12) or no difference in the number of emergency department visits in the end of life period (13). The home deaths are associated with better caregiver bereavement outcomes (14). Overall, the few studies conducted in care provided in the home at the end of life have focused on the active pain management and care provided by licensed health care professionals. The current literature does not describe how many individuals at the end of life access formal care provided in the home. In addition, it lacks population representativeness. The majority of research on end of life care focuses on the terminal cancer population, yet, cancer only accounts for 30% of all deaths in Canada. In Nova Scotia, the number of individuals at the end of life receiving services provided in the home is unknown. Furthermore, the different types of formal care provided in the home and their association with home deaths have not been examined.

This study addressed these gaps in the literature to enhance the knowledge that is of value to health care professionals and policy makers in the area of end of life care. Specifically, this study described how many individuals at the end of life received care (formal and informal) in the home in Nova Scotia; investigated the association between receiving formal care at home and the location of death; and investigated the association between the type of formal care (medical care only or home support with or without medical care). This study used data from Canada's first population-based mortality follow-back survey conducted in Nova Scotia. The mortality follow-back survey obtained information from the next-of-kin listed on the death certificate regarding the experience of and care provided at the end of life. This study design allowed for a population-based analysis, which best reflects the needs of the general population at the end of life. This project can contribute to the development of end of life care programs in Nova Scotia by identifying which home care services best assist an individual to die at home and identifying characteristics that may hinder individuals at the end of life from receiving these services.

CHAPTER 2 – BACKGROUND

In Canada, the demand for end of life care is growing as the number of annual deaths has increased from 237,708 in 2008/2009 to 253,241 in 2012/2013 (1). The need for comprehensive palliative care is projected to increase as the "baby-boom" generation enters their senior years. For instance, by 2031 all of the baby-boom generation will be over the age of 65, resulting in 23% of the Canadian population being senior citizens as compared to 15% in 2011 (15). The majority of these baby-boomers will die of a chronic condition as the leading causes of death are cancer, cardiovascular disease and respiratory disease (5). These chronic conditions can be diagnosed by health professionals typically many years before deaths, thus, allowing time to put additional care supports in place.

The aging population results in a larger proportion of the population being at the end of life. "End of life" typically means the six months before the individual's death (16,17). The end of life stage of life includes physical or psychological symptoms, changes in social relationships, beliefs, hopes, expectations, satisfaction and finances. Quality of life becomes a prominent concern at this time. We all wish to have a good death, and one commonly agreed-upon aspect of a good death is the dying having control over the location of death (18,19). From surveys of the preference of location of death among the general public as well as individuals with a terminal conditions, the vast majority of Canadians prefer to die in their home if the adequate amount of care is in place (6, 20, 21). Among terminally ill cancer patients in Nova Scotia, 80% prefer to die at home (22). In Canada, the number of people dying at home has increased (23), yet, the prevalence of deaths at home has only increased to 30% (6-10). The reality is that this "preference in death location" component of achieving a good death does not occur for the majority of dying individuals in Canada. End of life services provided in the home may support home deaths.

Canada is not alone in the difficulty in increasing home deaths. The increase in home deaths is not seen globally. While deaths in the home location have increased in the United States and Australia, they have declined in the United Kingdom, Italy and Japan (23). The decline in home deaths in the United Kingdom is surprising as it has the most comprehensive palliative care services within the European Union (1). The decline is attributed to the poorly coordinated services and the lack of universal standards for delivery of the palliative services (24). End of life services differ both in delivery and financing in different counties. While different countries can learn from each other to some extent, it is important to review the end of life care services in place in Canada.

2.1 What is end of life care?

End of life care is typically defined as care provided during the last six months of life. End of life care addresses the different aspects of care required by the dying individual by managing pain and other symptoms; providing social, psychological, cultural, emotional, spiritual and practical support; supporting caregivers and in providing support for bereavement (25). End of life care is provided in a variety of non-acute settings such as in long term care facilities, hospice or within their home. Acute care hospitals are also providing end of life care. Across Canada, 22% of hospital admissions have a sole diagnosis for palliative care (26), and another 5% were admitted for an alternative level of care such as long term care (26). Of these patients, 34% have a hospital stay of more than two weeks before death (26). Palliative care physicians in Britain consider that 7% of admissions for palliative care were potentially avoidable (2).

End of life care is sometimes referred to as palliative, terminal, or hospice care. Palliative care and hospice care are healthcare services that focus on relieving and preventing the suffering of patients (27). Hospice care provides only comfort care to individuals diagnosed with a terminal illness who are expected to die within six months, whereas palliative care does not have a time limit and life prolonging treatments are not avoided (28). Palliative care is appropriate for patients at all stages of illness and not just at the actively dying phase (29). Hospice and palliative care, however, have converged into one movement with the same principles and norms of practice. Thus, hospice and palliative care are sometimes considered as equivalent, indicated by “hospice palliative care” coined by the Canadian Hospice Palliative Care Association (30). In this project, I consider end of life care and hospice palliative care as synonymous and follow the Canadian Hospice Palliative Care Association’s definition of hospice palliative care which “aims to relieve suffering and improve the quality of living and dying… strives to help patients and families address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears; prepare for and manage self-determined life closure and the dying process; and, cope with loss and grief during the illness and bereavement" (35).

2.2 What is end of life care in the home?

Care in the home includes formal care provided by professionals as well as informal care provided by family and friends. With the increase of 1.2 million Canadians receiving formal care in the home in 2007 to 1.4 million Canadians receiving formal care in the home in 2012, formal care in the home are the fastest growing sector of the Canadian health care system (11). One in seven seniors over the age of 65 receive formal care in the home (11). Below I first explain delivery and finance of care in the home in general and then care in the home pertaining to end of life.

Care in the home umbrellas several services including home support and medical care. Home supports include the provision of personal hygiene, meal preparation and housekeeping. Personal hygiene/grooming encompasses the home care worker either supervising or assisting activities of daily living including hygiene, toileting, dressing, feeding, and mobility. Meal preparation includes assisting the individual with meal preparation, nutritional care and menu planning. Housekeeping includes assisting in the instrumental activities of daily living such as general housecleaning, laundry and changing linen (32). Medical care includes nursing assessments; performing nursing treatments and procedures; teaching and supervising self-care to clients receiving personal care; teaching personal care to family members and caregivers; rehabilitative exercises for pain management; providing personal care from a nurse; and initiating the referral process to external services. The intent of formal care in the home is to help individuals remain as independent as possible for as long as possible (33). These services allow people who suffer from some mental or physical incapacity to maintain their independence within their home setting.

Under the Canada Health Act, formal care in the home are lumped within the "extended health service” category (11). This means that formal care in the home is not covered under Medicare, and, therefore, publicly funded, universal, comprehensive formal care in the home are not available across Canada (11). However, due to the recognized value of these services, provinces and territories have funded formal care in the home for their residents. On average, Canadian provinces and territories spent 4% of their health care budgets on formal care in the home setting in 2010 (11). In 2010/2011, $5.9 billion was spent on formal care in the home nationally (11). This is minimal when compared to the national health care expenditure in the same timeframe of $200 billion (26). Furthermore, an estimated $1.5 billion was spent out-of-pocket and through private health insurance in order to pay for formal care in the home in 2010 (34). Combined, Canada spent publicly and privately between $7.09 billion and $8.7 billion on formal care in the home (34).

Each province and territory sets the eligibility criteria for publicly funded formal care in the home. The province or territory determines the extent of the coverage for the services provided in the home based on the acuity of illness, financial means of the individual and the health care budget allocated to home care services. Four provinces (British Columbia, Ontario, Manitoba and Prince Edward Island) have legislation or an Order in Council that defines and governs the delivery of formal care in the home (11). All provinces and territories provide medical care in the home through public sector employees such as registered nurses, homemaking and personal care services through private sector contracts. Alternatively, individuals receive monthly stipends and pay for formal care in the home from an agency that they hire (34). All provinces provide nursing services but vary widely in the provision of therapy services. Some programs provide all therapies (physiotherapy, occupational therapy, speech language therapy, respiratory therapy, dieticians and social work), some or none of the therapies (11). Formal care is available 24/7 in all provinces except in Prince Edward Island, Newfoundland and Labrador as well as in the territories where the access to formal care in the home is based on geography and population density (11).

The Canadian Home Care Association defines formal care in the home as an array of services for people of all ages, provided in the home and community setting that encompasses several services including end of life care (11). End of life formal care in the home are the services provided to individuals in the last six months of their life in the home setting. These services provide active, compassionate care to terminally ill individuals. In our knowledge, there is no publicly accessible information on the number of people at the end of their lives receiving formal care in the home.

When individuals are deemed to be at the end of their life by a physician and the formal care provider is notified as such, there is no restriction for a number of hours nor number of visits for formal care in the home in all provinces and territories (11). The medications and supplies available in the home setting vary widely between the provinces and territories. End of life care supplies and medications are covered by the public system, but the duration of coverage varies depending on the province's criteria for being deemed at the end of life (11). Formal care in the home for seniors with less than six months to live costs and uses roughly double the resources required for services provided in the home for other recipients (34).

2.3 Are end of life formal care in the home associated with home deaths?

Shepperd, Wee and Straus hypothesized that by having formal care in the home, the individual can live and die in their home with fewer hospital visits (35). Formal care in the home aims to reduce pain and increase the level of functioning of the individual. Even though these can be achieved in health facilities, the best place to maintain the highest level of functioning is in the individual's own home. Furthermore, providing end of life formal care in the home allows the dying and their family to have a choice of where and when they want care and, in turn, the location of death. These choices allow the individual to die with dignity.

To determine the effectiveness of end of life formal care in the home, Shepperd, Wee and Straus conducted a systematic review. They included four studies in their review (12-14, 36) and concluded that individuals receiving formal end of life care in the home were statistically significantly more likely to die at home compared with those receiving informal care (relative risk [RR] 1.33, 95% confidence interval [CI] 1.14-1.55, p-value=0.0002). They did not detect a statistically significant difference in functional status, psychological well-being or cognitive status between those receiving home based end of life formal care and those receiving only informal care (35).

The individual studies included in this systematic review identified additional benefits of end of life formal care in the home. Formal care in the home eased the practical and emotional difficulties experienced by the individual and their caregivers (12, 36). Pain and symptom relief, patient and family education and training provided in the home by the interdisciplinary team did not increase patient survival nor enhance their activities of daily living, cognitive functioning nor morale (36). Those receiving formal care in the home were more likely to die at home (12,13) with either fewer (12) or no difference in the number of emergency department visits in the end of life period (13). The home deaths were associated with better caregiver bereavement outcomes (14). Overall, the four studies included in this systematic review focused on the active pain management and care provided by licensed health care professionals.

This systematic review only included randomized trials. Other studies, using observational study designs, also examined the association between end of life formal care in the home and location of death. Enguidanos et al. (2005), with a cohort design, examined the effectiveness of formal palliative care in the home setting for terminally ill, home-bound Americans diagnosed with cancer, congestive heart failure or chronic obstructive pulmonary disease with a prognosis of approximately one year. They found that patients enrolled in the home palliative care program were statistically significantly more likely to die at home than those not enrolled in the program (37). A Swedish prospective cohort study conducted by Gyllenhammar et al (2003) supports these findings. The researchers reported that 53% of patients with incurable cancer that had been admitted to palliative home care died at home (38). See Appendix 3: Effectiveness of Care at Home at the End of Life for a summary of study findings regarding effectiveness services provided in the home at the end of life.

2.4 What other factors are known to influence the location of death?

The location of death is influenced by factors other than services provided in the home. To determine the predictors of a home death in palliative care patients, Gill, Laporte and Coyte (2013) conducted a critical literature review of 26 studies. They found that there was a large degree of variability in the literature on predictors of a home death among palliative care patients. Overall, predictors of a home death are: the presence of a caregiver, acute distress, older age, cause of death, sex, marital status, education, location of residence, functional dependence, home visits, re-hospitalization and income (39). Whether these predictors increase or decrease the likelihood of dying at home is inconclusive (42-44) (Appendix 4: Factors that Influence the Location of Death).

2.5 Limitations of the current literature

2.5.1 Lack of population representativeness

Studies using a representative sample of the general decedent population have not been conducted in Canada. The vast majority of studies in Canada pertaining to locations of death and health care utilization focused on cancer patients (51). Palliative care is frequently used as the location of participant recruitment, and 90% of individuals enrolled in palliative care services within Nova Scotia have cancer. This is not representative of the palliative population, as only 30% are diagnosed with cancer (52). Palliative care patients are more likely to die in their home, yet the population receiving palliative care services is not representative of the end of life population based on terminal illness (6). Most of these deaths are not sudden, but occur slowly, in old age or at the end of a quality-limiting or chronic illness (3). Within Canada, an estimated 644 people die everyday (1), and 58% of these Canadians die from cancer and heart disease, while another 16% succumb to stroke, chronic obstructive pulmonary disease and other chronic diseases (5, 52). Overall, many studies are limited to small samples of palliative patients in select settings and populations, therefore limiting the generalizability of results. Population-based studies regarding end of life care have been conducted internationally. Mortality follow-back surveys have been conducted in the United Kingdom, the United States and Italy to gain a holistic perspective of care at the end of life (9, 51, 53-61). The first mortality follow-back survey in Canada has recently been conducted in Nova Scotia. The association between services provided in the home and location of death has not been prominently researched at a population level.

2.5.2 Emphasis on medical services provided in the home

In addition to the active pain management and care provided by licensed health care professionals to recipients at the end of their life, formal care in the home also includes housekeeping, meal preparation, assistance with activities of daily living and family care. Few study have examined the association between the location of death and home support in the home. This is likely due to difficulties in capturing the wide range of home support that can be provided by public services, private services as well as volunteer organizations.

An examination of the association between home support and the location of death has potential to assist health policy in aging populations. The emphasis on formal medical care in the home in research may have contributed most of the home care service budgets going to health professional interventions (34). There may be a missing opportunity if other services provided in the home serve critically the complex needs of the palliative population.

CHAPTER 3 - OBJECTIVES

The overall goal of this study was to shed light on services provided to individuals at the end of life in their homes to assist policy. To meet this overall goal, I asked the following specific research questions:

(1) What is the proportion of the individuals at the last month of life who received formal and informal care at home in Nova Scotia?

(2) What is the association between receiving formal care at home and having a home death?

(3) Which type of formal care at home (medical only or home support with or without medical care) has stronger association with home death?

CHAPTER 4 - METHODS

4.1 Data

Data for this study came from the population-based mortality follow-back survey conducted in Nova Scotia in 2010-2012. This was the first mortality follow-back survey conducted in Canada. This survey provides valuable information that is otherwise unattainable through administrative data, such as unmet home support needs, factors associated with end of life care, symptom management, patient preferences and perceptions of the caregiver. The survey provides a snapshot of the experience of end of life care among adults in Nova Scotia with an emphasis on unmet needs, preferences, and satisfaction with the end of life care that the decedents received.

The study population was Nova Scotians who died between June 1, 2009 and May 31, 2011, and surrogate respondents were the next-of-kin listed on the death certificate. Excluded from the study population were decedents under the age of 18 as well as those with external causes of death, such as unintentional injury, motor vehicle accidents, intentional self-harm, assault, legal interventions, events of undetermined intent, medical or surgical complications and known to be sudden deaths. These causes of death are unpredictable and therefore would not have warranted end of life care. Death certificates with missing contact information for the next-of-kin were also excluded, as the proxy could not be contacted. The majority of death information became available in Nova Scotia Vital Statistics 3 to 6 months following the date of death. The survey had a response rate of 25%, resulting in 1316 next-of-kin participants.

The questionnaire administered was an adaptation of the “After-death bereaved family member interview” (52). This questionnaire has been evaluated to be valid and reliable (58). The questions pertained to care, needs and care preferences of the decedent in the last month and last few days of their life. This subjective measure provides a holistic view of the end of life care provided. Unlike administrative data, this survey provides information both on formal and informal care. Trained interviewers asked the informant questions over the telephone and recorded the answers both on paper and electronically. Each interview took between 30 and 45 minutes. All surveys were conducted with the informant within one year of the decedent’s death.

The data reside in the Department of Family Medicine, Dalhousie University.

For the analysis for each objective of this study, I established the following exclusion criteria (Figure 1). For objective 1, I excluded respondents if the decedent did not spend at least one day at home during the last 30 days of life. This exclusion resulted in the sample size of 694 for descriptive analysis. In addition, for objective 2, I excluded respondents (a) if they died in transit or (b) if they were missing pertinent data. These exclusions resulted in a sample size of 662 for the analysis for objective 2. Furthermore, for objective 3, I excluded respondents (c) if they did not receive formal care at home or (d) if they were missing pertinent data. These exclusions resulted in a sample size of 518 for analysis for objective 3.

4.2 Variables

4.2.1 Home death (dependent variable)

The dependent variable, home death is dichotomous (died at home vs. did not die at home). It was constructed based on the survey question, “Where did [DECEDENT’S] death take place?” The decedent was considered to have a home death if the informant responded favourably to option (a) at home (assisted living included). The decedent did not die at home if the respondent answered (b) in a hospital or (c) nursing home or other long-term care facility.

4.2.2 Care in the home variables (independent variables of main interest)

I created four variables regarding care in the home.

Use of informal care: I created a dichotomous variable, having informal care in the home during the last month of life or not. I assigned decedents as having informal care in the home if respondents responded positively the following question: “While [DECEDENT] was at home, did family members or friends help with his/her care?” I used this variable for the descriptive analysis.

Use of formal care: I created a dichotomous variable, having formal care in the home during the last month of life or not. I assigned decedents as having formal care in the home if the respondent responded “home” to the question “In what locations was specialized palliative care provided?” or if the respondents responded positively to at least one of the following questions: (1) “At any time during this last month did [DECEDENT] get any services from a home care agency?”; (2) “At any time during the last month while at HOME did [DECEDENT]’s get any services from a visiting nurse (e.g., VON)?”; or (3) “While at home during [DECEDENT]’s last 30 days, did she/he have a family doctor visit them in the home?” I used this variable in the analysis for objective (1) and (2).

Type of formal care: I created two variables regarding the type of formal care. First, I created a variable with the following three subcategories: medical care only, home support only, medical care and home support. Decedents had medical care if they answered having received nursing care, palliative care, medication management, respiratory care, mental health care, social work, or speech therapy, or they answered favorably to the question: “While at home during [DECEDENT]’s last 30 days, did she/he have a family doctor visit them in the home?” Decedents had home supports if they answered housekeeping, meals or personal hygiene/grooming to the question: “And what type of care was provided by the home care service (e.g. nursing, housekeeping)?” I classified decedents as: (1) having medical care only if they had medical care but did not receive home supports; (2) having home supports only if they had home supports but did not receive medical care; and (3) having medical care and home support if they received both medical care and home support. I used this variable for the descriptive analysis. Next, I created a dichotomous variable: medical care only vs. home support with or without medical care. I classified decedents as either “having home support with or without medical care” if they were previously classified as home support only or medical care and home support or not. I used this variable for analysis for objective 3.

4.2.3 Factors that influence the location of death

I included factors known to influence location of death: demographic factors, socioeconomic status, cause of death, and health care factors of the decedents and education of the informants. Health care factors include a symptom management variable. This variable is based on the rating between 0 (the worst care possible) and 10 (the best care possible) for the question: “How well did those taking care of decedent make sure his/her symptoms were controlled to a degree that was acceptable to him/her?” I created a dichotomous variable, symptom well-managed during the last month of life or not, by assigning decedents as having symptoms well-managed if the response was 10. Appendix 5: Associations between dying at home and receiving formal care, among those that spent at least one day at home in the last 30 days of life in Nova Scotia, June 1, 2009 – May 31, 2011 (n=662) describes details of all other independent variables.

4.3 Analysis

4.3.1 Descriptive analysis for research question 1: What is the proportion of individuals at the last month of life who received formal and informal care at home in Nova Scotia?

I described the distribution of each variable associated with the location of death. I also described the distribution of those with care in the home and those without. In addition, I described the type of care in the home (formal or informal).

4.3.2 Analysis for research question 2: What is the association between receiving formal care at home and having a home death?

I examined whether receiving formal care at home was associated with home death using the logistic regression model in the following form:

$$y_i = \alpha + \beta X_i + \gamma Z_i + \varepsilon_i \qquad (1)$$

where y_i is the location of death for individual i, X_i is a vector for receiving formal care at home, Z_i is a vector of other factors (age, sex, decedent marital status, cause of death, symptom management, education, location of majority of care, informant characteristics and additional health insurance coverage) and ε_i is an error term.

4.3.3 Analysis for research question 3: Which type of formal care at home (medical only or home support with or without medical care) has stronger association with home death?

I examined whether the type of formal care at home is associated with home death using the logistic regression model in the following form:

$$y_i = \alpha + \beta V_i + \gamma U_i + \varepsilon_i \qquad (2)$$

where y_i is the location of death for individual i, V_i is a vector of the type of formal care at home (medical care only or home support with or without medical care), U_i is a vector of other factors (age, sex, decedent marital status, cause of death, symptom management, education, location of majority of care, informant characteristics and additional health insurance coverage) including the interaction term (type of formal care at home x symptom management), and ε_i is an error term. In addition, I conducted stratified analysis by symptom management (symptoms well managed and symptoms not well managed).

4.3.4 Goodness-of-fit of models

To test the fit of all logistic regression models, I used Hosmer-Lemeshow goodness of fit. For all analyses, I considered p<0.05 as statistically significant. I used Stata 13 for all analyses.

4.4 Ethics

The original project for the mortality follow-back survey (Principal Investigator: Dr. Fredrick Burge) obtained ethics approval from the Capital Health Research Ethics Board. This thesis was a secondary analysis of the mortality follow-back survey and did not require additional ethics approval (Appendix 7: Ethics Approval).

CHAPTER 5 - RESULTS

5.1 Characteristics of the decedents receiving care at home

Of the 694 decedents who had spent at least one day at home during the last 30 days of life, 92.94% of decedents had care at home. Decedents who received care at home had a significantly higher proportion of having received the majority of care at home ($p<0.05$) (Table 2). As for the type of care at home, 80.98% had informal care at home and 78.67% had formal care at home (Table 1a). Decedents who received formal care at home had a higher proportion of cancer diagnoses, having symptoms well managed, and receiving the majority of their care at home (Table 3). Of those who received formal care at home, 54.98% received medical care only and 45.02% received home support with or without medical care (Table 1b). Compared to those who received medical care only at home, those who received home support at home with or without medical care had a higher proportion of older decedents, a non-cancerous cause of death, not being married, and having home as the location of the majority of care during the last 30 days of life (Table 4).

Of the 692 decedents who had spent at least one day at home during the last 30 days of life and did not die in transit, 235 (33.96%) died at home (Table 5). Compared to those died elsewhere, a greater proportion of those died at home died of cancer, had well managed symptoms, had the majority of their care at home and received formalized care ($p<0.05$).

5.2 Association between receiving formal care at home and having a home death

Unadjusted analysis showed that death at home was statistically significantly associated with receiving formal care at home, death due to cancer, living with others, having the majority of care at home and symptoms being well managed ($p<0.05$) (Table 6). Compared to those who did not receive formalized care at home, those who received formal care at home were 4.17 times more likely to die at home (95% confidence intervals [CI]: 2.49-6.97). Those who died of cancer were 2.04 times more likely to die at home than those who died of other causes (95% CI: 1.47-2.85). Those with well-managed symptoms were 1.61 times more likely to die at home than those with poorly managed symptoms (95% CI: 1.16-2.23). Those living with others were 1.59 times more likely to die at home than those living alone (95% CI: 1.06-2.39). Those receiving the majority of their care at home were 6.87 times more likely to die at home than those receiving the majority of their care in another location (95% CI: 4.04-11.69).

I ran a series of models to adjust for the decedents' demographic factors, medical factors, socioeconomic factors, and informant characteristics with interaction terms (Appendix 5: Associations between dying at home and receiving formal care, among those that spent at least one day at home in the last 30 days of life in Nova Scotia, June 1, 2009 – May 31, 2011 (n=662)). Statistically significant interaction terms were formal care at home and symptoms well managed (p=0.00) and formal care at home and cancer cause of death (p=0.01). Large standard errors for these interaction terms suggested that these estimates were unstable due to small numbers. I decided to exclude the interaction terms from the final model. The Hosmer-Lemeshow goodness-of-fit test for the full model was not significant (p=0.53), indicating the full model fits the data well. The parsimonious model (including only the type of services at home and cancer as a cause of death as independent variables), on the other hand, did not fit the data well (the Hosmer-Lemeshow goodness-of-fit test, p=0.04). Thus, the final model includes demographic factors, medical factors, socioeconomic factors and informant characteristics as independent variables.

After adjustment for the decedents' demographic factors, medical factors, socioeconomic factors, and informant characteristics, formal care at home remained statistically significant (p<0.05) (Table 6). Compared to those who did not receive formal care at home, those who received formal care at home were 3.38 times more likely to die at home (95% CI: 1.96-5.85). Those who died of cancer were 1.62 times more likely to die at home than those who died of other causes (95% CI: 1.09-2.39). Those receiving the majority of their care at home were 6.06 times more likely to die at home than those receiving the majority of their care in another location (95% CI: 3.51-10.46).

5.3 Association between type of formal care at home and having a home death

Among those receiving formal care, unadjusted analysis showed that death at home was statistically significantly associated with receiving home support with or without medical care at home, death due to cancer, having the majority of care at home and symptoms being well managed ($p<0.05$) (Table 7). Compared to those who received medical care only at home, those who received home support with or without medical care at home were 1.70 times more likely to die at home (95% CI: 1.19-2.42). Those who died of cancer were 2.09 times more likely to die at home than those who died of other causes (95% CI: 1.44-3.02). Those with well-managed symptoms were 1.71 times more likely to die at home than those with poorly managed symptoms (95% CI: 1.20-2.43). Those receiving the majority of their care at home were 6.05 times more likely to die at home than those receiving the majority of their care in another location (95% CI: 3.45-10.60).

I ran a series of models to adjust for the decedents' demographic factors, medical factors, socioeconomic factors, and informant characteristics with interaction terms (Appendix 6: Associations between dying at home and type of formal care received, among those that received formal care at home during the last 30 days of life in Nova Scotia, June 1, 2009 - May 31, 2011 ($n=518$)). Statistically significant interaction terms were home support with or without medical care at home and symptoms well managed ($p<0.05$). The Hosmer-Lemeshow goodness-of-fit test for the full model was not significant ($p=0.77$), indicating this model fits the data well. This model fits the data better than the full model with significant and non-significant model ($p=0.22$). Thus, the final model includes type of formal care at home, cancer as a cause of death, symptom management, location of majority of care and type of care at home x symptom management interaction terms.

In the final model with the interaction term, the type of formal care at home was statistically significantly associated with home death through the main effect and interaction term. Those who died of cancer were 2.06 times more likely to die at home than those who died of other causes (95% CI: 1.38-3.08). Those receiving the majority of their care at home were 5.25 times more likely to die at home than those receiving the majority of their care in another location (95% CI: 2.96-9.33). The stratified analysis (Table 8) shows that the type of formal care was statistically significant only among those with good symptom management. Among them, compared to receiving medical care only, receiving home support with or without medical care was 2.76 times (95% CI: 1.57-4.87) more likely to die at home.

CHAPTER 6 - DISCUSSION

Using the population-based mortality follow-back survey conducted in Nova Scotia in 2010-2012, this study identified that 92.94% of decedents who spent at least one day at home in the last 30 days of life had care at home. Furthermore, the type of care at home was associated with home death. Individuals with formal care at home were more likely to die at home compared to those individuals who did not receive formal care at home. Among those receiving formal care at home and whose symptoms were well-managed, having home support with or without medical care at home was positively associated with a home death. These results may encourage other researchers to conduct similar studies in provinces outside of Nova Scotia. In addition, these results might prompt clinicians to increase their formal home care referral practices. Furthermore, these results might be of use for home care policy planning both provincially and nationally by encouraging the strengthening of home support components of home care and/or the eligibility criteria for patients.

A primary result of this study is that the type of formal care at home was associated with whether the individual died at home. The type of formal care at home had an association with the location of death among those decedents with well-managed symptoms. Compared to those with medical care only at home, those with home support with or without medical care at home were more likely to die at home. To the best of my knowledge, this is the first study to examine which type of formal care provided in the home increases the likelihood of an individual to die at home. These results suggest that individuals wanting to have a home death must have well-managed symptoms in order to receive any benefits from formal care in the home. When symptoms are well-managed, having home support in addition to medical care at home is more beneficial in achieving a home death. Therefore, individuals with well-managed symptoms at the end of life who want to die at home can benefit from formal medical care at home and home supports in order to achieve a home death. These results are consistent with findings in the United States, United Kingdom and Norway (12-14, 37), where individuals at the end of life with services provided at home had a statistically significant association with a home death compared to those without services provided in the home.

At the end of life, 78.67% had formal care at home in Nova Scotia. Decedents who were more likely to receive formal care at home had cancer diagnoses, had symptoms well managed, and received the majority of their care at home. These results suggest that formal care at home were provided to the majority of individuals at the end of life in Nova Scotia.

This study has at least the following limitations: (1) a potential bias due to retrospective data collection from surrogates; (2) a possibility of misclassification bias in our definition of types of services at home (medical care only vs. home support with or without medical care); (3) inability to examine effects of home support only on a home death; (4) omission of some factors that are likely to influence the location of death; (5) relatively small sample size; (6) determination of the variable "symptoms well-managed" and (7) low response rate of the mortality follow-back survey.

This study used retrospective data collected from surrogates, that is, this study relies on the informant to remember events of the past accurately. This study is subject to recall bias of the exposure (care at home). Furthermore, this study is subject to the surrogate response bias as the informant is providing information about another person. The informant may not know whether the decedent had care at home nor the type of care at home. This study assumes that the informant knew who was providing the care at home, what their role in the decedent's care was, and how many different types of care at home the decedent received. The responses from the informant may not always coincide with the care at home actually received by the decedent. Therefore, the classification of the exposure may be incorrect for some individuals. Informants are more likely to identify anyone coming to provide care at home as a "nurse". This would lead to misclassifying some decedents having had home support as having had medical care at home. This misclassification could underestimate the true effect of medical care at home and overestimate the true effect of home support.

I could not create a variable category that indicated home support only. The home support with or without medical care at home category used in this study includes individuals who only received home support as well as individuals who received both medical care and home support. The reason why I could not create an exclusive, home support only variable was due to a small number of individuals only having home support, resulting in unstable estimates. This may underestimate or overestimate the effect of formal home supports.

This study did not adjust for some factors that are known to influence the location of death because they are not available in the Nova Scotia mortality follow-back survey. Factors such as acute distress, location of residence and functional dependence have been shown to predict the location of death (39), but were unavailable in the Nova Scotia mortality follow-back data. With the omission of these factors, this study may not reflect the true associations between care provided at home and home deaths.

This study has a relatively small sample size for the analyses attempted. The relatively small sample size did not allow me to create some variables (e.g., home support only) and a fuller exploration of interaction terms due to unreliable estimates.

I created the dichotomous “symptom management” variable based on a scale from 0 (not managed) to 10 (best possible care) with a cut-off point of 10. With this measure, I captured any concerns with the symptom management displayed by the decedent during the last 30 days of life, but admittedly I used a very stringent criterion. In this study, individuals with clinically well-managed symptoms would be classified as having not well-managed symptoms if the informant selected 8 or 9 from the scale. The symptom management variable in this study may have underestimated the positive association between home support with or without medical care in the home and home death among those with well-managed symptoms.

The response rate of the mortality follow-back survey was 25%. This was attributed to the inability to directly contact potential informants, inability to confirm that the intended informant received the mailed invitation or not and the highly emotional context of the survey. The decedents were relatively representative of death statistics for Nova Scotia reported by Statistics Canada with respect to cause of death, age and sex (62). The informants in the mortality follow-back survey indicated a low perception of unmet need with respect to symptom control but a high perception of unmet needs with respect to obtaining information, knowing what to expect and supporting emotional and spiritual needs of the family. These differences in perceptions suggests the study sample may not be representative of the Nova Scotian population, and the results of this study may not be generalizable.

Despite these limitations, this study has at least the following strengths: (1) it addresses health policy issues of growing need and concern; (2) it used a unique mortality follow-back survey; and (3) it used population-based data.

These results will be of interest to researchers, clinicians, and policy makers. This study can encourage other researchers to conduct similar studies in provinces outside of Nova Scotia. In addition, the strong associations between formal care in the home and home deaths might prompt clinicians to reconsider their home care referral practice. Furthermore, results of this study might be of use for home care policy planning both provincially and nationally. Examples include: Ontario's "Declaration of Partnership and Commitment to Action" which is a shared vision and goal to achieve immediate and long term improvements in palliative care delivery; New Brunswick's "Provincial Palliative Care Strategy" that will address the continuum of care setting; the development of a comprehensive provincial palliative care program and palliative care strategy by the Department of Health and Wellness in Nova Scotia, which will include strategies for enhancing home care services, coordination across multiple care settings, access to medications and specialized resources; and Prince Edward Island's "Integrated Palliative Care Program" that ensures access to palliative specialists, respite, and psychosocial support during and after deaths.

The Nova Scotia mortality follow-back survey is the first mortality follow-back survey conducted in Canada. This survey provides valuable information that is otherwise unattainable through administrative datasets. This includes unmet home support needs, factors associated with end of life care, symptom management, patient preferences and perceptions of the caregiver.

In addition, the Nova Scotia mortality follow-back survey provides population-based information on end of life. The association between services provided at home and the location of death has rarely been studied in Canada at the population level. The current literature is limited by small palliative samples in specific care locations or by cause of death. The use of the population-based data increases the generalizability of the findings of this study to other locations outside of Nova Scotia.

CHAPTER 7 - CONCLUSION

This study identified that receiving formal care at home was positively associated with a home death. Among those decedents with well-managed symptoms, receiving formal home support with or without medical care at home had a stronger positive association with a home death compared to receiving medical care only at home. This implies that individuals at the end of life need to firstly have their symptoms well managed to be able to die at home. With well-managed symptoms, formal home support had a positive association with a home death. The results of this study support the importance of providing formal home supports in addition to medical care only in the home for individuals with well-managed symptoms. This information will be useful for the development of a comprehensive provincial palliative care program by the Department of Health and Wellness in Nova Scotia.

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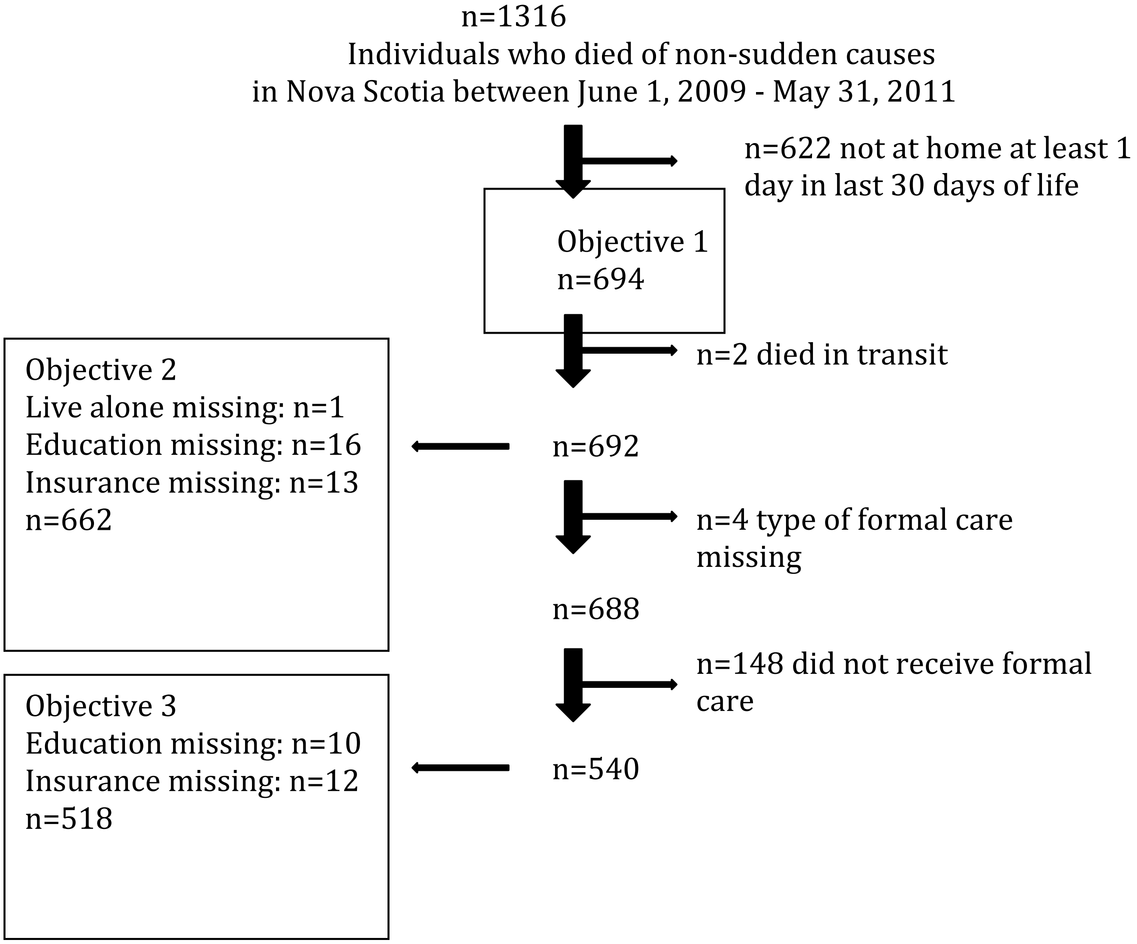
Appendix A: Figures

Figure 1: Exclusion Criteria



Objective 1: What is the proportion of the individuals at the last month of life who accessed formal and informal care at home in Nova Scotia?
Objective 2: What is the association between receiving formal care at home and having a home death?
Objective 3: Which type of formal care at home (medical only or home support with or without medical care) has stronger association with home death?

Appendix B: Tables

Table 1a: Use of formal and informal care during the last 30 days of life, Nova Scotia, June 1, 2009 - May 31, 2011 (n=694)

Formal care	Informal care Frequency (percent)			
	Did not have informal care	Had informal care	Missing	Total
Did not have formal care	49 (62.03)	99 (17.62)	0 (0.00)	148 (21.33)
Had formal care	30 (37.97)	462 (82.38)	53 (100.00)	546 (78.67)
Total	79 (100)	562 (100)	53 (100)	694 (100)

Table 1b: Use of informal care and type of formal care during the last 30 days of life, Nova Scotia, June 1, 2009 - May 31, 2011 (n=546)

Type of formal care	Informal care Frequency (percent)			
	Did not have informal care	Had informal care	Missing	Total
Medical care only	15 (50.00)	230 (49.68)	53 (100.00)	298 (54.58)
Home support only	2 (6.67)	28 (6.05)	0 (0.00)	30 (5.49)
Medical care and home support	13 (43.33)	201 (43.41)	0 (0.00)	214 (39.19)
Missing	0 (0.00)	4 (0.86)	0 (0.00)	4 (0.73)
Total	30 (100)	463 (100)	53 (100)	546 (100)

Formal care includes the care provided by contracted professionals outside of family and friends.
Informal care includes the care provided by family members and friends.
Medical care includes nursing care, palliative care, medication management, respiratory care, mental health care, social work, speech therapy and physician home visits.
Home support includes assistance with personal hygiene, housekeeping and meal preparation.

Table 2: Use of care at home during the last 30 days of life by sample characteristic, Nova Scotia, June 1, 2009 - May 31, 2011 (n=694)

Characteristic	Frequency (percent)		
	All	Did not have care at home	Had care at home
Total	694 (100.00)	49 (100.00)	645 (100.00)
Decedent characteristic			
Sex			
Male	389 (56.05)	33 (67.35)	356 (55.19)
Female	305 (43.95)	16 (32.65)	289 (44.81)
Age group			
19-64 years	151 (21.76)	11 (22.45)	140 (21.71)
65-84 years	340 (48.99)	26 (53.06)	314 (48.68)
85+ years	203 (29.25)	12 (24.49)	191 (29.61)
Education (highest level)			
Completed postsecondary	218 (31.41)	13 (26.53)	205 (31.78)
High school diploma	210 (30.26)	19 (38.78)	191 (29.61)
Less than high school	249 (35.88)	15 (30.61)	234 (36.28)
Don’t know	17 (2.49)	2 (4.08)	15 (2.33)
Private health insurance			
Yes	393 (56.63)	25 (51.02)	368 (57.05)
No	286 (41.21)	23 (46.94)	263 (40.78)
Missing	15 (2.16)	1 (2.04)	14 (2.17)
Cause of death			
Cancer	361 (52.02)	19 (38.78)	342 (53.02)
Not cancer	333 (47.98)	30 (61.22)	303 (46.98)
Symptom Management			
Symptoms well managed	315 (45.39)	19 (38.78)	296 (45.89)
Symptoms not well managed	379 (54.61)	30 (61.22)	349 (54.11)
Marital status			
Married	418 (60.23)	31 (63.27)	387 (60.00)
Not married	276 (39.77)	18 (36.73)	258 (40.00)
Lived alone			
Yes	155 (22.33)	9 (18.37)	146 (22.64)
No	538 (77.52)	40 (81.63)	498 (77.21)
Missing	1 (0.14)	0 (0.00)	1 (0.16)
Location of the majority of care ‡			
Home	511 (73.63)	24 (48.98)	487 (75.50)
Not at home	183 (26.37)	25 (51.02)	158 (24.50)
Informant characteristic			
Education (highest level)			
Completed postsecondary	355 (51.15)	25 (51.02)	330 (51.16)
High school diploma	242 (34.87)	13 (26.53)	229 (35.50)
Less than high school	94 (13.54)	10 (20.41)	84 (13.02)

Characteristic	Frequency (percent)		
	All	Did not have care at home	Had care at home
Don’t know	3 (0.43)	1 (2.04)	2 (0.31)

Differences were assessed using the Chi square test: $^{*}p<0.05$; † $p < 0.01$; $^{\ddagger}p<0.001$; $^{\S}p<0.0001$

Care at home includes any individual coming to the decedent’s home to provide assistance (informal or formal care)

Table 3: Use of formal care at home during the last 30 days of life by sample characteristic, Nova Scotia, June 1, 2009 - May 31, 2011 (n=694)

Characteristics	Frequency (percent)		
	All	Did not have formal care at home	Had formal care at home
Total	694 (100.00)	148 (100.00)	546 (100.00)
Decedent characteristic			
Sex			
Male	389 (56.05)	85 (57.43)	304 (55.68)
Female	305 (43.95)	63 (42.57)	242 (44.32)
Age group			
19-64 years	151 (21.76)	27 (18.24)	124 (22.71)
65-84 years	340 (48.99)	80 (54.05)	260 (47.62)
85+ years	203 (29.25)	41 (27.70)	162 (29.67)
Education (highest level)			
Completed postsecondary	218 (31.41)	42 (28.38)	176 (32.23)
High school	210 (30.26)	51 (34.46)	159 (29.12)
Less than high school	249 (35.88)	49 (33.11)	200 (36.63)
Don't know	17 (2.49)	6 (4.05)	11 (2.01)
Private health insurance			
Yes	393 (56.63)	67 (45.27)	219 (40.11)
No	286 (41.21)	79 (53.38)	314 (57.51)
Missing	15 (2.16)	2 (1.35)	13 (2.38)
Cause of death[‡]			
Cancer	361 (52.02)	48 (32.43)	313 (57.33)
Not cancer	333 (47.98)	100 (67.57)	233 (42.67)
Symptom Management[†]			
Symptoms well managed	315 (45.39)	52 (35.14)	263 (48.17)
Symptoms not well managed	379 (54.61)	96 (64.86)	283 (51.83)
Marital status			
Married	418 (60.23)	93 (62.84)	325 (59.52)
Not married	276 (39.77)	55 (37.16)	221 (40.48)
Lived alone			
Yes	155 (22.33)	29 (19.59)	126 (23.08)
No	538 (77.52)	119 (80.41)	419 (76.74)
Missing	1 (0.14)	0 (0.00)	1 (0.18)
Location of the majority of care[‡]			
Home	511 (73.63)	91 (61.49)	420 (76.92)
Not at home	183 (26.37)	57 (38.51)	126 (23.08)
Informant characteristic			
Education (highest level)			
Completed postsecondary	355 (51.15)	69 (46.62)	286 (52.38)
High school diploma	242 (34.87)	51 (34.46)	191 (34.98)

Characteristics	Frequency (percent)		
	All	Did not have formal care at home	Had formal care at home
Less than high school	94 (13.54)	27 (18.24)	67 (12.27)
Don’t know	3 (0.43)	1 (0.68)	2 (0.37)

Differences were assessed using the Chi square test: $^{*}p<0.05$; † $p < 0.01$; $^{\ddagger}p<0.001$; $^{\S}p<0.0001$

Formal care includes the care provided by contracted professionals outside of family and friends.

Table 4: Type of formal care received at home during the last 30 days of life by sample characteristic, Nova Scotia, June 1, 2009 - May 31, 2011 (n=542)

Characteristics	Frequency (percent)	
	Medical care only	Home support with or without medical care
Total	298 (100.00)	244 (100.00)
Decedent characteristics		
Sex		
Male	175 (58.72)	127 (52.05)
Female	123 (41.28)	117 (47.95)
Age group ‡		
19-64 years	84 (28.19)	39 (15.98)
65-84 years	150 (50.34)	109 (44.67)
85+ years	64 (21.48)	96 (39.34)
Education (highest level)		
Completed postsecondary	100 (33.56)	73 (29.92)
High school diploma	88 (29.53)	71 (29.10)
Less than high school	105 (35.23)	95 (38.93)
Don’t know	5 (1.68)	5 (2.05)
Private health insurance		
Yes	180 (60.40)	132 (54.10)
No	111 (37.25)	107 (43.85)
Missing	7 (2.35)	5 (2.05)
Cause of death†		
Cancer	191 (64.09)	121 (49.59)
Not cancer	107 (35.91)	123 (50.41)
Symptom Management		
Symptoms well managed	146 (48.99)	117 (47.95)
Symptoms not well managed	152 (51.01)	127 (52.05)
Marital status ‡		
Married	200 (67.11)	123 (50.41)
Not married	98 (32.89)	121 (49.59)
Lived alone		
Yes	63 (21.14)	62 (25.41)
No	235 (78.86)	182 (74.59)
Location of the majority of care‡		
Home	212 (71.14)	205 (84.02)
Not at home	86 (28.86)	39 (15.98)
Informant characteristic		
Education (highest level)		
Completed postsecondary	149 (50.00)	136 (55.74)
High school diploma	104 (34.90)	85 (34.84)
Less than high school	44 (14.77)	23 (9.43)
Don’t know	1 (0.34)	0 (0.00)

Differences were assessed using the Chi square test: $^{*}p<0.05$; $^{\dagger}p < 0.01$; $^{\ddagger}p<0.001$; $^{\S}p<0.0001$
Four respondents missing information on the type of formal care received were excluded in this table.

Medical care includes nursing care, palliative care, medication management, respiratory care, mental health care, social work, speech therapy and physician home visits.
Home support includes assistance with personal hygiene, housekeeping and meal preparation.

Table 5: Home death by sample characteristic among those who were at home at least 1 day in the last 30 days of life and did not die in transit, Nova Scotia, June 1, 2009 - May 31, 2011 (n=692)

Characteristics	Frequency (percent)		
	All	Died at home	Did not die at home
Total	692 (100.00)	235 (33.96)	457 (66.04)
Decedent characteristic			
Sex			
Male	387 (55.92)	131 (55.74)	256 (56.02)
Female	305 (44.08)	104 (44.26)	201 (43.98)
Age group			
19-64 years	150 (21.68)	59 (25.11)	91 (19.91)
65-84 years	340 (49.13)	113 (48.09)	227 (49.67)
85+ years	202 (29.19)	63 (26.81)	139 (30.42)
Education (highest level)			
Completed postsecondary	217 (31.36)	76 (32.34)	141 (30.85)
Some postsecondary	96 (13.87)	40 (17.02)	56 (12.25)
High school	114 (16.47)	35 (14.89)	79 (17.29)
Less than high school	248 (35.84)	78 (33.19)	170 (37.20)
Don’t know	17 (2.46)	6 (2.55)	11 (2.41)
Private health insurance			
Yes	391 (56.50)	134 (57.02)	257 (56.24)
No	286 (41.33)	95 (40.43)	191 (41.79)
Missing	15 (2.17)	6 (2.55)	9 (1.97)
Cause of death §			
Cancer	361 (52.17)	151 (64.26)	210 (45.95)
Not cancer	331 (47.83)	84 (35.74)	247 (54.05)
Symptom Management‡			
Symptoms well managed	314 (45.38)	127 (54.04)	187 (40.92)
Symptoms not well managed	378 (54.62)	108 (45.96)	270 (59.08)
Marital status			
Married	416 (60.12)	150 (63.83)	266 (58.21)
Divorced/separated	46 (6.65)	13 (5.53)	33 (7.22)
Never Married	34 (4.91)	7 (2.98)	27 (5.91)
Widowed	196 (28.32)	65 (27.66)	131 (28.67)
Lived alone			
Yes	155 (22.40)	40 (17.02)	115 (25.16)
No	536 (77.46)	194 (82.55)	342 (74.84)
Missing	1 (0.14)	1 (0.43)	0 (0.00)
Location of the majority of care §			
Home	509 (73.55)	218 (92.77)	291 (63.68)
Not at home	183 (26.45)	17 (7.23)	166 (36.32)
Received formalized care at home §			

Characteristics	Frequency (percent)		
	All	Died at home	Did not die at home
Yes	544 (78.61)	215 (91.49)	329 (71.99)
No	148 (21.39)	20 (8.51)	128 (28.01)
Informant characteristics			
Education (highest level)			
Completed postsecondary	354 (51.16)	124 (52.77)	230 (50.33)
Some postsecondary	128 (18.50)	42 (17.87)	86 (18.82)
High school	113 (16.33)	39 (16.60)	74 (16.19)
Less than high school	94 (13.58)	27 (11.49)	67 (14.66)
Don't know	3 (0.43)	3 (1.28)	0 (0.00)

Differences were assessed using the Chi square test: $^{*}p<0.05$; † $p < 0.01$; $^{\ddagger}p<0.001$; $^{\S}p<0.0001$

Table 6: Associations between dying at home and receiving formal care at home, among those who spent at least one day at home in the last 30 days of life in Nova Scotia, June 1, 2009 - May 31, 2011 (n=662)

Variable	OR (95% CI) for dying at home	
	Unadjusted	Adjusted
Formal care at home		
Received	4.17 (2.49-6.97)‡	3.38 (1.96-5.85) ‡
Not received	1.00	1.00
Sex		
Female	0.98 (0.71-1.36)	1.04 (0.70-1.54)
Male	1.00	1.00
Age group (years)		
19-64	1.37 (0.87-2.15)	0.86 (0.48-1.52)
65-84	1.05 (0.72-1.54)	0.87 (0.55-1.38)
85+	1.00	1.00
Decadent's education (highest level)		
Completed postsecondary	1.18 (0.80-1.74)	1.02 (0.63-1.64)
High school diploma	1.22 (0.83-1.82)	1.29 (0.82-2.02)
Less than high school	1.00	1.00
Private health insurance		
Yes	1.08 (0.78-1.50)	0.88 (0.60-1.30)
No	1.00	1.00
Cause of death		
Cancer	2.04 (1.47-2.85) ‡	1.62 (1.09-2.39)*
Not cancer	1.00	1.00
Symptom Management		
Symptoms well managed	1.61 (1.16-2.23) †	1.37 (0.96-1.96)
Symptoms not well managed	1.00	1.00
Marital status		
Married	1.29 (0.93-1.81)	1.03 (0.61-1.75)
Not married	1.00	1.00
Lived alone		
No	1.59 (1.06-2.39) *	1.59 (0.93-2.71)
Yes	1.00	1.00
Location of the majority of care		
Home	6.87 (4.04-11.69) ‡	6.06 (3.51-10.46) ‡
Not at home	1.00	1.00
Informant's education (highest level)		
Completed postsecondary	1.35 (0.81-2.26)	1.39 (0.76-2.53)
High school diploma	1.26 (0.73-2.15)	1.34 (0.73-2.44)
Less than high school	1.00	1.00
Goodness of Fit		0.53

*$p<0.05$; † $p < 0.01$; ‡$p<0.001$; §$p<0.0001$

OR: odds ratio; CI: confidence intervals
Formal care includes the care provided by contracted professionals outside of family and friend

Table 7: Associations between dying at home and type of formal care received, among those received formal care at home during the last 30 days of life in Nova Scotia, June 1, 2009 - May 31, 2011 (n=518)

Variable	OR (95% CI) for dying at home		
	Unadjusted	Adjusted (without interaction)	Adjusted (with interaction)
Type of formal care			
Home support with or without medical care	1.70 (1.19-2.42) †	1.72 (1.17-2.54) †	1.08 (0.63-1.86)
Medical care only	1.00	1.00	1.00
Cause of death			
Cancer	2.09 (1.44-3.02) ‡	2.05 (1.38-3.07) ‡	2.06 (1.38-3.08) ‡
Not cancer	1.00	1.00	1.00
Symptom Management			
Symptoms well managed	1.71 (1.20-2.43) †	1.57 (1.08-2.30)*	1.01 (0.60-1.71)
Symptoms not well managed	1.00	1.00	1.00
Location of the majority of care			
Home	6.05 (3.45-10.60) ‡	5.23 (2.95-9.27) ‡	5.25 (2.96-9.33)‡
Not at home	1.00	1.00	1.00
Interaction Term			
Home support x symptoms well managed			2.54 (1.18-5.46)*
Home support x symptoms not well managed			1.00
Medical care only x symptoms well managed			1.00
Medical care only x symptoms not well managed			1.00
Goodness of fit		0.35	0.77

*p<0.05; † p < 0.01; ‡p<0.001; §p<0.0001

+ Home support with or without medical care is not significant in the model due to the interaction terms. Home support with or without medical care is associated with a home death p=0.0000

OR: odds ratio; CI: confidence intervals

Medical care includes nursing care, palliative care, medication management, respiratory care, mental health care, social work, speech therapy and physician home visits.

Home support includes assistance with personal hygiene, housekeeping and meal preparation.

Table 8: Associations between dying at home and type of formal care received by symptom management, among those received formal care at home during the last 30 days of life in Nova Scotia, June 1, 2009 - May 31, 2011 (n=518)

	OR (95% CI) for dying at home	
	Symptoms well managed	Symptoms not well managed
Sample size (n)	249	269
Type of formal care		
Home support with or without medical care	2.76 (1.57-4.87)[‡]	1.09 (0.63-1.88)
Medical care only	1.00	1.00
Cause of death		
Cancer	2.11 (1.17-3.81)[*]	2.02 (1.16-3.51)[*]
Not cancer	1.00	1.00
Location of the majority of care (last 30 days)		
Home	6.37 (2.68-15.15)[§]	4.46 (2.08-9.57)[§]
Not at home	1.00	1.00
Goodness of fit	0.48	0.60

[*] $p<0.05$; [†] $p < 0.01$; [‡] $p<0.001$; [§] $p<0.0001$

OR: odds ratio; CI: confidence intervals

Medical care includes nursing care, palliative care, medication management, respiratory care, mental health care, social work, speech therapy and physician home visits.

Home support includes assistance with personal hygiene, housekeeping and meal preparation.

Appendix C: Effectiveness of Care at Home at the End of Life

Date	Population	Adjustments	Findings	Location	Source	Reference
2007	Homebound, terminally ill patients with a prognosis of approximately 1 year or less to live plus one or more hospital or emergency department visits in the previous 12 months	Sex, age, race, marital status, diagnosis, education, co-residency, income	Among homebound, terminally ill patients with a prognosis of approximately one year or less to live with at least one hospital or emergency visit in the previous 12 months, individuals with care at home services are statistically significantly more likely to die at home than another location compared to those receiving usual care, after adjusting for sex, age, race, marital status, diagnosis, education, co-residency, income (P<0.001)	USA	Individual Study	Brumley et al., 2007
2004	Terminally ill patients	Diagnosis, co-residency, sex, age	Among terminally ill patients, individuals that received care at home services are more likely to die at home than in another location compared to individuals receiving standard care, after adjusting for diagnosis, co-residency, sex and age (RR=1.15; 95%CI: 0.87, 1.51)	United Kingdom	Individual Study	Grande et al., 2000
2000	Patients with incurable malignant disease and an expected survival of 2-9 months		Among patients with incurable malignant disease and an expected survival of 2 to 9 months, individuals receiving care at home services are statistically significantly more likely to die at home than in another location compared to individuals not receiving care at home services (25% vs. 15% P<0.05)	Norway	Individual Study	Jordhoy et al., 2000

2005	Terminally ill, home-bound patients diagnosed with cancer, congestive heart failure, or COPD, experiencing two or more emergency visits or hospitalizations in the last year and having a prognosis of approximately one year of life expectancy	Ethnicity, age, marital status, gender, income, education, diagnosis, severity of illness	Among terminally ill, home-bound patients diagnosed with cancer, congestive hear failure or COPD and having two or more emergency visits or hospitalizations in the last year with a prognosis of one year, individuals with care at home services are statistically significantly more likely to die at home than in another location compared to individuals without care at home services, after adjusting for ethnicity, age, marital status, gender, income, education, diagnosis, severity of illness (p <0.001)	USA	Individual Study	Enguidanos et al., 2005
2003	Patients with incurable malignant disease that were admitted to palliative home care during 1999		Among patients with incurable malignant disease that had care at home services, 117 (53%) died at home, 31 died in hospital and 73 died in an institutional palliative care unit. This is not statistically significant.	Sweden	Individual Study	Gyllenhammar et al., 2003

Appendix D: Factors that Influence the Location of Death

Variable	Date	Population	Adjustments	Findings	Location	Source	Reference	Survey Question
Sex	2005	Cancer patients	income, age, education level, religion, place of residence, time since initial diagnosis, support network, person who pays health-care costs	Among cancer patients in Korea, women are statistically significantly less likely to die at home than in an institution compared to men, after adjusting for income, age, education level, religion, place of residence, time since initial diagnosis, support network, person who pays health-care costs (OR=0.62; 95% CI=0.41 to 0.93)	Korea	Individual Study	Choi et al., 2005	
	2001	Adults that had died of a cancer-related cause	marital status, income, race, type of cancer, longer survival postdiagnosis, greater availability of hospice providers, less availability of hospital beds	Among adults that died from cancer in the United States, men are statistically significantly less likely to die at home than in an institution compared to women, after adjusting for marital status, income, race, type of cancer, longer survival postdiagnosis, greater availability of hospice providers, less availability of hospital beds (RR= 0.84; 95% CI= 0.76 to 0.94)	USA	Individual Study	Gallo et al., 2001	
	2006	Deaths between 1992-2002		Among those that died between 1992 and 2002 in Korea, women are statistically significantly more likely to die at home than hospital compared to men (73.1% vs 67.3% P=<0.001)	Korea	Individual Study	Yun et al., 2006	
Age	2010	Hospitalized individuals over the age of 45 that usually reside in a nursing home	sex, race, comorbidities, hospitals by bed size, geographic region, insurance status	Among hospitalized individuals over the age of 45 that usually reside in nursing homes in the United States, individuals over the age of 75 years are statistically significantly less likely to die at home than in hospital compared to individuals under the age of 75 years, after adjustment for sex, race, comorbidities, hospital size, geographic region and insurance status (adjusted OR 2.80; P=0.005)	USA	Individual Study	Ahmed et al., 2010	
	2007	Cancer was the cause of death	Cancer type, gender, education, marital status	Among those with cancer in Mexico, individuals under the age of 55 years are statistically significantly less likely to die at home than in medical units compared to individuals over the age of 74 years, after adjustment for (45% vs 65% P=<0.001)	Mexico	Individual Study	Cardenas-Turanzas et al., 2007	
	2010	All adult non-traumatic deaths from 2005-2006		Among adults that died of a non-traumatic death between 2005-2006 in Botswana, individuals over the age of 80 years are statistically significantly more likely to die at home than other locations compared to those under the age of 80 years (OR=1.8; 95% CI= 1.5 to 2.1)	Botswana	Individual Study	Lazenby et al., 2010	
	2006	Deaths between 1992-2002		Among those that died between 1992 and 2002 in Korea, individuals under the age of 50 years are statistically significantly less likely to die at home than in hospital compared to individuals over the age of 50 years (<60.9% vs 77.1% P=<0.001)	Korea	Individual Study	Yun et al., 2006	
Education	2007	Cancer was the cause of death		Among those with cancer, individuals with professional education in Mexico are statistically significantly less likely to die at home than in a medical unit compared to individuals with no education (47% vs 59%, P=<0.001)	Mexico	Individual Study	Cardenas-Turanzas et al., 2007	M3. What was the highest level of schooling [DECEDENT] completed?
	2006	Deaths between 1992-2002		Among those that died between 1992-2002, individuals with no education in Korea are statistically signicantly more likely to die at home than in hospital compared to individuals with a college education (83% vs 36.1% P=<0.001)	Korea	Individual Study	Yun et al., 2006	
Marital Status	2007	Cancer was the cause of death		Among those with cancer in Mexico, individuals that are married are more likely to die at home than in a medical unit compared to individuals that are single or divorced/separated (40% vs 50% or 49% P=<0.001)	Mexico	Individual Study	Cardenas-Turanzas et al., 2007	M1. At time of death was decedent married, widowed, divorced, separated, never married?
	2001	Adults that had died of a cancer-related cause	sex, income, race, type of cancer, longer survival postdiagnosis, greater availability of hospice providers, less availability of hospital beds	Among adults with cancer in the United States, individuals that are married are statistically significantly more likely to die at home than in an institution compared to individuals that are not married, after adjusting for sex, income, race, type of cancer, longer survival postdiagnosis, greater availability of hospice providers, less availability of hospital beds (RR=1.22; 95% CI=1.12 to 1.32)	USA	Individual Study	Gallo et al., 2001	
	2006	Deaths between 1992-2002		Among those that died between 1992 and 2002 in Korea, individuals that are unmarried are significantly more likely to die at home than in hospital compared to individuals that are married (73.1% vs 66.9% P=<0.001)	Korea	Individual Study	Yun et al., 2006	

Co-residence	2002	Patients who had died approximately 9 months prior to study	sex, age, marital status, diagnosis, dependence in activities of daily living, stated preference	Among the palliative in Canada, individuals living with a caregiver are statistically significantly more likely to die at home than in another location compared to individuals living alone, after adjusting forsex, age, marital status, diagnosis, dependence in activities of daily living, stated preference (OR=7.85; 95% CI= 2.35 to 26.27)	Canada	Individual Study	Brazil et al., 2002	
	2008	Patients receiving palliative home care	sex, weight loss, stated preference, family coping	Among patients receiving palliative home care in Canada, individuals living alone are significantly less likely to die at home than in other locations compared to individuals living with another person, after adjusting for sex, weight loss, stated preference, family coping (OR=0.58; 95% CI=0.37 to 0.92)	Canada	Individual Study	Brink & Frise-Smith, 2008	
	2004	>80% of all Japanese patients had advanced malignant disease and received home care	age, functional status, caregivers/ status and roles, family physician support, number of home visits by home care nurse, preference stated	Among patients with advanced malignant disease and receiving home care in Japan, individuals living with a caregiver are significantly more likely to die at home than in hospital compared to individuals living alone, after adjusting for age, functional status, caregivers/ status and roles, family physician support, number of home visits by home care nurse, preference stated (P=0.009)	Japan	Individual Study	Fukui et al., 2004	
	2009	Patients suffering from chronic diseases eligible for palliative care	age, cause of death, sex, nationality, SES of the district of residence, marital status	Among patients suffering from chronic diseases eligible for palliative care in Belgium, individuals living in a multi-person dwelling are significantly more likely to die at home than in a hospital or nusing home compared to those living alone, after adjusting for age, cause of death, sex, nationality, SES of the district of residence, marital status (OR=1.53; 95% CI= 1.24 to 1.88)	Belgium	Individual Study	Houttekier et al., 2009	M2. Was (he/she) living alone?
Cause of Death	2009	Patients suffering from chronic diseases eligible for palliative care	age, co-residency, sex, nationality, SES of the district of residence, marital status	Among patients suffering from chronic diseases eligible for palliative care in Belgium, individuals dying of a non-cancerous condition are statistically significantly more likely to die at home than hospital compared to those with cancer, after adjustment for age, co-residency, sex, nationality, neighbourhood socioeconomic status, and marital status (OR=1.61; 95% CI=1.30-2.00)	Belgium	Individual Study	Houttekier et al., 2009	
	2006	Deaths between 1992-2002		Among those that died between 1992 and 2002 in Korea, individuals dying of cerebrovascular disease are statistically significantly more likely to die at home than in other locations compared to individuals dying of another cause of death (77.1% vs 74.0% P=<0.001)	Korea	Individual Study	Yun et al., 2006	
Management of Symptoms	2002	All deceased	age, sex, race, education, marital status, income, stated preference	Among palliative individuals in the United States, individuals with a high quality of dying as assessed by the Quality of Death and Dying Questionnaire are statistically significantly more likely to die at home than in other locations compared to individuals with low quality of dying, after adjusting for age, sex, race, education, marital status, income, stated preference (P=0.006)	USA	Individual Study	Curtis et al., 2002	E4. Did decedent experience any pain? E11. How much help did he/she receive to deal with these breathing problems? E15. How much help in dealing with these feelings did he/she receive? H3. How well did those taking care of decedent make sure his/her symptoms were controlled to a degree that was acceptable to him/her? RANKING
Additional Health Insurance	2005	Patients receiving palliative care in a pediatric oncology unit	gender, educational background of mother, educational background of the home care provider	Among patients receiving palliative care in a pediatric oncology unit in Brazil, individuals with parents with additional health insurance are statistically significantly more likely to die at home than in hospital compared to individuals with parents without additional health insurance, after adjusting for gender, educational background of mother, educational background of the home care provider (OR=4.95; 95% CI=1.03 to 26.75)	Brazil	Individual Study	Kurashima et al., 2005	M7. Did decedent have health insurance coverage that offered more than what the province provided?

Appendix E: Associations between dying at home and receiving formal care, among those that spent at least one day at home in the last 30 days of life in Nova Scotia, June 1, 2009 – May 31, 2011 (n=662)

				Model 1			Model 2			Model 3		
	Unadjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value
Received formal care	4.17	(2.49-6.97)	0.00	4.15	(2.48-6.95)	0.00	4.28	(2.55-7.18)	0.00	3.61	(2.13-6.12)	0.00
Demographic factors												
Female	0.98	(0.71-1.36)	0.90	0.98	(0.70-1.38)	0.92	1.10	(0.76-1.59)	0.61	1.10	(0.76-1.60)	0.61
Age			0.34			0.43			0.71			0.94
19-64 years	1.37	(0.87-2.15)	0.18	1.35	(0.85-2.16)	0.20	1.21	(0.74-1.99)	0.45	0.99	(0.58-1.68)	0.96
65-84 years	1.05	(0.72-1.54)	0.81	1.10	(0.74-1.63)	0.64	1.03	(0.68-1.57)	0.88	0.94	(0.61-1.44)	0.76
85+ years (reference)	1.00			1.00			1.00			1.00		
Married	1.29	(0.93-1.81)	0.15				1.12	(0.71-1.78)	0.63	0.98	(0.61-1.57)	0.93
Living with other individuals	1.59	(1.06-2.39)	0.03				1.59	(0.97-2.59)	0.07	1.75	(1.06-2.89)	0.03
Medical factors												
Cancer as cause of death	2.04	(1.47-2.85)	0.00							1.76	(1.21-2.55)	0.00
Symptoms well managed	1.61	(1.16-2.23)	0.00							1.40	(0.99-1.96)	0.05
Socioeconomic factors												
Education			0.56									
Completed postsecondary	1.18	(0.80-1.74)	0.41									
High school diploma	1.22	(0.83-1.82)	0.31									
Less than high school (reference)	1.00											
Having additional health insurance	1.08	(0.78-1.50)	0.65									
Informant characteristic												
Informant's education			0.51									
Completed postsecondary	1.35	(0.81-2.26)	0.25									
High school diploma	1.26	(0.73-2.15)	0.41									
Less than high school (reference)	1.00											
Location of Care												
Received majority of care at home	6.87	(4.04-11.69)	0.00									
Interaction Terms												
Formalized care at home x cancer cause of death (reference: no formalized care x non-cancerous cause of death)												
Cancer cause of death x Formalized care at home												
Formalized care at home x living with others (reference: no formalized care x living alone)												
Lives with others x Formalized care at home												
Formalized care at home x symptoms well managed (reference: no formalized care x symptoms not well-managed)												
Symptoms well managed x Formalized care at home												
Formalized care at home x majority of care at home (reference: no formalized care x majority of care not at home)												
Majority of care at home x Formalized care at home												
Hosmer-Lemeshow goodness of fit p-value					0.77			0.45			0.82	

	Model 4			Model 5			Model 6			Model 7		
	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value
Received formal care	3.66	(2.16-6.21)	0.00	3.62	(2.13-6.14)	0.00	3.38	(1.96-5.85)	0.00	3.45	(2.02-5.89)	0.00
Demographic factors												
Female	1.08	(0.74-1.58)	0.69	1.08	(0.74-1.58)	0.68	1.04	(0.70-1.54)	0.86			
Age			0.95			0.96			0.82			
19-64 years	0.97	(0.56-1.65)	0.90	0.99	(0.58-1.69)	0.97	0.86	(0.48-1.52)	0.59			
65-84 years	0.93	(0.61-1.43)	0.75	0.95	(0.61-1.46)	0.81	0.87	(0.55-1.38)	0.56			
85+ years (reference)	1.00			1.00			1.00					
Married	0.95	(0.58-1.54)	0.83	1.00	(0.61-1.63)	0.99	1.03	(0.61-1.75)	0.91			
Living with other individuals	1.80	(1.09-2.97)	0.02	1.82	(1.10-3.02)	0.02	1.59	(0.93-2.71)	0.09			
Medical factors												
Cancer as cause of death	1.75	(1.20-2.54)	0.00	1.74	(1.20-2.53)	0.00	1.62	(1.09-2.39)	0.02	1.58	(1.11-2.26)	0.01
Symptoms well managed	1.41	(1.00-1.98)	0.05	1.42	(1.01-2.01)	0.04	1.37	(0.96-1.96)	0.08			
Socioeconomic factors												
Education			0.52			0.50			0.46			
Completed postsecondary	1.09	(0.70-1.70)	0.69	1.01	(0.64-1.60)	0.97	1.02	(0.63-1.64)	0.95			
High school diploma	1.28	(0.83-1.97)	0.26	1.25	(0.81-1.93)	0.31	1.29	(0.82-2.02)	0.27			
Less than high school (reference)	1.00			1.00			1.00					
Having additional health insurance	0.98	(0.68-1.41)	0.91	0.95	(0.65-1.37)	0.77	0.88	(0.60-1.30)	0.53			
Informant characteristic												
Informant's education						0.40			0.55			
Completed postsecondary				1.48	(0.83-2.62)	0.18	1.39	(0.76-2.53)	0.28			
High school diploma				1.30	(0.73-2.30)	0.38	1.34	(0.73-2.44)	0.34			
Less than high school (reference)				1.00			1.00					
Location of Care												
Received majority of care at home							6.06	(3.51-10.46)	0.00	6.21	(3.62-10.65)	0.00
Interaction Terms												
Formalized care at home x cancer cause of death (reference: no formalized care x non-cancerous cause of death)												
Cancer cause of death x Formalized care at home												
Formalized care at home x living with others (reference: no formalized care x living alone)												
Lives with others x Formalized care at home												
Formalized care at home x symptoms well managed (reference: no formalized care x symptoms not well-managed)												
Symptoms well managed x Formalized care at home												
Formalized care at home x majority of care at home (reference: no formalized care x majority of care not at home)												
Majority of care at home x Formalized care at home												
Hosmer-Lemeshow goodness of fit p-value		0.48			0.61			0.53			0.04	

		Model 8			Model 9			Model 10			Model 11	
	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value
Received formal care	1.90	(0.99-3.64)	0.05	3.51	(0.76-16.35)	0.12	2.16	(1.15-4.04)	0.02	7.07	(0.91-55.12)	0.06
Demographic factors												
Female	1.03	(0.69-1.53)	0.88	1.04	(0.70-1.54)	0.86	1.02	(0.68-1.51)	0.93	1.04	(0.70-1.54)	0.85
Age			0.76			0.82			0.87			0.81
19-64 years	0.82	(0.46-1.47)	0.51	0.86	(0.48-1.52)	0.60	0.87	(0.49-1.56)	0.65	0.86	(0.48-1.53)	0.60
65-84 years	0.85	(0.54-1.35)	0.50	0.87	(0.55-1.38)	0.56	0.89	(0.56-1.42)	0.62	0.86	(0.54-1.37)	0.52
85+ years (reference)	1.00			1.00			1.00			1.00		
Married	0.98	(0.58-1.66)	0.94	1.03	(0.61-1.75)	0.91	1.02	(0.60-1.73)	0.94	1.03	(0.61-1.74)	0.91
Living with other individuals	1.61	(0.94-2.76)	0.08	1.66	(0.33-8.33)	0.54	1.62	(0.95-2.77)	0.08	1.58	(0.93-2.69)	0.09
Medical factors												
Cancer as cause of death	0.34	(0.09-1.25)	0.10	1.62	(1.09-2.40)	0.02	1.57	(1.06-2.33)	0.03	1.62	(1.09-2.40)	0.02
Symptoms well managed	1.33	(0.93-1.91)	0.11	1.37	(0.96-1.96)	0.09	0.34	(0.09-1.26)	0.11	1.38	(0.96-1.97)	0.08
Socioeconomic factors												
Education			0.47			0.47			0.47			0.46
Completed postsecondary	1.02	(0.63-1.65)	0.95	1.02	(0.63-1.64)	0.95	1.02	(0.63-1.65)	0.95	1.01	(0.63-1.63)	0.96
High school diploma	1.28	(0.82-2.02)	0.28	1.29	(0.82-2.02)	0.27	1.29	(0.82-2.02)	0.28	1.28	(0.82-2.01)	0.28
Less than high school (reference)	1.00			1.00			1.00			1.00		
Having additional health insurance	0.90	(0.61-1.33)	0.59	0.88	(0.60-1.30)	0.53	0.89	(0.60-1.32)	0.57	0.88	(0.60-1.30)	0.53
Informant characteristic												
Informant's education			0.67			0.55			0.53			0.56
Completed postsecondary	1.32	(0.72-2.41)	0.37	1.39	(0.76-2.52)	0.28	1.40	(0.77-2.56)	0.27	1.33	(0.76-2.52)	0.29
High school diploma	1.26	(0.69-2.31)	0.46	1.34	(0.73-2.44)	0.34	1.36	(0.74-2.48)	0.32	1.33	(0.73-2.42)	0.35
Less than high school (reference)	1.00			1.00			1.00			1.00		
Location of Care												
Received majority of care at home	6.10	(3.53-10.55)	0.00	6.06	(3.51-10.46)	0.00	6.03	(3.49-10.42)	0.00	12.68	(1.63-98.86)	0.02
Interaction Terms												
Formalized care at home x cancer cause of death (reference: no formalized care x non-cancerous cause of death)												
Cancer cause of death x Formalized care at home	5.94	(1.50-23.45)	0.01									
Formalized care at home x living with others (reference: no formalized care x living alone)												
Lives with others x Formalized care at home				0.96	(0.18-4.95)	0.96						
Formalized care at home x symptoms well managed (reference: no formalized care x symptoms not well-managed)												
Symptoms well managed x Formalized care at home							4.76	(1.21-18.70)	0.00			
Formalized care at home x majority of care at home (reference: no formalized care x majority of care not at home)												
Majority of care at home x Formalized care at home										0.44	(0.05-3.73)	0.45
Hosmer-Lemeshow goodness of fit p-value		0.69			0.52			0.64			0.29	

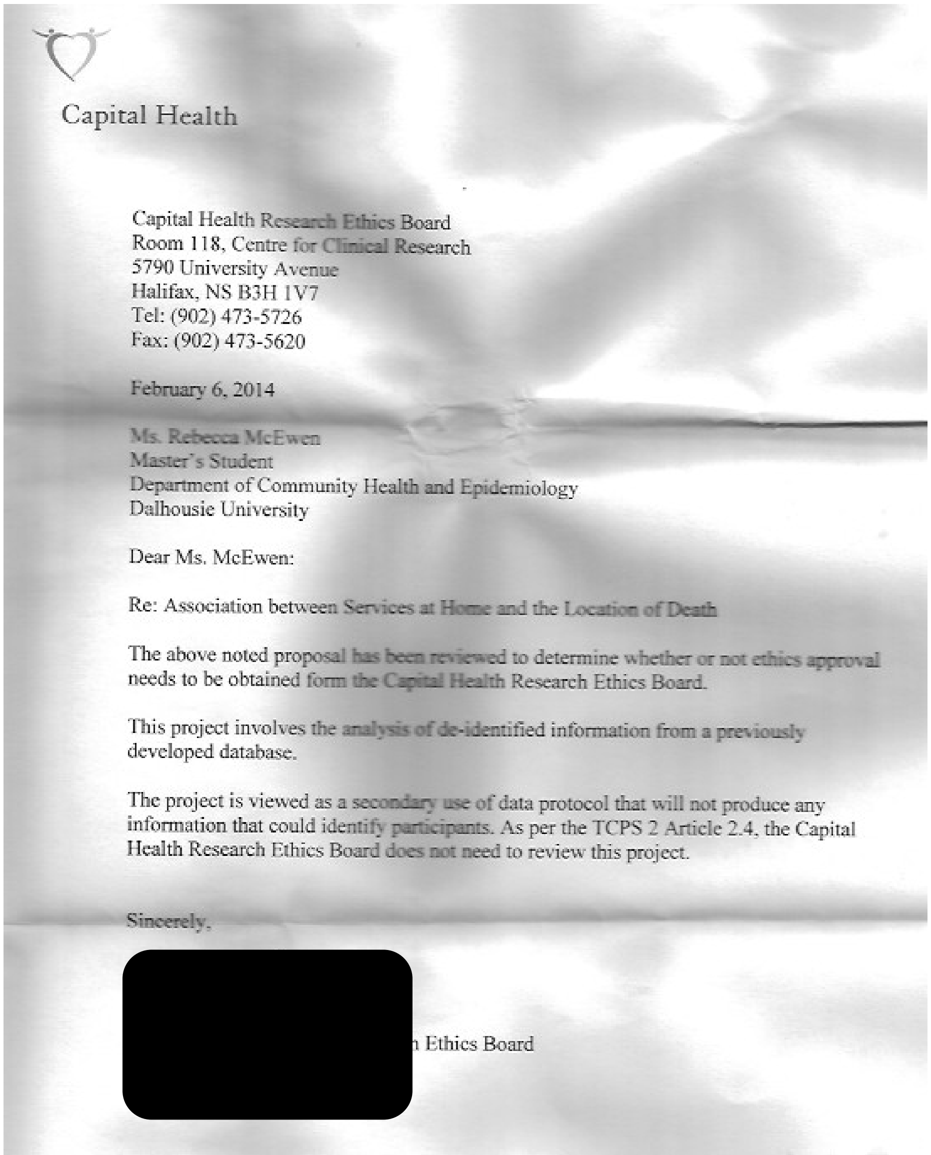
Appendix F: Associations between dying at home and type of formal care received, among those that received formal care at home during the last 30 days of life in Nova Scotia, June 1, 2009 - May 31, 2011 (n=518)

				Model 1			Model 2			Model 3		
	Unadjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value
Type of formal care												
Home support with or without medical ca	1.70	(1.19-2.42)	0.00	1.88	(1.30-2.71)	0.00	1.93	(1.33-2.81)	0.00	2.07	(1.41-3.05)	0.00
Medical care only (reference)	1.00			1.00			1.00			1.00		
Demographic factors												
Female	0.97	(0.68-1.39)	0.88	0.98	(0.68-1.41)	0.90	1.11	(0.75-1.66)	0.59	1.11	(0.74-1.67)	0.62
Age			0.23			0.06			0.24			0.78
19-64 years	1.53	(0.94-2.50)	0.09	1.85	(1.11-3.10)	0.02	1.59	(0.92-2.75)	0.10	1.22	(0.68-2.21)	0.51
65-84 years	1.17	(0.77-1.77)	0.47	1.29	(0.84-1.99)	0.24	1.19	(0.76-1.87)	0.45	1.06	(0.66-1.70)	0.82
85+ years (reference)	1.00			1.00			1.00			1.00		
Married	1.42	(0.99-2.04)	0.06				1.27	(0.77-2.09)	0.36	1.04	(0.62-1.75)	0.89
Living with other individuals	1.67	(1.08-2.57)	0.02				1.46	(0.87-2.45)	0.15	1.69	(0.99-2.88)	0.06
Medical factors												
Cancer as cause of death	2.09	(1.44-3.02)	0.00							2.17	(1.43-3.29)	0.00
Symptoms well managed	1.71	(1.20-2.43)	0.00							1.62	(1.12-2.35)	0.01
Socioeconomic factors												
Education			0.37									
Completed postsecondary	1.18	(0.77-1.81)	0.44									
High school diploma	1.36	(0.88-2.10)	0.16									
Less than high school (reference)	1.00											
Having additional health insurance	1.01	(0.71-1.44)	0.96									
Informant characteristic												
Informant's education			0.63									
Completed postsecondary	1.32	(0.75-2.33)	0.34									
High school diploma	1.24	(0.69-2.26)	0.47									
Less than high school (reference)	1.00											
Location of Care												
Received majority of care at home	6.05	(3.45-10.60)	0.00									
Interaction Term												
Type of formal care x symptom management												
Some home support x symptoms well managed												
Some home support x symptoms not well managed												
Medical care only x symptoms well managed												
Medical care only x symptoms not well managed												
Hosmer-Lemeshow goodness of fit p-value					0.80			0.70			0.95	

	Model 4			Model 5			Model 6			Model 7		
	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value	Adjusted OR	(95% CI)	p-value
Type of formal care												
Home support with or without medical ca	2.08	(1.41-3.06)	0.00	2.05	(1.39-3.03)	0.00	1.77	(1.18-2.65)	0.01	1.72	(1.17-2.54)	0.01
Medical care only (reference)	1.00			1.00			1.00			1.00		
Demographic factors												
Female	1.08	(0.71-1.63)	0.72	1.08	(0.71-1.63)	0.72	1.03	(0.67-1.58)	0.89			
Age			0.79			0.55			0.97			
19-64 years	1.22	(0.67-2.21)	0.52	1.25	(0.68-2.27)	0.47	1.08	(0.57-2.02)	0.82			
65-84 years	1.05	(0.65-1.69)	0.84	1.08	(0.67-1.73)	0.77	1.06	(0.64-1.76)	0.81			
85+ years (reference)	1.00			1.00			1.00					
Married	1.01	(0.59-1.72)	0.98	1.06	(0.61-1.83)	0.83	1.06	(0.59-1.89)	0.84			
Living with other individuals	1.74	(1.01-2.98)	0.05	1.76	(1.02-3.02)	0.04	1.61	(0.91-2.84)	0.10			
Medical factors												
Cancer as cause of death	2.16	(1.42-3.27)	0.00	2.14	(1.41-3.25)	0.00	2.01	(1.30-3.11)	0.00	2.05	(1.38-3.07)	0.00
Symptoms well managed	1.63	(1.13-2.37)	0.01	1.65	(1.14-2.40)	0.01	1.59	(1.08-2.34)	0.02	1.57	(1.08-2.30)	0.02
Socioeconomic factors												
Education			0.47			0.43			0.43			
Completed postsecondary	1.05	(0.65-1.70)	0.84	0.96	(0.58-1.60)	0.88	0.97	(0.58-1.63)	0.91			
High school diploma	1.32	(0.82-2.11)	0.25	1.28	(0.80-2.06)	0.30	1.30	(0.80-2.13)	0.29			
Less than high school (reference)	1.00			1.00			1.00					
Having additional health insurance	0.96	(0.64-1.44)	0.85	0.93	(0.62-1.40)	0.73	0.86	(0.57-1.32)	0.50			
Informant characteristic												
Informant's education						0.45			0.55			
Completed postsecondary				1.49	(0.79-2.83)	0.22	1.43	(0.74-2.77)	0.28			
High school diploma				1.30	(0.69-2.47)	0.42	1.38	(0.71-2.68)	0.34			
Less than high school (reference)				1.00			1.00					
Location of Care												
Received majority of care at home							5.11	(2.86-9.12)	0.00	5.23	(2.95-9.27)	0.00
Interaction Term												
Type of formal care x symptom management												
Some home support x symptoms well managed												
Some home support x symptoms not well managed												
Medical care only x symptoms well managed												
Medical care only x symptoms not well managed												
Hosmer-Lemeshow goodness of fit p-value		0.32			0.35			0.22			0.35	

		Model 8	
	Adjusted OR	(95% CI)	p-value
Type of formal care			
Home support with or without medical ca	1.08	(0.63-1.86)	0.78
Medical care only (reference)	1.00		
Demographic factors			
Female			
Age			
19-64 years			
65-84 years			
85+ years (reference)			
Married			
Living with other individuals			
Medical factors			
Cancer as cause of death	2.06	(1.38-3.08)	0.00
Symptoms well managed	1.01	(0.60-1.71)	0.96
Socioeconomic factors			
Education			
Completed postsecondary			
High school diploma			
Less than high school (reference)			
Having additional health insurance			
Informant characteristic			
Informant's education			
Completed postsecondary			
High school diploma			
Less than high school (reference)			
Location of Care			
Received majority of care at home	5.25	(2.96-9.33)	0.00
Interaction Term			
Type of formal care x symptom management			
Some home support x symptoms well	2.54	(1.18-5.46)	0.02
Some home support x symptoms not	1.00		
Medical care only x symptoms well r	1.00		
Medical care only x symptoms not we	1.00		
Hosmer-Lemeshow goodness of fit p-value		0.77	

Appendix G: Ethics Approval



Capital Health

Capital Health Research Ethics Board
Room 118, Centre for Clinical Research
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February 6, 2014

Ms. Rebecca McEwen
Master's Student
Department of Community Health and Epidemiology
Dalhousie University

Dear Ms. McEwen:

Re: Association between Services at Home and the Location of Death

The above noted proposal has been reviewed to determine whether or not ethics approval needs to be obtained form the Capital Health Research Ethics Board.

This project involves the analysis of de-identified information from a previously developed database.

The project is viewed as a secondary use of data protocol that will not produce any information that could identify participants. As per the TCPS 2 Article 2.4, the Capital Health Research Ethics Board does not need to review this project.

Sincerely,

[redacted] Ethics Board

Appendix H: Independent variables used in the analysis

Variable	Variable Category	Missing Frequency (%) and strategy to deal with missing values	Survey Question	Variable ID	Reference
Sex	Male or Female	0		dec_sex	Choi et al., 2005 Gallo et al., 2001 Yun et al., 2006
Age	19-64 Years, 65-84 Years, or 85+ Years	0		age_grp	Ahmed et al., 2010 Cardenas-Turanzas et al., 2007 Lazenby et al., 2010 Yun et al., 2006
Education	Completed Postsecondary, Some Postsecondary, High School or Less than High School	31 (2.36) Delete	M3. What was the highest level of schooling [DECEDENT] completed?	QM3_collapsed	Cardenas-Turanzas et al., 2007 Yun et al., 2006

Marital Status	Married, Divorced/Separated, Never Married or Widowed	0	M1. At time of death was decedent married, widowed, divorced, separated, never married?	QM1_collapsed	Cardenas-Turanzas et al., 2007 Gallo et al., 2001 Yun et al., 2006
Co-residence	Lives alone or Live with others	1 Delete	M2. Was (he/she) living alone?	qm2_living	Brazil et al., 2002 Brink & Frise-Smith, 2008 Fukui et al., 2004 Houttekier et al., 2009
Cause of Death	Neoplasms. Mental/Behavioural Disorders, Disease of the Nervous System, Disease of the Circulatory System, Disease of the Respiratory System or Other Cause of Death	2 Delete		cause_death_collapsed	Yun et al., 2006 Houttekier et al., 2009

Management of Symptoms	E4. Yes or No E11. Less than was needed or Right amount E15. Less than was needed or Right amount H3. Ranking 0-10 where 10 means the best care possible	E4. 95 E11. 759 E15. 684 H3. 84 Categorize as “missing”	E4. Did decedent experience any pain? E11. How much help did he/she receive to deal with these breathing problems? E15. How much help in dealing with these feelings did he/she receive? H3. How well did those taking care of decedent make sure his/her symptoms were controlled to a degree that was acceptable to him/her?		Curtis et al., 2002
Additional Health Insurance	Had Additional Health Insurance or Did not have Additional Health Insurance	32 (2.43) Delete	M7. Did decedent have health insurance coverage that offered more than what the province provided?	qm7_insurance	Kurashima et al., 2005
Informant’s Education	Completed Postsecondary, Some Postsecondary, High School or Less than High School	3 (0.23) Delete	N2. What is the highest level of schooling you have completed?		