Supporting Informal End-of-Life Caregivers in British Columbia

by

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Abstract

There is an increasing desire amongst Canada’s elderly to be supported to die at home. Families are vital in ensuring this, yet policies focused on end-of-life care do not address how to meet their needs. This study explores why informal family caregivers in British Columbia have inadequate access to end-of-life care resources, and proposes solutions to address problematic issues. A discourse analysis of provincial end-of-life policies, case studies of practice within the local health area of Vancouver-City Centre, and interviews with informal caregivers identified key problem areas. Four policy options for government consideration were designed and evaluated: increasing the availability and extent of publicly funded formal home support; providing a single point of contact; increasing the frequency and reach of family meetings; and creating local, community-based services. Providing a single point of contact for families and seniors, such as a patient navigator, is recommended as one approach to better assist informal caregivers in providing end-of-life care at home.

Keywords: informal caregiving; end-of-life care; palliative care; death and dying; home support; home and community care
Dedication

For my parents, Celso and Helen, without whom this research would have been uninspired.

And for my husband, Matthew. Only with your love, support and understanding was this possible. This capstone is as much your achievement, as it is mine. I love you, always.
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Executive Summary

Canada’s older population is projected to significantly increase within the next decade from approximately 3.8 million people in 2000 to over 6.9 million by 2021 (Fisher et al., 2000, p. 5), and while many seniors at end-of-life desire a home death, three-quarters of deaths in Canada still occur in hospital or long-term facilities (Carstairs & Keon, 2009). For seniors who wish to die at home, this can only be achieved through the help of informal caregivers: the unpaid family members providing care. Governments have increasingly downsized medical and hospital care, causing informal care to become the major form of care in old age. However, this shift in care from formal institutions to home and community can have detrimental impacts to informal caregivers’ well-being, with financial, employment, and emotional burdens often experienced by family members attempting to provide home care. If families are unable to cope with the demands of caregiving, this can negatively affect the ability of seniors at end-of-life to experience a good death, as well as result in an increased risk of seniors having to be readmitted to acute care facilities.

The objective of this study was to address the policy issue that informal caregivers in British Columbia currently do not have adequate access to resources which would allow them the greatest opportunity to provide quality care to an elderly family member who wishes to die at home. Resources to assist informal caregivers include mechanisms to mitigate employment risks, financial burdens, and psychological and physiological strain. However, achieving a good death for seniors at end-of-life is also contingent on specific indicators, such as proper pain and symptom management, meeting physical and emotional needs, adequately preparing for death, and honouring wishes for death. These measures must be met, as inability to provide quality care for dying seniors can also impact caregivers’ welfare.

In order to inform the development of policy options, the research methodology was guided by two research questions: 1) In what ways do current palliative care policies set the context for end-of-life seniors to have a good death at home?; and 2) In what ways are informal caregivers supported in their role to provide quality care to an elderly family member who wishes to die at home? To answer these questions, three separate research approaches were undertaken. The first was a discourse analysis to critique
current provincial policy which prescribes end-of-life care for seniors in British Columbia. The second was a case study analysis to evaluate end-of-life care practices and current support mechanisms available to seniors at end-of-life, as well as to informal caregivers. This was conducted within the local health area of Vancouver-City Centre, and reviewed the practices of two agencies providing palliative and end-of-life services: Vancouver Coastal Health and Providence Health Care. Data was collected from reports, documents and website text produced by both agencies on palliative and end-of-life care service, and interviews with palliative health care professionals. A total of seven palliative professionals were interviewed: three from Vancouver Coastal Health and four from Providence Health Care. Lastly, interviews were conducted with four informal caregivers from the Greater Vancouver area who have previously provided home care to an elderly family member at end-of-life.

The discourse analysis revealed a focus by the Province of British Columbia to substantially shift the delivery of end-of-life and palliative care away from formal, institutionalized care into homes and communities. This is happening, however, in the absence of sufficient direction, support or information for informal caregivers and elderly patients as to how to achieve quality care at home. Case study analysis found that current programs provided by government or the local health area are exclusionary and/or insufficient, given the diverse care needs of families and seniors with life-limiting conditions. As well, inexperienced health providers remains an issue, as many care professionals continue to be uncomfortable in discussing death and advance care planning with patients, while others are reluctant to make care decisions without the approval from palliative team specialists. The interviews with informal caregivers uncovered incongruence between current end-of-life practices and services needed, such as help with getting to and from medical appointments, increased support in making care decisions, and greater access to formal counselling. This only reinforces the need for better supports for families, as well as seniors at end-of-life.

Proposed alternatives to address the policy issue were evaluated using five criteria. To what extent the policy was able to increase access to resources, minimize caregiver burden and meet various indicators in achieving a good death for the senior at end-of-life, and the financial cost and implementation complexity were all considered in the analysis of these policy options: increasing the availability and extent of publicly
funded formal home support, providing a single point of contact for elderly end-of-life patients and their families; increasing the frequency and reach of family meetings; and creating local, community-based services and support networks.

This study recommends that the Province of British Columbia consider providing a single point of contact for elderly end-of-life patients and their families, as this policy emerged as the most viable alternative to the policy problem. The role of patient or nurse navigation, intended to expedite patient access to resources and improve coordination of care, has been previously piloted in organizations such as the BC Cancer Agency, Cancer Care Ontario, and Cancer Care Nova Scotia. Learnings from these pilot programs can be used to create similar initiatives in British Columbia tailored to assist informal caregivers and seniors diagnosed with a life-limiting condition. Future policy should also consider increasing the availability and extent of publicly funded formal home support, as this option showed significant potential to create greater access to resources for informal caregivers, minimize caregiver burden, and contribute to the ability of seniors at end-of-life to experience a good death.
1. Introduction

Canada’s older population is projected to increase from approximately 3.8 million people in 2000, to over 6.9 million by 2021 (Fisher et al., 2000, p. 5). This has led to greater attention by governments and health care providers on the care needs of older Canadians, including seniors’ access to end-of-life treatment at home. However, despite the preference of many seniors to die at home, three-quarters of deaths in Canada still occur in hospital or long-term facilities (Carstairs & Keon, 2009).

In recent years, governments have “[downsized] medical and hospital care, increasingly shifting the burden of care to families” (Chappell & Penning, 2005, p. 457). As a result, informal care, or untrained and unpaid care provided by family members, has become the major form of care in old age, far exceeding that provided by the formal health care system (Chappell, 2008). There are more than three million informal caregivers in Canada (Statistics Canada, 2010) providing up to 85% of the total personal care received by the elderly (Kane, 1990). Addressing the needs of informal caregivers is therefore important in ensuring end-of-life seniors who desire a home death have greater opportunities to achieve a good death in a home setting.

Shifting care provision from formal to informal systems can impact whether seniors at end-of-life are able to experience a good death. There are many attributes which contribute to a good death – for example, safety, respect, comfort, support, and the dying individual’s ability to tell his or her story (Carstairs, 2010; de Jong & Clarke, 2009). In the context of home care, informal caregivers are often responsible for assisting seniors at end-of-life with activities of daily living (Health Council of Canada [HCC], 2012), but must also attend to seniors’ pain and symptom management, psychosocial and emotional needs, and in preparing for end-of-life (Stajduhar & Cohen, 2009). However, persistent barriers related to employment risks, financial costs for home care, and psychological and physiological stressors can deter informal caregivers’ ability to help seniors at end-of-life achieve a good home death.
Despite the burdens and risk of distress that can befall informal caregivers, most would rather care for their elderly family members at home versus having them die in formal, institutionalized care. Being able to provide care to a senior at end-of-life can be personally satisfying and rewarding (Turner & Findlay, 2012, p. 3), enhancing the caregiver’s relationship with the individual for whom they are providing care (Fast et al., 2002). Given the projections for Canada’s older adult population to increase in rapid numbers over the next two decades, reliance upon caregivers by both seniors at end-of-life as well as formal health care institutions is expected to continue and increase; it is therefore essential to ensure the well-being of caregivers, “for society and for people that are growing older in Canada” (Jull, 2010, p. 6).

1.1. Policy Problem

Considering this evidence, the policy problem that this capstone will address is that informal caregivers in British Columbia currently do not have adequate access to resources which would allow them the greatest opportunity to provide quality care to an elderly family member who wishes to die at home. Resources can include equipment, medications, and in-home professional care assistance for the dying senior, as well as support mechanisms that would mitigate psychological, physiological and financial strains to caregivers in fulfilling their duties to provide quality end-of-life care in a home setting. Adequacy of access relates to elderly patients’ and informal caregivers’ eligibility for programs related to palliative and end-of-life care, and the ease with which both can receive resources and support.

This study focuses on provincial policies and health service delivery within the local health area of Vancouver-City Centre; however, this has been done being mindful that policy recommendations would have broader implications for the provision of home palliative care for seniors province-wide. In the sections that follow, evidence is provided to support the position that informal caregivers are in need of greater support, which will contribute to the ability of end-of-life seniors to experience a good death at home.
2. Background

In order to fully understand how end-of-life policy has affected informal caregivers and seniors at end-of-life, this section examines who typically undertakes the role of informal caregiving and the burdens they face. This is followed by a closer look at aging in Canada, and supports currently available to families and dying seniors. Finally, a view is provided into national approaches to end-of-life policy, as well as policy specifically within British Columbia.

2.1. Understanding Informal Caregiving

The following provides information on who undertakes the informal caregiving role, gendered differences in caregiving, and seniors caring for seniors. The importance of the informal caregivers’ role is also summarized here.

2.1.1. Who are the Informal Caregivers?

Informal caregivers are “individuals who provide care and assistance for their family members who are in need of support because of physical, cognitive or mental health conditions” (Canadian Caregiver Coalition, 2004, p. 1). There are nearly four million informal caregivers in Canada providing support to seniors with a short or long-term health condition (Statistics Canada, 2010). These people assist in completing instrumental activities of daily living, such as cleaning, cooking, housework, shopping, and transportation, and are also responsible for helping end-of-life seniors with activities of daily living such as bathing, eating, and toileting (HCC, 2012).

Informal caregivers tend to be educated, working, and either married or in a common-law relationship (Turner & Findlay, 2012, p. 3). In addition, informal caregivers, prior to undertaking this role, commonly report being in very good or excellent physical and mental health (Turner & Findlay, 2012, p. 3). These data indicate a certain
socioeconomic status, suggesting that those who are in reasonably stable personal circumstances are ordinarily the ones who undertake the informal caregiving role. Nevertheless, these people still have needs of their own which, if unmet, can jeopardize their ability to provide home care.

2.1.2. Gender Differences in Informal Caregiving

Gender disparities are apparent in informal caregiving, as women predominate in undertaking this role compared to men (Cranswick & Dosman, 2008; Turner & Findlay, 2012). This has been attributed primarily to social structure, in terms of government and health insurance arrangements (Chappell, 2011), and conventional ideology with regards to who is the earner and who is the caregiver in the household (Walker et al., 1998).

The delivery of care tasks is also divided along gender lines. While men are likely to provide assistance with tasks outside of the home, such as maintenance and yard work, women commonly undertake responsibility for providing personal care related to hygiene and care management tasks; navigating different service delivery systems; hiring professional help; managing finances; and organizing care schedules (Cranswick & Dosman, 2008).

2.1.3. Seniors Caring for Seniors

While the term “senior” is subject to alternative definitions, usage of 65 as an age marker is a common and practical way to define the senior population (Chappell et al., 2003). Based on this distinction, more than a quarter of caregivers in Canada are seniors (Statistics Canada, 2010). By the nature of their relationships to individuals at end-of-life, spouses who undertake the informal caregiving role are likely to be seniors themselves with their own health problems (Canadian Study on Health and Aging, 1994; HCC, 2012), more susceptible to negative aspects of caregiving than younger informal caregivers (Jull, 2010). Depending on the illness of the elderly individual requiring care, the responsibilities of caregivers can be intense, frequently unpredictable, and uncontrollable (Stephens et al., 1991); this creates a risk to seniors caring for seniors, as
pre-existing health conditions of older caregivers can be exacerbated as a result of the stresses of caregiving (de Frias et al., 2005).

2.1.4. The Importance of the Informal Caregivers’ Role

Informal caregiving complements that of formal social and health care systems, and allows for seniors who are ill and at end-of-life to remain in their homes and communities for as long as possible (HCC, 2012; Jull, 2010). While a third of caregivers typically provide care for less than a year, about an equal proportion do so for at least five years (Statistics Canada, 2010; Turner & Findlay, 2012, p. 2); this is likely a result of care provision having evolved from that of chronic conditions (Fast et al., 2002). However, studies have shown that these situations allow for the informal caregiver and the person receiving care to strengthen and enhance their relationships (Fast et al., 2002), when not much time may be left for the individual at end-of-life; the time spent caregiving can therefore be fulfilling for both parties.

The service that informal caregivers provide results in a significant cost savings to the formal health care system. One study conservatively estimates that informal caregivers provide approximately $25 billion of care per year to Canadian seniors (Hollander et al., 2009, p. 48). This takes into account the types of services being provided by middle-aged and older unpaid caregivers, as well as the average hours per week these individuals may be providing home palliative care.

2.2. Burdens Faced by Informal Caregivers

Caregiver burnout, a common consequence when informal caregivers are insufficiently supported, can result in increased risk of both caregivers and individuals at end-of-life having to be admitted to formal institutions for medical care (Canadian Institute for Health Information [CIHI], 2010; HCC, 2012). This section examines burdens faced by caregivers, such as risks to their employment and earning potential, as well as stressors that contribute to caregiver burnout: the financial costs of caregiving as well as psychological and physiological strain.
2.2.1. Risks to Employment and Earning Potential

Many informal caregivers undertake the responsibility freely out of a desire to help a family member at end-of-life. However, in doing so, caregivers must often leave their place of employment if unable to negotiate flexible working arrangements with an employer. Conflict arising between work and caregiving responsibilities can threaten caregivers’ current and future income security (Fast et al., 2002) in the form of reduced and foregone income, lost benefits, reduced pension, and reduced savings investments (Keating et al., 2013). Common impacts to work as a result of caregiving include lost days of work or taking periods or leave (Keating et al., 2013). Recent data indicate that over 520,000 employed caregivers missed at least one day of work per month to provide care; collectively, this amounts to nearly 1.5 million work days per month lost to caregiving responsibilities (Fast et al., 2011, p. 1). Further, an American study estimates that informal caregivers providing care to chronically or terminally ill individuals lose, on average, over $566,000 USD in wages and retirement income over their lifetimes (MetLife Mature Market Institute, 1999, p. 6).

Gendered differences in caregiving can also result in disparities with respect to lost employment and earning potential. Evidence shows that women have a greater propensity “to accommodate their employment to caregiving, to give up work or quit a job…to incur higher out-of-pocket expenses…given [that Canadian] women have lower average incomes than do men, this cost evidence suggests a new double jeopardy of being female and a caregiver” (Keating et al., 2013, p. 8). In addition, female caregivers are significantly more likely than men to miss full days of work, retire early, quit or lose their paid jobs, or turn down a job offer or promotion (Fast et al., 2011).

2.2.2. Personal Financial Costs

The trend towards de-institutionalized care for seniors has also allowed for costs to shift away from the public sphere to those of informal caregivers (Chappell & Penning, 2005). More than 40% of informal caregivers pay out-of-pocket for home care services, incurring expenses related to transportation, housing, food, and other home care-related costs (HCC, 2012, p. 29). This could consist of medications, which typically constitute a
large proportion of expenses, or costs in accompanying care recipients to specialized treatments or consultations (Keating et al., 2013).

Each province is also responsible for administering its own budget for home care services, resulting in variation and eligibility criteria for home care and palliative programs (HCC, 2012), such as uneven distribution of services and considerable differences between provinces with respect to service mix (Carstairs & Beaudoin, 2000). Limited provincial funding can result in capped hours for professional help with home palliative care (HCC, 2012), forcing caregivers to spend out-of-pocket for care not covered, but needed, by the individual at end-of-life. Nationwide, only 14% of caregivers of spouses and 5% of those providing care to parents accessed funding provided by government programs; however, only 3% of family caregivers in 2012 received a federal tax credit for which they were eligible, despite the fact that 42% of spousal caregivers and 28% of caregivers of parents would have liked more help than they received (Turcotte, 2013, p. 1).

2.2.3. Psychological and Physiological Strain

More than half of caregivers in Canada report having encountered difficulties and challenges in their care duties and, when asked about the most negative aspects of caregiving, 17% reported that it was emotionally demanding; 12% said that, because of caregiving, they did not have enough time for themselves or family; 10% said it created stress; and 7% reported fatigue (HCC, 2012, p. 28; Statistics Canada, 2010; Turner & Findlay, 2012, p. 3). The majority of caregivers providing care to a spouse also live in the same home as the person receiving care (Turcotte, 2013, p. 3); this type of environment can exacerbate emotional stress if caregivers are unable to effectively experience respite from their duties.

While providing informal care can be stressful, not being able to care for a family member at end-of-life can also be a cause of psychological strain. Many informal caregivers, upon committing to provide home care for a senior at end-of-life, are steadfast in their efforts to keep this promise; however, caregivers often undertake this role amongst "a lack of preparedness for caregiving, difficulty with accessing professional support and information, and frustration with the inadequate help they
receive” (Topf et al., 2013, p. 876). This can create complicated bereavement issues for caregivers when they are unable to fulfill their promise to provide end-of-life home care, indicating a need to ensure reasonable support mechanisms are available to caregivers not only while providing end-of-life home care, but also from time of diagnosis until after the elderly individual has passed on.

2.3. An Aging Nation

The current state of Canada’s aging population, the cost implications of an increasingly older population on the public health care system, and what constitutes a good death are detailed below.

2.3.1. Seniors and End-of-Life Care in Canada

End-of-life care “can be understood as a continuum of events starting with the diagnosis of one or more serious illnesses or injury” (Schuklenk et al., 2011, p. 10). In seniors, chronic conditions and multiple morbidities are often the case; this creates challenges in accurately predicting illness trajectory and determining care planning (Fisher et al., 2000). Canadians, however, are becoming more aware of end-of-life care issues; the value of providing appropriate and compassionate support to those at end-of-life, as well as those providing informal care, is therefore growing in recognition (Health Canada, 2007). This growing interest indicates an opportunity to ensure Canadians have access to accurate information about their options and the resources available to them for end-of-life.

Canada, however, lags behind other developed nations in end-of-life care delivery, ranking ninth out of 40 countries overall in its ability to provide a basic end-of-life health care environment¹; the United Kingdom, Australia and New Zealand rank

¹ The indicators for basic end-of-life health care environment include: political instability risk; GDP per head; an old age dependency ratio; life expectancy at birth; health care spending as a percentage of GDP; number of hospital beds per 1,000 non-accidental deaths; number of doctors per 1,000 non-accidental deaths; social security expenditure on health; and national pension scheme coverage (Economist Intelligence Unit, 2010, p. 36)
amongst the top three (Economist Intelligence Unit [EIU], 2010, p. 11). With the mortality rate projected to double between 2008 and 2056 (Carstairs, 2010, p. 10; Statistics Canada, 2013), and each death in Canada expected to affect the well-being, on average, of five other family members (Quality End-of-Life Care Coalition of Canada, 2010, p. 2), it is vital to address deficiencies in end-of-life health service delivery in order to mitigate impacts to families.

2.3.2. The Cost of Dying

Greater demands on the health care system are expected as a result of Canada’s aging population. Seniors account for less than 14% of the population, but consume nearly 44% of the total health care budget (CIHI, 2011a, p. 17), and constitute 40% of acute hospital stays (CIHI, 2011b, p. 28). In British Columbia, hospital spending represents, on average, 80% of total measured health costs in the last year of life (Cunningham et al., 2011, p. 5). This is in-line with findings which reveal health expenditures increase sharply for older British Columbians, up to over $22,000 per person for those over 90 years of age (Lee, 2006, p. 14). Further, one-third to one-half of a typical person’s health care expenditures often occurs in the final year of life (Lee, 2006, p. 5). Overall, as people are living longer with chronic conditions, it is expected that the cost of end-of-life care as a proportion of overall health care spending will increase over time (EIU, 2010, p. 25).

Despite these findings and the “widespread belief that healthcare systems are spending more and more to provide intensive and aggressive care to older patients living out their final months” (Canadian Health Services Research Foundation [CHSRF], 2003, p. 1), there is evidence which counters that the proportion of health care spending for seniors has remained stable over the last 10 years, increasing only marginally (CIHI, 2011a, p. 17). Advances in medical technology can significantly lower the intensity of treatments and, therefore, the overall cost per patient (Evans et al., 2001). Additionally, improved planning for end-of-life, including greater use of advance directives, allows older people and their families to choose suitable, and personally acceptable, levels of medical intervention in the case of serious illness – which can help to decrease overall end-of-life health care costs (Lee, 2006).
Regardless of the conflicting evidence which postulates that the cost of dying creates an increased strain on the system, there exists a value-based question around whether public spending on the cost of dying is “too high” (CHSRF, 2003, p. 2). Advocates of end-of-life care often refer to evidence that increased palliative care, community and home care can all reduce costs associated with in-patient hospital stays (EIU, 2010); home care services in British Columbia alone are estimated to cost one-fifth as much as acute care services (Lee, 2006, p. 15). But research suggests that “this trend toward de-institutionalization is less about the stated preferences of seniors and more about the organization of care, asserting that institutional settings have higher costs associated with them than do services provided through home care” (CIHI, 2011b, p. 90). In addressing these issues, policy implications may therefore arise as our society decides how to balance formal and informal avenues of end-of-life care in order to legitimize public spending on the cost of dying (CHSRF, 2003).

2.3.3. What is a Good Death?

Home care evolved during the 1970s out of increased fiscal pressures to reduce demand on hospital-based care (Dudgeon & Kristjanson, 1995), but research at that time also showed that the suffering of dying patients was intensified by the depersonalization of the general hospital ward, where patients were isolated in private rooms, visited infrequently by medical staff and were often unable to have their emotional needs met (Ajemian & Mount, 1980). This has contributed to the increasing desire of seniors to age in place and remain in their homes for longer. Evidence has shown that seniors perceive greater satisfaction with home care versus other care settings (Miller, Hollander, & MacAdam, 2008) and about 85% of older Canadians would prefer to remain in their present homes, even if their health conditions change over time (Canada Mortgage and Housing Corporation, 2008, p. 2).

While remaining at home may provide a sense of independence, this can place seniors at risk of being adversely affected in terms of financial status, degree of isolation, and overall reduced well-being (CIHI, 2011b), particularly if they are trying to manage on their own. Quality of life for seniors can be achieved in a home setting, but requires community support, appropriate housing, and informal and/or formal care (CIHI, 2011b).
As well, a number of indicators are understood to help ensure seniors at end-of-life experience a good death. These include safety, respect, comfort, support, and the ability to tell their story (Carstairs, 2010; de Jong & Clarke, 2009). Seniors require a safe environment – a place where their physical and emotional needs can be met (Carstairs, 2010). This must also take into account safety issues encountered in home care, such as difficulties faced by untrained individuals in following health care regulations (HCC, 2012). In preparing for death, advance care planning, while not a legally required practice in the province of British Columbia, can help to clarify each person’s preferences regarding end-of-life care and confirm that “family, friends and/or health care providers know your wishes, and can ensure these wishes are followed” (British Columbia Ministry of Health [MoH], 2013e, p. 2). Psychosocial, spiritual and emotional supports are also key factors which can promote a good death, as issues of faith and spirituality are seen as integral to overall healing at end-of-life (Steinhauser & Clipp, 2000). Telling stories of family (de Jong & Clarke, 2009) and having someone listen (Carstairs, 2010) are also important, as this fulfills the need of those dying to “contribute to the well-being of others” (Steinhauser & Clipp, 2000, p. 828).

The ideal way in which one person wishes to die may vary from what others want at end-of-life but for many, maintaining the quality of life in the dying process is contingent upon the markers above. Ensuring enough direction and guidance for informal caregivers can help them provide a good death at home and ensure quality of life for dying seniors (Ross et al., 2002).

2.4. Current Supports Available to Informal Caregivers and Seniors at End-of-Life

Both the federal government and the Province of British Columbia have established programs to assist informal caregivers in providing care for seniors who wish to die at home. This section details the main government programs currently available to caregivers, such as the Employment Insurance Compassionate Care Benefit and the BC Palliative Care Benefits Program, and the limitations of those programs.
2.4.1. **Canada’s Employment Insurance Compassionate Care Benefit**

The Government of Canada’s Compassionate Care Benefit program aims to assist family members who are employed and “have to be away from work temporarily to provide care or support to a family member who is gravely ill with a significant risk of death within 26 weeks” (Government of Canada, 2013). However, the Compassionate Care Benefit is limited to a maximum six-week period to those who are currently employed; this can be inadequate, given the long-term nature of many life-limiting illnesses and common palliative prognosis of six months or less (Robinson & Segal, 2013).

While it has been established that women predominantly undertake the caregiving role, women are the least likely to be eligible for the Compassionate Care Benefit due to their propensity, versus men, to be stay-at-home parents and part-time workers (Giesbrecht et al., 2010). Women make up the majority of claims for this program; however, on average they receive lower weekly benefit payments versus men due to more limited salaries (Canada Employment Insurance Commission, 2013). This suggests disparities in providing benefits under this program based not only on employment status and relation to the individual at end-of-life, but gender differences, as well.

2.4.2. **The BC Palliative Care Benefits Program**

This program offered by the British Columbia Ministry of Health “supports B.C. residents of any age who have reached the end stage of a life-threatening disease or illness and who wish to receive palliative care at home” (MoH, 2013a). It does this by offering medical supplies and equipment, and medications under the PharmaCare BC Palliative Care Drug Plan. This plan covers 100% of the eligible costs of prescription drugs and selected over-the-counter drugs needed for treatment at home; however, coverage is restricted to medications listed in the Plan P (Palliative Care Drug Plan) formulary, while equipment is limited to “some of the same medical supplies and equipment they [patients] would get if they were in hospital” (MoH, 2012a, p. 2). Therefore, for seniors requiring specific medications not under the Plan P formulary, or
who would benefit from certain equipment not covered by the program, these items would have to be paid for either by the patient or informal caregiver.

2.5. Policy Context

Provided here is a description of work undertaken by the Senate of Canada on end-of-life issues, and federal approaches to end-of-life care. This is followed by a look the current end-of-life policy framework in British Columbia.

2.5.1. The Senate of Canada

Since the mid-1990s, the Senate of Canada has worked to keep palliative and end-of-life care issues on the political agenda. In 1995, it tabled a report highlighting considerations for palliative care, education and training, research, guidelines and standards, advance directives, and legislative initiatives (Carstairs & Beaudoin, 2000). Five years later, it recommended that the federal government work in collaboration with the provinces to develop a national strategy for end-of-life care (Carstairs & Beaudoin, 2000). In 2005, the Senate tabled a third report on palliative care which looked at the progress to implement the recommendations outlined in the previous reports, and included 10 additional recommendations – specifically, in the areas of national strategy; patient and caregiver support; training and education for formal and informal health care providers; government and citizens working together; and planning for the future (Carstairs, 2005). The latest report, published in 2010, focuses on the current state of palliative care in Canada, why palliative care is important, what progress has been made and what still needs to be done. For informal caregivers, this means improving respite care; recognizing the importance of grief and bereavement services; minimizing excessive financial burden; ensuring sufficient information and education; providing adequate home care services; and making work options available (Carstairs, 2010).

While many of the Senate’s recommendations remain relevant to improving end-of-life care today, progress in the areas listed above has been insubstantial. Limited improvements have been made specifically in the areas of income and job protection,
palliative educational opportunities for health care providers, and public education around advance care directives (Macdonald, 2012).

2.5.2. The Federal Government and End-of-Life Care

While the Senate of Canada has made efforts to raise awareness around the importance of end-of-life care issues, no national policy currently exists to explicitly address the provision of home care. The 2004 Health Accord identified home care as a priority initiative, and acknowledged that improving access could “improve the quality of life for many Canadians by allowing them to be cared for or recover at home” (Government of Canada, 2004). This included agreement by First Ministers to provide increased coverage for short-term acute home care and end-of-life care, but no national strategy. However, despite significant investments over the last decade, “access to care has not substantially improved and patients are not reporting that their care is better integrated or more patient-centred” (HCC, 2014, p. 49). Canada’s performance in health outcomes also continues to lag behind many other high-income nations, and access to high-quality health services remains inequitable (HCC, 2014). While home care has been historically recognized by the federal government, a continued absence of a national policy to coordinate intergovernmental efforts in home care can only serve to perpetuate the challenges for Canadians with respect to achieving quality care at end-of-life.

2.5.3. British Columbia’s End-of-Life Framework and Action Plan

In British Columbia, it is projected that the percentage of seniors 80 years of age and older will grow from 4.4% of the population in 2012 to 7.4% of the population by 2036 (BC Stats, 2012, p. 9). As well, the prevalence of chronic conditions is expected to increase nearly 60% over the next 25 years (MoH, 2007). This will have substantial implications for health service use in the province and the actions taken to provide for an aging population.

In 2006, the Government of British Columbia released A Provincial Framework for End-of-Life Care. This framework was designed to give “health authorities, service providers and community groups a basis for planning exemplary end-of-life care
services” (MoH, 2006b, p. i). The framework also acknowledges the importance of being able to provide those at end-of-life with enough support to die at home, should that be the individual’s wishes (MoH, 2006b). The *Provincial End-of-Life Care Strategy and Action Plan for British Columbia*, which evolved out of the 2006 framework, outlines broad end-of-life policy in British Columbia and provides three priorities for end-of-life care in British Columbia:

- Priority 1: Redesign health services to deliver timely coordinated end-of-life care;
- Priority 2: Provide individuals, caregivers and health care providers with palliative care information, education, tools and resources; and
- Priority 3: Strengthen health system accountability and efficiency.

(MoH, 2013f, pp. 13-15)

Although British Columbia has formulated this direction for end-of-life care, it is important that it show leadership in delivering and improving these services. The reasons for this are explained below.

### 2.6. Moving Forward with Provincial Support for Informal Caregivers in Providing End-Of-Life Care for Seniors

Federal and provincial governments have long been aware of the need to address end-of-life policy issues in Canada. However, a national strategy for end-of-life care remains absent, contributing to a lack in cohesion, coordination and comprehensiveness in government efforts. Devolving responsibility for home care to the provinces has only exacerbated issues of access to high-quality health services (HCC, 2014), with variability in the delivery of end-of-life care and support mechanisms (HCC, 2012) making it difficult for informal caregivers and dying seniors to achieve a good death at home.

Existing programs are not doing enough to assist families and elderly patients. Financial, psychological and physiological burdens to informal caregivers are well documented (HCC, 2012), as are the risks to their employment and earnings (Fast et al., 2002; Keating et al., 2013; MetLife Mature Market Institute, 1999; Turcotte, 2013), yet
current programs intended to help families in caring for dying seniors bear significant limitations (Giesbrecht et al., 2010; Robinson & Segal, 2013). This devalues the service informal caregivers are providing, not only to the individuals they are caring for, but also in their contributions to relieve costs to the formal health care system.

British Columbia’s Ministry of Health has acknowledged “that many of the people who currently die in hospital could, with appropriate preparation and support, die at home” (MoH, 2006b, p. 1). For informal caregivers, greater preparedness with regards to the extent of caregiving demands, more equitable access to programs, better ways to navigate the various health service systems, and increased support from professional health care providers as seniors’ conditions worsen are all possible ways to improve their ability to fulfill caregiving duties. However, little remains known about which interventions are most effective in supporting informal caregivers in their role (Stajduhar, 2013). In order to identify the most valuable interventions and supports, this research seeks to determine what resources are currently of most use to caregivers, which programs are in need of improvement, and what is currently absent but needed by caregivers to mitigate their burdens and ensure seniors at end-of-life can experience a good home death. The following sections outline the research methodology used to uncover and determine how to actualize effective support mechanisms.
3. Methodology

In order to determine what policy options can best address the policy problem that informal caregivers in British Columbia currently do not have adequate access to resources which would allow them the greatest opportunity to provide quality care to an elderly family member who wishes to die at home, the overall purpose of this research was to determine how to improve access to supports through policy recommendations. This section describes the research questions used in this study, as well as the approach used to answer these questions.

3.1. Research Questions

Given the policy problem, this study was guided by two research questions in determining how to best address this issue. With respect to achieving quality care at home, the first research question in this study was: in what ways do current palliative care policies set the context for end-of-life seniors to have a good death at home? Because the role of informal caregivers is crucial in enabling dying seniors to experience a good death at home, the research also sought to answer a second question: in what ways are informal caregivers supported in their role to provide quality care to an elderly family member who wishes to die at home?

3.2. Research Approach

In order to answer these questions, the research methodology for this project comprised three main components:

- A discourse analysis to critique current provincial policy aimed at prescribing particular end-of-life care practices in relation to seniors and home care;
- A case study analysis to evaluate current support mechanisms available to seniors at end-of-life as well as their informal caregivers; and
• Interviews with individuals who have provided home care to an elderly family member at end-of-life to assess support mechanisms.

Provincial policies focused on end-of-life care will have an impact on service delivery province-wide. Therefore, in order to better understand the impacts of policy and how this translates into practice, this capstone concentrated on end-of-life home care and supports offered within the health service delivery area of Vancouver and, specifically, the local health area of Vancouver-City Centre.

![Local Health Area 161 Vancouver-City Centre](image)

**Figure 1. Local Health Area 161 Vancouver-City Centre**

Note: BC Stats, 2013b, “161 City Centre”

With a population of nearly 670,000 people as of 2012, and a population growth rate of over 2% between 2011 and 2012 (BC Stats, 2013a, p. 2), the city of Vancouver ranks third highest in population growth in British Columbia. Situated within the larger municipality of Vancouver, the local health area of Vancouver-City Centre has been chosen in this study to represent urban-dwelling residents, as this large population base
allows for densification of end-of-life care services and supports for informal caregivers. Containing the scope of this project within the boundary of Vancouver-City Centre allowed for specific conclusions to be drawn which will have greater relevance for this particular local health area, but also for other highly populated regions in British Columbia that have a concentration of services for seniors and their families.

Table 1 provides an overview of the research questions addressed by each research method. The research methods are described below.

Table 1. Overview of Research Methods Used to Answer Research Questions

<table>
<thead>
<tr>
<th>Research Method</th>
<th>Research Question #1</th>
<th>Research Question #2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Critical Discourse Analysis</td>
<td>In what ways do current palliative care policies set the context for end-of-life seniors to have a good death at home?</td>
<td>In what ways are informal caregivers supported in their role to provide quality care to an elderly family member who wishes to die at home?</td>
</tr>
<tr>
<td>Case Study Analysis</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Interviews with Informal Caregivers</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

3.2.1. Critical Discourse Analysis: Provincial End-of-Life Policies

This study highlights a need to understand how provincial policies focused on end-of-life care in British Columbia set the context for seniors to have a good death at home, as this serves to inform the role and responsibilities of informal caregivers in fulfilling those wishes. A critical discourse analysis was employed to uncover how language has been used to both frame the issue as well as position how end-of-life care will be addressed. Analysis was conducted by considering the three dimensions of the critical discourse analysis framework: the discursive practice of written language texts to uncover underlying messages; a text analysis to contextualize the production, distribution and consumption of text; and social practice, exploring discursive events as instances of power and ideology (Fairclough, 1995). More on the critical discourse analysis used in this study is provided in Appendix A.
The provincial policy documents used in the critical discourse analysis were selected based on their relevance to seniors at end-of-life and their intent to create a health care environment conducive to home care for seniors at end-of-life. Documents were also chosen based on their recent and direct application to end-of-life care delivery in British Columbia and, therefore, service delivery within the local health area of Vancouver-City Centre. The British Columbia Ministry of Health documents and text used in the critical discourse analysis were:

- A Provincial Framework for End-of-Life Care (2006b);
- The Joint Protocol for Expected/Planned Home Deaths in British Columbia (2006a);
- The Provincial End-of-Life Care Action Plan for British Columbia (2013f); and
- Website text focused on End-of-Life Care (2013c), Expected/Planned Home Deaths (2013d), and Caring for Seniors (2013b).

### 3.2.2. Case Study Analysis

While learning how dominant discourses in policy can influence the delivery of end-of-life care across the province, this does not contribute to the understanding of how individual health authorities execute government direction. By conducting a case study analysis, it was possible to examine how palliative services are provided to dying seniors as well as how informal caregivers are supported in their efforts specifically within the local health area of Vancouver-City Centre. Examining cases within this local health area made it possible to assess whether practices resulting from current provincial end-of-life policies are effective and where improvements can be realized.

Case study analysis allows for exploration of individuals and organizations, simple through complex interventions, relationships, communities, and programs (Yin, 2003). In this study, the two cases under examination were Vancouver Coastal Health and Providence Health Care, as these are the organizations situated within the local health area of Vancouver-City Centre. An evaluation of individual practices applied by these organizations to support informal caregivers and seniors at end-of-life was conducted using specific study propositions and the following criteria: adequate preparation and advance care planning; effective pain and symptom management; provision of psychosocial, spiritual and bereavement support; support for informal
caregivers; and sufficient financial support. This was followed by a cross-case comparison of practices employed by both agencies. A brief overview of these two cases is provided in Table 2, while data sources, or units of analysis, have been summarized in Table 3 below. A fuller description on the case study analysis employed in this study is provided in Appendix B.

**Table 2. Overview of Cases Used in Analysis**

<table>
<thead>
<tr>
<th></th>
<th>Case #1: Vancouver Coastal Health</th>
<th>Case #2: Providence Health Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>General description</td>
<td>Serves 25% of BC’s population or over one million people including the residents of Vancouver, Richmond, the North Shore and Coast Garibaldi, Sea-to-Sky, Sunshine Coast, Powell River, Bella Bella and Bella Coola.</td>
<td>Providence Health Care provides health care services to patients and residents from British Columbia. Providence falls within the Vancouver Coastal Health region but is governed by its own, independent Board of Directors.</td>
</tr>
<tr>
<td>Full and part time staff</td>
<td>13,000</td>
<td>Approximately 9,000</td>
</tr>
<tr>
<td>Physicians</td>
<td>2,500</td>
<td>Approximately 1,000</td>
</tr>
<tr>
<td>Researchers</td>
<td>Over 600 principal investigators, graduate, and post-graduate trainees conduct both clinical and basic science research</td>
<td>Approximately 200</td>
</tr>
<tr>
<td>Volunteers</td>
<td>5,000</td>
<td>Approximately 1,600</td>
</tr>
<tr>
<td>Home care nursing visits per day (on average)</td>
<td>891</td>
<td>-</td>
</tr>
<tr>
<td>Home nursing visits per year</td>
<td>Over 199,000</td>
<td>-</td>
</tr>
<tr>
<td>Home support hours per year</td>
<td>Over 1.9 million hours</td>
<td>-</td>
</tr>
<tr>
<td>Residential care client visits per day (on average)</td>
<td>6,240</td>
<td>-</td>
</tr>
<tr>
<td>Daily visits with assisted living tenants (on average)</td>
<td>891</td>
<td>-</td>
</tr>
</tbody>
</table>

Sources: (Providence Health Care [PHC], 2013c; Vancouver Coastal Health [VCH], 2013e; Vancouver Coastal Health Research Institute [VCHRI], 2012)
Table 3. Case Study Units of Analysis

<table>
<thead>
<tr>
<th>Cases</th>
<th>Units of Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case #1: Vancouver Coastal Health</td>
<td>• Vancouver Coastal Health’s Community Engagement Report on a Regional Palliative/End-of-Life/Hospice Care Services Strategy (Tolson &amp; Evoy, 2005);&lt;br&gt;• Website text on Home and Community Care (VCH, 2013b); and&lt;br&gt;• Interviews with palliative care professionals working within Vancouver Coastal Health.</td>
</tr>
<tr>
<td>Case #2: Providence Health Care</td>
<td>• Document on Palliative Care at St. Paul’s Hospital (PHC, 2013b);&lt;br&gt;• Website text on End-of-Life Care (PHC, 2013a); and&lt;br&gt;• Interviews with palliative care professionals working within Providence Health Care.</td>
</tr>
</tbody>
</table>

As one data source used in the case study analysis, three palliative health care professionals from Vancouver Coastal Health and four from Providence Health Care were interviewed between November 2013 and January 2014. Interviews covered a broad set of topics, including information needs, impacts to caregivers’ personal and work lives, and the role of health professionals. Data was analyzed using thematic analysis, “a method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 79). An example of the schedule used for interviews can be found in Appendix C.

3.2.3. Interviews with Informal Caregivers

Evaluating the needs of informal caregivers was done by speaking with family members who provided home care to a senior at end-of-life. Given the potentially sensitive nature of the research topic, interviews were conducted with informal caregivers not currently providing care, but who had done so previously. A total of four informal caregivers were interviewed from the greater Vancouver area between November 2013 and January 2014 to discover their individual experiences with caregiving, the specific burdens they encountered, and how their needs were or were not met by the health authorities. Analysis of the data obtained through interviews with informal caregivers was conducted using thematic analysis. The recruitment, interview format and analysis used in the interviews with informal caregivers are more fully described in Appendix D. Interviews included discussions on caregivers’ relationship to
the senior at end-of-life, their day-to-day tasks, and impacts to their personal and work lives. An example of the interview schedule can be found in Appendix E.

All necessary ethical approvals were obtained prior to beginning research; these are detailed in Appendix F. The section that follows provides a summary and discussion of the findings resulting from the research approach.
4. Research Findings

Presented here are the findings for each component of the research methodology: the critical discourse analysis of provincial end-of-life policies; the case study analysis of end-of-life care practices at Vancouver Coastal Health and Providence Health Care; and interviews with former informal caregivers who have provided home care to a senior at end-of-life.


The discursive practice, text analysis, and social practice findings from the critical discourse analysis are discussed below.

4.1.1. Discursive Practice

Discourse of Knowledge and Goals: A discursive analysis of British Columbia’s end-of-life policies confirms that the Province of British Columbia is interested for seniors to experience a good home death. However, actions outlined in meeting end-of-life care goals and priorities are described very generally without providing any specific direction. While text from the Provincial End-of-Life Care Action Plan for British Columbia has been presented intentionally as a guide for “health authorities, physicians, health care providers, and community organizations in planning integrated primary and community care services” (MoH, 2013f, p. 4) and to allow for flexibility in interpreting the action items, it also creates a high degree of variability and lack of accountability. For example, one priority outlined in the Provincial End-of-Life Care Action Plan is to “provide individuals, caregivers and health care providers with palliative care information, education, tools and resources” (MoH, 2013f, p. 14), yet the actions in relation to this goal do not specifically describe the ways in which knowledge,
awareness and information will be shared or disseminated. Further, only one of the four actions highlighted in meeting this goal references seniors and informal caregivers, and does so only vaguely: “increase public knowledge and awareness of palliative care as an approach to care that improves the quality of life for both the patient and the family at any stage in a serious illness” (MoH, 2013f, p. 14). This lack of specificity and direction in required actions detracts from the policy’s direction to achieve the outlined goals.

**Discourse of Integration:** Provincial policy documents addressing end-of-life care for seniors in British Columbia exhort a need for better integration of care and services, yet policies are presented in such a way that is not inclusive of seniors and caregivers. For example, the *Provincial End-of-Life Care Action Plan* uses 17 instances of the term, “integrate” e.g. integrat* in describing the need for better integration in end-of-life health service delivery. In addition, there are eight occurrences of the word, “team” – as in, team of doctors, health teams, care teams, consultation teams, etc. But the policy also emphasizes a need to provide “individuals and families…with information and resources to effectively manage their own care journey” [emphasis added] (MoH, 2013f, p. 14). This excludes patients and families from the care teams of which they should be a part. Additionally, the information needs of seniors and informal caregivers are situated as secondary to the needs of professional caregivers. One action item relates to promoting “support for end-of-life care education for family physicians, specialists and health care professionals” [emphasis added] (MoH, 2013f, p. 14) with no mention of dying seniors and the family providing informal care. Focusing only on the educational needs of professional providers minimizes the need for dying seniors and informal caregivers to be better educated in end-of-life care issues, and excludes them from the discussion around the supports they require.

**Discourse of Home Death Management:** In contrast to the *Provincial End-of-Life Care Action Plan*, the *Joint Protocol for Expected/Planned Home Deaths in British Columbia* is a comprehensive document, detailing the “process and procedures involved in managing anticipated natural home deaths in the context of a terminal illness” (MoH, 2006a, p. 1). While this document is “intended for health care professionals and agencies involved in expected/planned home deaths” (MoH, 2006a, p. 1), it contains a wealth of information useful also for seniors at end-of-life as well as their families. But by focusing solely on the involvement of professional providers, the families’ role in
managing a planned home death remains unacknowledged. This, again, excludes seniors and caregivers and instead focuses on ensuring that knowledge and information around “protocol” and “procedure” is available primarily for agencies and professional providers. Positioning end-of-life care policies and practices in this way disregards the need for information often cited by individuals at end-of-life and their families at a time when information needs are at their greatest.

**Discourse of Partnerships:** Lastly, provincial policies reference different partnerships in the delivery and coordination of end-of-life care services. Partners such as the British Columbia Ministry of Health, the BC Medical Association, Michael Smith Foundation for Health Research, the Provincial Health Services Authority, BC Cancer Agency, and BC Renal Agency are listed in the *Provincial End-of-Life Care Action Plan*, while the *Provincial Framework for End-of-Life Care* mentions partnerships with the Canadian Hospice Palliative Care Association and Canadian Council on Health Services Accreditation. Naming such agencies specifically while being non-committal with regards to actionable items is indicative of policy makers’ desire to exemplify the work that has been done in partnership with these agencies, without actually having assigned responsibility to any organization in fulfilling the actions needed to ensure quality end-of-life care in British Columbia. Further, mention is made neither of funding sources, nor who will be responsible for leading these partnerships.

Overall, while the intent of the policies may be well-meaning, the analysis of discursive practices reveals that the dominant discourses uphold the importance of meeting and addressing the information and educational needs of palliative health care professionals versus that of dying seniors and informal caregivers. While it is important to ensure professional caregivers are trained to perform their jobs well, disregarding the information needs of informal caregivers restrains their ability to provide quality care to seniors who wish to die at home. This approach is in contrast to other jurisdictions, such as the United Kingdom, whose policies are designed to allow the public to contribute significantly to health care development and delivery (National Institute for Health and Care Excellence, 2013), thus ensuring services are of greatest relevance for patients.

Policies that would be of most value would describe how seniors at end-of-life and their informal caregivers can better intersect with professional care providers. A
more intentional focus by government to create greater accountability in its policy
direction and action plans, as well as consider seniors and informal caregivers as part of
the greater palliative health care team, are ways in which end-of-life care can be
advanced in a more inclusive and progressive way.

4.1.2. Text Analysis

A textual analysis of provincial end-of-life policies reveals British Columbia’s
desire to alter service delivery and focus on community-based services. However, this is
done primarily at the exclusion of patients and families from the conversation. Further,
policies do not provide data to reinforce how the direction will benefit seniors at end-of-
life. In the Provincial End-of-Life Care Action Plan for British Columbia, the terms “shift”
and “change” are used a total of 11 times. Specifically, the emphasis is on shifting away
from hospital care towards integrated health services and services based in the
community. For example, the document states the following:

These strategies provide a foundation of meaningful support for the
significant shift in clinical practice and service planning required to
implement a proactive, integrated approach to end-of-life care [emphasis
added] (MoH, 2013f, p. 11).

Through integrated primary and community care strategies, the Ministry
of Health and health authorities are working with physicians and other
health care providers, community organizations and researchers to
redesign and realign services in partnership with patients. An integrated
system of primary and community care offers improved patient
experience of care in community based settings with timely access to
quality hospital services when needed [emphasis added] (MoH, 2013f, p.
10).

These two statements, when viewed together, imply a number of things for policy
direction. First, the way services are delivered requires substantial change; this is
evidenced in the way “significant” has been used along with the need to “redesign” and
“realign” services. As well, the emphasis on “community” indicates a focus on improving
services to seniors and families outside of hospital settings. Website text describing
palliative programs also focuses on what services can be accessed to receive “care at
home.” This use of text points to the government’s desire to move away from costly
services provided in institutionalized settings toward community and home-based care settings.

While a greater shift towards care in the community may serve to focus efforts on home care, this, along with more proactive identification of those requiring palliative care, does not necessarily translate to better care at home for seniors at end-of-life. In order to achieve quality home care, dying seniors and informal caregivers need to be well prepared and supported for an expected home death. However, broad statements are presented in the policies without any evidence to prove expected outcomes; further, they do not clearly indicate how issues will be addressed. For example, the Provincial End-of-Life Care Action Plan states that:

As hospital staff identify people with palliative and end-of-life care needs more readily, and referrals to appropriate community based services are made, more individuals will receive quality end-of-life care at home. This will support improved quality of life, patient and family engagement in the community [emphasis added] (MoH, 2013f, p. 5).

Strategies such as these may be intended to improve deinstitutionalized palliative care, but focus primarily on hospital staff and other professional providers with very minimal mention of how informal caregivers and dying seniors are to be engaged and involved with regards to their care and support needs. Being dismissive of these individuals restrains the overall system’s ability to ensure quality care can be achieved for elderly patients at end-of-life.

Based on the textual practices analyzed in the selected documents, the Ministry of Health has provided little information in its policies to clarify how health partners and professional agencies will interface with dying seniors and their families; this is the case, despite a political desire to significantly shift services away from the hospital to community settings. Forcing significant shifts in end-of-life care delivery in the absence of reasonable and specific actions to better support informal caregivers ultimately restricts informal caregivers’ efforts and does little to create a system where a good home death for end-of-life seniors can be achieved.
4.1.3. **Social Practice**

An exploration of the policies’ social practices reveals that seniors at end-of-life and their informal caregivers are not necessarily positioned as the primary beneficiaries of the direction put forward by government. Given the aim to “increase individual, community and health care services’ capacity and support people at end of life to remain at home and in their communities to the greatest extent possible” (MoH, 2013f, p. 11), it is clear that seniors with life-limiting conditions and seniors at end-of-life are being encouraged to remain at home and receive care from family members; this has been done in order to reduce the need for hospital stays. While it is hard to dispute the need to “maintain the capacity of hospital resources to respond to those who require hospital care” (MoH, 2013f, p. 5), this direction suggests that the primary effort of health authorities and the Ministry of Health is to lower costs to the system, rather than focusing on individual seniors’ wishes for end-of-life care.

Many achievements are referenced in the *Provincial End-of-Life Care Action Plan for British Columbia*, including updating advance care planning legislation, provision of resources to health care professionals in helping individuals plan for end-of-life, implementation of after-hours palliative nursing programs province-wide, acquisition of partnership funding to develop new palliative leadership approaches, and more (2013f, p. 11). These claims, however, are made without evidence as to how end-of-life care outcomes have improved as a result; progress on various programs is often generalized and presented without any specifics. For example, “the B.C. Palliative Care Benefits Program, which provides access to the same drugs and palliative supplies and equipment at home as if the person were in hospital, has served *increasing numbers of clients in the last six months of life*” [emphasis added] (MoH, 2013f, p. 10). Increased uptake of a government program may indicate greater awareness and promotion of that program, but not necessarily that it is meeting users’ needs. More evidence, in terms of requisitioned drugs, supplies and equipment, as well as the specific numbers of clients referenced, is required in order to substantiate this statement. In essence, the policies provide many examples as to how end-of-life care has improved over the years, but it remains unclear how actions such as these have served to help seniors at end-of-life along with their families.
 Additionally, while British Columbia’s end-of-life care policies present numerous priorities, goals and actions, they do not specify who will be responsible or accountable for the implementation and evaluation of each. Language such as, “this framework is not intended to be prescriptive” (MoH, 2006b, p. 6) and “flexibility to determine how end-of-life care can best be delivered” (MoH, 2006b, p. 6) absolves partners or organizations from taking any real action. However, information available on British Columbia’s Ministry of Health websites is targeted to the general public and more likely to direct families and seniors at end-of-life to sources where they can obtain more information regarding home care. This text is much more productive in ensuring that informal caregivers and seniors can access the information they need.

4.2. Case Study Analysis

The findings from the individual cases of Vancouver Coastal Health and Providence Health Care are described below, based on the criteria for interpreting the findings. This is followed by a comparative analysis examining how the practices of these agencies differ in relation to each other.

4.2.1. Case #1: Vancouver Coastal Health

In evaluating Vancouver Coastal Health, three different units of analysis were examined: a Community Engagement Report on a Regional Palliative/End-of-Life/Hospice Care Services Strategy, published in 2005 by members of Vancouver Coastal Health’s Community Engagement department; website text on Home and Community Care; and interviews with palliative health care professionals working within Vancouver Coastal Health. Findings have been summarized below with the Word tables used in this case study analysis provided in Appendix G, and elaboration of the final analysis presented in Appendix H.

Adequate Preparation and Advance Care Planning: Overall, health care services currently exist within Vancouver Coastal Health to assist elderly patients and families in preparing for end-of-life (VCH, 2013d). However, these services can be difficult to access for a number of reasons:
• Eligibility criteria with respect to citizenship, residency, and care needs can be restrictive (VCH, 2013c).

• Health care providers lack experience and comfort in initiating conversations about treatment and palliation, as well as knowledge about palliative services available (Tolson & Evoy, 2005).

• Health care providers can be heavily reliant on palliative professionals to provide consults to older patients, exacerbating the workload of palliative care units (Palliative Health Care Professional, interview, 2013, December 3).

• Advanced care planning is not materializing in practice. This may be due partly to the difficulty in planning for end-of-life given unknown or unpredictable illness trajectory, as well as health care professionals' discomfort in helping families to initiate these discussions (Palliative Health Care Professional, interview, 2013, December 3).

Effective Pain and Symptom Management: Achieving proper pain and symptom management at home can be daunting. While nurses provide guidance to informal caregivers in how to administer medications and other kinds of treatment upon discharge, it is possible that not enough is being done to communicate a realistic expectation of the duties involved. As well, a home death may not be feasible in all cases based on the family dynamics and extent of responsibilities required in managing pain and symptoms (Palliative Health Care Professional, interview, 2013, December 3).

Provision of Psychosocial, Spiritual and Bereavement Support: Responses to family members' needs for coping are either limited or reactive versus proactive. For example:

• Social workers become involved only after elderly patients have been admitted, typically when their family caregivers can no longer manage (Palliative Health Care Professional, interview, 2013, December 4).

• Palliative volunteers commonly “do not really help with tasks but simply visit for companionship…talking, reading, sitting quietly” (Program Manager, Vancouver Hospice Society, e-mail message to author, 2013, December 9).

• Dedicated counselling services for elderly patients and informal caregivers are absent (Palliative Health Care Professional, interview, 2013, December 3).

Lastly, none of the data makes significant mention of spiritual services, indicating that this, too, may be a reactive response to elderly patients’ or informal caregivers’ needs for spiritual support.
**Support for Informal Caregivers:**: Respite services and home support provided by Vancouver Coastal Health are highly variable and inadequate. This is shown by:

- The maximum allotment for home support being four hours a day or 28 hours per week, despite many elderly patients requiring constant care;
- Costly private home support or nursing, with private nursing costing up to $10,000 per month for 24-hour, registered nursing care; and
- Changeability in public and private health care workers, which can be stressful on elderly patients and their families.

(Palliative Health Care Professionals, interviews, 2013, December 3 and 19)

**Sufficient Financial Support:**: Access to financial support for informal caregivers and seniors at end-of-life is extremely limited.

- Eligibility for the BC Palliative Care Benefits Program is dependent on agreement by the patient, family and care team on goals of care, as well as a prerequisite for elderly patients to sign a Do Not Resuscitate (DNR) order. For personal philosophical, cultural or religious reasons, some patients and families may not want to agree to this (Palliative Health Care Professionals, interviews, 2013, December 3 and 19).
- The Employment Insurance Compassionate Care Benefit program provides up to six weeks of benefits to a family caregiver but restricts eligibility only to those employed. As well, the six-week period of coverage is an absolute and cannot be extended (Government of Canada, 2013); this can be challenging, given that end-of-life trajectory is largely a well-informed guess.
- Availability of rental or loan equipment from the Canadian Red Cross Society is subject to narrow restrictions, which can be limiting for families who could potentially manage more easily with certain types of equipment but do not have access (Palliative Health Care Professional, interview, 2013, December 3).

**Summary and Limitations of Vancouver Coastal Health Findings**

For this study, health care providers from Vancouver Coastal Health’s Community Care teams were invited to participate in the research interviews; however, these individuals were unable to accommodate the “request at this time due to time

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2 The Community Care teams provide home nursing and home support services for both Vancouver Coastal Health as well as Providence Health Care.
constraints" (Manager, Vancouver Coastal Health Hospice Palliative Care, email message to author, 2013, November 8), citing lack of time and capacity. While it would have been useful to hear the perspectives of those working in the community, as they engage directly with informal caregivers and elderly patients at end-of-life, the interviews with others working in palliative care and peripherally to Community Care provided a well-rounded view of services available to palliative seniors and families residing within Vancouver-City Centre.

Based on the evaluation, there exist a number of actions that would improve support for elderly patients at end-of-life and their informal caregivers. Further training for health care professionals working with palliative patients and their families; providing information resources for families regarding end-of-life care; partnering with community groups to provide information sessions to the public about death and dying; creating standardized training programs for palliative and hospice volunteers; instituting a new role of a palliative/end-of-life/hospice care coordinator; and improving home hospice support and resources (Tolson & Evoy, 2005) are all strategies that have been previously considered by Vancouver Coastal Health. However, current practice indicates inadequacy in resources for informal caregivers and elderly patients. Services exist, but there is room for improvement in areas such as training in palliative issues and end-of-life planning for health professionals; better education of pain and symptom management for informal caregivers; greater availability of professional counselling services; increased levels of support for personal care and household needs in the home; and changes to eligibility criteria for palliative and end-of-life programs provided by government and health authorities.

4.2.2. Case #2: Providence Health Care

The practices of Providence Health Care were evaluated by examining three separate data sources: St. Paul's Hospital’s document on palliative care, website text on end-of-life care, and interviews with palliative care professionals working within Providence Health Care. The findings have been summarized below, based on the same criteria used for case #1. Word tables used to conduct the analysis are provided in Appendix I, while further details of the analysis can be found in Appendix J.
**Adequate Preparation and Advance Care Planning:** The Providence Health Care palliative care team conducts patient consults and provides information to help families prepare for end-of-life and connect elderly patients with resources. However, there exists a risk of miscommunication and inconsistency in adherence to patients’ goals of care due to:

- Lack of experience and comfort with health care providers’ ability to directly address palliative issues;
- Irregularity in how often family meetings are conducted, as these typically take place only when complex family dynamics are involved; and
- Uncoordinated efforts amongst health care providers to help families and patients plan for end-of-life

(Palliative Health Care Professional, interview, 2013, December 16).

However, palliative health care experts within Providence Health Care stressed the importance for families and health providers to have these discussions and ensure all involved are provided the opportunity to make better informed end-of-life care choices (Palliative Health Care Professionals, interviews, 2013, December 16 and 2014, January 28).

**Effective Pain and Symptom Management:** Pain and symptom management was confirmed as one of the most difficult things to achieve at home for an elderly loved one, as informal caregivers receive only minimal instruction on how to administer medications for pain. However, it can also be challenging within the hospital as inexperienced health care providers may not fully understand treatment needs: “So many times the symptom management isn’t there because [the health care provider outside of the palliative care unit] is afraid…they don’t even order them sometimes, what is appropriate” (Palliative Health Care Professional, interview, 2013, December 16).

**Provision of Psychosocial, Spiritual and Bereavement Support:** Psychosocial, spiritual and bereavement supports for informal caregivers and elderly patients at end-of-life are critically lacking within Providence Health Care mainly because:
• These types of services are promoted through communication channels very minimally, if at all;
• High caseloads prohibit health care workers from effectively teasing out how well informal caregivers are coping (Palliative Health Care Professional, interview, 2013, December 16);
• Emotional support for families and patients happens in reactive versus proactive ways. This may also be a result of high workloads and a predisposition for many doctors to quickly discharge patients out of their wards, given limited beds and high numbers of patients (Palliative Health Care Professional, interview, 2013, December 16).

Support for Informal Caregivers: Access to respite services, home support and around the clock care in near-death stages are all lacking within Providence Health Care. Inexperienced health care providers or lack of sensitivity around palliative treatment can lead to cases where a family member needs more help, but has not been identified as needing help by a health care professional; health care providers should be able to elicit from family members whether things are not going well at home, but this is a learned skill that many do not currently have. Primary health care providers require a greater familiarity of palliative resources that can be provided to elderly patients who wish to experience a home death, but greater home support resources are also needed to enable informal caregivers to provide quality home care (Palliative Health Care Professional, interview, 2013, December 16).

Sufficient Financial Support: Palliative care professionals within Providence Health Care will often encourage patients to apply for programs such as the BC Palliative Care Benefits Program and the Employment Insurance Compassionate Care Benefit before leaving the hospital. However, these programs are described only briefly in the palliative care unit’s document and not at all on the website for end-of-life/palliative care. While health care professionals may be attuned with and willing to help patients complete these forms, eligibility for these programs is confining, which may inhibit those who need certain types of care to remain at home.

Summary and Limitations of Providence Health Care Findings

Many of Providence Health Care’s home care services, such as nursing and home support, fall within the Vancouver Coastal Health region; as a result, many of these services are provided by Vancouver Coastal Health. It is for these reasons that
certain documents, such as the document provided by St. Paul’s acute palliative care unit, and the website text on end-of-life/palliative care, may not go into detail about services available in the community. Given the nature of St. Paul’s acute palliative setting, the team’s role is short-term versus long-term treatment of chronic illness i.e. treatment and discharge to home, hospice or residential care, versus readying patients specifically for end-of-life. However, the unit’s function is vital as it is a connection for patients in accessing home-based palliative care services.

There are many ways in which Providence Health Care helps seniors and informal caregivers to achieve a desired home death. Interactions with elderly patients and families within the hospital setting are helpful in relaying information about what to expect, and also help to connect them with other care providers in order to obtain the health services they need. Moreover, discussions around advanced care planning, and resources such as the BC Palliative Care Benefits Program, can be initiated by those working within the palliative care team.

However, there needs to be more consistency across the hospital setting and amongst other primary care providers, such as family physicians, to also provide this information. Health care providers inexperienced in palliation or who are uncomfortable with discussing death are currently deterring patients and families from acquiring relevant information with respect to choices for end-of-life care at home, as well as resources in the community. As well, informal caregivers require more education on treating pain and symptoms to build greater confidence in their abilities to manage administration of medications at home.

Lastly, much of the current system in helping elderly, end-of-life patients and their informal caregivers is reactive versus proactive; this includes psychosocial support and counselling, family meetings to determine goals of care, and even palliative care as a whole. This creates an environment in which patients and families are sent home without enough support, only to end up back in acute hospital care. The solution proposed by Providence Health Care’s palliative care professionals is to increase home care supports available to patients and families in order to successfully remain at home.
4.2.3. **Comparative Case Analysis**

Overall, both Vancouver Coastal Health and Providence Health Care are committed to serving elderly patients at end-of-life and supporting informal caregivers in their role to help a loved one die at home. Both cases revealed extremely similar modes of palliative and end-of-life care delivery with very few differences. As a result, summarized here are the findings from the case study analysis in aggregate.

Palliative care professionals are restricted by the level of support for home death, with only a limited allocation for each patient dependent on the illness trajectory. Additionally, elderly patients at home who are imminently expected to experience death may not have access to around the clock care, despite this resource being referenced in website text and end-of-life policy documents. Private nursing and care aide services can be used by elderly patients and informal caregivers, but extremely high costs to hire these individuals can be a financial barrier; this can result in many elderly patients being unable to access care levels beyond what is provided by the local health area.

Accessing certain types of end-of-life support is possible only through the referral of a professional health care provider. For this reason, patients and families are reliant on the knowledge of health professionals; if their family doctor does not know about community supports, for example, the senior and informal caregiver will not, either. It may only be when an elderly patient has been diagnosed with a life-limiting illness and/or is admitted to a palliative care ward that they discover resources they could have accessed earlier in their illness trajectory.

Services such as these can help to mitigate informal caregiver burden earlier on and ensure elderly patients’ conditions are being managed at home in the best way possible. However, as recommended by palliative care providers working within Vancouver-City Centre, more home support is needed. In addition, counselling services, more regular communication with patients and families, and greater sensitivity and responsiveness to patient and family members' needs for coping, by all health care professionals, are areas that need improvement. By taking a proactive stance to home care and emotional support throughout an elderly patient’s chronic illness, the risk of that patient having to be admitted to a formal institution for care is diminished; this can result in a cost savings to the system, better quality of life for patients who wish to remain at
home as long as possible, and decreased burden to family caregivers supporting elderly individuals at home.

In hospital, the inexperience of professional health providers remains an issue. Many professionals continue to be uncomfortable with discussing death and advance care planning with patients, while others are reluctant to make care decisions without the approval from palliative team specialists. This has led to inconsistency in both the delivery of care to elderly patients, as well as information download to family members around end-of-life home treatment and options. What is needed are more family and palliative care team discussions to ascertain goals of care, and greater efforts to provide informal caregivers with adequate knowledge in providing pain and symptom management to elderly patients at home. Only by building palliative care capacity amongst all health care providers and families can these issues be resolved.

4.3. Interviews with Informal Caregivers

Immediately emerging from the four interviews conducted with informal caregivers was the realization that each person’s situation was very different from that of the other interviewees (see Appendix K for descriptions of caregivers who participated). Despite the diversity of informal caregivers’ situations who volunteered to participate in this study, there were a number of common themes which surfaced regarding supports currently being utilized, as well as supports families needed but to which they did not have access in providing end-of-life care to an elderly individual at home. These are highlighted in the following sections.

4.3.1. Supports Currently in Place

Almost all of the interviewees accessed home support provided by the local health area. Not surprisingly, the amount of support which each informal caregivers’ elderly family member received varied depending on the assessed levels of care required. As one family caregiver explained:

Because mother became palliative twice, or maybe three times, she was allotted more time for external nurse care…and that lasted for quite some
time, and it was a few hours a day, but it was really extremely appreciated. It varied depending on mother’s situation, but I remember that at the most intense point it was four hours a day, and I think it was five days a week. I may be exaggerating, but it was a substantial amount of time (Caregiver 3, interview, 2013, November 29).

However, while the informal caregivers interviewed were genuinely appreciative of the home support they received, there were some concerns as well. One was the variability in the home support workers coming into the home. These home care workers were different from shift to shift, creating anxiety for elderly patients and informal caregivers as this detracted from any ability to create familiarity or consistency in routine amongst the family. This also resulted in differing levels of care, depending on the readiness and skill level of the home support worker assigned, but “because it was free and because I needed it, we kind of put up with it” (Caregiver 3, interview, 2013, November 29).

Additionally, informal caregivers indicated a need for greater levels of home support, especially in the final days of life: “They [the community palliative care nurses] were good. They did their…job fine, you know? But, you know, we really needed…the last ten days of her life, we really needed nursing support more in the home, and we only got one night of it” (Caregiver 4, interview, 2014, January 14).

Most of the informal caregivers interviewed talked about the importance of having a good family physician – in particular, one who is willing to make house calls when the elderly patient starts having difficulty with getting to appointments:

We had a wonderful GP [general practitioner] who lives a block away, and when my husband couldn’t go to see him at the clinic, which is four or five blocks away, couldn’t get out of the car …the GP would come along, listen to his chest…he was fabulous. Wonderful support, very caring (Caregiver 1, interview, 2013, November 28).

Another informal caregiver echoed this sentiment, suggesting that house calls be provided to seniors at end-of-life to help ease their burden, as well as the burden to family members: “Luckily, my mother’s doctor, in the end, did house calls…yeah, that would be huge, if they could come to you as opposed to you going to them. Huge! They need mobile teams” (Caregiver 2, interview, 2013, November 28).
In terms of equipment or items needed for home care, minor pieces such as grab bars and raised toilet seats are subsidized through the BC Palliative Care Benefits Program, while most major items such as wheelchairs could be borrowed from the Canadian Red Cross Society for free or by donation. Informal caregivers confirmed this was useful, as it meant not having to pay for major equipment out of pocket:

Red Cross was a place [where] I...borrowed a wheelchair for a few months. I got my first bath seat there and borrowed a few things from them and then gave them a donation. So they were extremely useful (Caregiver 1, interview, 2013, November 28).

They [home care support workers] made recommendations on things to attach into their bathroom so they wouldn’t fall off the toilet or they wouldn’t slip in the shower, and all of that equipment we actually got on loan through the Canadian Red Cross...they have a whole equipment shop, and we ended up getting it on loan...and then I ended up returning it after we didn’t need it (Caregiver 2, interview, 2013, November 28).

Family caregivers discussed the need for emotional support and respite care; however, the types of support desired varied from person to person. For example, one felt it was adequate knowing that others were or have experienced a similar situation, while another found comfort in providing “a listening ear” for others:

I've got quite a few supportive women friends, and they were wonderful to me. So, they gave me lots of emotional support. And they phoned me, and asked me how I was doing. It was the ones that would phone and ask how he was doing, and I'd tell them, but I'd think, 'What about me?’ (Caregiver 1, interview, 2013, November 28).

I also took advantage of a lot of community seminars...to learn about dealing with elderly parents, to learn about Alzheimer's, the disease, how families cope. So I did take advantage of a lot of those services (Caregiver 2, interview, 2013, November 28).

Some caregivers discussed how they learned about home care resources through support groups and others who had been through similar experiences. However, other informal caregivers were uninterested in attending support groups; they were inclined to read about coping mechanisms or discuss their emotions with friends not going through the same experience:
[Support groups] would just be another burden to go to. I’d be listening to somebody else’s woes – I just couldn’t handle it. I didn’t want to…hear other spouses telling me of the agony of what they’re going through or what their spouse is going through. I’ve got enough on my own plate…I feel terrible for these people as well, but I don’t want to add to their suffering by listening to mine. What’s the point? (Caregiver 4, interview, 2014, January 14).

This reveals that a broad range of emotional support resources is required to ensure the diverse psychological needs of informal caregivers can be met.

4.3.2. **Unavailable Supports**

Transportation, and specifically, getting to medical appointments, as well as parking expenses were cited by most family caregivers as substantial burdens. As an elderly patient’s chronic illness progresses so, too, can the need for increased appointments with medical specialists. The act of repeatedly transporting a family member to and from appointments, waiting for long periods of time, as well as paying for parking were all tiresome tasks:

The worst part was driving him there and waiting to see the oncologist when he felt so lousy. He progressively got weaker and weaker…getting to those appointments was tough (Caregiver 1, interview, 2013, November 28).

When you have somebody in a walker and they need to get to a medical appointment to have a blood test every two weeks, which is what happens when you have heart problems, it was an ordeal to transport an 88 year old man in my car and take him to the doctor and not be able to get parking by the doctor’s…it just became such a strain on me, personally, that we started to get extra help, but the help was in the home. It still didn’t deal with transportation to all of these medical appointments (Caregiver 2, interview, 2013, November 28).

However, one informal caregiver mentioned getting help from volunteers willing to drive cancer patients to and from appointments:

There is the freemasons who drive, who are wonderful, and we did use them on a couple of occasions when I had conflicts and I had to go to an appointment, myself…you phone them up the day before and you tell them what time you have to be at the Cancer Agency and they drive you…if you’re being driven by one person in their car, the chances are,
you’re going to be picked up on time, you’re going to get there on time, it’s going to be more comfortable, and you’re not likely to pick up bugs other people have got [if travelling on transit] (Caregiver 1, interview, 2013, November 28).

Many elderly, end-of-life patients required additional levels of home care not covered by the local health area. These individuals and their families hired private home support or home nursing care, paying for these services out of pocket. However, private care expenses were substantial, and also did not provide all types of care that were needed:

In the end…when we were paying for care seven days a week, 12 hours a day, that was costing us $22 an hour for a [licensed practical nurse] through a care agency…we were spending over a $100,000 dollars a year, and I knew we could not keep that pace up forever (Caregiver 2, interview, 2013, November 28).

We couldn’t take him [their father] home because we couldn’t make arrangements to have somebody come and give him his insulin shot…there’s no service that’s available. Even Nurse Next Door – they’re not registered nurses (Caregiver 2, interview, 2013, November 28).

Other things which informal caregivers mentioned needing help with included more help in managing medications and making care decisions, as they often felt overwhelmed with the responsibility to be the primary decision-maker; greater sensitivity of health care professionals in tending to the elderly patient’s or family member’s emotional needs, as some had concerns about their situation they felt went unaddressed by health professionals; and an overall need for more counselling services.

4.3.3. Other Considerations in Supporting Informal Caregivers

Based on conversations with informal caregivers who provided home care to a senior at end-of-life, the challenges in providing care can differ hugely based on the family member’s illness. For example, an individual diagnosed with cancer may undergo chemotherapy or radiation treatment; someone with dementia may need to be in a facility designed for those who may be a wander risk; and a person with type 2 diabetes may need to self-administer daily insulin doses by needle. This variability in treatment leads to significant differences in the types of care that informal caregivers may need to
provide to their elderly family member at home; because of this, a wide range of resources from the local health area is needed to support the majority of family caregivers in providing home care to a senior at end-of-life.

Many family caregivers also mentioned that multiple trips to emergency were often common in caring for a dying senior at home. This can be stressful for both the elderly patient as well as the family member providing care:

He [the father] was rushed to emergency six times in four weeks. By the time we were on the third bounce back, the hospitalist and the social worker…basically said, “He can’t go back to the home.” So he was placed immediately in one of the care facilities, and then he begged me every day to go home (Caregiver 2, interview, 2013, November 28).

This may indicate a need for more home support, or access to mobile teams dedicated to respond in emergency or crisis care situations.

In most of the interviews, informal caregivers described the responsibility to be an advocate for their elderly family member. However, they also highlighted significant challenges in trying to navigate the system and that having a person to assist with this would be a considerable help:

I just felt there was no one service or counseling or something that could help you navigate through the system…what I learned is the family member has to be the advocate ‘cause the parent is not necessarily thinking clearly…you have to be there at the hospital when they hit emergency, because they can’t answer how many medications they’re on. You have to be there to negotiate the home care, because they’re not aware of some things that might be happening or should be happening…you just have to be a real strong advocate (Caregiver 2, interview, 2013, November 28).

While this can be emotionally challenging for informal caregivers in the best of circumstances, there is a risk that many family caregivers may be unable to fulfill this role, based on their disposition or personality, lack of knowledge, or unwillingness to be an advocate for their elderly family member.

As one possible community-based solution to generate greater awareness around end-of-life and palliative care services, one informal caregiver suggested
creating a health care co-op; this would help connect patients and families with others living in the same neighbourhood. In this co-op, resources would be coordinated amongst neighbours and others interested in helping or receiving assistance as they attend to end-of-life home care needs:

I’d like to see...a health care co-op...whose members would be both the caregivers and the recipients of care, that’s partially funded by government and partially paid by the recipient...where the caregiver and the members...get to meet as members of the same co-op and begin to establish a protocol of how to work together... it could be a resource in my neighborhood where, you know, you could go in there and say, ‘This is what I’m going through – my sweetheart and I – and we need someone to help us out’ (Caregiver 4, interview, 2014, January 14).

This type of resource could potentially help to manage the expectations of informal caregivers in undertaking the caregiver role, and coordinate basic services which may be unavailable through formal channels – for example, home support such as meal preparation, transport to and from appointments, respite care or companionship services.

Lastly, the informal caregivers participating in the research unanimously exclaimed having no regrets in either giving up work or adapting their lives to take care of an elderly family member at end-of-life. It is for this reason that identifying and ensuring adequate support mechanisms are in place to help them fulfill a loved one’s wishes to die at home.

4.4. Summary: Research Findings

The discourse analysis revealed that the Province of British Columbia is focused on substantially shifting the delivery of end-of-life and palliative care into the community and away from formal, institutionalized care. However, no specific direction is provided as to how elderly patients and informal caregivers will be supported in the midst of these changes, or how they can interface with professional health partners and agencies to achieve quality care at home. Further, older patients and their families are largely excluded from the palliative care teams of which they should be a part, with policies situating their information needs as secondary to those of health care professionals.
Current end-of-life policies, therefore, do little to empower elderly individuals and family members in palliative care; they serve only to further perpetuate the status quo.

From the case study analysis, it was clear that home support for older patients is critically inadequate. Home support, 24-hour care at imminent death, and respite care are services currently available, but are subject to strict eligibility or must be paid for out of pocket; this can be exclusionary to those who need these types of supports. As well, counselling services, communication with families regarding end-of-life issues, and sensitivity and responsiveness to seniors’ and informal caregivers’ needs are all areas requiring improvement.

Interviews with informal caregivers exposed disparities between their needs and current practices employed by health agencies. More help is needed in the home, not only for personal care, household needs and managing medications, but also for administering illness-specific treatments, assisting in emergency or crisis situations and in making care decisions. Those hiring private care in the home had concerns about cost, consistency in health care workers, and the quality and types of care being provided. Additionally, many described frequent transport to and from appointments, parking expenses and long wait times as distressing. Finally, many informal caregivers felt challenged in trying to navigate a complex health care system on their own, particularly when dealing with professional health providers largely insensitive or unresponsive to their emotional needs. This indicates that informal caregivers need greater assistance in accessing available services, being able to ask the right questions, and obtaining appropriate information given elderly patients’ goals of care.

These results inform what policy options can best address the issue that informal caregivers in British Columbia currently do not have adequate access to resources which would allow them the greatest opportunity to provide quality care to an elderly family member who wishes to die at home. The sections that follow describe the criteria and measures used to evaluate potential policy options that can help mitigate resource access challenges facing family caregivers and elderly patients.
5. Criteria for Analysis of Policy Options

In developing appropriate responses to the support needs for informal caregivers and dying seniors, potential policy options have been evaluated using the following criteria: access to resources, minimization of caregiver burden, and good death, which together, indicate overall effectiveness of the policy, as well as financial cost, implementation complexity, and overall effectiveness. These criteria and measures are summarized in Table 4 and detailed below. Potential policy options are presented in the following section.

**Table 4. Criteria and Measures Used in Policy Analysis**

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
<th>Measurement</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Resources</td>
<td>To what extent does the policy option increase informal caregivers’ access to resources which would allow them the greatest opportunity to provide quality care to an elderly family member who wishes to die at home?</td>
<td>Policy increases access to resources in a substantial or significant way</td>
<td>High = 3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Policy moderately increases access to resources</td>
<td>Medium = 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Policy increases access to resources only marginally or not at all</td>
<td>Low = 1</td>
</tr>
<tr>
<td>Minimization of Caregiver Burden</td>
<td>To what extent is the policy able to minimize or alleviate one or more of the following burdens to informal caregivers?</td>
<td>Policy adequately addresses three of the burdens listed</td>
<td>High = 3</td>
</tr>
<tr>
<td></td>
<td>• Employment risks;</td>
<td>Policy adequately addresses two of the burdens listed</td>
<td>Medium = 2</td>
</tr>
<tr>
<td></td>
<td>• Financial burdens; and</td>
<td>Policy adequately addresses one or none of the burdens listed</td>
<td>Low = 1</td>
</tr>
<tr>
<td></td>
<td>• Psychological and physiological strain.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Criteria</td>
<td>Description</td>
<td>Measurement</td>
<td>Value</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Good Death (weight =0.5)</td>
<td>To what degree can the policy meet one or more of the following indicators?   • Enable proper pain and symptom management;   • Help to meet dying seniors’ physical and emotional needs;   • Help dying seniors adequately prepare for death; and   • Ensure that dying seniors’ wishes for death are honoured.</td>
<td>Policy adequately meets at least three of the indicators listed</td>
<td>High = 3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Policy adequately meets two of the indicators listed</td>
<td>Medium = 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Policy adequately meets one or none of the indicators listed</td>
<td>Low = 1</td>
</tr>
<tr>
<td>Financial Cost</td>
<td>What is the financial cost to implement the policy relative to the status quo?</td>
<td>Low or minimal financial investment required to implement policy</td>
<td>High = 3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Moderate financial investment required to implement policy</td>
<td>Medium = 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Significant financial investment required to implement policy</td>
<td>Low = 1</td>
</tr>
<tr>
<td>Implementation Complexity</td>
<td>What is the degree of administrative complexity required to implement the policy?</td>
<td>Minimal amount of administration required to implement policy</td>
<td>High = 3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Moderate amount of administration required to implement policy</td>
<td>Medium = 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Significant amount of administration required to implement policy</td>
<td>Low = 1</td>
</tr>
</tbody>
</table>

**Access to Resources**

This criterion evaluates the option’s ability to deal directly with the policy problem, as it refers to its overall ability to increase informal caregivers’ access to resources which would allow them the greatest opportunity to provide quality care to an elderly family member who wishes to die at home. If the policy option is able to substantially increase access, it scores highest. Conversely, if the policy shows little or no ability to increase caregivers’ access to resources, it scores poorly.
Minimization of Caregiver Burden

This study has shown that caregiver distress is an important issue worthy of attention by policy makers. If informal caregivers “burn out,” this can increase the risk that they, along with the elderly individuals they are caring for, will need to be admitted for institutionalized care. This criterion examines how well the policy option is able to mitigate caregiver distress through minimizing employment risks, financial burdens, and psychological and physiological strain.

Good Death

The desire to experience a good death is inherent in the choice of seniors to die at home, nearer to friends and family. Indicators such as adequate pain and symptom management (HCC, 2012; Stajduhar & Cohen, 2009), having their physical and emotional needs met (Ajemian & Mount, 1980; Carstairs, 2010; Stajduhar & Cohen, 2009; Steinhauser & Clipp, 2000), and being able to adequately prepare for death and ensuring their wishes for death are honoured (MoH, 2013e; Stajduhar & Cohen, 2009) are ways in which achieving a good death can be measured. Policies that are able to achieve these attributes score favourably, while those unable to meet these needs of seniors at end-of-life score poorly. As this option addresses informal caregiver burden indirectly, it has accordingly been assigned a weighting of 0.5.

A policy that is able to improve access to resources, minimize caregiver burden, and contribute to a good death will ultimately score well. As such, these criteria considered together demonstrate the overall effectiveness of the policy in addressing the problem of inadequate access for caregivers and seniors to end-of-life resources.

Financial Cost

Cost is an important criterion that must be considered. Given ever-diminishing budgets for health care, cost in this study refers to the financial expenditures needed to implement a policy option, relative to making no changes. If minimal financial cost is required in the implementation and maintenance of the policy, the option scores favourably; conversely, if high financial costs are associated with the policy, the option scores unfavourably.
Implementation Complexity

Any policy option will have some measure of implementation complexity, beyond financial costs, depending on what is required to actualize the option. With regards to this study, health authorities are already grappling with limited resources and decreased program funding. A policy option can score well on this criterion if a minimal amount of change management is required in its implementation, or if reasonable reallocation of resources to activate the policy is possible.
6. Policy Options

Given the research findings from the discourse analysis, case study analysis and interviews with informal caregivers, four different policy options are proposed. These are briefly described below. More detail on each policy option is provided in Appendix L.

6.1.1. Increase the availability and extent of publicly funded formal home support

Findings suggested that a lack of home support detracted from informal caregivers’ ability to manage their care duties without feeling significantly burdened. An increased allowance for home support and help with household needs can ensure informal caregivers are able to better manage with elderly, end-of-life patients in the home; this can serve to mitigate safety issues with regards to pain and symptom management, minimize caregiver burden, particularly in later stages of patient illness, and create greater opportunities for proactive caregiver respite. As well, it is worthwhile to consider expanding the extent of professional home care to areas such as emergency or crisis response, or bespoke treatment based on specific illnesses and required treatment.

6.1.2. Provide a single point of contact for elderly end-of-life patients and their families

The research findings revealed complexity within the health care system that is extremely challenging for informal caregivers and end-of-life seniors to discern. A single point of contact for elderly, end-of-life patients would help families in navigating the health care system, completing applications for social programs such as the BC Palliative Care Benefits and federal Compassionate Care Benefit programs, and obtaining necessary equipment for the home. This individual would also help informal caregivers connect with relevant care professionals, coordinate appointments based on treatment plans and goals of care, and act as the advocate for both families as well as
elderly, palliative patients. Due to the highly specialized nature of this role, continuing professional development for these health professionals is vital in ensuring ongoing standards of care (Brown et al., 2002).

6.1.3. **Increase frequency and reach of family meetings**

Research results suggested that significant barriers to accessing end-of-life care include a lack of awareness of services, as well as not enough understanding amongst all involved as to treatment options. Conducting more frequent family meetings with the broader palliative care team would help to build capacity and understanding amongst health professionals, caregivers, and seniors with respect to palliative treatment and services. In addition, this would help to reduce anxiety amongst informal caregivers and elderly patients by creating opportunities to engage in transparent communication about treatment options and goals of care. These meetings are proposed for all elderly patients arriving in hospital within 72 hours of their arrival, or elderly patients and/or families who have requested more information about palliative care.

6.1.4. **Create local, community-based services and support networks**

Many informal caregivers indicated a need for more help with tasks such as transporting elderly family members to and from appointments, making care decisions, and accessing counselling, respite and emotional support, with the findings suggesting that current resources do not address these needs directly or in any significant way. Local, community-based support and care networks for older patients and their families can comprise a number of resources: a shuttle service for appointments, companionship, assisting in the home to allow family caregivers to take a break from their duties, or counselling. Expanded support networks in the community could emulate current best practices of hospice volunteers, or existing organizations known for providing first-class support to elderly patients at end-of-life and their families – but the primary attribute is that the creation of resources and services would be left to those within the community based on their specific needs.
The next section looks at each of these policy options in turn, evaluating the viability of each to make a difference to informal caregivers and elderly patients in ensuring greater access to resources at end-of-life.
7. Analysis of Policy Options

The table below summarizes the evaluation of each policy option based on the criteria and measures described. Green represents a high (3) scoring, yellow a medium (2) scoring, and red a low (1) scoring.

Table 5. Overview of Policy Analysis Findings

<table>
<thead>
<tr>
<th>Criteria</th>
<th>1. Increase the availability and extent of publicly funded formal home support</th>
<th>2. Provide a single point of contact for elderly end-of-life patients and their families</th>
<th>3. Increase frequency and reach of family meetings</th>
<th>4. Expand community-based services and support networks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to Resources</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Minimization of Caregiver Burden</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Good Death (weight=0.5)</td>
<td>1.5</td>
<td>1</td>
<td>0.5</td>
<td>1</td>
</tr>
<tr>
<td>Financial Cost</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Implementation Complexity</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total Scores</td>
<td>9.5</td>
<td>12</td>
<td>7.5</td>
<td>7</td>
</tr>
</tbody>
</table>

7.1.1. Increase the availability and extent of publicly funded formal home support

Various sources examining the merits and challenges of increasing publicly available home support were used to evaluate this policy option.

Access to Resources: Increasing publicly funded home support would create increased access to resources for the provision of end-of-life home care. The 2009 Canadian Community Health Survey-Healthy Aging revealed that many seniors were not
having all of their home care needs met, with many attributing this to personal circumstances, such as inability to pay, or lack of service availability (Hoover & Rotermann, 2012). Further, having unmet needs can result in negative health impacts yet, seniors who reported receiving care only from formal sources were less likely to have tangible support, meaning they felt they would be unable to access help if they were bed-bound, needed to get to the doctor, had to prepare meals or complete daily chores while ill (Hoover & Rotermann, 2012). While positive impacts of the 2004 Health Accord are marginal, First Ministers have historically acknowledged that “home care is an essential part of modern, integrated and patient-centered health care” (Government of Canada, 2004), recognizing that increased end-of-life services in the home such as case management, nursing, palliative-specific pharmaceuticals and personal care would contribute to quality of life. Greater home support does not necessarily guarantee increased access to resources for all populations, in particular, those with language or cultural barriers (Giesbrecht, 2013); however, this recognition of the importance of increased home care, particularly at end-of-life, reveals that greater access to resources would contribute to an increased number of informal caregivers being able to provide quality care. Therefore, this policy option scores high (3) in terms of increasing access to resources.

Minimization of caregiver burden: In a study assessing the complaints of family members caring for older dementia patients, 77% of family caregivers identified the need for more home support to help with challenges such as having no one else to help provide support in the home, a feeling of no personal liberty, and being forced to change working hours (Thomas et al., 2002, pp. 1039-1040). Palliative care professionals also expressed that greater public home support, such as 24-hour care, increased respite services, and adult programming, are all ways to mitigate families’ caregiving burden (Ackenhusen, 2011), particularly as the cost of private care can be extremely restrictive in obtaining the support they need (Palliative Health Care Professionals, interviews, 2013, December 3 and December 19). With regards to employment changes, three of the four informal caregivers interviewed in this study resorted to leaving work, while one remained employed only by hiring live-in, full-time home support; this suggests that increased formal support in the home can help to minimize employment risks, as well as mitigate productivity losses in the workforce.
Lastly, international studies have shown that increasing formal, publicly available home care services, as well as specialized services at home (Mestheneos & Triantafillou, 2005), can contribute to improving informal caregivers’ well-being. For these reasons, increasing the availability and extent of publicly funded formal home support scores high (3) in being able to minimize caregiver burden.

**Good death:** Seniors require greater home support as their illnesses progress, as unmet needs for professional home care can result in negative consequences: injuries; depression and reduced morale; higher hospitalization rates; and increased risks of falls, institutionalization and premature death (Hoover & Rotermann, 2012). Greater levels of formal treatment in the home can help to minimize these risks and contribute to end-of-life seniors’ ability to experience a good death. Patients receiving hospital care at home report high levels of satisfaction with their location and quality of care, and dementia patients experienced improvements with problems related to sleep, agitation and aggression, and feeding (Shepperd et al., 2009). In preparing for death, patients who engaged in end-of-life discussions with their physicians experienced lower health care costs by reductions in intensive, curative treatments; further, higher costs were associated with worse quality of life at death (National Cancer Institute, 2013). While this does not specifically relate to professional care in the home, this evidence suggests that access to health care professionals in the final days of life can help to ensure dying seniors’ wishes for death are honoured, as well as help to meet elderly patients’ physical and emotional needs. Further, all studies referenced revealed only positive outcomes of such a policy direction, suggesting that increased home support does not detract from end-of-life seniors being able to experience a good death. For these reasons, this policy option receives a high score (3).

**Financial cost:** In 2009/10, the health authorities combined spent approximately $339 million on subsidized home support, or $30 to $40 per hour of home support (Office of the British Columbia Ombudsperson, 2012, p. 32). However, there is evidence to suggest that a redistribution of costs from acute to home and community care can result in financial savings. In Ontario, a program focused on shifting elderly alternate level of care patients from hospital to home found that every 10% of patients resulted in a $35 million saving to the formal health care system (Canadian Home Care Association, 2010, p. 3). A study which reviewed individual patient data on avoiding institutional
admission by receiving hospital care at home found that, in general, costs were lower for patients receiving hospital care at home than those receiving inpatient care (Shepperd et al., 2009, p. 179). Conversely, doing nothing may have negative cost implications for formal health care. As the country’s population continues to age, demand for home care services will only increase and “if that demand isn’t met, people who could have received care at home will instead end up in costly acute care settings, creating an incredible financial strain on the health care system” (Collier, 2011, p. E451). This supports the belief of palliative care experts in Vancouver that home care may cost more in community but would cost less in acute care (Palliative Health Care Professional, interview, 2013, December 16). However, the potential savings this policy may generate remains uncertain given the significant financial investment, and redistribution of costs in the health care system, required. As well, the time frame to realize this cost savings is also indeterminate. For these reasons, this option scores low (1) in terms of financial cost.

**Implementation complexity:** There are many factors necessary in ensuring that home support is designed to meet the needs of end-of-life seniors in the community. This includes the commitment and collaboration of the entire health and palliative care team; creating an environment where health care workers have the opportunity to engage and dialogue with leadership on a daily basis; developing protocols for a range of patients; and the support of government health ministries (Canadian Home Care Association, 2010). Successful care models effective in meeting patient needs also demand ongoing involvement of patients and informal caregivers in program planning, implementation and oversight (Kodner & Spreeuwenberg, 2002). This must be done in the context where formal home care services currently available have been criticized as lacking: “Adult Day Program[s]...are at least a year wait list...and Home Support is limited with poor continuity. These challenges are myriad, and make it difficult to provide effective services to clients and their families” (Chant, 2011). Further, a push to increase home support may be met with opposition from doctors. Ontario doctors assert that care providers receive around 40% less pay for the extra time and effort required to work out of office and treat patients in their homes; governments will therefore need to reform payment models in order to encourage doctors to accept this method of care delivery (Webster, 2011).
Thought must also be given to administering costs for increased public home support. In many cases now, individuals receiving home and community care must pay a portion of the costs. Health authorities use a formula set by regulation to calculate how much subsidized home support clients will be charged, which is based on the patient’s income from the previous year. Currently, under this formula, about 71% of home support clients pay nothing to receive these services; 3% pay up to $10 per day; 6% pay between $10 and $20 per day; 20% pay more than $20 per day; and seniors with earned income pay a maximum of $300 per month for home support (Office of the British Columbia Ombudsperson, 2012, p. 32). This formula will likely need to be reviewed and/or adjusted to account for costs associated with increased levels of public home support. For these reasons, implementation complexity receives a low score (1) for this policy option.

### 7.1.2. Provide a single point of contact for elderly end-of-life patients and their families

The concept of “patient navigation” was used as a basis for evaluating the feasibility of this policy option. This is a role that has been previously tested within the Canadian health care system, primarily at cancer agencies and “intended to expedite patient access to services and resources, and improve continuity and co-ordination of care throughout the cancer continuum” (BC Cancer Agency [BCCA], 2005, p. 3).

**Access to Resources:** The use of nurse navigators in cancer agencies has resulted in satisfaction amongst patients and their families. Evaluations with patients and health care providers reveal that navigators can help patients in asking questions, as well as create increased capacity to ensure patients are able to get the care they want and need (BCCA, 2005, p. 3). In addition, nurse navigators have proven themselves as being able to meet patients’ and families’ needs in coordinating and improving access to treatments, helping with the logistics of getting to appointments, and assisting with dealing with financial impacts, such as drug costs and loss of income (Cancer Care Nova Scotia, 2004). Because of the high ratings nurse navigators have received, this policy option scores high (3) in its ability to increase access to resources for patients and families.
Minimization of caregiver burden: By acting as a bridge between patients and health care providers, patient or nurse navigators are able to assist families in the role of advocacy. For informal caregivers, this can result in better patient-physician communication and a greater ability for their informational needs to be met. As well, psychosocial issues and common employment and insurance problems are more likely to be addressed (BCCA, 2005, p. 3), particularly as patient navigators are best placed to identify how well informal caregivers are coping (Palliative Health Care Professional, interview, 2013, December 16). Further, having a single point of contact can also help to smooth the transition to home by expediting equipment and resource coordination (Palliative Health Care Professional, interview, 2013, December 4). Therefore, because of this policy option’s ability to address all three burdens identified in the criterion, it scores high (3) in its ability to minimize caregiver burden.

Good death: Pilot projects in British Columbia have commonly appointed nurses in the role of patient navigator. Experience in medicine has enabled these nurse navigators to oversee treatment processes, provide information and support to their patients, and link with other health care professionals; this coordination of efforts has resulted in patients receiving psychosocial supports, increased home care and information, but has also helped patients “develop effective coping strategies\(^3\) that maximize healthy functioning” (BCCA, 2005, p. 3). While nurse navigators have shown to help improve care to end-of-life patients in these areas, there is a lack of evidence to suggest this role has any significant positive impact on the ability to manage pain and symptoms at home, adequately prepare patients for death, or ensure their wishes for death can be honoured. Therefore, this option scores medium (2) in ensuring a good death at home.

Financial cost: Evidence shows that timely access to information and emotional support at time of diagnosis is imperative in being able to help patients adapt and better prepare for their new circumstances; however, failing to recognize and treat patients with high emotional distress can result in increased health care costs (BCCA, 2005, p. 3).

\(^3\)Coping strategies relate to “knowledge or, or access to assessment and planning which will enhance their psychological, social, and physical functioning…[as] many patients require assistance with identifying and obtaining illness-related information and services” (Conkling, 1989, p. 290).
Nurse navigators have been used to assist patients and families with navigating the health care system after diagnosis. At an approximate maximum wage of $46.22 per hour (Vancouver Island Health Authority, 2011) with modest overtime, the estimated wage for a full time nurse navigator is just over $100,000 per year. Nurse navigator caseloads are likely to be similar to that of Home Care case managers in Vancouver; the size of these caseloads at any given point in time is approximately 100 patients, with about a quarter of those cases being fairly complex (Palliative Health Care Professional, interview, 2014, January 7). However, the patient navigator position could be considered a reorganization of roles from one area of nursing to another; instituting dedicated patient or nurse navigator roles, therefore, would not necessarily increase human resource costs but merely redistribute them. The relative financial cost against doing nothing for this option is low; therefore, this criterion scores high (3).

**Implementation complexity:** Successful programs for nurse navigators across Canada have varied in their implementation. In British Columbia, most navigation programs evolved organically, with ‘best practice’ navigators using skills and resources based on their individual interpretation of patient needs (BCCA, 2005, p. 3). In Ontario, specific training was provided to nurse navigators for cancer patients, with a specific emphasis on the diagnostic phase of care (Cancer Care Ontario, 2013). Nova Scotia’s program identified a number of key elements for success: strong commitment from the district to the program; recruiting a professional with the right skills and personality; ongoing communication plans; good working relationships with health professionals; comprehensive orientation and ongoing educational opportunities; and central leadership and expertise (Cancer Care Nova Scotia, 2004). A pilot project in Vancouver-City Centre for elderly, palliative patients would be the first of its kind, but learnings could be taken from successful programs in British Columbia and elsewhere in order to adapt nurse navigation for families providing home care to seniors at end-of-life. It is reasonable to infer, therefore, that creating a program would not require a significant amount of administration; thus, this criterion scores medium (2) in implementation complexity.

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4 It is common for nurses in British Columbia to work a significant amount of overtime. In 2009, nurses worked a total of approximately 1.4 million hours of overtime; this amount decreased to a cumulative total of 980,000 overtime hours in 2010 (MoH, 2012b).
7.1.3. **Increase frequency and reach of family meetings**

To evaluate this option, literature identifying the advantages and potential disadvantages of conducting regular family meetings was used.

**Access to Resources:** Increasing the frequency and reach of family meetings is effective in improving access to resources for informal caregivers. Recent studies reveal real benefits to family members in meeting their care needs, specifically around having information for what to do at home and who to contact when help is needed for specific problems (Hudson et al., 2009). Patient care planning can be optimized when family members are involved in discussions with members of the health care team, as well as create opportunities for health providers to identify family members who may need greater levels of support (Hannon et al., 2012). For these reasons, increasing the regularity and reach of family meetings scores high (3) in terms of access to resources.

**Minimization of caregiver burden:** In a recent study, the benefits of family meetings were assessed from the perspective of family members using the Family Inventory of Needs; this is a tool commonly used to assess the importance and fulfilment of care needs (Hannon et al., 2012). The results showed improvements in meeting the care needs of family members in most of the areas assessed, including: feeling that they had their questions answered honestly; a greater awareness of the facts of prognosis; knowing exactly what is being done for the patient and what treatments they are receiving; a greater understanding of what symptoms the disease and treatment can cause; knowing when to expect occurrence of symptoms; having information for what to do for the patient at home; and knowing more about others who can help with specific problems (Hannon et al., 2012). A different study noted similar results, with the majority of family members reporting that they had clearly understood the purpose of the meeting; that they had been able to talk about what was important; that the meeting had helped move them towards an acceptable solution; and that they were more confident in dealing with their situation as a result of the meeting (Hudson et al., 2009). While these benefits to informal caregivers are not insignificant, neither study specifically revealed how family meetings could mitigate either employment risks or financial burden; for this reason, this policy option does not adequately meet the criterion of minimizing caregiver burden and scores low (1).
**Good death:** Many of the benefits mentioned above can contribute, however, to the elderly patient at end-of-life experiencing a good death. As a result of attending a multi-disciplinary family meeting, informal caregivers have greater information and awareness around prognosis, treatments for the patient, and what to expect regarding symptoms (Hannon et al., 2012). Family doctors have an important role in helping seniors and families prepare for end-of-life, with over 60% of British Columbians who identify their doctor as their preferred first point of contact and nearly 80% who want their family doctor coordinating their care (British Columbia Medical Association, 2012, p. 18); this reinforces the importance of general practitioners’ participation in family meetings as trusted advisors for the family. However, while these data suggest that family meetings can help to ensure better pain and symptom management, it remains unclear whether this option provides greater ability to achieve dying seniors’ emotional needs, or honour wishes for death. Creating the opportunity to improve in these areas is also contingent on being able to identify and ensure that the appropriate health care professionals participate in the meetings (Hudson et al., 2009). Therefore, this option scores low (1) in being able to achieve a good death at home.

**Financial cost:** Evidence suggests that most health professionals do not receive sufficient training to conduct family meetings; as such, it would be prudent to develop training focused on preparing health care workers for conducting family meetings in palliative care (Fineberg, 2005). Training and development for health care providers has been proposed in the literature in areas such as meeting design: clarifying the purpose of meetings, obtaining genuine and documented informed consent from the patient and family, and ensuring good opportunities and support for patients and families to express their own views during the meeting (Griffith et al., 2004). The cost to develop and deliver training programs can be highly variable, depending on the breadth and type of material, level of interactivity, and simulations required (Kapp & Defelice, 2009). However, there is existing literature identifying gaps in clinicians’ ability to conduct family meetings and educational interventions; these studies can serve to inform the development of training for Vancouver-City Centre health care providers. As such, a moderate financial investment is expected in implementing this policy; the criterion of cost therefore scores medium (2).
Implementation complexity: In practice, family meetings already require a significant time investment which can be challenging given palliative health care providers’ current workloads (Hannon et al., 2012). As well, part of the challenge in organizing effective family meetings is the lack of clinical evidence demonstrating the process for training staff to conduct or participate in family meetings (Fineberg, 2005). Also claimed is a dearth of literature describing when such meetings should be initiated, who should attend them, and how they should be conducted and evaluated (Griffith et al., 2004). Further, there is conflicting evidence to suggest whether trying to accommodate the schedules of all involved is a significant problem. While there is some concern with regards to the scheduling of family meetings (Palliative Health Care Professional, interview, 2014, January 7), literature suggests greater levels of satisfaction with family meetings amongst health care professionals can be achieved so long as meetings are tailored to the needs of each family (Hannon et al., 2012). Regardless, this disparity in findings suggests significant challenges in shifting institutional practice to create an environment which promotes the increased frequency of family meetings. As a result of significant administration required to implement the policy, this option scores low (1) for implementation complexity.

7.1.4. Create local, community-based services and support networks

The research suggests that programs offered by specialist organizations, such as support groups or volunteer drivers through the BC Cancer Agency (Caregiver 1, interview, 2013, November 28; Palliative Health Care Professionals, interviews, 2013, December 4 and 16), or care coordination services provided by the Alzheimer Society of B.C. (Palliative Health Care Professional, interview, 2013, December 4), may be good support models to emulate. However, these resources are available exclusively to those with cancer or dementia, which excludes seniors at end-of-life diagnosed with all other life-limiting conditions from receiving these types of support (Palliative Health Care Professionals, interviews, 2013, December 3 and 4). As well, findings revealed that support preferences can vary widely (Caregiver 2, interview, 2013, November 28; Caregiver 4, interview, 2014, January 14), implying that bespoke programs may be more effective in ensuring enough breadth in resources for informal caregivers. The United
Way of the Lower Mainland (2011) provides grants to non-profit, community-based organizations offering support programs for informal caregivers, but the scope of these programs can be limited based on the ability of groups to meet specific funding criteria and conditions, and their capacity to offer programming.

Creating or expanding individualized community-based services is dependent on two things: the needs of the community being served, but also the capacity of those within the community to coordinate, decide and deliver resources and services. For these reasons, health co-operatives have been used in this section as the basis for evaluating the policy option. By definition, a co-operative is “an organization owned by the members who use its services or are employed there” (Canadian Co-operative Association, 2008). In terms of service provision, co-operatives can have a local focus and provide services within a small geographic area, or across large and multiple regions; they can be organized as small clinics or as a complex, integrated networks (Girard, 2009).

Health co-operatives exist in Canada and worldwide, and can “include, but are not limited to, any combination of: primary health clinics; integrated health clinics, ambulance services; home care; information and education; health promotion; group purchasing of health supplies; mental health facilities; and health insurance” (Panayotof-Schaan, 2009, p. 7). However, common attributes of health co-operatives are their intent to fill missing gaps in health care systems as well as emphasize user responsibility (Panayotof-Schaan, 2009).

**Access to Resources:** Evidence shows that health co-operatives create many benefits to seniors at end-of-life and informal caregivers: it is more possible for seniors to remain in their own communities, the non-profit structure allows more affordable service, and higher quality of care can be achieved (Restakis, 2008). Québec’s network of co-operatives has strong support from the government, which has committed to paying a portion of the hourly fee required by home support services; the balance is paid by the health co-operative member, with the total amount required dependent on the income level and health status of each individual (Girard, 2009). This can assure access to resources insofar as the entire cost of services does not have to be borne by elderly patients or informal caregivers. As well, the ability for health co-operatives to define the
services offered can ensure that portfolios include items such as personal care or respite services for family members (Girard, 2009).

However, the success of the health co-operative is highly dependent on the commitment of its members and volunteers (Restakis, 2008). In addition, there exist two significant limitations:

- Very few co-operatives offer long-term care despite the current challenges in long-term care delivery, including the cost of services, quality, and continuity of care; and
- Few co-operatives offer acute, ambulatory, and advanced diagnostics, even though regional health organizations may contract with for-profit or other third-sector organizations to deliver these services.

(Marchildon, 2009, p. 20)

There may be a role for these types of health co-operatives in Canada, but the reasons for limited delivery of these services are unknown. While the potential for this policy to significantly increase access to resources is high, the services needed by informal caregivers would take time to design, develop and implement. Further, the current lack of long-term, ambulatory, and advanced diagnostic services under the health co-operative model, which would positively affect seniors’ health care, suggests little desire by governments and Canadians to develop these models. For these reasons, expanding community-based services scores medium (2) in being able to increase access to resources.

**Minimization of caregiver burden:** Home care is a commonly provided service to health co-operative members in Canada. A home care health co-operative in Quebec, for example, provides services such as light and heavy housekeeping, clothing care, meal preparation, running errands, accompanying seniors during medical appointments, and providing respite care to informal caregivers (Restakis, 2008), and individuals from this co-operative rate the quality of the services received very positively (Leviten-Reid, 2009). Health co-operatives have been shown to reduce overall health care costs to the patient and family (Restakis, 2008) and, being member driven, exhibit great potential to innovate and respond to the needs of the community. For example, a community clinic in Saskatchewan created a service to operate a bus providing clients with transportation to
and from clinic appointments (Fairbairn, 2009); given that transportation emerged as a significant burden to informal caregivers in this study, it is reasonable to infer that the same could occur in Vancouver-City Centre. As well, health co-operatives in Japan have been proven to encourage peer support (Panayotof-Schaan, 2009), providing an avenue to mitigate psychological strain. While there is a lack of evidence to support the notion that health co-operatives can alleviate employment risks to informal caregivers, they are proven to minimize other significant burdens. Therefore, this option scores medium (2).

**Good death:** Health co-operatives have the latitude to decide which services to provide, resulting in tailored services based on the needs of its members (Doucette, 2009). Innovative approaches include an interprofessional approach to providing care, meaning “clients not only have access to doctors but to different services within each clinic, including counseling, physical and occupational therapy, and services provided by nutritionists and diagnostic technicians” (Fairbairn, 2009, p. 17). In Japan, health co-operative volunteers are trained to undertake a range of regular community health checks, including tests for individuals’ blood pressure, weight, diabetes, and more – the results of which are then forwarded to a health professional within the co-operative for further analysis and follow up (Restakis & Filip, 2008). This type of operation helps to keep costs down while “keeping a close watch on evolving health issues as they emerge in a particular community” (Restakis & Filip, 2008, p. 6). As well, health care co-operatives have the ability to reduce hospitalization rates for seniors living in co-operative settings; this suggests that the co-operative model has significant potential to ensure seniors at end-of-life are able to remain at home and out of acute care (Restakis, 2008). Studies do not provide specific evidence as to whether pain and symptoms can be properly managed, if adequate preparation for death can occur, or whether wishes for death can be honoured. Given the potential, however, to create a flexible and tailored approach to care, and evidence which shows that dying seniors’ physical and emotional needs can be met by health co-operatives, this option scores medium (2) in being able to help seniors achieve a good death.

**Financial cost:** Funding is a major component in any co-operative. Start-up funding commonly comes from a variety of sources including private donations or loans from local credit unions but for health co-operatives, in particular, funding can be
secured form local health authorities (Restakis, 2008). However, this source can vary widely depending on the jurisdiction, the specific policies of regional government health agencies, and the history between co-ops and the public health sector (Restakis, 2008). In addition to third-party and government grants, common sources of ongoing funding for health co-operatives can also include membership fees, rent from health care providers, and payments by patients using services excluded from health care plans (Panayotof-Schaan, 2009). However, some members may not like paying membership fees, and younger members having less experience with co-ops may not be willing to contribute (Restakis, 2008). In order to sustain operations of the health co-operative in the long term, it is imperative to ensure strong financial management and multiple sources of finding (Panayotof-Schaan, 2009). Because of these challenges and anticipated significant costs associated with funding health care co-operatives, this policy option scores low (1) in meeting this criterion.

**Implementation complexity:** The number of health co-operatives has increased substantially in the last two decades, suggesting that support from individuals and governments is growing (Panayotof-Schaan, 2009). However, specific investment requirements are necessary in creating a health co-operative; as well, mutual trust, shared decision-making, member participation, and collective risk-sharing are elements of any type of co-operative (Restakis, 2008). A general lack of knowledge and understanding of the co-operative model amongst the general public, funders, and policy-makers has led to a “relatively low number of new co-ops for the provision of services to seniors” (Restakis, 2008, p. 14). Capital, equipment, business acumen, managerial expertise, financial expertise, and member and volunteer commitment are also imperative to the success of the co-operative. Given the significant amount of administration required in creating a health co-operative, including the need for capital and financial investment, as well as high involvement and support from stakeholders, this option scores low (1) for implementation complexity.
8. Recommendations

Based on the analysis of the policy options, the option to provide a single point of contact for elderly end-of-life patients and their families is the highest rated and is, therefore, the most viable alternative in resolving the issue that informal caregivers in British Columbia currently do not have adequate access to resources which would allow them the greatest opportunity to provide quality care to an elderly family member who wishes to die at home. Provided below are some thoughts on implementation as well as future policy considerations.

8.1. Policy Implementation

The concept of patient navigation was used in the analysis, as this role has been previously piloted at organizations such as the BC Cancer Agency, Cancer Care Ontario, and Cancer Care Nova Scotia. Learnings from these pilot programs can be used to create similar initiatives in British Columbia tailored to assist informal caregivers and seniors diagnosed with a life-limiting condition. These end-of-life patient navigators would be responsible for coordinating services, attending to the needs of informal caregivers and elderly patients, as well as helping patients and families access all end-of-life care resources which may be of benefit. British Columbia’s pilot patient navigators should also be expected to assist families with the logistics of getting to and from appointments, and in dealing with financial impacts, such as drug costs and potential loss of employment income.

In other jurisdictions, it is often experienced nurses appointed in the patient navigator role, and there is no reason to deviate from this in an end-of-life pilot program for British Columbia. Social workers may be considered for these positions; however, according to interviews with palliative care professionals, they simply do not have the capacity at the present time due to current caseloads. However, redistribution of
workloads from current cases to end-of-life cases may make social workers a possible alternative to nurses in the patient navigator role. As well, non-professionals who have experience in caring for seniors at end-of-life may also be suitable for the navigator role, as findings suggested that informal caregivers often learn about programs, services and coping strategies from others who have been through a similar situation.

End-of-life patient navigators should be experienced in dealing with elderly, palliative patients, as sensitivity and responsiveness of health care providers to the needs of families and seniors is a vital skill in this role. Training for end-of-life patient navigators should be considered, as this may help to clarify the role for individuals unfamiliar with the duties of patient navigation. End-of-life patient navigators in British Columbia can benefit from training focused on the types of end-of-life resources available, and should be expected to retain a high degree of knowledge of government funded programs for informal caregivers and seniors at end-of-life; home and community care within the local health area; equipment sources; how to access resources; and other ways to mitigate financial, psychological, and physiological to caregivers. Engaging in continuing professional development will be crucial in ensuring patient navigators can maintain their expertise and standards of care.

Funding for this pilot program would be required from government. In Ontario, for example, a pilot was run with 14 provincially funded navigators, with some programs securing funding from outside of government (Walkinshaw, 2011). The amount of funding necessary can be derived by using current pay rates for experienced nurses, determining the number of patient navigators to be created for the pilot, and the length of time the pilot will be in effect. For a more long-term view, funding following the initial pilot should be considered in anticipation of keeping patient navigators within the health system.

To evaluate the outcomes of the pilot, evaluation measures need to be determined. This can include satisfaction research amongst willing palliative patients and informal caregivers – those who have received support from the patient navigators. As well, assessing indicators for good death and the ways in which caregiver burden are mitigated can reveal whether the pilot with end-of-life patient navigators is successful, and identify areas for improvement.
8.2. Future Policy Considerations

While the policy option to increase the availability and extent of publicly funded formal home support scored poorly in terms of financial cost and implementation complexity, it did however, show great potential to minimize caregiver burden and contribute to elderly end-of-life patients’ ability to experience a good death. The option would also be expected to create greater access to resources for informal caregivers, increasing their ability to provide quality home care to seniors at end-of-life. Government officials, if serious about improving the ability for elderly British Columbians to die at home, would do well to consider if and how they might be able to actualize this policy option. One starting point might be to undertake a review of home care to identify gaps in service delivery: what is currently being provided, what supports do end-of-life patients and informal caregivers need, and are those needs being met? Having a better understanding of service areas which are not delivering will help to inform future home care program designs.

Other steps to consider in moving towards this policy option might be to initiate a review of physician payment models in order to address the concerns raised by doctors in delivering home care, as well as a review of the formulas currently used to determine co-payment by elderly patients and their families in receiving home and community care. The overall purpose of these reviews would be to identify whether the existing models are appropriate and how they might adapt, if the availability and extent of publicly funded formal home care was to increase.
9. Discussion of Limitations and Future Research

While this study examines provincial end-of-life policy, it undertook an in-depth analysis of only a single local health area in British Columbia: Vancouver-City Centre, which has a high population density and generally well-established home and community care programs. As such, the results presented here are expected to have greater relevance for other urban areas in British Columbia versus that of rural or remote communities. While patient navigators may be able to assist end-of-life seniors in less populated areas, further study is necessary to determine how this type of policy can be tailored to best suit rural populations and remote contexts versus that of urban populations.

As well, this research was unable to include the perspectives of those working within Vancouver-City Centre’s Community Care teams; these individuals are the frontline workers dealing directly with informal caregivers and seniors at end-of-life on a daily basis. It is therefore recommended that future research in this area aim to evaluate practices being done specifically by these individuals.

This study also does not consider palliative patients with behavioural issues or mental illness. This group of people appears at risk of not being accepted into hospices due to their required levels of care, and there are little, if any, resources in place to support this group in the absence of an informal caregiver who can provide care in a home setting (M. Giesbrecht, email message to author, 2013, July 15). Additionally, there is an opportunity to explore the effects of end-of-life policy on marginalized population groups such as cultural minorities and Aboriginal populations, those who live alone, or do not have family able to care for them (M. Giesbrecht, email message to author, 2013, July 15).
The findings from this study suggest that more research is needed with respect to differences in access to end-of-life care and resources for immigrant individuals, those whose first language is not English, and those of poorer socioeconomic status. The results imply that it may be useful to consider tailored end-of-life services for specific palliative illness trajectories – dementia or Alzheimer’s versus cancer versus other life-limiting conditions, for example. The design of this research study did not lend itself to examining these populations or illness-specific care in any detail. However, future research may wish to consider delving into these matters further.
10. Conclusions

The shift in philosophy amongst health care providers and the general public towards a home is best mentality is becoming widely accepted, yet this study proves that not enough is being done to support families providing informal care, or seniors who desire a home death. Given the increased risks of institutionalization for dying seniors or multiple trips to emergency when their family caregivers cannot manage, a proactive stance to end-of-life care can help to alleviate demands on formal health systems and mitigate costly acute services.

Providing a single point of contact to assist dying seniors and informal caregivers in navigating the health care system after the patient has been diagnosed with a life-limiting illness is one way to balance the responsibilities between formal and informal systems. Limited uptake of existing resources indicates a lack of awareness amongst those who may require these services; a patient navigator can help to coordinate resources and ensure patients and families are receiving all supports available to them, resulting in a more efficient use of programs currently being provided by the public system. Initiating a pilot program in British Columbia for end-of-life patient navigators is recommended to better assist informal caregivers in their role. Governments should also consider how to move forward with increasing the availability and extent of publicly funded formal home support, as this policy option shows significant potential in mitigating caregiver burden and helping seniors at end-of-life achieve a good death at home.

As retired college professor Morrie Schwartz once said, “Death is the great equalizer” (Albom, 1997). However, to ensure all Canadians can receive quality end-of-life care, many inequalities will need to be addressed. This research supports the view that shifting the responsibility of end-of-life care from formal to informal systems cannot be done responsibly without providing adequate support to family caregivers in fulfilling their care duties. Only with adequate access to programs and resources can it be
assured that seniors at end-of-life will be able to experience a good death at home. Governments will need to decide their role, what needs to change, and to what extent they are willing to support Canadians through this inevitable journey we all must face.
References


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Canadian Home Care Association. (2010). *High impact practices. home first: Maximizing use of investments while creating better outcomes for seniors and reducing ALC.*

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Hannon, B., O'Reilly, V., Bennett, K., Breen, K., & Lawlor, P.G. (2012). Meeting the family: Measuring effectiveness of family meetings in a specialist inpatient palliative care unit. *Palliative & Supportive Care, 10*(1), 43-49. doi:10.1017/S1478951511000575


Appendices
Appendix A.
Details for Discourse Analysis Methodology

Discourse analysis is an analytical framework used by researchers to critically examine the use of text and language, particularly to gain insights into “the ways in which language is used to pursue political and organizational objectives as well as how policy documents are interpreted by their intended audience” (Jacobs, 2006, p. 40). In this capstone, a critical discourse analysis was used to analyze provincial policies focused on the delivery of end-of-life care for seniors. Analysis was conducted by considering the three dimensions of the critical discourse analysis framework: the discursive practice of written language texts to undercover underlying messages and how this feeds into debate; a text analysis to contextualize the production, distribution and consumption of text; and social practice, exploring discursive events as instances of power and ideology (Fairclough, 1995). By this method, it was possible to identify dominant discourses which prescribe particular care practices either supporting or restraining the ability of informal caregivers to provide quality end-of-life care to seniors who wish to die at home.
Appendix B. Details for Case Study Analysis Methodology

Case study analysis allows for exploration of individuals and organizations, simple through complex interventions, relationships, communities, and programs (Yin, 2003). Descriptive case study analysis can be employed in order to describe the intervention and the real-life context in which it occurred (Yin, 2003). Based on the critical components of case study research design (Yin, 2003), study propositions were developed to focus attention on specific items to be examined within the scope of study; these are shown in Table 6 below.

Table B1. Case Study Propositions

<table>
<thead>
<tr>
<th>Proposition</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal caregivers are burdened by out-of-pocket medical expenses related to home care e.g. medications, specialist treatment or consultations</td>
<td>(HCC, 2012; Keating et al., 2013, p. 7)</td>
</tr>
<tr>
<td>Informal caregivers are burdened by out-of-pocket expenses related to required in-home care e.g. hours capped for home nursing care</td>
<td>(HCC, 2012)</td>
</tr>
<tr>
<td>Informal caregivers have to often pay out-of-pocket for respite services</td>
<td>(MoH, 2013a; Chappell, 2011, p. 13)</td>
</tr>
<tr>
<td>Informal caregivers often experience distress or burnout as a result of their caregiving duties</td>
<td>(CIHI, 2011b, p. x; HCC, 2012, p. 28; Statistics Canada, 2010; Turner &amp; Findlay, 2012, p. 3)</td>
</tr>
<tr>
<td>Informal caregivers are often ill-prepared by or do not have access to help from professional health care providers when agreeing to take care of a dying senior at home</td>
<td>(Topf et al., 2013, p. 876)</td>
</tr>
<tr>
<td>Seniors at end-of-life are not accessing palliative care programs for which they are eligible</td>
<td>(MoH, 2013f, p. 7)</td>
</tr>
<tr>
<td>Seniors at end-of-life experience difficulty in acquiring necessary medical supplies, equipment, and medications under the BC Palliative Care Program</td>
<td>(MoH, 2012a, p. 2)</td>
</tr>
</tbody>
</table>

A cross-case synthesis was employed by linking case study data with the propositions using the criteria found in Table 7. These criteria were chosen based on the
home-based care guidelines as provided in the Ministry of Health’s 2006 *Provincial Framework for End-of-Life Care*. Interpretation of the findings was conducted by determining how well each case was able to match or meet these guidelines. Word tables were created to display the data from the individual cases according to this uniform framework, allowing for exploration of overall patterns and outcomes of interest in drawing cross-case conclusions (Yin, 2003).

### Table B2. Criteria for Interpreting the Case Study Findings

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparation and Advance Care Planning</td>
<td>• care providers begin the process of preparing the patient and family for the end of life and the decisions they will need to make along the way;</td>
</tr>
<tr>
<td></td>
<td>• providing families and individuals with information;</td>
</tr>
<tr>
<td></td>
<td>• referring to available services;</td>
</tr>
<tr>
<td></td>
<td>• deciding on likely members of care team;</td>
</tr>
<tr>
<td></td>
<td>• identifying roles of patient and family members;</td>
</tr>
<tr>
<td></td>
<td>• determining means of communication and coordination of services;</td>
</tr>
<tr>
<td></td>
<td>• provide info and resources to support ACP (understanding of options, providing instructions for treatment, choices for end-of-life care)*</td>
</tr>
<tr>
<td>Pain and Symptom Management</td>
<td>• providing pain and symptom management to patient;</td>
</tr>
<tr>
<td></td>
<td>• primary care providers consult with specialist clinicians;</td>
</tr>
<tr>
<td></td>
<td>• palliative specialist involvement when necessary</td>
</tr>
<tr>
<td>Psychosocial, Spiritual and Bereavement Support</td>
<td>• provision of these services by community groups;</td>
</tr>
<tr>
<td></td>
<td>• clarity of roles;</td>
</tr>
<tr>
<td></td>
<td>• regular communication;</td>
</tr>
<tr>
<td></td>
<td>• sensitivity and responsiveness to patient and family members’ needs for coping</td>
</tr>
<tr>
<td>Support for Informal Caregivers</td>
<td>• access to (flexibility of) respite services;</td>
</tr>
<tr>
<td></td>
<td>• access to home support for personal care and household needs;</td>
</tr>
<tr>
<td></td>
<td>• around the clock care in near-death stage</td>
</tr>
<tr>
<td>Financial Support</td>
<td>• health team assists with BC Palliative Care Benefits Program enrolment;</td>
</tr>
<tr>
<td></td>
<td>• access to program is equitable (availability of medications)*</td>
</tr>
</tbody>
</table>

*starred items denote congruence with 2013 Provincial End-of-Life Care Action Plan*

Sources: (MoH, 2006b; MoH, 2013f)
Multiple units of analysis were used to provide in-depth information into the issues under investigation (Woods & Catanzaro, 1988); these included health authorities’ publicly available strategy documents, reports and descriptions, as well as verbal accounts from palliative health care professionals working within Vancouver City-Centre’s agencies of Vancouver Coastal Health and Providence Health Care.

Three palliative health care professionals from Vancouver Coastal Health and four from Providence Health Care were interviewed between November 2013 and January 2014. These individuals were recruited either directly through email, or by referral from another health care professional working within the local health area. All palliative health care workers were told of the purpose of the study and why their input was being requested. Their input was used to help provide insight and context into end-of-life care service delivery, and the local health area’s ability to support end-of-life seniors and their informal caregivers in ensuring quality home care. Compensation for participating in interviews was not offered.

Speaking with front line palliative care experts also served to discern the ways in which current end-of-life policies are effective and where improvements can be realized. A semi-structured interview format was chosen to cover a sequence of topics in response to prepared questions, while allowing “openness to changes of sequence and question forms in order to follow up the answers given and the stories told by the interviewees” (Kvale, 2007, p. 65). This enabled a measure of flexibility in the discussion with interview participants, based on individual experiences and stories shared. Interviews were approximately an hour in length, and occurred in the place of each participant’s choice. General topics discussed included: the role of the informal caregiver; information needs; impacts to caregiver’s personal and work life; day-to-day tasks; medical equipment and medications; and access to medical professionals and other needed resources.
## Appendix C.
Sample Interview Schedule: Palliative Health Care Professionals

<table>
<thead>
<tr>
<th>Sample Discussion Topic</th>
<th>Sample Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>The role of the informal caregiver</td>
<td>• In your experience, do you find that families are increasingly taking up the caregiving role for someone who is at end-of-life? Why do you say that?</td>
</tr>
<tr>
<td>Initial information needs</td>
<td>• Please describe what happens when you have a discussion with a family about end-of-life care options. How does this normally initiate? What is discussed?</td>
</tr>
<tr>
<td></td>
<td>• What questions do caregivers have when considering whether or not to provide home care to their family member?</td>
</tr>
<tr>
<td>Impact to caregiver’s personal and work life</td>
<td>• What types of changes do caregivers typically have to make in order to care for their family member?</td>
</tr>
<tr>
<td>Day-to-day tasks</td>
<td>• What are the daily tasks that a home caregiver might be responsible for?</td>
</tr>
<tr>
<td>Medical equipment and medications</td>
<td>• Please describe the process that is required for a patient and their caregiver to obtain palliative home care equipment and/or medication.</td>
</tr>
<tr>
<td>Additional expenses</td>
<td>• What might informal caregivers have to pay for out-of-pocket i.e. is there anything not available through the palliative programs that you find caregivers typically need?</td>
</tr>
<tr>
<td>Medical professionals</td>
<td>• After the choice has been made to provide home care to a person who is at end-of-life, at what stages will caregivers typically seek your assistance?</td>
</tr>
<tr>
<td></td>
<td>• What do they typically need assistance for?</td>
</tr>
<tr>
<td></td>
<td>• How do you usually go about helping to get caregivers the help or information they need?</td>
</tr>
<tr>
<td>Other resources</td>
<td>• Beyond government programs, what other resources exist that can help caregivers provide home care to someone at end-of-life?</td>
</tr>
<tr>
<td></td>
<td>• In your opinion, what is needed to ensure caregivers have the best opportunity to provide home care to a family member who is at end-of-life?</td>
</tr>
</tbody>
</table>
Appendix D. Details for Interviews with Informal Caregivers

Recruitment of informal caregivers was done through numerous agencies involved in delivering support programs to informal caregivers. A total of 13 agencies providing services to family caregivers within the local health area of Vancouver-City Centre were contacted between November 2013 and January 2014; however, while many advised they would look into the request, only five were willing to distribute the information about the study. These organizations used various channels to share the study details: posting the study information on their website, sharing on their social media channels, or emailing to specific individuals they felt met the criteria. Potential interview participants were instructed to contact the principal investigator directly if interested to participate.

As in speaking with palliative care health professionals, a semi-structured interview format was employed to gather information while maintaining flexibility in the discussions based on individuals’ personal experiences and the stories they chose to share. Interviews were conducted with informal caregivers to assess whether they felt adequately supported in their role to provide quality home care to a senior at end-of-life. Data obtained through these interviews has been used to explore caregivers’ positive and negative experiences of the services and support they required in their role. The discussions with informal caregivers lasted approximately an hour in length, and all were conducted in person, at a location of the interview participant’s choosing; this was typically a coffee shop or a café near to the interviewee’s home or place of work. General topics discussed included: the informal caregiver’s relationship to person at end-of-life; day-to-day tasks; medical equipment and medications; additional expenses; help from medical professionals; impact to personal and work life; and information needs.

Similar to the analysis of the interviews with palliative health care professionals, analysis of the data obtained through interviews with informal caregivers was conducted using thematic analysis. Through this analysis, overarching patterns have been identified and a rich description of the data set has been provided in order to highlight the
predominant or most important themes (Braun & Clarke, 2006) emerging from the interviews.
## Appendix E.
### Sample Interview Schedule: Informal Caregivers

<table>
<thead>
<tr>
<th>Discussion Topic</th>
<th>Sample Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship to person at end-of-life</td>
<td>• Can you please describe your relationship with the person you were caring for?</td>
</tr>
<tr>
<td>Day-to-day tasks</td>
<td>• What were your daily home care tasks?</td>
</tr>
<tr>
<td>Medical equipment and medications</td>
<td>• What types of equipment and medications were needed by your family member? • Please describe the process you went through to obtain those pieces of equipment and/or medication. • What, if anything, helped to make that process easier? What did you find difficult?</td>
</tr>
<tr>
<td>Additional expenses</td>
<td>• Was there anything that you ended up having to pay for out-of-pocket? • What were those things? Were you able to afford what you needed?</td>
</tr>
<tr>
<td>Medical professionals</td>
<td>• How often did you seek help or ask for information from a medical professional? • What did you typically need assistance for? • Can you describe how you approached those people? How easy or challenging was it to get the information or help you needed?</td>
</tr>
<tr>
<td>Impact to personal and work life</td>
<td>• Can you describe what changes you had to make in order to care for your family member?</td>
</tr>
<tr>
<td>Initial information needs</td>
<td>• Please describe what happened when you found out your family member was at end-of-life. Was there a conversation with a medical professional? What was discussed? • Looking back, do you feel you had enough information when you offered to take care of your family member? Why or why not?</td>
</tr>
</tbody>
</table>
Appendix F. Ethical Considerations and Approvals

Approvals were obtained from the relevant institutions prior beginning the research. This included Operational Research Approval from the Vancouver Coastal Health Authority Research Institute for research conducted at Vancouver General Hospital (Vancouver Acute), and Institutional approval from the Providence Health Care Research Institute for St. Paul's Hospital, as well as approvals from the Office of Research Ethics at Simon Fraser University.

In order to obtain approvals, a number of ethical considerations were outlined for ethical submission:

- Potential risks associated with participating in this study beyond what might be encountered in the course of daily life were low to none for both informal caregivers and palliative care experts.
- The risk of magnitude of harm to the participants resulting from breach of confidentiality was deemed as low, and was further mitigated by the voluntary nature to participate in the study, the advance notice of topics to be discussed during the interviews, and the ability to withdraw from the study at any time, up until the time data analysis has begun, without consequence.
- Confidentiality of all research interviewees was maintained, and all were asked to review and sign informed consent statements prior to participation in the interviews.
- Interviews were audio recorded for transcription and analysis purposes. Raw data was stored securely and were destroyed following data analysis. Research data will be maintained for a duration of two years from the time the study is completed, after which time it will be destroyed.
## Appendix G. Case Study Analysis Word Tables for Case #1: Vancouver Coastal Health

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
<th>1. VCH Community Engagement Report</th>
<th>2. Website text on Home &amp; Community Care</th>
<th>3. Interviews with palliative care professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparation and Advance Care Planning</td>
<td>Care providers begin the process of preparing the patient and family for the end of life and the decisions they will need to make along the way</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Providing families and individuals with information</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Referring to available services</td>
<td>❌</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Deciding on likely members of care team</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Identifying roles of patient and family members</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Determining means of communication and coordination of services</td>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Provide info and resources to support ACP (understanding of options, providing instructions for treatment, choices for end-of-life care)</td>
<td>✔️</td>
<td>❌</td>
<td>✔️</td>
</tr>
<tr>
<td>Pain and Symptom Management</td>
<td>Providing pain and symptom management to patient</td>
<td>✔️</td>
<td>➔</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Primary care providers consult with specialist clinicians</td>
<td>✔️</td>
<td>➔</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Palliative specialist involvement when necessary</td>
<td>✔️</td>
<td>➔</td>
<td>✔️</td>
</tr>
<tr>
<td>Psychosocial, Spiritual and Bereavement Support</td>
<td>Provision of these services by community groups</td>
<td>✔️</td>
<td>➔</td>
<td>✔️</td>
</tr>
<tr>
<td></td>
<td>Clarity of roles</td>
<td>✔️</td>
<td>➔</td>
<td>✔️</td>
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<tr>
<td></td>
<td>Regular communication</td>
<td>➔</td>
<td>➔</td>
<td>✔️</td>
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<tr>
<td></td>
<td>Sensitivity and responsiveness to patient and family members' needs for coping</td>
<td>✔️</td>
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<td>✔️</td>
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<td>Criteria</td>
<td>Description</td>
<td>RATING SUMMARY</td>
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<tr>
<td>Support for Informal Caregivers</td>
<td>access to (flexibility of) respite services</td>
<td>● ● ●</td>
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<td></td>
<td>access to home support for personal care and household needs</td>
<td>● ● ●</td>
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<td></td>
<td>around the clock care in near-death stage</td>
<td>● ● ●</td>
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<tr>
<td>Financial Support</td>
<td>health team assists with BC Palliative Care Benefits Program enrolment</td>
<td>● ● ●</td>
<td></td>
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<td></td>
<td>access to program is equitable (availability of medications)</td>
<td>● ● ●</td>
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**Legend**

<table>
<thead>
<tr>
<th>Fully meets criterion</th>
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<tr>
<td>Partially meets criterion</td>
<td>●</td>
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<tr>
<td>Does not meet criterion</td>
<td>●</td>
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<tr>
<td>Criteria</td>
<td>Description</td>
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<tr>
<td>Preparation and Advance Care Planning</td>
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<td></td>
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<td>provide info and resources to support ACP (understanding of options, providing instructions for treatment, choices for end-of-life care)</td>
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<td>Pain and Symptom Management</td>
<td>providing pain and symptom management to patient</td>
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<tr>
<td></td>
<td>primary care providers consult with specialist clinicians</td>
</tr>
<tr>
<td></td>
<td>palliative specialist involvement when necessary</td>
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<tr>
<td>Criteria</td>
<td>Description</td>
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<td>--------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Psychosocial, Spiritual and Bereavement Support</td>
<td>provision of these services by community groups</td>
</tr>
<tr>
<td>clarity of roles</td>
<td>☀ Social workers able to mediate challenging situations, provide clarity; however, caregivers noted greater need to be better educated in communicating with dying family member, death and dying process</td>
</tr>
<tr>
<td>regular communication</td>
<td>☀ Not mentioned</td>
</tr>
<tr>
<td>sensitivity and responsiveness to patient and family members’ needs for coping</td>
<td>☀ Acknowledges that health care providers need to be sensitive in patients and families’ wishes in navigating the dying experience but that specialized training in these areas is needed; healthcare staff often overworked and rushed and therefore not able to be attentive</td>
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<tr>
<td>Support for Informal Caregivers</td>
<td>access to (flexibility of) respite services</td>
</tr>
<tr>
<td>access to home support for personal care and household needs</td>
<td>☀ Inconsistency of workers coming into the home is overwhelming for informal caregivers; adds work and stress</td>
</tr>
<tr>
<td>around the clock care in near-death stage</td>
<td>☀ 24-hour nursing care in last days of life needed, as well as health care professionals on an emergency basis</td>
</tr>
<tr>
<td>Financial Support</td>
<td>health team assists with BC Palliative Care Benefits Program enrolment</td>
</tr>
<tr>
<td>access to program is equitable (availability of medications)</td>
<td>☀ Not mentioned</td>
</tr>
</tbody>
</table>

**Legend**

- Fully meets criterion 
- Partially meets criterion 
- Does not meet criterion
<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
<th>2. Website text on Home &amp; Community Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparation and Advance Care Planning</td>
<td>care providers begin the process of preparing the patient and family for the end of life and the decisions they will need to make along the way</td>
<td>Home Care Nurses provide assessment, education, counselling, palliative care; all home care nurses experienced in palliative care; extent/availability of services unspecified on website</td>
</tr>
<tr>
<td></td>
<td>providing families and individuals with information</td>
<td>Same as above</td>
</tr>
<tr>
<td></td>
<td>referring to available services</td>
<td>Case management available to “families who need help coordinating services to meet their health care needs”; extent/availability of assistance unspecified on website</td>
</tr>
<tr>
<td></td>
<td>deciding on likely members of care team</td>
<td>Same as above</td>
</tr>
<tr>
<td></td>
<td>identifying roles of patient and family members</td>
<td>Same as above</td>
</tr>
<tr>
<td></td>
<td>determining means of communication and coordination of services</td>
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</tr>
<tr>
<td></td>
<td>provide info and resources to support ACP (understanding of options, providing instructions for treatment, choices for end-of-life care)</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>Pain and Symptom Management</td>
<td>providing pain and symptom management to patient</td>
<td>Adult Day Services (fee-based) available to help with health monitoring and administering medications; services capped based on program availability and personal needs</td>
</tr>
<tr>
<td></td>
<td>primary care providers consult with specialist clinicians</td>
<td>Case management available to “families who need help coordinating services to meet their health care needs”; extent/availability of assistance unspecified on website</td>
</tr>
<tr>
<td></td>
<td>palliative specialist involvement when necessary</td>
<td>Same as above</td>
</tr>
<tr>
<td>Psychosocial, Spiritual and Bereavement Support</td>
<td>provision of these services by community groups</td>
<td>Adult Day Services (fee-based) provides social programs e.g. discussion and exercise groups; services capped based on program availability and personal needs</td>
</tr>
<tr>
<td></td>
<td>clarity of roles</td>
<td>Home Care Nurses provide assessment, education, counselling, palliative care; all home care nurses experienced in palliative care; extent/availability of services unspecified on website</td>
</tr>
<tr>
<td></td>
<td>regular communication</td>
<td>Same as above</td>
</tr>
<tr>
<td>Criteria</td>
<td>Description</td>
<td>2. Website text on Home &amp; Community Care</td>
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<tr>
<td></td>
<td></td>
<td>Rating</td>
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<tr>
<td>sensitivity and responsiveness to patient</td>
<td></td>
<td>Same as above</td>
</tr>
<tr>
<td>and family members’ needs for coping</td>
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<tr>
<td>Support for Informal Caregivers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>access to (flexibility of)</td>
<td></td>
<td>Home Support (costs covered) “provide</td>
</tr>
<tr>
<td>respite services</td>
<td></td>
<td>assistance with support and relief for</td>
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<tr>
<td></td>
<td></td>
<td>your primary caregiver”; extent/availability</td>
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<tr>
<td>access to home support for personal care</td>
<td></td>
<td>Adult Day Services (fee-based) provides</td>
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<tr>
<td>and household needs</td>
<td></td>
<td>help with personal care e.g. bathing</td>
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<td></td>
<td></td>
<td>programs; services capped based on</td>
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<td></td>
<td></td>
<td>program availability and personal needs;</td>
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<td></td>
<td></td>
<td>Home Support (costs covered) “provide</td>
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<td>assistance with daily living activities</td>
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<td>at home such as bathing, dressing</td>
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<td>and grooming…medication administration</td>
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<tr>
<td></td>
<td></td>
<td>and other care needs”; extent/availability</td>
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<tr>
<td></td>
<td></td>
<td>assistance unspecified on website</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Not mentioned</td>
</tr>
<tr>
<td>Financial Support</td>
<td></td>
<td>Case management team helps to determine</td>
</tr>
<tr>
<td>health team assists with BC Palliative</td>
<td></td>
<td>costs and arrange for services;</td>
</tr>
<tr>
<td>Care Benefits Program enrolment</td>
<td></td>
<td>extent/availability of assistance</td>
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<td></td>
<td></td>
<td>unspecified on website</td>
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<tr>
<td>access to program is equitable (availability</td>
<td></td>
<td>From Home Health team: “For the most</td>
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<td>of medications)</td>
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<td>part you will be expected to pay for</td>
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<td></td>
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<td>your supplies, medications and</td>
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<td></td>
<td></td>
<td>equipment” (for home health i.e.</td>
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<td></td>
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<td>outside of palliative program); limited</td>
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<td></td>
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<td>options for having costs covered by</td>
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<tr>
<td></td>
<td></td>
<td>other funding agencies; Choice in</td>
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<td></td>
<td></td>
<td>Supports for Independent Living (CSIL)</td>
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<tr>
<td></td>
<td></td>
<td>provides direct funding to patients</td>
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<tr>
<td></td>
<td></td>
<td>with high physical care needs to hire</td>
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<tr>
<td></td>
<td></td>
<td>home support workers Instead of paying</td>
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<tr>
<td></td>
<td></td>
<td>a home support agency to provide</td>
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<tr>
<td></td>
<td></td>
<td>services, we provide you with money to</td>
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<tr>
<td></td>
<td></td>
<td>hire your own home support workers</td>
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<tr>
<td></td>
<td></td>
<td>(limited eligibility, outside of</td>
</tr>
<tr>
<td></td>
<td></td>
<td>palliative program)</td>
</tr>
</tbody>
</table>

**Legend**

- **Fully meets criterion**
- **Partially meets criterion**
- **Does not meet criterion**
<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
<th>3. Interviews with palliative care professionals working within Vancouver Coastal Health</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Preparation and Advance Care Planning</strong></td>
<td>care providers begin the process of preparing the patient and family for the end of life and the decisions they will need to make along the way</td>
<td>▼ This does happen, but often dependent on sensitivity and health care bias/expertise with respect to palliation</td>
</tr>
<tr>
<td></td>
<td>providing families and individuals with information</td>
<td>▼ Same as above</td>
</tr>
<tr>
<td></td>
<td>referring to available services</td>
<td>▼ If palliative, specialists assigned based on care needs; if not palliative, seems more complicated (not enough collaboration/communication between service providers)</td>
</tr>
<tr>
<td></td>
<td>deciding on likely members of care team</td>
<td>▼ Same as above</td>
</tr>
<tr>
<td></td>
<td>identifying roles of patient and family members</td>
<td>▼ Done through conversations with family and patient; attempts to determine family dynamic and whether home death is realistic</td>
</tr>
<tr>
<td></td>
<td>determining means of communication and coordination of services</td>
<td>▼ Person within the hospital will often help with this, but would be useful to have a single point of contact in most cases; currently, only case managers or social workers assigned if family dynamics are problematic versus health-related issue</td>
</tr>
<tr>
<td></td>
<td>provide info and resources to support ACP (understanding of options, providing instructions for treatment, choices for end-of-life care)</td>
<td>▼ Should be done but can be complicated based on unpredictable/unknown illness trajectory; GPs and others not necessarily initiating those conversations</td>
</tr>
<tr>
<td><strong>Pain and Symptom Management</strong></td>
<td>providing pain and symptom management to patient</td>
<td>▼ Easier done in hospital than at home; caregivers in home setting left on own to make care decisions (can be difficult for some)</td>
</tr>
<tr>
<td></td>
<td>primary care providers consult with specialist clinicians</td>
<td>▼ If palliative, specialists assigned based on care needs; if not palliative, seems more complicated (not enough collaboration/communication between service providers)</td>
</tr>
<tr>
<td></td>
<td>palliative specialist involvement when necessary</td>
<td>▼ Palliative health care professionals consulted often within hospital but perhaps too much e.g. some basic palliative care could be attempted by other health professionals before consult requested</td>
</tr>
<tr>
<td>Criteria</td>
<td>Description</td>
<td>3. Interviews with palliative care professionals working within Vancouver Coastal Health</td>
</tr>
<tr>
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<td><strong>Psychosocial, Spiritual and Bereavement Support</strong></td>
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Appendix H. Detailed Case Study Analysis of Case #1: Vancouver Coastal Health

**Adequate Preparation and Advance Care Planning:** Health care services currently exist within Vancouver Coastal Health to assist elderly patients and families in preparing for end-of-life, as well as determining whether a home death is a reasonable option. Home and Community Care offers a number of supports, such as home care nurses experienced in palliative care who can conduct assessments and provide education and counselling services to elderly clients (VCH, 2013d). In addition, case managers are available to help families coordinate services based on their needs (VCH, 2013a). However, these services are restricted to those meeting certain eligibility criteria relating to citizenship, residency, and care needs (VCH, 2013c); some elderly patients may therefore be at risk of not receiving adequate support for their life-limiting conditions.

Discussions about end-of-life are challenging, even for health care professionals working in palliative care. Families and elderly patients require that care providers be comfortable to discuss options for treatment and palliation, as well as exhibit greater sensitivity to their needs in navigating the dying experience (Tolson & Evoy, 2005). However, health care providers can lack experience to initiate these conversations – in some cases, because their understanding and training in palliation and comfort measures is inadequate (Palliative Health Care Professional, interview, 2013, December 4). Many health professionals are predisposed toward life-prolonging measures; as a result, the information they provide to elderly patients and informal caregivers may not be suitable or in-line with the patients' “goals of care.” There is a risk, therefore, that families and patients may receive advice inappropriate for their specific situation.

Palliative care is a team approach, made up of the elderly patient and the family, as well as a host of specialists and health care providers. As such, older patients and informal caregivers may be required to interact with numerous individuals providing care; this can become overwhelming for families in situations where high levels of care are necessary. Increased focused on service coordination through a newly created palliative/end-of-life/hospice coordinator role has been considered to assist elderly patients and
families in navigating the complexities of the health care system (Tolson & Evoy, 2005). It is also important, however, to recognize that “the front line people really are the home care nurse and the physician” (Palliative Health Care Professional, interview, 2013, December 3). Because of this, it is crucial for these individuals to have a good foundation of knowledge with respect to resources and palliative care options available.

However, while elderly patients and their families are heavily reliant on health professionals for information about palliative options, health care providers are heavily reliant on palliative professionals to provide consults to older patients. While these consults are important in deciding likely members of the care team and identifying appropriate services, it is possible that primary care providers may be unnecessarily consulting with palliative care units:

We get a lot of consults and people rely on us a lot. Sometimes it’s frustrating ’cause you feel like saying, ‘Have you given them anything for nausea yet?’ ‘Well no, I was waiting for you to come.’ ‘Well, why don’t you try and maybe with these simple things you won’t need our involvement’ …most physicians should be able to do basic palliative care: basic pain and nausea management, basic discussing end-of-life care (Palliative Health Care Professional, interview, 2013, December 3).

This apparent lack of confidence in health care professionals to address palliative issues can result in a needlessly high number of consults with palliative care teams. This can detract from the ability of palliative professionals to efficiently provide help to elderly patients and families.

Lastly, advanced care planning, while emphasized in British Columbia Ministry of Health policy documents as an area of importance, is not materializing in practice. This may be due partly to the difficulty in planning for end-of-life given unknown or unpredictable illness trajectory. However, the importance of advanced care planning is found neither in the Community Engagement Report on a Regional Palliative/End-of-Life/Hospice Care Services Strategy, nor on Vancouver Coastal Health’s Home and Community Care web pages; this indicates misalignment between government priorities and what is happening in practice. For families who have not had discussions about desired end-of-life treatment for their elderly loved ones, this can result in surprisingly
divergent views between patient and family members as to whether a home death is possible, creating stress and tension between family members:

There’s two ways it can go. One is the patient doesn’t want to go home and the family wants to take them home but the patient feels safer [in the palliative care unit]…or the other is the patient wants to go home but the family doesn’t think they can manage…it gets awful if the family doesn’t want to do it, if the family’s nervous and the patient wants to be at home (Palliative Health Care Professional, interview, 2013, December 3).

While a greater focus within the formal health care system to encourage these discussions is therefore needed, it may also be worthwhile to consider how to build greater awareness amongst the general public around the importance and gravity of end-of-life planning.

**Effective Pain and Symptom Management:** For seniors at end-of-life who desire a home death, one crucial element of success is proper pain and symptom management. In discharge planning, it is common for nurses to provide guidance to informal caregivers in how to administer medications and other kinds of treatment. Adult Day Services through Vancouver Coastal Health’s Home and Community Care program can also help with administering medications, albeit a fee-based service which older patients and/or families would have to pay for.

Managing pain, however, can be complicated. The responsibility to make care decisions in the home falls to family caregivers and, in cases where this burden becomes too great or emotionally trying, there is a significant risk that a desired home death may not occur:

If somebody is at home and being managed and their symptoms are not enough to bring them into hospital – those are the ones that usually stay at home and can die at home. If somebody’s at home [with] symptoms that are severe enough to bring them into hospital? Those are the ones that are harder to get them home and manage at home (Palliative Health Care Professional, interview, 2013, December 3).

The responsibility for making the care decisions in the home can either be a nerve-wracking or manageable experience, depending on the family caregiver’s ability to cope: “Some people really like that, they like to be in charge, and some people find it very
stressful” (Palliative Health Care Professional, interview, 2013, December 3). However, the ability for informal caregivers to manage pain and symptoms is also dependent on whether they received enough information from their professional health provider about how to make decisions and administer treatment in the home.

Finally, while skill-based and emotional challenges are inherent with informal caregivers attempting to provide care at home, it is possible that not enough is being done to communicate a realistic expectation of the duties involved. In some cases, a home death may not be feasible, given the personality of informal caregivers, the relationship of family members to the elderly individual at end-of-life, and the extent of responsibilities required in managing pain and symptoms. More straightforward communication of what is required to achieve a good home death for elderly patients is needed amongst all involved: patients, families, and professional health care providers.

**Provision of Psychosocial, Spiritual and Bereavement Support:** With regards to psychosocial, spiritual and bereavement support, responses to family members’ needs for coping are often reactive versus proactive. For example, while social workers are highly skilled in helping informal caregivers with their emotional needs, this generally happens only after elderly patients have been admitted when their caregivers can no longer manage. Unfortunately, this approach has done little to mitigate caregiver burnout. When elderly patients who were once at home end up back in hospital, “it could be sudden decline, worsening of symptoms, but it’s most often caregiver distress…[self-care] is something that doesn’t happen” (Palliative Health Care Professional, interview, 2013, December 4).

Palliative volunteers are a valuable source of support for elderly patients and family members, and currently undergo intensive training in providing bereavement and follow-up services with informal caregivers; however, the scope of assistance which volunteers can provide is currently limited. Volunteers with the Vancouver Hospice Society, for example, “do not really help with tasks but simply visit for companionship…talking, reading, sitting quietly” (N. Bird, e-mail message to author, 2013, December 9). Vancouver Coastal Health has considered building volunteer capacity to further support families through increased respite services, emotional
support, and in-home care but there is no evidence within the data to suggest significant advancement in this strategy.

Although palliative care units comprise a host of different specialties, dedicated counselling services are absent. Home care palliative nurses are available to help provide counselling, although the extent and availability of these services is subject to client eligibility requirements. As well, palliative care providers in acute settings provide some measure of individual counselling, but this is limited to their interaction with patients “in the moment” rather than on an ongoing basis. In cases where a family member or elderly patient may desire formal counselling, they would have to pay for this service out of pocket. Support groups are available through organizations such as the Alzheimer’s Society and BC Cancer Agency; however, informal caregiving for elderly patients goes beyond cognitive impairment or cancer, and those caring for seniors without these conditions remain at a loss for formal counselling. It is also important to recognize that support groups may be helpful, but are not for everyone: “people who are hard-wired for stress don’t want that [help or support]...because they’re very independent and they’re going to do it all themselves and so, they never shared a thing in their life” (Palliative Health Care Professional, interview, 2013, December 4).

Lastly, none of the data makes significant mention of spiritual services, indicating that this, too, may be a reactive response to elderly patients’ or informal caregivers’ needs for spiritual support. Limited programming and irregular checks with informal caregivers mean that elderly patients and their families are largely left on their own to find means of psychosocial, spiritual and bereavement support.

**Support for Informal Caregivers:** Support for informal caregivers can be in the form of respite services, home support for personal care and household needs, as well as around the clock in-home care when death of an elderly patient is imminent. The analysis of Vancouver Coastal Health reveals that respite services for informal caregivers and home support are highly variable. Home support is provided by Vancouver Coastal Health, based on need; the degree of support provided to families and elderly patients in the home is determined by a community health nurse and is subject to the availability of home nursing supports at any given time. Currently, the maximum allotment for home support is four hours a day or 28 hours per week. Given
that many elderly patients require constant care and the competing demands of informal caregivers, such as work, children or other responsibilities besides caregiving, formal palliative care workers cite this allowance as inadequate (Palliative Health Care Professionals, interviews, 2013, December 3 and 19).

For those ineligible to receive home support provided by Vancouver Coastal Health, nursing assistance through private agencies is available but is costly. Private nursing can cost up to $10,000 per month for 24-hour, registered nursing care, although costs vary depending on the qualifications of the care professional – whether that individual is a care aide, live-in housekeeper, licensed practical nurse, or registered nurse. However, private nursing agencies do not assign single care workers to individual families; whoever is assigned to provide care one day may be completely different the next. This changeability in health care workers can be stressful on elderly patients and their families, as this inhibits formulation of trust, routine, and expectations around consistency of care. Private health care workers are also hampered in their ability to learn the family situation and create a sense of comfort for the person to whom they are providing care. All of this contributes to what is already an overwhelming situation, and does little to abate anxiety amongst elderly patients at end-of-life and their families.

**Sufficient Financial Support:** Financial support to informal caregivers and seniors at end-of-life is extremely limited. The BC Palliative Care Benefits Program covers medications and equipment focused on palliation; this is appropriate given that elderly patients qualify only when their trajectory is six months or less, and when treatment is aimed at comfort versus prolongation of life. However, this suggests that there is agreement on goals of care amongst all involved: the elderly patient, family members, and the palliative care team. This can be challenging when disparate views exist around desired end-of-life treatment. In order to be eligible for this program, elderly patients must also sign a Do Not Resuscitate (DNR) order; for personal philosophical, cultural or religious reasons, some patients and families may not want to agree to this, as many believe interventions should be taken right up until death. However, without the DNR form and agreement for strictly palliative measures, older patients at end-of-life are excluded from receiving any benefits under this program.
The Employment Insurance (EI) Compassionate Care Benefit (CCB) provides up to six weeks of EI benefits to a family caregiver. However, it is restrictive in the sense that the individual must be employed and therefore eligible to receive employment insurance. In addition, the family caregiver applying for CCB must show that their regular weekly earnings from work have significantly decreased before they can receive any financial assistance. While the program does allow for more than one family caregiver per patient to apply for benefits, the six-week period of coverage is an absolute and cannot be extended. This can be challenging, given that end-of-life trajectory is largely a well-informed guess; if the elderly individual at end-of-life requires care beyond the six-week period, informal caregivers will not be eligible for any more coverage under this program.

Lastly, the data analysis showed that equipment is available to elderly patients for free or rent from the Canadian Red Cross Society; this can help informal caregivers manage end-of-life care at home without causing undue financial strain. However, availability is subject to restrictions – for example, patients able to get out of bed on their own do not qualify for hospital beds, even though having a hospital bed in the home can make it easier for family members to provide care. This can be limiting for families who feel they could manage more easily with certain types of equipment, but who cannot access those pieces due to eligibility constraints.
### Appendix I. Case Study Analysis Word Tables for Case #2: Providence Health Care

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
<th>RATING SUMMARY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparation and Advance Care Planning</td>
<td>care providers begin the process of preparing the patient and family for the end of life and the decisions they will need to make along the way providing families and individuals with information referring to available services deciding on likely members of care team identifying roles of patient and family members determining means of communication and coordination of services provide info and resources to support ACP (understanding of options, providing instructions for treatment, choices for end-of-life care)</td>
<td>1. Document on Palliative Care at St. Paul’s Hospital 2. Website text on End-of-Life Care 3. Interviews with palliative care professionals</td>
</tr>
<tr>
<td>Pain and Symptom Management</td>
<td>providing pain and symptom management to patient primary care providers consult with specialist clinicians palliative specialist involvement when necessary provision of these services by community groups clarity of roles regular communication</td>
<td>1. Document on Palliative Care at St. Paul’s Hospital 2. Website text on End-of-Life Care 3. Interviews with palliative care professionals</td>
</tr>
<tr>
<td>Psychosocial, Spiritual and Bereavement Support</td>
<td>provision of these services by community groups clarity of roles regular communication</td>
<td>1. Document on Palliative Care at St. Paul’s Hospital 2. Website text on End-of-Life Care 3. Interviews with palliative care professionals</td>
</tr>
<tr>
<td>Criteria</td>
<td>Description</td>
<td>RATING SUMMARY</td>
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<td>----------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
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<tr>
<td></td>
<td></td>
<td>1. Document on Palliative Care at St. Paul’s Hospital</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>sensitivity and responsiveness to patient and family members' needs for coping</td>
<td>•</td>
</tr>
<tr>
<td>Support for Informal Caregivers</td>
<td>access to (flexibility of) respite services</td>
<td>•</td>
</tr>
<tr>
<td></td>
<td>access to home support for personal care and household needs</td>
<td>•</td>
</tr>
<tr>
<td></td>
<td>around the clock care in near-death stage</td>
<td>•</td>
</tr>
<tr>
<td>Financial Support</td>
<td>health team assists with BC Palliative Care Benefits Program enrolment</td>
<td>•</td>
</tr>
<tr>
<td></td>
<td>access to program is equitable (availability of medications)</td>
<td>•</td>
</tr>
</tbody>
</table>

**Legend**
- Fully meets criterion
- Partially meets criterion
- Does not meet criterion
<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
<th>Rating</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparation and Advance Care Planning</td>
<td>care providers begin the process of preparing the patient and family for the end of life and the decisions they will need to make along the way</td>
<td>✗★</td>
<td>End of life care not specifically mentioned</td>
</tr>
<tr>
<td></td>
<td>providing families and individuals with information</td>
<td>✫</td>
<td>Explains what is palliative care, the goals of palliative care (e.g. symptom management) and where it can be provided; provides a checklist of what information and forms patients/families should take home with them</td>
</tr>
<tr>
<td></td>
<td>referring to available services</td>
<td>✫</td>
<td>Describes that homebound palliative patients will be connected with community services, home care nursing, community palliative care services, family doctor; describes other informational pamphlets that are available; non-staff practitioners (forms and instructions available)</td>
</tr>
<tr>
<td></td>
<td>deciding on likely members of care team</td>
<td>✫</td>
<td>Describes options for leaving hospital (e.g. home, hospice, residential care facility) and discussion with doctors, nurses, social worker</td>
</tr>
<tr>
<td></td>
<td>identifying roles of patient and family members</td>
<td>✫</td>
<td>Brief description of family meeting, identifying goals of care, plans for discharge from hospital; specifically requests for one family contact to be designated</td>
</tr>
<tr>
<td></td>
<td>determining means of communication and coordination of services</td>
<td>✫</td>
<td>Identifies family meeting, care team of doctors, nurses, social worker and other services which patient should be connected to if going home; encourages patients to ask questions about their care and for clarification; advises that interpreters are available for those who speak another language or use sign language</td>
</tr>
<tr>
<td></td>
<td>provide info and resources to support ACP (understanding of options, providing instructions for treatment, choices for end-of-life care)</td>
<td>✫★</td>
<td>Mentions ‘Care Plan’ as a written plan of the patient’s needs and wishes, but only generally and not in any detail</td>
</tr>
<tr>
<td>Criteria</td>
<td>Description</td>
<td>1. Document on Palliative Care at St. Paul’s Hospital</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Rating</td>
<td>Explanation</td>
</tr>
<tr>
<td>Pain and Symptom Management</td>
<td>providing pain and symptom management to patient</td>
<td>●</td>
<td>Identifies goal to ‘relieve your pain and other uncomfortable symptoms’ but does not go into any details</td>
</tr>
<tr>
<td></td>
<td>primary care providers consult with specialist clinicians</td>
<td>●</td>
<td>Describes that homebound palliative patients will be connected with community services, home care nursing, community palliative care services, family doctor; describes other informational pamphlets that are available; non-staff practitioners (forms and instructions available)</td>
</tr>
<tr>
<td></td>
<td>palliative specialist involvement when necessary</td>
<td>●</td>
<td>As above</td>
</tr>
<tr>
<td>Psychosocial, Spiritual and Bereavement Support</td>
<td>provision of these services by community groups</td>
<td>●</td>
<td>Mentions referrals to community services, in general</td>
</tr>
<tr>
<td></td>
<td>clarity of roles</td>
<td>●</td>
<td>Describes access to pastoral (spiritual) care worker while in Palliative Care Unit (PCU)</td>
</tr>
<tr>
<td></td>
<td>regular communication</td>
<td>●</td>
<td>Not mentioned</td>
</tr>
<tr>
<td></td>
<td>sensitivity and responsiveness to patient and family members’ needs for coping</td>
<td>●</td>
<td>Identifies goal to ‘attend to the needs of your body, mind and spirit’ and ‘give support to both you and your family’</td>
</tr>
<tr>
<td>Support for Informal Caregivers</td>
<td>access to (flexibility of) respite services</td>
<td>●</td>
<td>Not mentioned</td>
</tr>
<tr>
<td></td>
<td>access to home support for personal care and household needs</td>
<td>●</td>
<td>Describes referral to Home Care Services and help with going home: home care nurse visit, occupational therapist to assess equipment, social worker to discuss financial issues, pharmacists to review medication, respiratory therapists for oxygen needs</td>
</tr>
<tr>
<td></td>
<td>around the clock care in near-death stage</td>
<td>●</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>Criteria</td>
<td>Description</td>
<td>1. Document on Palliative Care at St. Paul's Hospital</td>
<td></td>
</tr>
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<td>-------------------------</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Rating</td>
<td>Explanation</td>
</tr>
<tr>
<td>Financial Support</td>
<td>health team assists with BC Palliative Care Benefits Program enrolment</td>
<td>●</td>
<td>Describes the program and encourages patients to complete the form before leaving hospital, as well as DNR form (but calls it the 'Provincial No Cardiopulmonary Resuscitation' form)</td>
</tr>
<tr>
<td></td>
<td>access to program is equitable (availability of medications)</td>
<td>●</td>
<td>Indicates what program covers, including equipment, most medications and extra home support worker hours but does not specify eligibility other than trajectory of six months and DNR (but mentions DNR separately from program form)</td>
</tr>
</tbody>
</table>

**Legend**

- Fully meets criterion
- Partially meets criterion
- Does not meet criterion
<table>
<thead>
<tr>
<th>Criteria</th>
<th>Description</th>
<th>2. Website text on End-of-Life Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparation and Advance Care Planning</td>
<td>care providers begin the process of preparing the patient and family for the end of life and the decisions they will need to make along the way</td>
<td>Palliative Care Outreach Team (POCT) available to assist 'in situations with difficult to manage symptoms, tough decisions and deciding about best treatments'and 'support each person and family in distress about the illness'; describes goals to identify goals of care</td>
</tr>
<tr>
<td></td>
<td>providing families and individuals with information</td>
<td>Describes what palliative care is and goals of palliative care</td>
</tr>
<tr>
<td></td>
<td>referring to available services</td>
<td>Describes Palliative Care Outreach Team (POCT) involvement</td>
</tr>
<tr>
<td></td>
<td>deciding on likely members of care team</td>
<td>Not mentioned</td>
</tr>
<tr>
<td></td>
<td>identifying roles of patient and family members</td>
<td>Not mentioned</td>
</tr>
<tr>
<td></td>
<td>determining means of communication and coordination of services</td>
<td>Not mentioned</td>
</tr>
<tr>
<td></td>
<td>provide info and resources to support ACP</td>
<td>Encourages patients to keep track of their own symptoms over time and discuss concerns with family; refers to Canadian Virtual Hospice for more info on ACP; goals include having discussions on what is important to person and family, and future care planning</td>
</tr>
<tr>
<td>Pain and Symptom Management</td>
<td>providing pain and symptom management to patient</td>
<td>Describes this as one goal of palliative care</td>
</tr>
<tr>
<td></td>
<td>primary care providers consult with specialist clinicians</td>
<td>Describes team approach to chronic illness and treatment</td>
</tr>
<tr>
<td></td>
<td>palliative specialist involvement when necessary</td>
<td>Encourages patients to discuss palliative care with their health care providers; willingness to involve the Palliative Care Outreach Team (POCT) to assist</td>
</tr>
<tr>
<td>Psychosocial, Spiritual and Bereavement Support</td>
<td>provision of these services by community groups</td>
<td>Not mentioned</td>
</tr>
<tr>
<td></td>
<td>clarity of roles</td>
<td>Not mentioned</td>
</tr>
<tr>
<td></td>
<td>regular communication</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>Criteria</td>
<td>Description</td>
<td>Rating</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>2. Website text on End-of-Life Care</td>
<td>sensitivity and responsiveness to patient and family members' needs for coping</td>
<td>✔</td>
</tr>
<tr>
<td>Support for Informal Caregivers</td>
<td>access to (flexibility of) respite services</td>
<td>✔</td>
</tr>
<tr>
<td></td>
<td>access to home support for personal care and household needs</td>
<td>✔</td>
</tr>
<tr>
<td></td>
<td>around the clock care in near-death stage</td>
<td>✔</td>
</tr>
<tr>
<td>Financial Support</td>
<td>health team assists with BC Palliative Care Benefits Program enrolment</td>
<td>✔</td>
</tr>
<tr>
<td></td>
<td>access to program is equitable (availability of medications)</td>
<td>✔</td>
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<th>Criteria</th>
<th>Description</th>
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<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preparation and Advance Care Planning</td>
<td>care providers begin the process of preparing the patient and family for the end of life and the decisions they will need to make along the way</td>
<td></td>
<td>Consult teams discuss what is needed and what resources are/are not available if going home but even more needed to ensure families have realistic expectations (GPs, acute care, palliative units, etc.)</td>
</tr>
<tr>
<td></td>
<td>providing families and individuals with information</td>
<td></td>
<td>As above</td>
</tr>
<tr>
<td></td>
<td>referring to available services</td>
<td></td>
<td>Assessments are conducted by palliative consult nurses to determine what services are needed; nurses help to make connections with health service providers</td>
</tr>
<tr>
<td></td>
<td>deciding on likely members of care team</td>
<td></td>
<td>As above</td>
</tr>
<tr>
<td></td>
<td>identifying roles of patient and family members</td>
<td></td>
<td>Family meetings could occur more often to help identify goals of care</td>
</tr>
<tr>
<td></td>
<td>determining means of communication and coordination of services</td>
<td></td>
<td>Acute palliative care connects patients/families with proper services</td>
</tr>
<tr>
<td></td>
<td>provide info and resources to support ACP (understanding of options, providing instructions for treatment, choices for end-of-life care)</td>
<td></td>
<td>This happens but goals of care can change and may need to be re-evaluated, which can be complex/complicated</td>
</tr>
<tr>
<td>Pain and Symptom Management</td>
<td>providing pain and symptom management to patient</td>
<td></td>
<td>Consults may result in suggestions for symptom management going to physicians; may be inadequate if health care provider inexperienced or does not properly explain to patient/family; educating family members on pain and symptom management is minimal</td>
</tr>
<tr>
<td></td>
<td>primary care providers consult with specialist clinicians</td>
<td></td>
<td>Consults may result in connecting patients/families with medical units, transitional services e.g. connecting to home care and community nursing</td>
</tr>
<tr>
<td></td>
<td>palliative specialist involvement when necessary</td>
<td></td>
<td>Non-palliative care providers may lack expertise, experience in when to involve palliative care; are reliant on palliative specialist expertise</td>
</tr>
<tr>
<td>Criteria</td>
<td>Description</td>
<td>Rating</td>
<td>Explanation</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Psychosocial, Spiritual and Bereavement Support</td>
<td>provision of these services by community groups</td>
<td>●</td>
<td>Home Hospice through VCH can be called in to assist with counselling, paperwork, financial needs and includes doctors, nurses, social workers, pastoral care workers (very limited staff/resource) and social worker doing assessment needs to clear service with family and patient; hospice volunteers also available for peer counselling for end of life; bereavement support available; lack of counselling services</td>
</tr>
<tr>
<td>clarity of roles</td>
<td></td>
<td>●</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>sensitivity and responsiveness to patient and family members' needs for coping</td>
<td></td>
<td>●</td>
<td>Health care workers responsible for teasing out how well family is coping but often does not happen (high caseloads, predisposition to get patients out of wards quickly)</td>
</tr>
<tr>
<td>Support for Informal Caregivers</td>
<td>access to (flexibility of) respite services</td>
<td>●</td>
<td>Caregivers encouraged to use respite (can be reactive versus proactive)</td>
</tr>
<tr>
<td>access to home support for personal care and household needs</td>
<td></td>
<td>●</td>
<td>Lack of supports in community; things often do not go well at support due to not enough or no supports; health care providers need to be able to elicit what is going well/not well at home from family members (learned skill); community nurses not always palliative nurses</td>
</tr>
<tr>
<td>around the clock care in near-death stage</td>
<td></td>
<td>●</td>
<td>24-hour nursing at end-of-life not always available</td>
</tr>
<tr>
<td>Financial Support</td>
<td>health team assists with BC Palliative Care Benefits Program enrolment</td>
<td>●</td>
<td>Willingness to discuss/help complete BC Palliative and CCB forms (often social worker to actually help fill out forms)</td>
</tr>
<tr>
<td>access to program is equitable (availability of medications)</td>
<td></td>
<td>●</td>
<td>Patient prognosis is less than six months; may outlive those six months and either come off or stay on benefits (reasons for this unclear); four hours per day/28 hours per week home support allocation based on chronic needs and availability of resources</td>
</tr>
</tbody>
</table>

**Legend**

- Fully meets criterion 🔵
- Partially meets criterion 🔴
- Does not meet criterion 🔴
Appendix J  
Detailed Case Study Analysis of Case #2: Providence Health Care

**Adequate Preparation and Advance Care Planning:** Through patient consults conducted by the palliative care team within Providence Health Care, health care professionals are providing families and elderly individuals with information to help them prepare for end-of-life and whether a home death is possible for the patient. These assessments also serve to connect elderly patients with care providers and different resources, depending on what is needed. For example, one palliative care provider explains:

In my consult I say things like, ‘Get connected with physiotherapy and occupational therapy before they go home to assess what their needs are...home care nursing, home care supports.’ Are they appropriate for BC Palliative Benefits? Do they need home hospice volunteers? I try to get this set up before they ever go home (Palliative Health Care Professional, interview, 2013, December 16).

In addition, the *Palliative Care at St. Paul’s Hospital* document provides a good overview of the PCU, what each specialist is responsible for, and the types of information patients and families should take with them when leaving PCU for home, hospice or residential care. Through information available in this document and online, patients are also encouraged to ask questions in their interactions with health professionals about their care to ensure clarity around what happens after being discharged from the hospital. Patients can read information about how to monitor their symptoms and involve others in discussion around palliative care planning: “If you have concerns about the future let your chronic disease team know that you wish to discuss this. It is also good to discuss these concerns with your family and those you trust to speak for you if you should become too sick to speak for yourself” (PHC, 2013a).

In practice, however, this level of detail and information can be inconsistent both inside and outside of the PCU. Depending with which care team patients and families may be interacting, they may not be receiving the best or most accurate information; this can be the result of dealing with health care providers inexperienced in palliative care.
I think it’s the nature of where we work in acute care with the rapid turnover of residents and nurses...people just change over so fast....there are some people who definitely know what to do, like a lot of the social workers...but the teams, as a general rule...they know the paperwork, but they just want somebody from Palliative Care to come in. It’s almost like they need us to bless it (Palliative Health Care Professional, interview, 2013, December 16).

While palliative specialists may run the risk of being over-consulted, the rigour in patient decisions made outside of PCU may be lacking without this palliative consult. This can result in elderly patients or families receiving inadequate information about the experience of home death: “Sometimes we actually do go and stop other teams from sending people home because they think they’re ready to go and we think, ‘What? They’re just going to bounce back here because they don’t have any supports’” (Palliative Health Care Professional, interview, 2013, December 16).

Compounding this experience is a tendency for family meetings not taking place as often they should – typically only when complex family dynamics are involved: “Sometimes we [the palliative care team] get called in to help clarify goals of care and it’s like, ‘Well, have you sat down? Have you actually had a family meeting?’ And that often has not ever happened” (Palliative Health Care Professional, interview, 2013, December 16). More regular family meetings can help to define goals of care, clarifying for elderly patients, informal caregivers, and all members of the palliative care team what treatments are possible moving forward:

I think if you had family meetings for everybody – holy smokes! What an interesting difference that would make. If you had a family meeting within the first say, 72 hours that you’re here, or at least the first week, you would figure out what people’s goals are, how they’re struggling, what the future might look like, what’s important to the patient and family...those issues which are so central to making a plan for the future (Palliative Health Care Professional, interview, 2013, December 16).

With respect to end-of-life planning, there was very little to no direction on advance care directives found in the written data. However, palliative health care experts within Providence Health Care stressed the importance for families and health providers to have these discussions, likening the planning process to one as important as that of expectant mothers:
I like to try and introduce to people that our society today encourages and supports adults once they find out...that they’re pregnant. They encourage...healthy maternal health, healthy mom-baby health...in society we frown on those who don’t prepare for...this new life, by the right choices [and other preparations]...it’s quite the reverse when we know that we have somebody who is coming to the end of their life...why don’t we prepare for death the same way? In my perfect world, we embrace both [palliative care and maternity care] with the same energy (Palliative Health Care Professional, interview, 2013, December 17).

Death doesn’t happen quickly. We live longer. We live with a lot of co-morbidities in the last few years of life. A lot of people don’t make choices for end-of-life care. They don’t talk about it. There’s not very much ease within families, of all sorts, to talk about how you envision yourself. Unlike birthing, where people plan, and have midwives, and get lots of information...when it comes to dying we don’t do that (Palliative Health Care Professional, interview, 2014, January 28).

There was acknowledgement, however, that planning for end-of-life can be a difficult process, beyond the discussion of care goals. A more realistic view is needed around whether dying at home is possible, given family circumstances and the elderly patient’s conditions: “Lots of different factors influence the experience of death at home. I think we need to divorce ourselves from a romanticized version of death at home. Death at home is good when it can be done, not good when it can’t be done” (Palliative Health Care Professional, interview, 2014, January 28).

Overall, while planning for end-of-life is an important step, it is not consistently being done. This is due to hesitancy by families to discuss death and dying, but also because professional health care providers are not acting in a coordinated enough manner to ensure these conversations take place.

**Effective Pain and Symptom Management:** Reducing pain, controlling symptoms and helping to maximize the quality of elderly patients’ lives are all goals of Providence Health Care’s end-of-life and palliative care delivery (PHC, 2013a). While PCU professionals may suggest pain and symptom treatment for elderly patients being taken care of by other hospital units, there is a risk of treatments being unavailable where inexperienced health care providers are involved: “So many times the symptom management isn’t there because [the health care provider outside of PCU] is
afraid...they don’t even order them sometimes, what is appropriate” (Palliative Health Care Professional, interview, 2013, December 16).

As well, pain and symptom management is one of the most difficult things for family members to do at home for an elderly loved one:

I think we have that expectation that we all can do the same thing...I, as your caregiver, should be able to give it [medication] to you. And certainly there are a group of people that will say, ‘I can do that. Just teach me how to do it and I can do that.’ And there are other people that will be terrified. We have nurses that don’t want to give the opioids for comfort because they’re afraid they’re going to kill them [patients]. So how do we have the expectation that a family member should be okay with that (Palliative Health Care Professional, interview, 2013, December 16)?

Informal caregivers receive only minimal instruction on how to administer medications for pain, and limited education around what to do if their elderly loved one experiences shortness of breath or other symptoms at home. This can exacerbate stress amongst family caregivers and increase the risk of a return to hospital for greater levels of professional palliative assistance.

**Provision of Psychosocial, Spiritual and Bereavement Support:** Psychosocial, spiritual and bereavement supports for informal caregivers and elderly patients at end-of-life is critically lacking within Providence Health Care. Information available through the palliative care document and website highlights these services very minimally, if at all. It can be argued that all health care workers – whether family physicians, or those from palliative care, emergency, intensive care, or other medical units in hospital – are responsible for teasing out how well informal caregivers are coping, yet this often does not happen due to high caseloads, and a predisposition for many doctors to quickly discharge patients out of their wards, given limited beds and high numbers of patients.

Informal caregivers and elderly patients at end-of-life do receive emotional support in hospital, but in reactive versus proactive ways. Patients and families may interact with social workers who are very experienced and sensitive to the needs of those with whom they encounter; however, meeting with a social worker typically only happens in cases of complex family dynamics or where discharge planning is
complicated. Further, psychosocial support and counselling is generally unavailable after elderly patients and informal caregivers leave the hospital, despite the recognition that greater levels of emotional support are needed throughout the elderly patient’s life-limiting illness:

There’s this idea of anticipatory grief. Loss is one of the most difficult things we deal with as human beings…and the loss doesn’t just happen at the death. This is, my mother can’t eat anymore, my mother can’t walk anymore, she can’t talk to me anymore. It’s all along the way. All of those things are quite psychologically burdensome (Palliative Health Care Professional, interview, 2013, December 19).

Greater availability of professional counselling can therefore be helpful to those who may need this type of support.

**Support for Informal Caregivers:** Access to respite services, home support and around the clock care in near-death stages are all lacking. Again, determining whether informal caregivers are coping well or need more help is ultimately the responsibility of professional health care providers. However, inexperience in or lack of sensitivity around palliative treatment can lead to cases where a family member needs more help, but has not been identified as needing help by a health care professional:

I think if you come across as a really confident caregiver no one’s going to [question it]…I think part of the problem in acute care is get-em-in, get-em-out. Certainly, I’m not knocking the teams, but I do sometimes wonder how come that team that I work so closely with, and I know you’re all caring, compassionate people, but how did you miss this?...They let it go (Palliative Health Care Professional, interview, 2013, December 16).

Health care providers need to be able to elicit from family members whether things are not going well at home, but this is a learned skill that many do not currently have.

It is clear from the data, particularly the interviews with palliative care professionals within Providence Health Care, that more home care resources are needed. When elderly patients end up back in hospital it is often as a result of their, and/or their informal caregivers’, inability to cope at home: “Sometimes that’s just their disease progressing, but sometimes it’s because it just didn’t go well at home. They didn’t have enough supports or they had no supports” (Palliative Health Care
A prime example of this is the inconsistency of availability for 24-hour nursing when death at home is imminent. This lack of support, particularly at end-of-life, detracts from informal caregivers’ ability to care for an elderly loved one wishing to die at home.

**Sufficient Financial Support:** With respect to the BC Palliative Care Benefits Program and the Employment Insurance Compassionate Care Benefit (CCB), palliative care professionals working within Providence Health Care are generally aware of and will encourage patients to apply for these programs before leaving the hospital. However, these programs are described only briefly in the PCU document and not at all on the website for end-of-life/palliative care. While health care professionals may be attuned and willing to help patients complete these forms, eligibility is still confined to those strictly at end-of-life, which may inhibit those who need certain types of care to remain at home. One palliative care professional described a case of a patient who needed a high level of supports at home but was ineligible to receive benefits:

I can’t get her palliative supports out in the community...equipment and even just maybe the frequency of nursing and kind of supports. ‘Cause she needs BC Palliative Benefits, but she doesn’t meet the criteria. And so the family struggles and cares for these people, you know? We see so many patients here like that. I mean, it’s astounding. It’s amazing how many people are living out in the community very poorly and don’t have
supports….it would be so much better if they did (Palliative Health Care Professional, interview, 2013, December 16).
Appendix K.
Descriptions of Informal Caregiver Interview Participants

Caregiver 1 is a female widower who provided end-of-life care to her elderly husband when she was 62 years old. Because they had a revenue property and she was on the verge of retirement, she chose to give up work completely to become his at-home caregiver.

Caregiver 2 is a middle-aged woman who is married with children. She and her brother made the care decisions for their two parents who both fell ill at the same time, in their late 80s – he with congestive heart failure and type 2 diabetes and she with early onset Alzheimer’s.

Caregiver 3 is also a middle-aged woman with a husband and children. Her elderly mother had a cognitive impairment and needed increasing amounts of care over time. Living in the same home in a separate apartment on the ground floor, the informal caregiver and her husband chose to continue work and hired full-time, live-in support.

Caregiver 4 is a male widower who chose to give up work to care for his wife after she was diagnosed with cancer. She received, in his opinion, severely inadequate cancer treatment. She experienced a home death, surrounded by her husband and friends.
Appendix L. Detailed Policy Options

Increase the availability and extent of publicly funded formal home support

Both professional palliative health workers and informal caregivers disclosed that the current levels of home care provided by the local health area are insufficient and not comprehensive. The allowance of home support each family receives is subject to an assessment of care needs; however, the current maximum allotment of four hours a day or 28 hours per week can be unsatisfactory for many elderly patients needing high levels of care. An increased allowance for in-home personal care and to help with household needs can help to ensure informal caregivers can better manage with elderly, end-of-life patients in the home; this can serve to mitigate safety issues with regards to pain and symptom management, minimize caregiver burden, particularly in later stages of patient illness, and create greater opportunities for proactive caregiver respite. As well, it is worthwhile to consider expanding the extent of professional home care to areas such as emergency or crisis response, or bespoke treatment based on specific illnesses and required treatment.

However, increasing the availability of publicly funded home support, as well as expanding home support services, is expected to be costly; high hours of publicly funded home support, a greater range of in-home treatment options, and more visits in the home by family physicians will all contribute to these increased costs. Further, greater levels of administration are required in assigning home care workers to families and older patients. As well, mitigation measures would need to be determined to ensure home care supports are not abused or overused. For example, 28 hours maximum per week may be inadequate for some patients and families, but mechanisms will need to be considered to ensure that individuals are receiving only the levels of home care they need.

Provide a single point of contact for elderly end-of-life patients and their families

Because a palliative care team can comprise many medical professionals, informal caregivers are often left to connect with various specialists and departments, and coordinate appointments for their elderly loved one based on treatment plans and
goals of care. Often, informal caregivers are also responsible for acting as the advocate for their elderly family members: knowing the medications, negotiating home care, and speaking up for the patient’s desired end-of-life treatment. A single point of contact for elderly, end-of-life patients would assist families in this advocacy role by helping them navigate the health care system, complete applications for social programs such as the BC Palliative Care Benefits and federal Compassionate Care Benefit programs, and obtain necessary equipment for the home.

In order to recommend appropriate supports for which the elderly patient and family may be eligible, this single point of contact would need to be well-informed of palliative programs available from the local health area and supports available in the community, and would also require expertise and proficiency in negotiating palliative care and resources. As well, this individual would be required to have excellent social and interpersonal skills, as he or she would need to be sensitive to older patients’ and families’ needs, responding to the family’s situation based on a thorough and personal understanding of their needs. For these reasons, continuing professional development for these health professionals is vital in ensuring ongoing standards of care (Brown et al., 2002). From the research findings, social workers emerged as a key support system, highly trained in these areas; however, existing staff are already challenged in managing high caseloads. Therefore, additional hiring or creation of a completely new role would need to be considered in putting this option into practice.

Increase frequency and reach of family meetings

In the research findings, informal caregivers and elderly palliative patients cited insensitivity and unresponsiveness of professional care providers to emotional needs as a challenge. Palliative health care experts also revealed that health providers, in particular, some family physicians, as well as those from other medical units in hospital, can be over reliant on their expertise. Additionally, government policy has been focused on the information needs of health care professionals; perhaps, this was in recognition of a greater need for training and experience in palliation for professional health providers.

To build capacity and understanding around palliative treatment and services, family meetings with the broader palliative care team are proposed – not just in cases of complex family dynamics or discharge, but for all elderly patients arriving in hospital
within 72 hours of their arrival, or elderly patients and/or families who have requested more information about palliative care. As suggested by some palliative care professionals, scheduling family meetings in this manner would serve to:

- Clarify goals of care and ensure entire team has a singular understanding of elderly patients’ end-of-life wishes;
- Determine how well the family is coping, if at all;
- Streamline care plans by mitigating miscommunication about what treatments are and are not possible; and
- Build capacity and understanding of palliative care and palliation measures across different hospital teams and amongst various health care professionals.

In so doing, this can also help to inform next steps in treatment and clarify what home services are needed by the family upon discharge.

However, because these meetings are meant to involve elderly patients, family members, and all relevant health care providers, coordinating these schedules is expected to be extremely challenging, given busy schedules of many professional health care providers. It may be necessary, therefore, to create a specific scheduling system or consider conducting meetings via teleconference or internet, versus attempting to meet only in person.

Create local, community-based services and support networks

Many informal caregivers indicated a need for more help with tasks like transporting elderly family members to and from appointments, making care decisions, and accessing counselling, respite and emotional support. Local, community-based support and care networks for older patients and their families can comprise a number of resources: a shuttle service for appointments, companionship, assisting in the home to allow family caregivers to take a break from their duties, even counselling. Expanded support networks in the community could emulate current best practices of hospice volunteers, or existing organizations known for providing first-class support to elderly patients at end-of-life and their families – but the primary attribute is that the creation of resources and services would be left to those within the community based on their specific needs.
In order to implement this policy, interprofessional meetings will need to be organized to determine certain details and logistics. For example: what agencies will be responsible? What services would they provide? What would be the extent of volunteer duties? What training needs to be provided? As well, coordination of volunteers would need to be done by a central agency, in which case, involvement of community-based organizations is required, but their resources may already be restrained. Thus, what agencies might be willing to accept this responsibility?