

Palliative Care Services Utilization and Location of Death

Barbara Cameron

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School of Nursing
Faculty of Health Sciences
University of Ottawa

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Abstract

In this study, the utilization of palliative care services, acute care services, and location of death for clients who were palliative and receiving services from Champlain Community Care Access Centre (CCAC) in Ontario during their last month of life were investigated. An adaptation of Andersen's Behavioral Model of Health Services Utilization provided context and structure to this study. This is an historical, quantitative descriptive study using chart audits for data collection. The data on CCAC clients who were palliative and who died during the month of July 2009 were tracked during their last month of life. Collection of socio-demographic data, services provided through CCAC, emergency department visits, hospital admissions, and location of death provided the data for this study. The clients who died at home used more CCAC services than those who died at other locations and frequently community palliative care physicians provided their medical care.

The findings of this study included:

- 1) The majority of the clients, who expressed a preference, died in their preferred location.
- 2) The role of community palliative care physicians was an important component of the services that supported the clients to die in their location of choice.
- 3) Over 25% of the study sample died in a hospital and the clients used a large number of in-patient hospital days with one quarter of the hospital deaths taking place in an emergency department or an intensive care unit.
- 4) During the last month of life, 25% of the clients received chemotherapy and/or radiation therapy.

5) The clients who died at home used more CCAC services than those who died in other locations and who used institutional resources.

The implications for practice, policy, research, and education are discussed.

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Chapter One: Introduction

There is little known about the use of Community Care Access Centre (CCAC) services for clients who are palliative and their location of death. The aim of this study was to investigate palliative care services utilization and location of death for clients of the Champlain CCAC Ottawa Palliative Program in Ontario, Canada.

Background

People who wish to live at home until they die often do not achieve this desire. The existence of palliative home care programs improves the odds of people dying at home, yet the admission of many clients who are palliative to an acute care hospital or a palliative care unit occurs in their final days. This is often contrary to their wishes (Brazil, Howell, Bedard, Krueger & Heidebrecht, 2005; Burge, Lawson & Johnston, 2003a; Constantini et al., 2003; Davies, Linklater, Jack, Clark & Moller, 2006; Heyland, Lavery, Higginson, Astin & Dolan, 2000; McWhinney, Bass & Orr, 1995; Neutel, Bishop, Harper & Gaudette, 2005).

Hospitalization for people with end stage disease may be due to a range of reasons. These include but are not limited to: an oncology emergency such as spinal cord compression, poor pain control and inadequate symptom management, inability of the caregiver to cope with the patient's care at home, lack of services in the community, inadequate funding, or a lack of health care professionals who are experienced and knowledgeable in community palliative care (Burge et al., 2003a, Lynn, 2000). These are some of the reasons for hospitalization of patients who are palliative.

In the early and mid-twentieth century, if people survived birth and infancy, they could expect their death to occur anytime over the next 60 or so years (Lunney, Lynn, Foley, Lipson & Guralnik, 2003, Lynn, 2000). Usually, the cause of death was from untreatable conditions such as infection, injury, cancer, diabetes, or heart disease (Lynn, 2000).

Beginning in the 1950's, dying in a hospital or in long term care facility (nursing home) became the norm (Davies et al., 2006; Fukui et al., 2003; Higginson, Astin & Dolan, 1998; Lynn, 2000). Senior citizens were no longer living with their extended families as their children were likely to have moved to other places for employment opportunities (Canadian Institute of Health Information, 2007). As economics changed, both men and women began to work outside the home, limiting time available to care for aging parents.

The development of scientific knowledge has grown exponentially in the past few decades and the focus of medicine has been on treatment and cure (Lynn, 2000). Today, more than ever before, the aging baby boomer generation is dying more slowly and at an older age (Canadian Hospice Palliative Care Association, 2011; Williams et al. 2010).

An article by Wilkinson and Lynn (2005) discussed the three most common ways older people die and the usual progression of the diseases:

- Death from cancer often occurs after a life of good health and usually has a steady, steep decline as death approaches.
- Death from organ failure such as heart or lung disease has a less predictable course with intermittent periods of acute episodes followed by relatively stable periods. Death is sudden during a crisis.

- After a long, progressive period of frailty and dementia, death occurs.

The kind of terminal disease and how the disease progresses influences the health care and palliative care that is required. The population that is now living longer creates a great strain on the current health care system due to these diseases that are chronic, progressive, and disabling (Teno, 2005; Williams et al., 2010). The health care community must adapt to the choices and services that are required by this burgeoning demographic that is increasing the demand for palliative care in the elderly. To provide high-quality health care consideration of individual needs is necessary and improvement of health care provision in hospitals, community settings, and long term care planning is required. As Lynn (2000) says, “good care is at least as much a question of social engineering as it is a question of patient autonomy” (p. 2509).

The growing aging population’s preference is often to remain at home for palliative care and to die at home (Brazil et al., 2005; Bruera et al., 1999; Burge, Lawson & Johnston, 2003a; Constantini et al., 2003; Davies et al., 2006; De Conno et al., 1996; Fried, van Doorn, O’Leary, Tinetti, & Drickamer, 1999; Grunfeld et al., 2004; Hansen, Tolle & Martin, 2002; Heyland et al., 2000; Higginson, Astin & Dolan, 1998; Karlsen & Addington-Hall, 1998; McWhinney et al., 1995; Neutel et al., 2005).

Management of the challenges in community palliative care provision often focuses on the problem at the local level, rather than examining the system for possible solutions. Lack of hospital beds, emergency department overcrowding, lack of community health professionals and services, and clients with life-threatening illnesses ending their final days outside of their home when this is not their preference, seem to be interconnected. To find solutions, research is necessary to

define the current use of services and resources by clients who are terminally ill. This study contributes evidence and recommendations to decision- and policy-makers for realistic plans for the growing aging and dying population.

Purpose

The purpose of this study was to investigate the utilization of palliative care services, acute care services, and location of death for clients of the CCAC receiving palliative care during their last month of life. To plan for the increasing demands on health care services, evidence of current services utilization is required. To meet the needs of future clients with life-threatening illnesses requiring palliative care, it is important to know which services and how many services are currently accessed that support clients dying in their location of choice. This information is needed specifically when planning future resource allocation for clients who are terminally ill and preferred to die in their chosen location.

Objectives

There were five objectives for this study:

1. To describe palliative home care and acute care services utilization data during the last month of life.
2. To identify the preferred location and actual location of death.
3. To determine patterns in palliative care services utilization in the last month of life.
4. To examine the relationship between quantity of palliative care services and location of death and proportion of time spent at home.
5. To make recommendations for policy and practice in palliative care services

The word quantity refers to the combination of the number of different CCAC services utilized and the number of contacts for each of the CCAC services used. A high number of services and contacts indicates a large quantity of services.

Research Questions

1. Where did the clients die?
2. Was the location of death the clients' preferred location of death?
3. Is there a relationship between the quantity of palliative care services utilization and location of death?
4. Is a greater quantity of CCAC palliative care services related to the proportion of time clients who were palliative spent at home?
5. What palliative care services were utilized during the last month of life?

Operational Definitions

Client: Client refers to an individual who is a recipient of Community Care Access Centre services.

Community Care Access Centre (CCAC): Community Care Access Centres are the local point of access to community-based health care services in Ontario. The Ontario Ministry of Health and Long-Term Care fund CCACs. Coordination of a variety of health services to maintain an individual's health, independence and quality of life was the rationale for the creation of CCACs (Ontario Association of Community Care Access Centres, 2009).

CCAC Ottawa palliative program: The palliative program consists of a team of case managers, with specialized skills to assess the needs of clients who are terminally ill and requiring palliative care and co-ordinate their services at home. The

providers of the services are employees of the agencies that the CCAC contracts to provide care.

Informal caregiver: This is someone who provides care to an individual, without financial remuneration, and who may or may not reside with him/her. The term informal caregiver is evolving and some researchers prefer the term family caregiver, unpaid caregiver or family carer. For this study, informal caregiver was chosen.

Month before death: In this study, the definition of the month before death is the five weeks before death. CCAC services are ordered on a weekly basis and since the month of July has 31 days, when counting backwards four weeks from the date of death, five weeks are involved.

Nursing visit: A home visit made to a client's home to provide nursing assessment and symptom management.

Patient: Patient refers to an individual who is a hospital patient. When an author of an article uses the term 'patient', I use 'patient' in the thesis.

Personal support worker: An unregulated (not licensed) worker with training to provide personal care for a block of time, usually one to three hours per visit.

End-of-life personal support worker: A personal support worker spends a block of time, usually 8 – 12 consecutive hours in the home of a client receiving palliative care.

Shift nursing: A block of time, usually eight consecutive hours, spent by a Registered Practical Nurse providing nursing care in a client's home.

Palliative Care Definition

The World Health Organization defines palliative care as follows:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual” (World Health Organization [WHO], 2009, ¶ 1). This definition is accepted world-wide.

The provision of palliative care in the Ottawa community is generally guided by the question, “Would you be surprised if this patient was still living in six months?” If the response is yes, the patient probably requires palliative care. Generally those working in palliative care in the Ottawa community understand the term end-of-life care to refer to care required when a patient is very close to death. Both terms, palliative care and end-of-life care, are used internationally. In some cases, facilities and/or service providers of palliative care require the patient to be near death to be eligible for admission or services. Palliative care is the term used throughout this paper unless end-of-life care is part of a name or title.

Palliative Care Research

The field of palliative care and related research, as an area of specialization, is relatively new to the health care system (Lynn, 2000). A research base in this area is in its early developmental stages compared with other specialities such as research into cardiac or respiratory disease. Replication of many palliative care studies have not occurred in other settings or with population sub-groups (Teno, 2005).

Most often palliative care research is focused on patients with metastatic cancer rather than those with, for example, cardiac or pulmonary disease (Addington-Hall & McPherson, 2001; Davies et al., 2006). This is due to our knowledge of disease progression with cancer diagnoses. As Lynn (2000) identifies non-oncological diseases have a long disease progression with exacerbations that include acute episodes with periods of stability. The patient with cardiac disease has often lived with the condition for a lengthy period. For these patients/clients death typically occurs suddenly from a complication or exacerbation while the patient with cancer follows a more consistent, predictable path. The predictability of cancer progression is one of the reasons patients with advanced cancer are identified for palliative care services and are chosen as participants in palliative care research. The majority of the CCAC clients who are receiving palliative care have a cancer diagnosis. This supports Wilkinson and Lynn's (2005) findings on the three most common ways older people die.

In a report by the Canadian Cancer Society's Steering Committee on Cancer Statistics 2011, it was identified that cancer will be the cause of death for approximately 25% of Canadians. This is an increase in the number of deaths due to cancer is related to the large and growing elderly population and the disproportionate prevalence of cancer in older people.

As palliative care research grows, governments, policy-makers, and health care providers must ensure that people who live with life-threatening diseases have access to the most appropriate palliative care available. Evidence generated by palliative care research must inform health care, service delivery, and the use of resources. This is critical when considering not only escalating costs of health care

in Canada today, but also the increasing numbers of people who will require palliative care over the next 30 years as the baby boomers age (Lynn, 2000).

Palliative Care in Canada: An Historical Review

The national context.

The Special Senate Committee on Euthanasia and Assisted Suicide recommended access to quality palliative care as a Canadian national priority in 1995. The Canadian Senate released a report in 2000 indicating the issues and recommendations in the 1995 report were still outstanding and not financially supported (Carstairs, 2000). These two reports resulted in the federal government appointing a federal Cabinet Minister whose portfolio was responsible for palliative care (Dudgeon et al., 2007). A new Secretariat on Palliative and End-of-Life Care was created within the federal Ministry of Health Canada and a federal Cabinet Minister was responsible for palliative care from 2001 to 2003 (Carstairs, 2005). Senator Sharon Carstairs was appointed the Minister with Special Responsibilities for Palliative Care in 2001. (Carstairs, 2010). The Palliative and End-of-Life Care Unit within Health Canada has since replaced the Secretariat (Health Canada, 2009). Senator Carstairs continued to promote palliative care until her retirement from the Senate in October 2011. Senator Carstairs identified what is still required to ensure quality palliative care for all Canadians in her report tabled June 2010 in the Canadian Senate. She did acknowledge great strides had been made (Carstairs, 2010).

The national strategy, developed in conjunction with the provinces, highlighted the pressing need for a national palliative care program and the development of palliative care services, among other recommendations. Dudgeon et

al. (2007), identified the need for improved home care services for clients who are terminally ill.

The Canadian Hospice Palliative Care Association.

The Canadian Hospice Palliative Care Association (CHPCA) was created in 1991 and is a non-profit charitable association with a mission to provide national leadership for hospice and palliative care in Canada (CHPCA, 2009). This mission is met through a variety of actions including: access to hospice palliative care resources, facilitating professional networking through conferences and provincial associations, funding raising activities in local communities and interest groups, development of hospice palliative care norms and standards, and report writing on hospice palliative care issues for advocacy and policy development. CHPCA has been instrumental in moving hospice palliative care forward in Canada and influencing provincial and federal governments to increase research and compassionate care funding to improve the quality of hospice palliative care.

In 2002, the CHPCA developed a *Model to Guide Hospice Palliative Care*, and this model is recognized and used worldwide in the field of palliative care (Ferris et al., 2002). The CHPCA norms, and principles of care provide the foundation for the model that has five sections:

- The underlying understanding of health and illness.
- The definition of hospice palliative care and the values, principles and foundational concepts that underlie all aspects of hospice palliative care.
- A guide to the delivery of hospice palliative care to patients and families, including a conceptual framework – the “Square of Care”.

- A guide to organizational development and function, including a conceptual framework – the “Square of Organization”.
- A guide to applying the model to all aspects of hospice palliative care.

The model integrates palliative care for the patient and family, and the functions of organizations that provide palliative care. Members of CHPCA developed the model with assistance from the 11 provincial hospice palliative care associations and many experts in the field of palliative care (Ferris et al., 2002). The CHPCA model was not appropriate for use in this study, as it does not address services utilization levels.

The province of Ontario.

The Ontario Ministry of Health and Long Term Care announced four initiatives in 1993 to improve palliative care in the community and long-term care environments. These initiatives targeted education of family physicians and other health care providers, hospice volunteer visiting services, and pain and symptom management services and did have a positive impact on palliative care, however these initiatives were not enough to address the multiple complex issues still present in the provision of care for the dying (Dudgeon et al., 2007). Some of the problems Dudgeon et al. referred to included: the high number of patients who do not die in their location of choice, geographic inequities in palliative care resources and provision, and insufficient numbers of family physicians who home visit when patients are no longer able to go to their offices.

In 2005, with national funding, the Ontario government developed three primary objectives for an End-of-Life Care Strategy (Ontario Ministry of Health and Long Term Care, 2005). Priorities were the redirection of care from acute hospital

settings to appropriate alternate settings of the client's choice, client-centred care and interdisciplinary service capacity enhancement, and improvement of access, coordination, and consistency of services and supports. Funding of \$115.5 million spread over three years. The enhancement of home care services was one of the targeted areas to meet the strategy objectives (Ontario Ministry of Health and Long Term Care, 2005). In 2005, the provincial health care system was scrutinized and redefined to address the enrichment of home care services, as well as other recommendations to improve efficiency and access to health care in Ontario.

The year 2007 was one of complete reorganization in the way health care was structured and funded by the Ontario Ministry of Health and Long Term Care. The province was divided into 14 Local Health Integration Networks (LHIN) that were responsible for the planning, coordination, and funding of health care in their regions (Champlain LHIN, 2008). Each LHIN created End-of-Life Care Networks to address local needs and concerns regarding palliative care services. The goal of these networks was to maximize resource utilization and integration of care for those with life-threatening diseases (Dudgeon et al., 2007).

The Ontario Ministry of Health and Long Term Care have implemented significant changes to the Ontario health care system. The Physician Hospital Care Committee (2006) that had representation from the Ontario Hospital Association, the Ontario Medical Association and the Ontario Ministry of Health and Long Term Care wrote a report entitled *Improving Access to Emergency Care: Addressing System Issues*. This report made recommendations to address topics of concern. Two issues identified in the report that are relevant to this study are overcrowding and long wait times in emergency departments, and the shortage of hospital beds. When

clients who are palliative are able to live and die at home with appropriate resources, the necessity to use emergency departments and limited hospital beds will be reduced (Cancer Care Ontario, 2009a).

One key issue identified in the above report addressed community health services. “In Ontario, there is a lack of capacity to comprehensively manage common chronic diseases, such as chronic obstructive pulmonary disease, congestive heart failure and type 2 diabetes, to address mental health issues, *and to provide adequate palliative care in the community setting*” (italics added) (Report of the Physician Hospital Care Committee, 2006, p. 53).

February 2009, the Ontario Ministry of Health and Long Term Care announced a new initiative that is a first for North America. It set targets for time periods that are acceptable to wait in emergency departments in Ontario hospitals. The Ministry posts online the current wait times in local emergency departments for public access. Champlain CCAC case managers, who work in emergency departments in Ottawa hospitals, noted that many of the clients coming to emergency departments are people with symptoms related to their terminal illnesses and require a great deal of time and resources and therefore increase overall wait times, (S. Bauer, personal communication, 2008).

Research to determine utilization of CCAC palliative services accessed by clients who are palliative and their caregivers will provide valuable information regarding palliative health care. The results will assist health policy-makers in their planning and decision-making role for future palliative care services and resources.

The Ontario health budget for 2010 was 46 billion dollars (Ontario Minister of Finance, 2010). This health budget represented one-third (36%) of the total 126 billion dollar 2010 budget for all of Ontario (Ontario Minister of Finance, 2010).

Another provincially funded organization, Cancer Care Ontario, recognize the need for improvement in palliative care. Cancer is the second leading cause of death in Ontario and estimated to be the cause of death of more than 25,000 Ontarians in 2006 (Cancer Care Ontario, 2009d).

How and where health dollars are spent is the responsibility of each provincial health ministry. “Understanding the factors that influence utilization is helpful in identifying reasons for differences in utilization, [...] and outcomes, and for formulating policies and programs that encourage appropriate utilization, discourage inappropriate utilization, and promote cost-effective care” (Phillips, Morrison, Andersen & Aday, 1998, p. 574). To ensure taxpayers are receiving the most effective and efficient use of health care resources, the decision-makers must know the facts on utilization of services and funds.

The regional setting.

The Ontario Ministry of Health and Long Term Care through the 14 Local Health Integration Networks (LHINs) to the 14 Community Care Access Centres (CCACs) fund home-based health services. The CCAC geographical boundaries match those of the LHINs created in 2007. The role of the LHINs is one of planning, co-ordination, dissemination of funds for hospitals, long-term care facilities, and community health services in each specific region (Champlain LHIN, 2008). The Champlain CCAC provides home health care services and covers a large

geographical area including Renfrew County, Ottawa, and the Eastern Counties (Champlain LHIN, 2008).

The CCACs provide many services to individuals at home that are available in a hospital facility. The home-based services include case management; nursing care through home visits and shift nursing; occupational, speech, and physiotherapy; nutrition counselling; personal support; medical supplies and equipment; Ontario Drug Benefit coverage; and placement in long term care facilities. The 14 CCACs in Ontario offer a palliative care program that includes case management and palliative care services to adults (over 18 years of age) in the final stages of a life-threatening illness.

The local setting.

The Champlain CCAC has three main offices, Ottawa, Cornwall, and Renfrew. The study was conducted from the records of the clients who were palliative and from the Ottawa office of the Champlain CCAC. The Ottawa site provides services to the urban and rural geographical regions of Ottawa (almost 80% rural). Of the 774,075 citizens of Ottawa, the number of residents aged 50 - 65 years old, and belonging to the 'baby boomer' generation, comprises 28% or 213,110 people (City of Ottawa, 2009).

The hospital facilities in Ottawa that provide tertiary and secondary care include The Ottawa Hospital with two in-patient sites - the General Campus and the Civic campus. There are two community hospitals, the Queensway-Carleton Hospital and the Montfort Hospital. A 36-bed palliative care unit is located in Bruyère Continuing Care (formerly Elisabeth Bruyère Health Facility). Two hospices, The Hospice at May Court and Friends of Hospice, offer volunteers, day programs and

counselling support for individuals with life-threatening illnesses and their families. The Hospice at May Court also has nine residential beds for palliative care, and Friends of Hospice is in the process of fundraising to build a residential unit. The Union Mission, along with the Inner City Health Project, provides 15 in-patient hospice palliative care beds for the homeless and is a unique hospice service for this population (Podymow, Turnbull, & Coyle, 2006).

When patients of the Ottawa Regional Cancer Centre are no longer receiving curative or palliative treatment with radiation or chemotherapy, their medical care is transferred from an oncologist to their family physicians. Because many people do not have a family physician, they do not have the opportunity to receive medical continuity of care. Therefore, as symptom management issues occur, they are likely to access an emergency department or /and be admitted to a hospital. Use of emergency departments by clients who are palliative is more difficult for them because of long wait times in emergency departments and a frequent lack of hospital beds.

A scarcity of nurses who work in the community to provide home care, and family physicians exists in Ontario and Ottawa, as reported in the local newspaper (The Ottawa Citizen, 2006a, 2006b, 2007). The shortage of health professionals means that many of the community-based nurses are young in their careers, with limited experience, and not all clients who are palliative have a family physician to support them at home with their community health team.

Ottawa is fortunate to have two physician groups whose practice is solely the provision of palliative care at home. Acceptance as a patient of either of the two community palliative care physician groups requires a referral by a physician.

Patients who do not have a family physician often ask an oncologist to make the referral to a community palliative physician, but it is often late in the disease progression. A Palliative Pain and Symptom Management Consultation Service is also available as a resource for all community health care professionals. The two palliative physician groups and the Palliative Pain and Symptom Management Consultation Service collaborate with the Ottawa CCAC palliative program that coordinates and organizes health services at home.

Chapter Two: Literature Review

Introduction

A review of the literature was conducted to identify the following areas: influences that determine where death occurs including preferred location of death, emergency department use in palliative care, and a conceptual model for palliative care services utilization.

The literature review used the following electronic databases: CINAHL, PubMed, EMBASE, and psychINFO. The search limits were English language, full text, and years 1997 to 2009 and updated to 2011. Location of death, emergency departments, palliative care, end-of-life care, hospital admissions, death, cancer deaths, home care, health services utilization, and community health were the terms used for the searches.

The Google search engine was used with the following terms: physician shortage, hospital bed shortage, nurses work survey, Ontario Ministry of Health and Long Term Care, Health Canada, Government of Canada, Ontario Association of Community Care Access Centres, Canadian Hospice Palliative Care Association, Canadian Institute of Health Information, Local Health Integration Networks and Ottawa Citizen.

Hand searches of the journal Palliative Medicine were conducted for 2003 and 2005. These searches identified many relevant articles that provided reference lists that were also searched. Personal collection of articles on palliative care acquired by the author was also accessed.

Influences that Determine Where Death Occurs

Research supports that most people with a life-threatening illness want to be cared for at home and die in the comfort and familiarity of their own home (Brazil, et al., 2005; Bruera et al., 1999; Burge, et al., 2003a; Constantini et al., 2003; Davies, et al., 2006; De Conno et al., 1996; Earle et al., 2003; Fried, et al., 1999; Grunfeld et al., 2004; Hansen, et al., 2002; Heyland, et al., 2000; Higginson, et al., 1998; Karlsen & Addington-Hall, 1998; McWhinney, et al., 1995; Neutel, et al., 2005). The investigation of preferred location of death and related demographics is evident in much of the palliative care literature. Palliative care researchers from many countries have identified indicators or factors that influence palliative care and/or death at home. Some of these countries include the United Kingdom (Armes & Addington-Hall, 2003; Catt, et al., 2005; Davies, Linklater, Jack, Clark & Moller, 2006; Earle & Ayanian, 2006; Gott, Seymour, Bellamy, Clark & Ahmedzai, 2004; Grande, Todd, Barclay & Farquhar, 1999; Hallenbeck, 2008; Karlsen & Addington-Hall, 1998; Ingleton, et al., 2004), Italy (Costantini, et al., 2003; De Conno, et al. 1995), Sweden (Ahlner-Elmqvist, Bjordal & Kaasa, 2008), Belgium (Cohen, et al., 2006), United States (Grabbe et al., 1995), Japan (Fukui et al., 2003), and Canada (Brazil, Howell, Bedard, Krueger & Heidebrecht, 2005; Burge, Lawson & Johnston, 2003a; Canadian Institute for Health Information, 2007).

One of the consistent findings is that the patient's verbal expression of a desire to die at home is a key determinant for a home death. Additional home death predictors are the presence of family and loved ones, professional support, symptom control, ability of family to provide care and availability of equipment (Brazil et al., 2002; Karlson & Addington-Hall, 1998; McWhinney et al. 1995). The informal

caregiver is a key element when providing palliative care at home. This is a challenging role for many in today's employed, mobile, and aging population. The availability of an informal caregiver is important, as well as, support for the caregiver during this time of caring for a loved one who is dying.

Identification of preferred location of death and socio-demographics of those dying in their chosen location is a consistent finding in much of the palliative care literature and includes sex, age, type of cancer, financial resources, neighbourhood, race, and other demographics (Costantini, et al., 2003; Fukui et al., 2003; Hansen et al., 2002; Higginson et al., 1998; Porta et al., 1997; & Sahlberg-Blom, Ternstedt & Johansson, 1998).

Of interest and relevance to this study is the literature that notes which factors support the client's desire to die at home. Some of these factors consist of: family physicians visits at home particularly in the last month of life, more than one informal caregiver, home care nurses visiting frequently during the client's stable period, client's greatest functional dependency is in the week prior to death, shift nursing is available and utilized, a community palliative care team, adequate support exists for the informal caregiver, and lastly, any required special equipment is provided (Brazil et al., 2005; Bruera et al., 1999; Constantini et al., 2003; Fukui et al., 2003; Grande et al., 1998, 1999; Karlson & Addington-Hall, 1998; McWhinney et al., 1995; & Porta et al., 1998).

A study by the Canadian Institute of Health Information (CIHI) (2007) noted that if a married, terminally ill person develops unmanaged symptoms, the spouse is likely to bring him/her to the hospital. Because women live longer than men and represent the majority of long term care residents, they are likely to die in a long term

care facility. Men are less likely to die in hospital because family caregivers are more available for caregiving. The availability of long term care beds determined if the terminally ill individual was moved from the hospital to a long term care facility rather than returned home (p. 22).

In the literature a variety of reasons were provided for a patient is admitted to a hospital to die, when this is not their wish. The reasons include: poor pain and symptom control; safety; not wanting to be a burden to the family and thinking the family lacks the ability to provide care; no family physician to home visit; the inability of the caregiver to cope any longer; living alone; requiring social care (e.g. help with housekeeping, grocery purchases, laundry); a rapid deterioration in the patient's condition; or an oncology emergency (Evans, Cutson, Steinhauser & Tulsky, 2006; Fried et al., 1999; Karlson & Addington-Hall, 1998; McWhinney et al., 1995). Not all of these reasons for hospitalization appear to be insurmountable for clients who are palliative and wish die at home, particularly when CCAC palliative care services and other community resources (e.g. meals on wheels) are available.

Research literature that looks at reasons for hospitalization of clients who are receiving palliative care does not identify what is missing in the provision of palliative services at home that leads to the unwanted admission to the hospital or other options to improve the situation. Cancer Care Ontario (2009b) identifies a number of potentially avoidable reasons for emergency department visits or hospital admissions for terminally ill individuals including dehydration, constipation, dressing changes, and fatigue which can be managed in a home setting (Opportunities to optimize pain management and quality of care, ¶ 1). Again, there is no discussion of other options available to address these symptoms besides hospital visits.

A study by Evans et al. (2006), examines the reason for, and the experience of clients who were transferred from home palliative care services to inpatient facilities. Consideration of the reasons for an admission to an acute care hospital did not occur nor how to decrease the number of facility admissions to meet the patient's goal of a home death. This indicates a clear gap in knowledge that needs addressing for the benefit of the population requiring palliative care that is served by community professionals and the health care system. Cancer Care Ontario (2009a) notes that acute care environments such as hospitals or emergency departments are not designed to provide quality palliative care to patients with cancer at the end of their life (Aligning care with patients' needs and wants ¶1).

A study entitled *Health Care Use at the End of Life in Western Canada* (Canadian Institute for Health Information, 2007) stresses the need to improve our knowledge around death and dying, and the health care services that provide care and reassurance at the end of life. Unfortunately, medical services, formal home care, and informal care by caregivers were not included in the health services examined in this study.

Barriers exist in palliative care research and the challenges of "recruitment, attrition, and the vulnerability of the patient group [which] make randomised controlled trials in palliative care difficult" (Grande, Todd, Barclay, Stephen & Farquhar, 1999, p. 1472). These difficulties are reflected in the size and composition of samples in published research (Porta et al., 2007; Sahlberg-Blom, et al., 1998; Schers, van de Ven, van den Hoogen, Grol, & van den Bosch, 2004). When research requires data from administrative sources such as databases, electronic

sources or paper records, interaction with the client who is palliative is not necessary. This minimizes the challenges noted by Grande et al.

Ethical issues arise in randomized controlled studies in palliative care when the research requires withholding, altering, or changing health care and services for patients with a terminal illness that may result in unfavourable outcomes. For this reason, randomized controlled studies are often not used in palliative care research. A randomized controlled study was not used for this research. Given the historical data, it would not have provided answers to the research questions.

Qualitative researchers in palliative care must consider the likelihood of attrition of the sample by virtue of the population studied. The unstable health status of the participants may also influence the research findings due to the declining health of the sample that makes their ability to participate difficult, challenging, and sometimes not possible.

Emergency Department Use in Palliative Care

A Report of the Physician Hospital Care Committee (2006), entitled *Improving access to emergency care: Addressing system issues*, examines the issue of overcrowding of emergency departments in Ontario. The report included a package of 17 recommendations to address the system-wide problem of accessing emergency departments in Ontario. The report identifies that causes of overcrowding in emergency departments relate to two issues: a lack of in-patient bed availability, and poor integration between hospital and community health care resources. CCACs have a predominant role to play in avoiding hospital admission. The provision of adequate home care services to facilitate discharge from hospital and use of home care services are preventative measure to avoid hospital admission that could

reduce overcrowding and long wait times in emergency departments and shortage of in-patient hospital beds. The report did not discuss the impact of these challenges on the utilization of community health care services and resources.

In 1974, Aday and Andersen's study, *A Framework for the Study of Access to Medical Care*, attributed increased use of emergency departments to a lack of primary care physicians, unwillingness/disinclination of physicians to home visit and preference for specialization by physicians. Thirty plus years later, this situation remains relatively unchanged.

Currently the highest users of emergency departments are 75 years of age and up, and since 1992, the number of visits by this age group has increased by 50% (Report of the Physician Hospital Care Committee, 2006). Case managers working in emergency departments in Ottawa hospitals report that many clients visiting the emergency departments are individuals at the end stage of life-threatening diseases (personal communication, 2008) advised S. Bauer, former Chief Executive Officer of Champlain CCAC.

There could be a positive impact on the over use of emergency departments and bed shortages in hospital if the number of clients who were palliative and died in locations other than acute care hospitals increased. The shortage of hospital beds in Ontario often precipitates visits to emergency departments in order to access hospital admission when families can no longer cope or symptoms are unmanaged (Cancer Care Ontario, 2009c).

A study conducted in Spain examined survival of patients with lung cancer when admitted to hospital via the emergency department or as an elective admission. Porta et al. (1998) found that the client who decided to go to an

emergency department was critically ill and survival time was less than those who had an admission other than through the emergency department. In other words, the outcome was different depending on the route of admission to the hospital – the patient via the emergency department versus the patient sent to the hospital for admission by a primary care professional or through an outpatient clinic for a planned admission. The patient who had an elective admission had the same disease burden as the patient admitted via the emergency department.

An Italian study, in 2003, by Costantini et al. investigated the *Effect of a Palliative Home Care Team on Hospital Admissions Among Patients with Advanced Cancer*. The results of this study concluded that home palliative care services decreased the number of days in hospital. Studies conducted in the United States (Grabbe et al., 1995), United Kingdom (Armes & Addington-Hall, 2003; Davies, Linklater, Jack, Clark & Moller, 2006; Hallenbeck, 2008; Karlsen & Addington-Hall, 1998) and other European countries (Costantini, et al., 2003; De Conno, et al. 1995) support this finding. Although palliative home care services vary by country, generally the outcomes indicated a decrease in hospitalization when designated community palliative resources exist. These studies did not examine the actual services used, preference for location of care, and quality of care provided by home services. Serra-Prat, Gallo and Picaza (2001) recommend assessing the impact of community palliative care programs on hospitalization from the onset of palliative treatment to death.

There are a number of oncology emergencies requiring an admission to a hospital. Adequate treatment of these emergencies cannot occur in outpatient clinics or the community. These include febrile neutropenia, treatment toxicities (intractable

vomiting or diarrhea), spinal cord compression, and superior vena cava syndrome with unrelieved dyspnea. “Emergency admissions [have] (...) a greater likelihood of intrahospital mortality [than] can be explained by the possibility of larger acute physiological decline, when the presentation is emergent” (Bozcuk et al., 2004, p.1018).

Family physicians influence use of emergency departments by their patients who are in the final phase of a terminal illness (Burge, et al., 2003b). The greater the continuity of care provided by the family physician, the fewer visits to emergency departments and hospitalizations. Burge, et al. (2003b) measured the number of visits made by the patient to the family physician – not physician home visits. Gill, Mainous and Nsereko (2000) found that patients who have a regular source of health care made fewer visits to an ED (emergency department). Burge et al. do not indicate if home care visit nurses constituted a ‘regular source of care’ and thereby had the same effect on emergency departments or hospital visits. Another study, from the United Kingdom, identified that there are more hospital emergency admissions of clients who are terminally ill and who live in deprived areas than those who live in wealthier areas (Davies et al., 2006).

A Conceptual Framework for Palliative Care Services Utilization

Andersen’s (2008) behavioral model of health services utilization.

In the late 1960s, Andersen developed an integrated theoretical framework of Health Services Utilization (Figure 1) 1960s to “affect characteristics of the health care delivery system and of the population at risk in order to bring about changes in the utilization of health care services” (Aday & Andersen, 1974, p. 208).

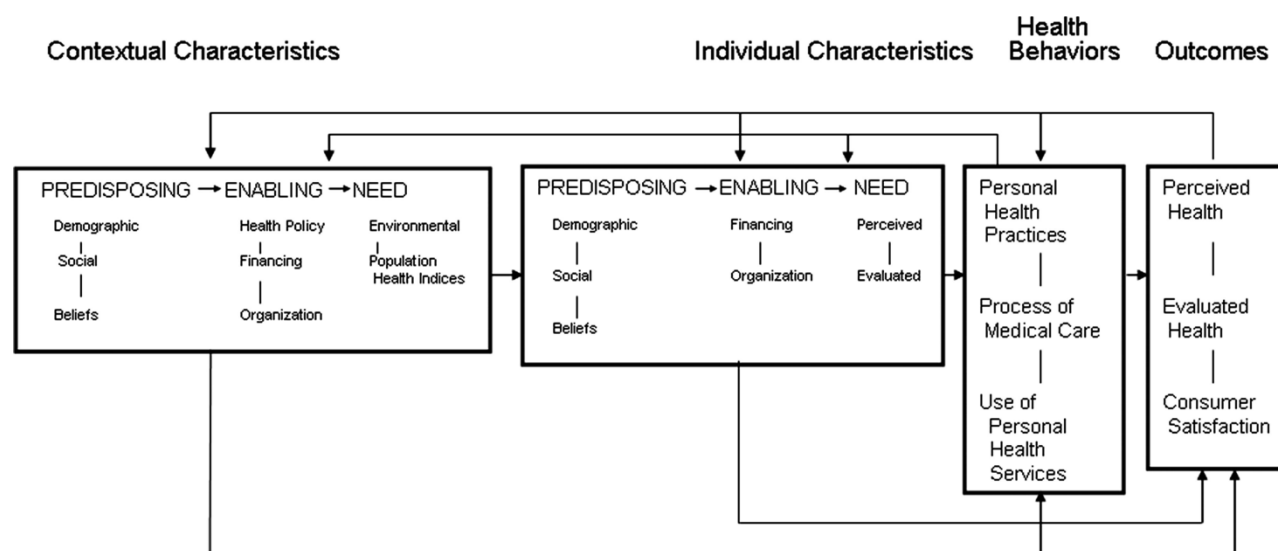


Figure 1. Andersen's Model of Health Services Utilization (2008), p. 651. Andersen, R. M. (2008). National health surveys and the behavioral model of health services use. *Medical Care*, 46(7), 647-65. (Permission granted)

For Andersen, the concept of 'access' to health care emerged as belonging to one of two themes: individual issues or systems issues (Aday & Andersen, 1974). Consideration of individuals, who wished to use the health care system and were unable to do so, was a gap in the model identified by Andersen (2008). To validate whether these themes influence access to obtaining care Andersen recommended examining specific populations for health care utilization rates (Aday & Andersen, 1974). Two other authors (Freeborn & Greenlick, 1973), who were examining services utilization, believed that the availability of services at the time and place required by the patient and his/her perception of the care received related to a change in condition indicated satisfaction with accessibility to health care.

Andersen's Behavioral Model of Health Services Utilization (2008) is based on the belief that "people's use of health services is a function of their predisposition

to use services, factors which enable or impede use, and their need for care” (Andersen, 1995, p. 1). Andersen enhanced his model over time and incorporated changes made by other health services researchers who had used his model (Andersen, 2008; Blalock et al., 2005; Evashwick, Rowe, Diehr & Branch, 1984; Litaker, Koroukian & Love, 2005; Phillips, Morrison, Andersen & Aday, 1998; Pickard, 2006; Tomiak, Berthelot, Guimond & Mustard, 2000). This model has evolved through five phases, with the most recent version in 2007 (Andersen, 2008). The focus of the final version is on examining health services use through understanding the contextual and individual characteristics (Andersen, 2008).

Components of Andersen’s (2008) model.

Andersen’s (2008) model has four categories that influence the use of health services: environment, population characteristics, health behaviour, and outcomes. Within each of these categories are factors or characteristics that provide detail and expand the category concepts.

The environment is comprised of the specific health care system and the external physical, political, and economic environment. Population characteristics are represented by predisposing factors that reflect individual characteristics such as socio-demographics and education. The enabling resources relate to the access and the use of services including income, social support and geography of residence. Need relates to objective and subjective health status and involves functional ability, symptoms and co-morbidities. Health behaviour encompasses the use of health services such as physician visits, hospital admissions and use of community resources. The outcome depends upon the focus of the research such as the health status or the individual’s expectations.

Application of Andersen's (2008) model in research.

Researchers have applied this model to studies on a variety of topics.

Examples of studies using Andersen's (2008) model include: inappropriate drug use, oral care, diabetes self-management programs, access to medical care, national health surveys, and the elderly population's use of health care services (Andersen, 2008; Blalock et al., 2005; Evashwick, Rowe, Diehr & Branch, 1984; Litaker, Koroukian & Love, 2005; Phillips, Morrison, Andersen & Aday, 1998; Pickard, 2006; Tomiak, Berthelot, Guimond & Mustard, 2000).

This model was also used in a number of Canadian studies. Burge, Lawson, Johnston and Grunfeld (2008) examined inequalities related to age and access to palliative care for patients with cancer in Nova Scotia. Although there had been earlier studies showing age-related inequalities, they had not "simultaneously [adjusted] for multiple demographic, health service, and socio-cultural indicators" (Burge et al., 2008, p. 1203). The study by Burge et al. included demographic, health service and socio-cultural indicators from Andersen's model.

Gucciardi, DeMelo, Offenheim and Stewart (2008) found the model appropriate for their study regarding secondary prevention issues for attrition behaviour in diabetics in Toronto. Previously, the model had been applied to disease related research but had not been used in secondary preventative health services research. The variables used in the Gucciardi et al. study (sex, age, primary language, marital status, education, employment status, income, regular physician, and diabetes related symptoms) matched Andersen's categories of factors influencing health behaviour.

Andersen's model was also the basis for another Canadian research study related to factors that affect admission to nursing homes in Manitoba (Tomiak, Berthelot, Guimond & Mustard, 2000). The predisposing factors consisted of age, marital status, and education; enabling factors were household size, urban/rural geography, income, home ownership, and number of physicians in the area; and need factors included functional disability, hospital and physician use, co-morbidities, and specific medical ailments.

In the United States, Grabbe et al. (1995) applied Andersen and Newman's 1973 model to examine the relationship between the use of formal home care and functional status in the year before death. Financing of the American health care system, including home care, does not follow a universal health care plan as it is in Canada. This difference means the income of the health care user is an important component to consider in the United States. "The quantity and type of care needed by clients are functions of price of care, income, health status, and the availability and relative price of substitute services" (Grabbe et al., 1995, p. 340). Reversal of Andersen's model is applied in a study by Grabbe et al., and begins with the individual variables and builds on the influences of different levels of the health system to culminate with the use of home care. This application of Andersen's model appears to be unique in the literature. Most studies adapt Andersen's model to correspond with the authors' area of research, maintaining the original order and flow of the components while modifying the characteristics that make up the variables.

Adaptations made to Andersen's (2008) model for this research.

For the purposes of this study, an adaptation of the 2008 version of Andersen's model is used. Adaptations of Andersen's (2008) model for this study make it more relevant when examining palliative care services utilization and when relating to the research questions driving this investigation (Figure 2).

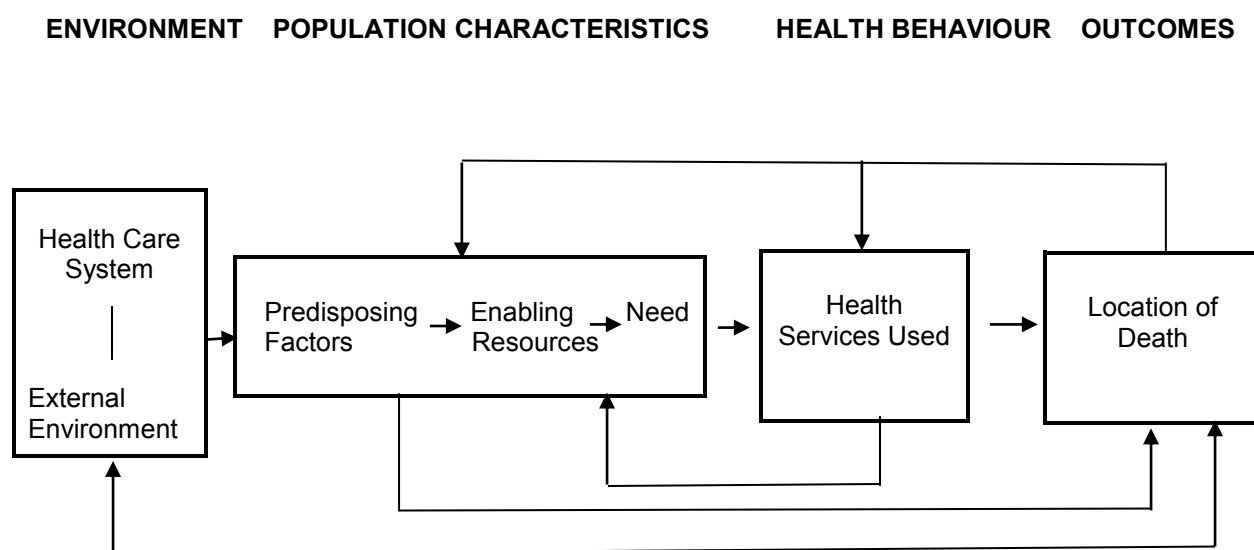


Figure 2. Adaptation of Andersen's Model of Health Services Utilization (2008) for this study. Andersen, R. M. (2008). National health surveys and the behavioral model of health services use. Medical Care, 46(7), 647-65

Within 'Health Behaviour' 'Personal Health Practices' category was eliminated as this information is not available in the charts audited for data collection or pertinent to this study. However the 'Health Services Used' category was retained as it relates to services utilization, a central component of this study. 'Location of Death' is the 'Outcome' in this study. The primary modification of Andersen's model was the identification of the specific indicators chosen to represent the categories identified in his model (See Table 1).

The indicators selected in this adapted model are relevant to this study. The adaptations made to Andersen's model changed it from a behavioural model to a

systems model of palliative care service usage. This systems model suits a quantitative study. The adapted model removed qualitative variables such as satisfaction and individual influences on location of death.

Application of Andersen's (2008) model (adapted).

An adaptation of Andersen's (2008) Behavioural Model of Service Utilization provided context and structure to this study (See Table 1). The discussion of the current federal, provincial, regional, and local practices that influence the provision of palliative care in Ottawa addressed the health care system and external environment within the environment category. Characteristics of the external environment that impact services utilization discussed in this paper were the aging population, current economic situation and the availability of health human resources.

Population characteristics reflected the specific variables collected from the chart audits and included the three elements - predisposing factors, enabling resources, and need. Predisposing factors are existing conditions and socio-demographic characteristics (gender, age marital status, language, postal code, and type of residence were collected.

Enabling resources facilitate or impede the use of services (Gucciardi et al., 2008). The enabling resources in this study included the availability of informal caregivers and support services, rural or urban home setting, the availability of specific CCAC services required to manage at home, and a physician who home visits and has experience with palliative care at home.

Table 1

Application of Andersen's Model (2008) as adapted for this Study

ENVIRONMENT	Health Care System	Health Canada policies (federal) Ontario Ministry of Health and Long Term Care Policies (provincial) Champlain Local Health Integration Network (regional) Champlain Community Care Access Centre Ottawa (local)
	External Environment	Growing Aging Population Economics (funding) Health Human Resources (availability)
POPULATION CHARACTERISTICS	Predisposing Characteristics	Socio-demographic factors Caregivers
	Enabling Resources	Physician involvement Family/personal situation
	Need	Diagnosis/prognosis Co-morbidities Treatments Symptom management
HEALTH BEHAVIOR	Health Services Used	Champlain CCAC Ottawa palliative program services Emergency department visits Hospital admissions
OUTCOMES	Location of Death	Preferred location for death Actual location of death Length of time at home in last month of life

A client's diagnosis, prognosis, co-morbidities, provision of active or palliative chemotherapy and/or radiation treatment and symptom management were conditions that indicated the need for services. The client, caregiver, and professional service providers determined the need that was the third element in population characteristics in Andersen's model (Gucciardi et al., 2008).

Health behaviour for this study included the use of health services and included all CCAC services: nursing services, personal support services, therapy services, and equipment rental. Data on other health services that were important to

be included in this research were ambulance use, trips to emergency departments, hospitalizations, and length of stay. The final category in Andersen's framework is outcomes. To identify the outcomes, services utilization during the last month of life was sought guided by Andersen's (2008) model. The selection of information will provide information on the length of time that clients spent at home during their last month of life, patterns or trends in services utilization, and if the clients' preferences were achieved by dying in the location of choice and, if not, the actual location of death.

Summary

Research consistently indicates that people with life threatening illness prefer home as the location for death. Although, verbalizing this desire to die at home may mean they were more likely to do so, other indicators play an important role in location of death. These indicators are more dependent on circumstances and the health care system resources, than related to individual choice.

The informal caregiver is a key element when providing palliative care at home. However, the availability of an informal caregiver is challenging in today's mobile, aging, and working population. The availability of one or more primary informal caregivers was identified in the literature as being necessary to ensure the support required for patients to remain at home until death (Brazil et al., 2002; Karlson & Addington-Hall, 1998; McWhinney et al. 1995).

Although there are legitimate medical reasons for a patient who is palliative to visit an ED or be admitted to a hospital, several researchers have highlighted that there is inappropriate or unnecessary use of EDs and hospitalizations (Burge et al.

2003b; Gill et al., 2000; Porta et al., 1998). Many medical issues can be managed at home from service providers who are knowledgeable about palliative care.

Andersen's (2008) Behavioural Model of Health Services Utilization has been used and adapted for many areas of health care research. Adaptation of the model for this research study was useful in providing a conceptual framework for examining palliative care services utilization.

Chapter Three: Methods

Design

This study is an historical, quantitative, descriptive design. Chart audits of client records and databases provided services utilization patterns during the last month of life and location of death.

Sample and Setting

The Champlain CCAC Ottawa site, The Ottawa Hospital, and Bruyère Continuing Care Palliative Care Unit were the three sources of data for this study. The Hospice at May Court, located in Ottawa, provides residential care for people in their last phase of life. This Hospice receives some funding from the Champlain CCAC and the residents remain clients of the CCAC Ottawa Palliative Program while continuing to have access to CCAC services.

The sample was clients for whom the CCAC had client records. The inclusion criteria were the records of those clients who received services from Champlain CCAC Ottawa Palliative Program and died during the month of July 2009. This sample included the records of clients who had been clients of Champlain CCAC Ottawa Palliative Program for less than one month, and were admitted and died sometime during the month of July 2009. The only exclusion criterion was Champlain CCAC Ottawa Palliative Program records of Union Mission Hospice residents, as this is a specialized hospice service for the homeless, and therefore not representative of the general population.

The Ontario Ministry of Health and Long Term Care require that CCAC clients who are hospitalized for more than 14 days be discharged from the CCAC program. An MIS Standards (Management Information Systems) discharge is the coding for

this type of discharge. After 14 days, if the client returns home with CCAC services, a new admission is required. The client returns to his/her previous Palliative Program case manager.

A review of the CCAC palliative program records from October 2008 to December 2008 indicated approximately 108 discharges per month from the CCAC Ottawa Palliative Program, of which 72 were confirmed deaths. The remaining 36 reflected discharges due to the Ontario Ministry of Health and Long Term Care MIS Standards. Readmission of some of the discharges to CCAC occurred, while others died in hospital or were transferred to Bruyère Continuing Care Palliative Care Unit or a long-term care facility.

Data Sources for the Study

The majority of the data for this study were collected from Champlain CCAC Ottawa site. Champlain CCAC Ottawa Palliative Program client records and related databases of those who died during the month of July 2009 provided the data for the study.

The Champlain CCAC Ottawa records for the palliative program are a combination of paper-based and electronic-based records. They consist of the case manager's written chart, Champlain CCAC database and a standardized 'Chart in the Home', which is used throughout Champlain Region for clients who are palliative. The 'Chart in the Home' contains the service providers' and family's documentation and is returned to the Champlain CCAC Ottawa office upon the client's discharge. The variety of chart documentation was helpful in limiting missing data, addressing legibility, and clarifying confusing information. Data required from The Ottawa

Hospital and Bruyère Continuing Care Palliative Care Unit was in their respective electronic databases.

Chart Audits

Chart audits have long been used to review health records for development of best practice guidelines, quality assurance, and morbidity and mortality patterns, (Badcock, Kelly, Kerr & Reade, 2005; Burge et al., 2008; Hall, Schroder & Weaver, 2005; Higuchi, Edwards, Danseco, Davies & McConnell, 2007; Lowenstein, 2005; Pan, Fergusson, Schweitzer & Hebert, 2005; University of Toronto, 2008).

A tool is critical for conducting chart audits (Badcock et al., 2005 & Lowenstein, 2005). As a tool that specifically addressed demographics and services utilization information, the factual content of the records, databases, and Andersen's model and categories facilitated development of a chart audit tool. Application of specific parameters to the data and drop down menus, whenever possible, ensured consistency in data collection. My familiarity with the records and databases from working at the CCAC also facilitated the development of the tool (See Appendix A for data collected).

When developing a best practice evaluation tool, Higuchi et al.(2007) found "chart audits at the home healthcare agency had more documentation on assessments, judgement, action plan, communication of plan, and ongoing monitoring, compared with the hospital site" (p. 48). Pan et al., (2005) found that the most available and accurate information collected from chart audits related to demographics, outcomes, and discharge.

There are advantages and disadvantages of this method of data collection. The advantages include: chart audits are less time consuming than surveys and

interviews, it is straightforward, standardized, and it does not interfere with the ongoing activities of the agency. The audit tool is applicable with paper-based and electronic-based records. Client consent is not required if the chart audits do not include identifying information (Hall et al., 2002; University of Toronto, 2008).

The limitation of chart audits relates to the differences in the recorders' documentation skills that may lead to missing data, conflicting information or information that cannot be coded. Hand-written documentation may be illegible (Badcock et al., 2005; Hall et al., 2002; Lowenstein, 2005; Pan et al., 2005; University of Toronto, 2008). Documentation of relevant information may not be found in the chart, for example, if the client changed their preferred location for death.

Chart Audit Tool for the Study

An electronic chart audit tool, using Excel, was designed to facilitate data collection and minimize data entry errors. Socio-demographic information, services provided by the Champlain CCAC Ottawa palliative program, emergency department visits and hospital admissions were entered directly into the tool (See Appendix A). The services consisted of home visits by health care professionals including case managers, nurses, therapists, social workers, dieticians, and, unregulated health care providers such as personal support workers, as well as equipment rental by CCAC. The Ontario Ministry of Health and Long Term Care require CCACs to document the client's preferred location of death. This variable and the actual location of death were noted.

Emergency department visit frequencies, hospital admission date, hospital discharge date, discharge location, and diagnosis was the information acquired from

The Ottawa Hospital database. The Bruyère Continuing Care Palliative Care Unit records were required for two clients, as the information on other clients who died at Bruyère Continuing Care Palliative Care Unit was available in the CCAC documentation.

It was beyond the scope of this study to investigate the use of community resources in addition to those outlined that clients who were palliative and their families may have accessed. These unrecorded supports may have included meals on wheels, privately hired housekeepers, lawn maintenance and snow removal contracts, and private or volunteer drivers. The Ottawa community hospitals, Queensway-Carleton Hospital and the Montfort Hospital's health records for the CCAC study clients were not retrieved. Few clients in the study sample were admitted to either of the community hospitals and/or visited their emergency departments. The required data were available in the CCAC documentation.

Before commencing formal data compilation, a pilot of the chart audit tool was conducted, using five client records from Champlain CCAC Ottawa. The chart audit tool remained the same after the pilot, without any required changes or refinements.

Data Collection Process

Data collection via chart audits began the fall of 2010 at Champlain CCAC Ottawa. A flow chart of the data collection process is presented in Figure 3.

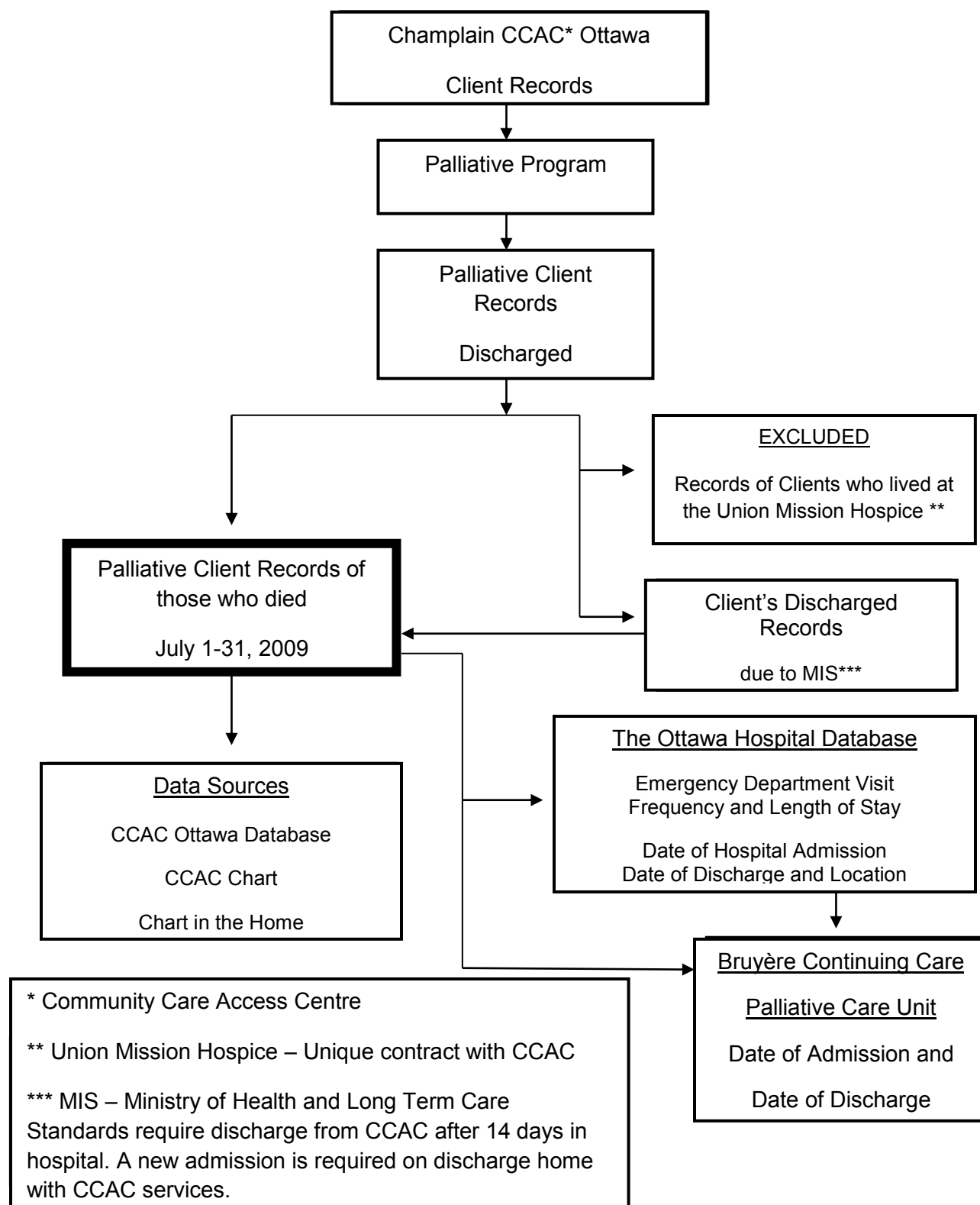


Figure 3. Flow Chart of Data Collection Process

Data Collection Elements

Socio-demographic data.

Collection of socio-demographic data elements were from the electronic and paper-based records. The gender of the client was documented. The age of the client was recorded using age ranges of 10 years starting at age 40 up to 90 years of age. There were also two additional ranges of under age 39 and over 90 years of age. The age of the clients were grouped into ranges to facilitate comparison and is used in much of the literature on palliative care. Marital status was partner or no partner, and included heterosexual, homosexual, and common-in-law relationships.

The informal caregiver classification was husband, wife, daughter, son, sister, female relative, or no one. These options covered all caregiver relationships from the sample. Although data were collected on the presence and relationship of a caregiver to the client who was dying, the role of the caregiver in determining the place of death was not part of this study. The data required to examine the caregivers' impact on location of death were not available from the resources accessed for this research.

English, French or other represented the client's preferred language. Use of CCAC's nomenclature for site of living location was home, retirement home, or hospice. Also noted was the clients' access to and/or use of private insurance for nursing care at home. The choices for preferred and actual location of death consisted of home, hospice, Bruyère Continuing Care Palliative Care Unit, hospital or unknown.

Physician services.

Physician services were provided in several different ways. If the client had a family physician, and if this physician provided home visits was recorded. Recipients of service from the Palliative Pain and Symptom Management Consultation Service were noted along with the clients whose medical care was provided by community palliative physicians.

Health profile.

There were numerous health profile data elements collected in this study. The health profile included diagnoses, co-morbidities, clients' access to private insurance for nursing, wait times for hospital, hospice or palliative care unit admission, preferred and actual locations of death, dates of admission to the CCAC palliative program, provision of chemotherapy and/or radiation treatments during their last month of life, the number of visits to emergency departments, ambulance use, the number of hospital admissions, the number of in-patient hospital days, MIS discharges, hospital discharge locations, causes of death, and dates of death. The diagnoses and co-morbidities were identified during data collection and then incorporated into the data collection tool. Co-morbidities were defined in this study as any diseases other than the cause of death that were documented in the data sources.

Services utilization.

The services provided through Champlain CCAC during the client's last month of life were recorded. The specific number of nursing visits, shift nursing hours, personal support services hours, and end-of-life personal support services hours were collected. Additionally, it was recorded if the client received visits at

home from a occupational therapist, physiotherapist, speech therapist, or a social worker, and if CCAC rented equipment for their use. Notation was made of the availability of the services, and number of CCAC contracted agencies accessed.

Hospital-related services.

Hospital-related services collected included the number of trips to an emergency department; number and length of hospital admissions; whether the client received chemotherapy and/or radiation therapy for curative purposes or palliation treatment; ambulance use; and disposition of the client after hospital discharge.

From the Champlain CCAC Ottawa palliative program records, it was identified if an emergency department visit and/or an admission to The Ottawa Hospital occurred. Records of these clients were reviewed from The Ottawa Hospital database. If it was documented in the Champlain CCAC Ottawa palliative program record or The Ottawa Hospital record that admission to Bruyère Continuing Care Palliative Care Unit occurred, these records were reviewed.

Data Analysis

The research objectives and questions directed the analysis of the data. This was accomplished employing Andersen's (2008) model to investigate the relationship of environmental, population characteristics and health behaviour to services utilization in the last month of life and location of death. The chart audit tool for the study and the data analysis were developed using Excel 2003. More specifically, Excel 2003 Data Analysis Program and Excel 2003 Pivot Tables application provided the descriptive analysis for this study.

The dependent variable was the location where death occurred and there were four possible locations of death: home, hospice, palliative care unit, and hospital. Data on type of services used, quantity of services used, type, number, and length of hospital interactions were the independent variables analyzed. Descriptive analysis included sum, mean, mode, range, percentages, and frequencies (Gravetter & Wallnau, 2004; Polit, 1996; & Polit & Beck, 2004). Collection of socio-demographics included physician services and health profile. Data analysis details are described for each research question.

1. What palliative care services were utilized during the last month of life?

To analyse the palliative care services used during the last month of life it was determined, from the information collected with the use of the chart audit tool, whether a client received nursing visits, shift nursing, personal support services, personal support services end-of-life and therapy services. The number of visits/hours for each service was totaled per client. The findings were not compared with other CCACs or provinces for two reasons. A study by Seow, Barbera, Howell & Dy (2010a, 2010b) that was similar to this research study and looked at home care services for clients on CCAC palliative programs, did not include the last two weeks of life. The last two weeks of life was a relevant time period in this study. Secondly, the purpose of this study was to examine the services used and compare across the four settings where death occurred for the Ottawa CCAC Palliative Program clients.

2. Where did the clients die?

Documentation in the chart audit tool of the location of death collected from the chart audits supplied the location of death data. This allowed computation of the total number of deaths in each location.

3. Is there a relationship between the quantity of palliative care services utilization and location of death?

In order to assess if there was a relationship between the quantity of palliative care services utilization and location of death, the data on nursing services, personal support services, therapy services, and the rental of equipment for clients' use at home was examined by location of death. It was noted which location of death had clients who used a greater or lesser number of visits/hours.

Nursing services included the number of nursing visits made each week from week five to week one (week of death) for each client. Shift nursing services were also part of the nursing services data collected and included the availability of shift nursing, the number of shift nursing hours used per week, per client, if the shift nursing agency was the same one that was providing visit nursing, and if private insurance was used to purchase additional shift nursing services.

Personal support services included the number of hours of personal support services and personal support services end-of-life provided from week five to week one for each client. The therapy data was calculated as a monthly total of the number of physiotherapy visits, occupational therapy visits, nutrition visits and speech therapy visits made. It was collected monthly rather than weekly because there were few therapy visits made to the clients during their last month of life. Lastly, it was documented if equipment was rented by the CCAC for the client.

Using nursing visits as an example, the total number of nursing visits made each week, for each client was totaled along with the number of clients who received these visits weekly. Then the average number of visits made each week was calculated. Means, modes and ranges were computed. This analysis was followed for each service and then the findings were grouped according to the client's location of death – home, hospice, hospital or palliative care unit. This provided useful information for comparison of services use by the sample as a whole and by location of death.

Initially, calculating the average number of visits/hours using the total number of clients who died in each location did not prove to be meaningful because the number of clients using the services some weeks was few and other weeks there were many clients receiving services. It was only when the average number of visit/hours for each week were examined in conjunction with the number of clients using the services that the values made sense. The next phase was examination of each of the services by week with the location of death for each client. Analysis of the weekly number of visits/hours for each service and the data on the location of death provided results that allowed comparisons between each service and locations of death that assisted in understanding the data.

Through the process of data analysis it became evident which services were used most frequently and where the clients who were high users of services died, and if the high service users died in their preferred location. From this information, identification of trends and patterns related to services utilization of Champlain CCAC Ottawa palliative program clients and their location of death was possible.

4. Is a greater quantity of CCAC palliative care services related to the proportion of time clients who were palliative spent at home?

The number of emergency department visits, hospital admissions, and hospital in-patient days for each client provided the data to compute how many days the client spent at home during

their last month of life. The clients were grouped according to their location of death. Examining the number of CCAC services used and the number of visits/hours of services received with the number of days at home during the study period followed.

5. Was the location of death the clients' preferred location of death?

The clients' preferred location of death is part of the information required by CCAC. Chart audits revealed the preferred location for death and the actual location of death. Calculation of the number of clients who died in their preferred location, and those that did not, took place. Identification of the location of death for those clients who did not die in their preferred location followed. It was then possible to compare the totals for the clients who died in their preferred location and those that died in one of the other settings.

Ethical Considerations and Confidentiality

The ethical principles of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans guided the ethical conduct of this study. The Interagency Advisory Panel on Research Ethics' *Introductory Tutorial for the Tri-Council Statement* (Canadian Institutes of Health Research Natural Sciences and Engineering Research, 1998) was completed on December 10, 2007. Although this study involved records and databases, confidentiality and anonymity were

maintained. It was important to ensure personal identifying information was not evident in the data, analysis, or results. Confidentiality and anonymity of clients and their caregivers were protected in several ways. The individual's personal identifying information was recorded and assigned a code number. The code number was used on the chart audit to maintain confidentiality and anonymity. The code number key was only accessed to obtain the information required to gain the specifically identified records from The Ottawa Hospital and Bruyère Continuing Care Palliative Care Unit. Chart audits at either of these locations used the code number, without any personal identifying information. After completion of data collection, the key code was separated from the data and stored by the researcher in a secure location.

Analysis and results were an aggregate of data. At completion of the study, all material was securely stored a the key code, at the University of Ottawa, for the required period. Access to the key code was restricted to professionals completing the chart audit. Finally, the researcher is a professional, whose registration includes a code of ethics, which requires respecting client confidentiality and privacy.

This study involved four organizations: The Ottawa Hospital, Bruyère Continuing Care, The University of Ottawa, and Champlain CCAC Ottawa. The Council of Research Ethics Board (COREB) Common REB Application Form was submitted for approval. The Champlain CCAC Ottawa research approval process required the Chief Executive Officer and Senior Management Team to review the research proposal and to ensure that approval had been received from the COREB. (S. Bauer, personal communication, February 2008). The data collected were not related to living human subjects and was secondary data from administrative

databases and records. The use of aggregate data ensured no individual was identifiable.

Chapter Four: Findings

In this chapter, the analysis of the data is presented. An overview of the sample data results is reviewed. This is followed by the findings sorted by socio-demographics, physician services, and health profile for each location of death. The services utilization results are discussed in response to each research question.

Summary of Study Sample

One hundred and seventy-two chart audits were completed, of which 87 met the eligibility criteria for this study. In the Champlain Community Care Access Centre (CCAC) Ottawa Palliative Program, the number of deaths in a month is identified as the number of clients who were discharged from the Palliative Program. In July 2009 131 clients were discharged and their charts were audited. Some of the discharged clients actually died in June 2009 and their discharges were processed in July 2009. There were 15 MIS (Management Information Services - Ministry of Health and Long Term Care Standards) discharges of clients hospitalized for 14 days or more. A new admission was required upon return home and the charts from pre and post hospital admission were included. Of the 15 MIS discharges some clients had readmission to CCAC, others died in the hospital and others transferred to the hospice or palliative care unit. The locations of death were recorded for who died in a hospital, hospice or palliative care unit. Clients who died in a hospice for the homeless were excluded from the sample, per eligibility criteria. Eighty-five charts from July 2009 met the eligibility criteria.

Because some of the clients who died in July 2009 may have had their discharge processed in early August 2009, 41 discharged charts from the first two

weeks of August 2009 were also audited and two met the eligibility criteria. This provided 87 charts eligible for this study.

Demographics of the Sample

The number of males and females in the sample were almost equal at 42 and 45 respectively. Fifty-eight clients had a marital partner. At the time of their admission to the Champlain CCAC Ottawa Palliative Program, 74 clients lived at home and 13 lived in a Retirement Home.

The ages of the clients ranged from under 39 years old to over 90 years old with the majority falling within the 60 to 89 years of age range (69). The most frequent primary caregiver was a wife (30) followed by a daughter (21).

Demographics for clients who died at home

Forty-three of the 87 clients in the study died at home and 83.7% of the 43 clients spent all of the month before death at home. The chart audits revealed that 90.7% of the clients who wished to die at home were able to do so.

There were more females than males (24:19) who died at home. One third of the clients were 80 to 90 years old and one-quarter were 70 to 80 years old. These two age groups represented the majority (26) of those who died at home.

The number of days the clients who died at home received services from the Champlain CCAC Ottawa Palliative Program ranged from under a week to over a year. One third of the clients whose death occurred at home were on the program for one month or less. Those receiving service for three to six months comprised one quarter of those who died at home.

The majority of the clients had a marital partner (21) and a daughter was the most frequent person in the primary caregiver role (14). None of the clients who died

at home were without caregivers (43). Thirty-four clients who died at home lived in their own home while the remainder lived in retirement homes.

Demographics for clients who died at the hospice.

Nine of 87 clients in the study died at the hospice. This number represented 90% of the clients who chose the hospice as their preferred location for death. The number of male clients (5) outnumbered the female clients by one. The clients' ages ranged from 60 to 89 years old. The majority of the clients from this location were 60 to 69 years of age (5).

The number of days clients received services from the Champlain CCAC Ottawa Palliative Program ranged from under two weeks to over a year. One third of the clients who died at the hospice were on the Champlain CCAC Ottawa Palliative Program for two weeks or less before admission to the hospice (3).

The majority of clients had a marital partner (6) and their primary caregiver was their spouse. None of the clients was without a caregiver. Almost 79% lived in their own home prior to moving to the hospice and the remainder lived in a retirement home.

Demographics for clients who died in a hospital

Twenty-two of the 87 clients in the study died in a hospital. No one had identified a hospital as his/her preferred location for death. Nine of the clients who died in a hospital identified their preferred location for death as home, while two clients identified the hospice as their preference. Half of those who died in a hospital did not have their preferred place of death documented.

Twelve of the 22 clients in this group were female. Thirteen clients who died in the hospital were in the age range of their 50s or 70s (7, 6 respectively).

The number of days that clients who died in a hospital received services from the CCAC Ottawa Palliative Program ranged from under two weeks to over one year. Six clients were on the program for 31-60 days and 91-180 days while five clients were on the program for two weeks or less.

Nine of the male clients who had a marital partner (14) and died in a hospital were cared for by their wives. One client did not have a caregiver. Home was the residence for 20 of the clients who died in a hospital and the others lived in retirement homes.

Demographics for clients who died in the palliative care unit.

Thirteen clients died in the Palliative Care Unit, and eight were male. The majority was in their sixties or seventies (5, 6 respectively).

The number of day's clients who died in a palliative care unit received services on the Champlain CCAC Ottawa Palliative Program ranged from under two weeks to over one year. Four clients were on the program for 61-90 days and two clients were on for 31-60 days, 91-180 days and 181-360 days.

Over half of the clients (8) who died in a palliative care unit had a marital partner and the wife was the most common primary caregiver (7). One client did not have a caregiver. All of the clients who died at the Palliative Care Unit lived in their own home prior to admission to the Palliative Care Unit.

Table 2 compares client's age ranges, primary caregivers, number of visits to an emergency department and number of days spent as an in-patient in hospital across locations of death.

Table 2

Comparison of Variables by Location of Death

Variables	Location of Death			
	Home	Hospice	Hospital	PCU
Age Range				
30 – 39	0	0	2	0
40 – 49	2	0	0	0
50 – 59	4	0	7	1
60 – 69	9	5	4	5
70 – 79	11	1	6	6
80 – 89	15	3	3	1
90 & Over	2	0	0	0
Primary Caregiver				
Husband	10	3	2	1
Wife	11	3	9	7
Daughter	14	1	3	3
Son	4	2	0	1
Sister	2	0	3	0
Relative (F)	2	0	4	0
No One	0	0	1	1
No. ED Visits				
0	35	7	1	4
1	6	1	13	7
2	2	1	7	2
3	0	0	1	0
Hosp In-pt Days				
1 – 14	7	3	5	1
15 – 30	6	1	2	1
31 – 60	7	0	6	2
61 – 90	1	0	1	4
91 – 180	11	3	6	2
181 – 360	10	1	1	2
361 & Over	1	1	1	1

Note. PCU = Palliative Care Unit; (F) = Female; No. = Number; ED = Emergency Department; Hosp in-pt Days = Hospital In-patient Days

Physician Services for the Sample.

Physician services were categorized by the number of people who: had a family physician and if that physician made home visits, accessed the Palliative Pain and Symptom Management Consultative Service (PPSMCS), and received care from a community palliative care physician (CPCP). Although three quarters of the

sample had a family physician, little less than half of those physicians did not provide home visits. More than half of the sample received their palliative medical care from a CPCP (45). Physician services and type of physician involvement are compared by location of death in Figure 4.

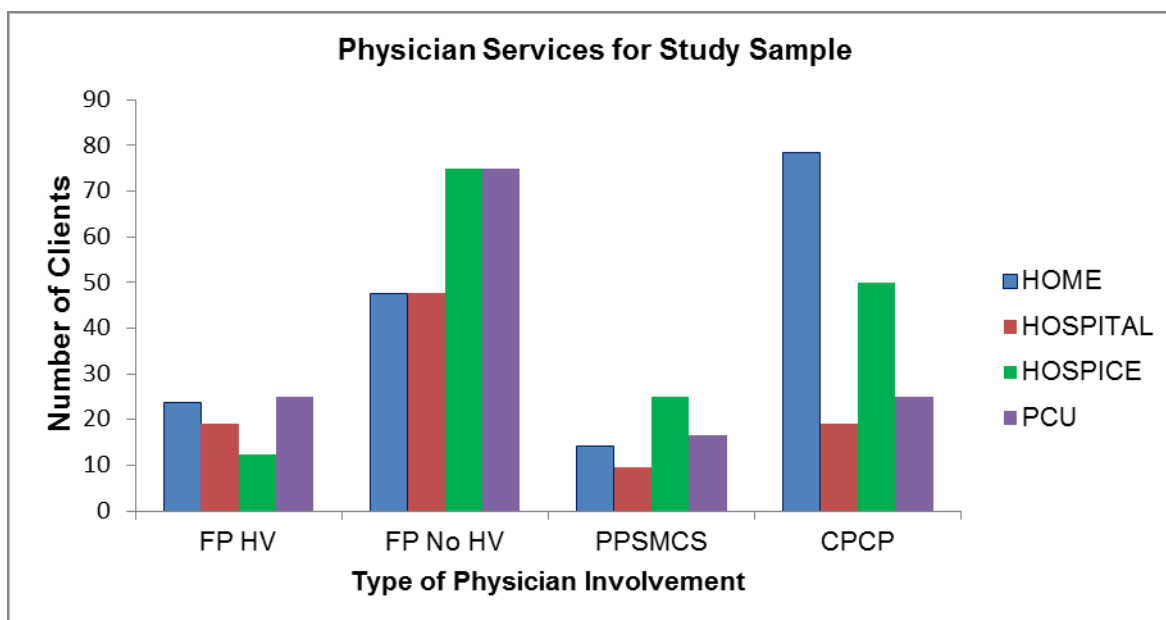


Figure 4. Physician Services by Type of Involvement. PCU = palliative care unit; FP = family physician; HV = home visit; PPSMCS = Palliative pain and Symptom Management Consultative Service; CPCP = community palliative care physician.

Physician services for clients who died at home.

Although many of this group of clients had a family physician (30), only one third of these physicians provided home visits (10). A community palliative care physician cared for more than three quarters of these clients at home (33).

Physician services for clients who died at the hospice.

Seven of the clients who died at the hospice had a family physician that did not provide home visits as a part of their medical practice. Four clients received their palliative medical care from CPCP.

Physician services for clients who died in a hospital.

There were 18 clients who died in a hospital who did not have a family physician or one who provided home visits. The community palliative care physicians provided care for four of the clients who died in a hospital.

Physician services for clients who died in the palliative care unit.

Ten of the clients who died at the Palliative Care Unit had a family physician that did not home visit their patients. Four clients received palliative medical services while at home from CPCP.

Health Profile of the Sample

The most frequent diagnosis was cancer including: gastrointestinal; breast; female reproductive system such as uterine, cervical, or endometrial; prostate; bladder; lung; brain; pancreatic; melanoma; kidney or unknown primary. Non-malignant diagnoses noted were pulmonary fibrosis, dementia, liver disease, congestive heart failure, cardiac disease, or chronic obstructive pulmonary disease.

The number of co-morbidities were lengthy so similar illnesses were grouped together. The cardiac-related diseases included coronary artery disease, peripheral vascular disease, hypertension, congestive heart failure, arteriosclerosis, aortic stenosis, and atrial fibrillation. Respiratory illnesses included chronic obstructive pulmonary disease, emphysema, pneumonia, and pulmonary fibrosis. Remote cancers included breast, renal, cervical, and vulvar. Mental illness diagnoses were recorded: depression, psychosis, or schizophrenia. Kidney disease, end stage renal failure, and acute kidney disease were together as was arthritis, osteoarthritis, and rheumatoid arthritis. Cognitive impairment and Alzheimer's dementia were separated, as not all dementias are Alzheimer's. Sensory co-morbidities included

hard of hearing or deaf, blind, tinnitus, and glaucoma. Cerebrovascular accident and transient ischemic attack were combined and the last group included skeletal ankylosing spondylitis, degenerative disc disease, and fractures. The following co-morbidities stood alone: diabetes, hypothyroidism, polymyalgia, alcoholism, and myelodysplastic syndrome.

The number of co-morbidities ranged from one to five. Just less than half of the charts (41) did not have documentation indicating illnesses other than their life-threatening disease.

During the last month of life, one third of the sample made one visit to an emergency department (27). Forty clients made 54 visits to an emergency department.

Of the 22 clients who died in a hospital, two died in an Intensive Care Unit and three died in an emergency department. The 39 hospitalized clients from the sample spent a total of 397 days as in-patients, with an average of 10.2 days.

Although almost three quarters of the clients did not receive chemotherapy or radiation during their last month of life, one quarter received active or palliative chemotherapy and/or radiation therapy. Six clients who died during July 2009 were on the Champlain CCAC Ottawa Palliative Program for seven days or less. The median was 71 days and the mode 40 days with a range of one to 524 days. Half of the clients who died in July 2009 remained in their homes for the whole month.

Health profile for clients who died at home.

The recorded causes of death for the clients who died at home were cancer (38), pulmonary fibrosis (2), cardiac disease (2) and dementia (1). Many of the charts did not have co-morbidities documented (22).

The majority (35) of clients who died at home did not visit an emergency department in their last month of life. Eight of the clients who died at home made 10 visits to an emergency department.

There were 36 clients of those who died at home, who did not have a hospital admission during their last month of life. The seven clients admitted to a hospital spent a total of 73 days in the hospital, an average of 10.4 days for each of the hospitalized clients.

During their last month of life, eight of the clients who died at home received chemotherapy and/or radiation therapy including four clients who were receiving active chemotherapy treatment. The charts of two clients that died at home did not indicate if they received chemotherapy or radiation therapy.

Health profile for clients who died at the hospice.

Cancer was the terminal illness for seven of the clients who died at the hospice and the remaining two had end-stage cardiac disease. The number of co-morbidities ranged from zero to five and five charts did not identify any co-morbidity.

The majority (7) of this study group did not visit an emergency department during July 2009. Two of the clients who died in a hospice made three visits to an emergency department.

Four of the clients who died at the hospice spent a total of 54 days in a hospital during their last month of life. This is an average of 13.5 days for each of the clients who were hospitalized. Five clients were not hospitalized.

Six of the clients who died at the hospice received chemotherapy and/or radiation therapy during their last month of life. Three of those receiving treatment received active chemotherapy and/or radiation therapy.

Health profile of clients who died in a hospital.

Cancer was the primary diagnosis for 19 of the clients who died in a hospital followed by cardiac disease (2) and pneumonia in combination with multiple morbidities (1). There were zero to five co-morbidities with no documentation in six charts and another six clients had one other disease.

Of the 21 clients who died in a hospital, only 13 made one trip to an emergency department. There were 30 emergency department visits by 21 clients who died in a hospital. One of the clients who died in a hospital was admitted to the hospital during an outpatient appointment to the Ottawa Regional Cancer Centre. Seven clients had two emergency department visits.

During July 2009, three clients died in an emergency department and two clients died in an Intensive Care Unit. Fourteen clients had one admission and two clients had five admissions. The number of days a client spent as a hospital in-patient during their last month of life ranged from one to 25 days. There were 168 in-hospital days by the 22 clients who died in a hospital, averaging 9.6 days.

Chemotherapy and/or radiation therapy were provided to six of the clients who died in a hospital. Active chemotherapy was documented for two of those receiving treatment.

Health profile for clients who died in the palliative care unit.

All 13 clients who died in the Palliative Care Unit had a diagnosis of cancer. Six of the clients who died in a palliative care unit did not have any documentation identifying co-morbidities.

The majority of the clients (7) who died in a palliative care unit made one trip to an emergency department. Nine clients who died in a palliative care unit made eleven visits to an emergency department.

There were 114 in-patient hospital days spent by 10 clients who later died in the Palliative Care Unit. Eight clients had one hospital admission and two clients were hospitalized twice during their last month of life. The number of days spent in a hospital ranged from zero to 21 for the clients who were hospitalized.

Seven clients did not receive chemotherapy and/or radiation therapy treatment during their last month of life. Two clients who died in a palliative care unit received treatment and there were three clients where it was unknown if treatment occurred.

Table 3 provides a comparison of some of the socio-demographics and health profiles by location of death.

Table 3

Comparison of Some Demographics and Health Profiles by Location of Death

DEMOGRAPHICS							
HOME n = 43		HOSPICE n = 9		HOSPITAL n = 22		PCU n = 13	
Males	19	Males	5	Males	10	Males	8
Females	24	Females	4	Females	12	Females	5
Preferred Loc Death		Preferred Loc Death		Preferred Loc Death		Preferred Loc Death	
Home	39	Home	2	Home	9	Home	6
Hospice	2	Hospice	5	Hospice	2	Hospice	1
PCU	0	PCU	0	PCU	0	PCU	0
Unknown	2	Unknown	2	Unknown	11	Unknown	6
Partner	28	Partner	8	Partner	14	Partner	7
No Partner	15	No Partner	1	No Partner	8	No Partner	5
Residence		Residence		Residence		Residence	
Home	34	Home	7	Home	20	Home	13
Retirement Home	9	Retirement Home	2	Retirement Home	2	Retirement Home	0
Days on CCAC Pall		Days on CCAC Pall		Days on CCAC Pall		Days on CCAC Pall	
14 & under	7	14 & under	3	14 & under	5	14 & under	1
15-20	6	15-20	1	15-20	2	15-20	1
30-60	7	30-60	0	30-60	6	30-60	2
61-90	1	61-90	0	61-90	1	61-90	4
91-180	11	91-180	3	91-180	6	91-180	2
181-360	10	181-360	1	181-360	1	181-360	2
361 & over	1	361 & over	1	361 & over	1	361 & over	1

HEALTH PROFILE							
HOME n = 43		HOSPICE n = 9		HOSPITAL n = 22		PCU n = 13	
Cause of Death		Cause of Death		Cause of Death		Cause of Death	
Cancer	38	Cancer	7	Cancer	19	Cancer	13
Pulmonary Fibrosis	2	Pulmonary	0	Pulmonary Fibrosis	0	Pulmonary	0
Cardiac	2	Fibrosis	2	Cardiac	2	Fibrosis	0
Dementia	1	Cardiac	0	Dementia	0	Cardiac	0
		Dementia		Pneumonia (+ multi-morbidities)	1	Dementia	
No. of Co-morbidities		No. of Co-morbidities		No. of Co-morbidities		No. of Co-morbidities	
Zero	2	Zero	4	Zero	6	Zero	6
One	10	One	1	One	6	One	3
Two	1	Two	1	Two	3	Two	2
Three	4	Three	0	Three	1	Three	1
Four	4	Four	1	Four	3	Four	1
Five	2	Five	1	Five	2	Five	0
No. of Hosp Admits in Last Month		No. of Hosp Admits in Last Month		No. of Hosp Admits in Last Month		No. of Hosp Admits in Last Month	
0	36	0	5	0	3	0	3
1	7	1	4	1	15	1	8
				2	4	2	2
12 Admits by 7 clients		4 Admits by 4 clients		23 Admits by 19 clients		12 Admits by 10 clients	
Treatments		Treatments		Treatments		Treatments	
Chemotherapy &/or Radiation	8	Chemotherapy &/or Radiation	6	Chemotherapy &/or Radiation	6	Chemotherapy &/or Radiation	2
Active treatment	4/8	Active treatment	3/6	Active treatment	3/6	Active treatment	0
No	33	No	2	No	15	No	7
Unknown	2	Unknown	1	Unknown	1	Unknown	3

HOME n = 43		HOSPICE n = 9		HOSPITAL n = 22		PCU n = 13	
No. of Days at Home in Last Month		No. of Days at Home in Last Month		No. of Days at Home in Last Month		No. of Days at Home in Last Month	
14	1	1	1	6	2	1	1
15	1	6	1	10	1	7	1
18	1	9	2	13	1	8	1
23	2	11	1	16	1	11	3
25	1	17	1	17	2	15	2
27	1	28	1	20	1	16	1
31	36	31	1	24	2	17	3
				27	3	21	1
				28	1		
Total= 1261 days by 43 clients		Total= 129 days by 9 clients		29	2	146 days by 13 clients	
Average 29.3 days		Average 14.3 days		30	2	Average 12.8 days	
				31	4		
				Total= 395 days by 22 clients			
				Average 19.9 days			

Note: PCU = palliative care unit; LO = location; CCAC Pall = Community Care Access Centre Palliative Team; MD = physician; HV = home visit; CPCP = community palliative care physician; PPSMCS = Palliative Pain and Symptom Management Consultative Service; No. = number; ED = emergency department; Hosp = hospital.

Services Utilization

1. What palliative care services were utilized during the last month of life?

For this study, the palliative care services utilized were CCAC services including nursing visits, shift nursing, PSS, EOL PSS, therapy visits (physiotherapy, occupational therapy, nutrition and social work) and equipment rental. The use of emergency departments, hospitalizations and type of physician services were also included.

2. Where did the clients die?

The clients died in one of four locations: Home, a hospice, a hospital or the palliative care unit.

3. Is there a relationship between the quantity of palliative care services utilization and location of death?

The following are the findings of the services utilization (visit nursing, shift nursing, PSS, EOL PSS and therapy) for the sample and each location of death. Table 4 presents a summary of each service by location of death. Each service is categorized by the percentage of clients who died at each location averaged over the last five weeks of life, and the average number of visits/hours received during the last month of life at each location of death. The percentage of clients who died at each location was used rather than the actual number of clients to allow comparison using a value meaningful across all the services and locations of death.

Table 4

Comparison of Services by Location of Death

Location Of Death	Services									
	Visit Nsg		Shift Nsg		PSS		EOL PSS		Therapy	
	%	Ave	%	Ave	%	Ave	%	Ave	%	Ave
Home (n = 43)	81.8	71.8	11.3	218.7	43.7	186.8	14.9	179.3	51.2	0.9
Hospice (n = 9)	37.7	14.6	4.4	3.0	43.7	8.6	11.1	26.0	4.4	0.2
Hospital (n = 22)	29.9	34.6	5.4	30.4	17.3	24.4	5.4	15.1	45.5	0.7
PCU (n = 13)	43.3	6.8	7.7	16.0	20.0	22.0	9.9	30.2	2.3	0.4

Note. % = percentage of the number clients who received services and died at the location, averaged over the last month of life. Ave = number of visits/hours received by the clients who died at the location averaged over the last month of life. The values are rounded to the nearest decimal point. Nsg = Nursing; PSS = Personal Support Services; EOL PSS = End-of-Life Personal Support Services; PCU = Palliative Care Unit.

Nursing visit services.***Nursing visit services for the sample.***

Nursing visits with the Champlain CCAC Ottawa Palliative Program refer to services provided by a nurse who has expertise in palliative care nursing, usually a Registered Nurse, who visits the client at home to provide ongoing assessment and symptom management. During July 2009, there were 875 nursing visits made to 75 clients, ranging from one to 43 visits. The total number of nursing visits by week varied each week. There were 145 nursing visits provided during week 1; 192 visits made during week 2; 185 visits occurred during week 3; 219 visits, the highest number of visits made in one week, were made during week 4; and during the week when death occurred – week 5, 134 visits were made.

Clients who died at home.

The forty-three clients who died at home received 633 nursing visits, with an average of 3.7 visits. For each client, these visits were tracked weekly during their last month of life. During week one, 29 clients received 78 nursing visits. Week two, 32 clients had 116 nursing visits, week three, 35 clients had 131 nursing visits, week 4 four, 40 clients had 176 nursing visits and week five (the week death occurred) 40 clients received 132 nursing visits. During the fifth week, one client did not receive nursing visits because the client was at his/her cottage when death occurred. This was a death at home.

The number of clients who received nursing visits each week does not always reflect the total number of clients who died at each location. The reasons some clients did not receive visits during a particular week during their last month of life varied: Admission to the palliative program had not occurred; some clients were in the hospital; a visit was not required or requested. The total number of clients who received visits, plus those that did not equals the number of clients who died in each location.

Clients who died at the hospice.

There were 73 nursing visits made with an average of 4.3 visits to the nine clients who died at the hospice. Five clients received 20 and 22 nursing visits during weeks one and two respectively. Three and two clients received 12 nursing visits during weeks three and four respectively. During week five (week death occurred) two clients received seven nursing visits.

The reasons nursing visits were not made are the same as those who died at home with the addition of admission to the hospice. Five of the clients were admitted to the hospice during week four and week five all nine had been admitted.

Clients who died in a hospital.

There were 173 nursing visits made, with an average of 4.6 visits, to the 22 clients who died in a hospital. Week one and two 12 clients received 36 and 40 nursing visits respectively. Week three 13 clients and week four 14 clients received 41 nursing visits. During week five 15 nursing visits were made to 7 clients.

The reasons nursing visits were not made is the same as for those clients who died at home: not admitted to the palliative program, no visit required or requested and client an in-patient in a hospital.

Clients who died in the palliative care unit.

There were no nursing visits made to any of the clients who died in the Palliative Care Unit during the last two weeks of life because they either had been admitted to the Unit or were hospitalized. Nursing visits were made to clients who died in the palliative care unit are as follows: Week one 17 visits to nine clients; week two 29 visits to 11 clients; and, week three 15 visits to 6 clients.

Week three there were 5 clients in a hospital and 7 clients in a hospital during week four and therefore did not receive nursing visits.

Shift nursing services.***Shift nursing services for the sample.***

Shift nursing services refers to care by a nurse, usually a Registered Practical Nurse, who provides bedside nursing care during a block of time at the client's home. There were 1253.5 hours of shift nursing services provided to 19 clients during July 2009. The shift nursing hours ranged from one to 261 hours.

Clients who died at home.

Shift nursing hours ranged from four hours to 12 hours with eight to 12 hours as the usual number of hours for providing this service. Shift nursing hours totaled 1093.5 hours for the clients who died at home. Week four and five 8 clients received 428 and 405.5 hours of shift nursing respectively.

Clients who died at the hospice.

Two clients received shift nursing (4, 11 hours) during their last month of life prior to their admission to the hospice.

Clients who died in a hospital.

Shift nursing services totaled 144 hours for the clients who died in a hospital. One client received shift nursing during the first four weeks (24, 40, 40, 32 hours per week) and two clients received a total of 16 hours of shift nursing week five.

Clients who died in the palliative care unit.

One client who died in the palliative care unit received 16 hours of shift nursing during Week 3.

Personal support services.

Personal support services for the sample.

Personal support workers (PSS) provide the client in-home assistance with personal and bedside care, as well as respite for caregivers and family members. This service is usually provided in short blocks of time – one to three hours. The Ontario Ministry of Health and Long Term Care guidelines regulate a maximum of 15 hours per client per week. PSS provided 1168.5 hours over the month of July 2009 to the study sample with a range of one to 75 hours for the 44 clients who used this service.

Clients who died at home.

There were 933.75 hours of PSS provided to the clients who were recipients and died at home. During week four the largest number of clients (24) received the highest number of PSS hours (266.5).

Clients who died at the hospice.

There were 43 hours of PSS provided to clients at home over week one to week three (17, 16, 10 hours) before admission to the hospice.

Clients who died in a hospital.

Those clients who received PSS and died in a hospital used 122 hours over the last month of life. The number of hours per week ranged from 11 (week five) to 34 (week two).

Clients who died in the palliative care unit.

There were 110 hours of PSS provided to 13 clients over the first three of five weeks. Week two was the largest number of clients (5) and used the highest number of hours (52) of those who died in a palliative care unit.

End-of-life personal support services.

End-of-life personal support services for the sample.

The end-of-life personal support services (EOL PSS) are part of the designated CCAC budget of hours available to the Champlain CCAC Ottawa Palliative Program clients when additional PSS are required at the end stage of their illness. EOL PSS supplied 1056 hours, with a range of one to 289.5 hours for the seventeen clients who used these hours.

Clients who died at home.

There were 896.5 hours of EOL PSS provided to clients who died at home. The number of clients and hours per week were as follows: Week one, 7 clients received 171.5 hours; week two, 5 clients received 239 hours; week three, 5 clients received 186 hours, week four, 10 clients received 221 hours; and, week five, 5 clients received 79 hours.

Clients who died at the hospice.

During Week two, one client, who died at the hospice, used 26 hours of EOL PSS hours.

Clients who died in a hospital.

There were 75.5 EOL PSS hours provided to some clients who died in a hospital. Week one, three, four and five, one client received EOL PSS (3, 20, 16.5, 15 per week) and week two, two clients received 21 hours.

Clients who died in the palliative care unit.

Week one, one client received 18 hours, week two, three clients received 74 hours, week three two clients received 59 hours. Clients received 151 EOL PSS hours over weeks one to three with a range of 18 to 59 hours.

Therapy services.***Therapy services for the sample.***

Therapy services at the Champlain CCAC were comprised of Physiotherapy, Occupational Therapy, Social Work, Nutrition, and Speech Therapy. Due to the limited number of therapy visits made to the study sample, the total number of visits made during July 2009 was reported on a monthly basis rather than weekly accounting. Twelve clients received a total of 18 visits by a physiotherapist. Occupational therapists made 36 visits to 20 clients. Three clients were seen by a nutritionist for one visit each. Social workers conducted a total of 9 visits to five clients and no one received the services of a speech therapist.

Clients who died at home.

Occupational therapy was the most frequently accessed therapy with 28 visits made to 15 clients. There were five physiotherapy visits made to three clients and five social worker visits to five clients and lastly, two dietician visits to two clients.

Clients who died at the hospice.

Two of the clients who died at the hospice received three visits from an occupational therapist during their last month of life. A physiotherapist and a dietician saw one client each for one visit. Social work and speech therapy services were not provided.

Clients who died in a hospital.

Seven clients who died in a hospital received 11 physiotherapy visits during their last month of life. A social worker provided three visits to two clients and an occupational therapist visited one client.

Clients who died in a palliative care unit.

One client received three occupational therapy visits during their last month of life.

Equipment.

With one exception, all of the clients in this study made use of medical equipment provided by the CCAC Palliative Program. The most common types of equipment rented by the CCAC on the client's behalf included hospital beds, air mattresses, bedrails, commodes, raised toilet seats, walkers, wheelchairs, and pumps for administering medication. Medical supplies required to administer medication were also provided.

Services utilization figures by location of death for the sample.

The summary of services utilization averages by location of death is depicted in Figure 3. A comparison of the average services utilized with the average percentages of clients who utilized the service is portrayed in Figure 4.

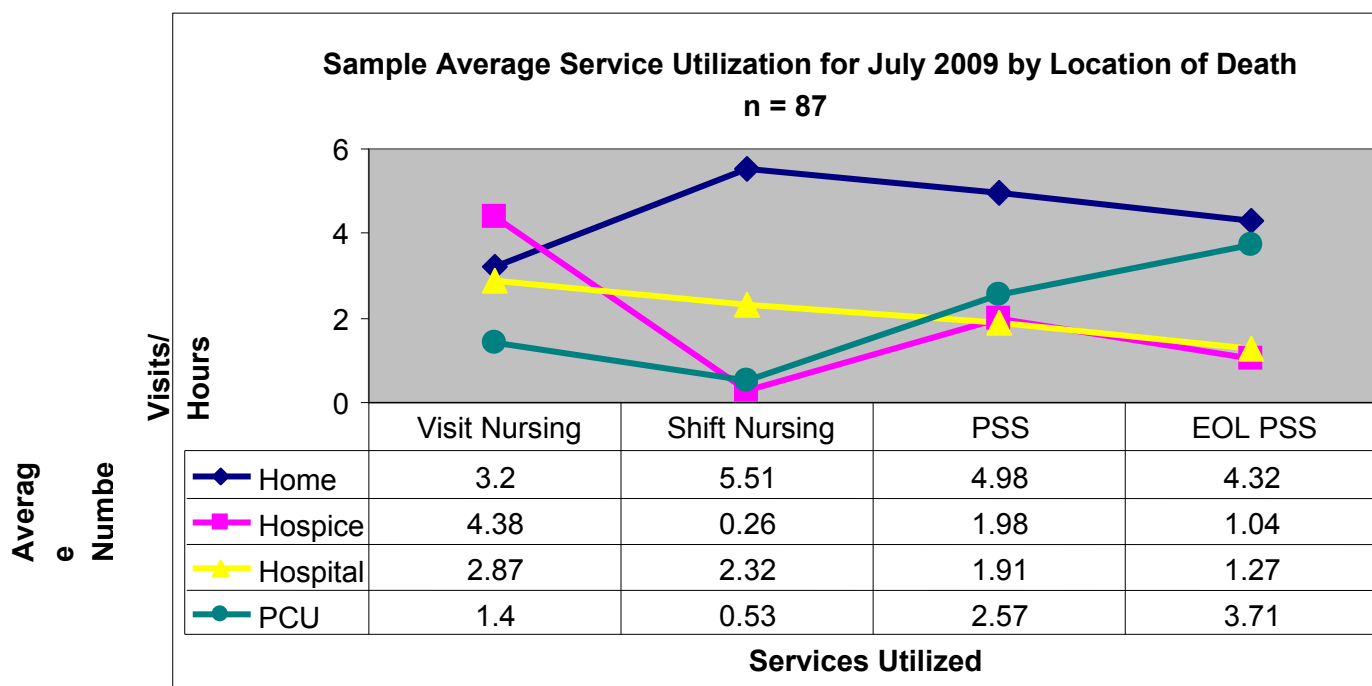


Figure 5. Averages of Service Utilization n = 87. Visits refer to the units in which visit nursing services are provided. Hours refer to the units in which shift nursing, personal support (PSS) and end-of-life personal support services (EOL PSS) are provided. PCU = palliative care unit.

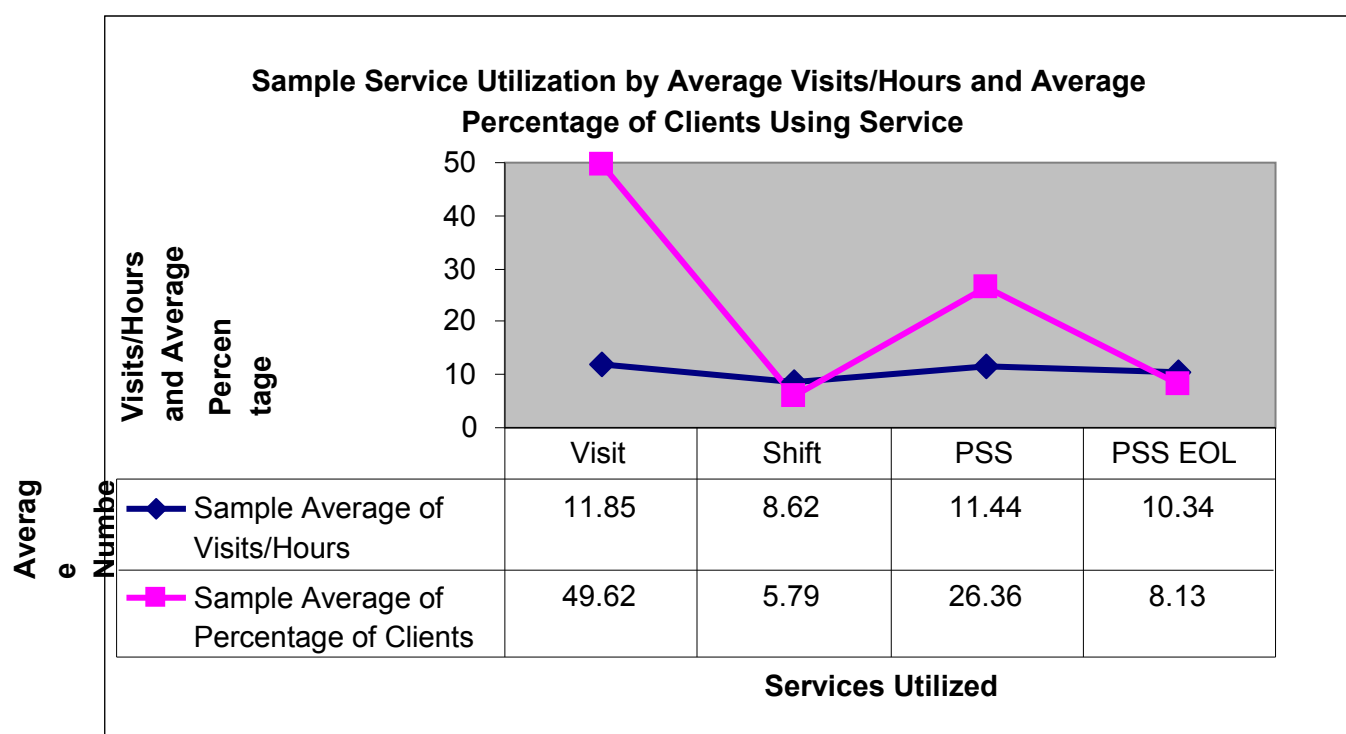


Figure 6. Averages of Service Utilization and Averages of Percentage of Clients Using Service n = 87. Visits refer to the units in which visit-nursing services are provided. Hours refer to the units in which shift nursing, personal support (PSS) and end-of-life personal support services (EOL PSS) are provided. PCU = palliative care unit.

4. Is a greater quantity of CCAC palliative care services related to the proportion of time clients who were palliative spent at home?

Clients who died at home

The clients who died at home spent a total of 1261 days at home during their last month of life. This is an average of 29.3 days for the 43 clients. Thirty-six clients spent their last month at home. The seven remaining clients were at home from 14 to 27 days with six data points.

Clients who died at a hospice

Clients who died at a hospice spent an average of 14.3 days at home. This is a total of 129 days and ranged from 1 to 31 days for the nine clients with seven data points.

Clients who died at a hospital

The 22 clients who died in a hospital spent a total of 395 days at home with an average of 19.9 days. The number of days at home ranged from 6 to 31 days with 12 data points.

Clients who died at the palliative care unit

The 13 clients who died at the palliative care unit spent an average of 12.8 days at home. This was a total of 146 days with a range of 1 to 21 days and eight data points.

Table 5 compares the number of days a client spent on the CCAC palliative program by location of death.

Table 5

Number of Days on the Palliative Program by Location of Death

Days on Palliative Program	Location of Death			
	Home n = 43	Hospice n = 9	Hospital n = 22	PCU n = 13
1 – 14	7	3	5	1
15 – 30	6	1	2	1
31 – 60	7	0	6	2
61 – 90	1	0	1	4
91 – 180	11	3	6	2
181 – 360	10	1	1	2
361 & Over	1	1	1	1

Note. PCU = Palliative Care Unit

5. Was the location of death the clients' preferred location of death?

The preferred and actual location of death was key information for this study. The majority of clients who wished to die at home were able to do so (91%). Many clients who indicated the hospice as their preferred location to die met their goal (56%). No one indicated a preference to die in the palliative care unit or a hospital. The timing of asking the client their preferred location for death was not recorded in the chart documentation. There were 21 charts where the preferred location of death was not documented.

Forty-seven clients identified home as their preferred location to die. Forty-three clients died at home. Of the clients who preferred to die at home but did not do so, two died at the hospice and six clients died in the palliative care unit. Two clients who died at home had not identified a preferred location to die.

Nine clients died in a hospice. It was the preferred location for death for eight clients. Two of these clients died at home and one died in the palliative care unit. Two clients who died in a hospice had not identified a preferred location.

No one identified the hospital as his or her preferred location for death.

Twenty-two clients died in a hospital.

Thirteen clients died in the palliative care unit. No one reported a preference to die in the palliative care unit. Six clients wanted to die at home, one wanted to die in a hospice and six had not identified a preferred location for death.

Table 6 presents, by location of death, where the clients who indicated a preference wished to die compared to where the deaths actually occurred.

Table 6

Preferred and Actual Location of Death

Preferred Location of Death n = 87	Total # Clients	Actual Location of Death n = 87	Total # Clients
Home	56	Home	43
Hospice	10	Hospice	9
Hospital	0	Hospital	22
PCU	0	PCU	13
Unknown	21		

Note. PCU = Palliative Care Unit

Summary

In summary, there are five key findings from this study, which was an investigation of the utilization of palliative care services, acute care services and location of death for palliative CCAC clients during their last month of life. The results are as follows:

1. The majority of the clients, who had expressed a preference, died in their preferred location, dying at home or in a hospice.
2. The role of the community palliative care physicians was an important component of the services that supported the clients to die in their location of choice. Seventy-seven percent of the clients who achieved their goal of dying at home received their medical care from palliative care physicians, who visited their clients at home.
3. Over 25% of the study sample died in a hospital and the clients used a larger number of in-patient hospital days than the clients who died at home or in the hospice. Almost one quarter of the clients who died in a hospital died in an emergency department or an ICU.
4. During the last month of life, 25% of the clients received chemotherapy and/or radiation therapy and, for 45% of the clients who received treatment, it was considered active treatment for their cancer.
5. The clients who died at home used more CCAC services than those who died in other locations. A larger percentage of clients who died at home received CCAC services, compared to the number of clients dying in other locations. Of the clients who died at home, 83.7% spent the entire month before death at home.

These findings are discussed in further detail in chapter five.

Chapter Five: Discussion

In this final chapter, the key findings from this study are discussed. The benefits of using an adaptation of Andersen's Behavioral Model of Health Services Utilization (2008) for this study are examined. The results of the research are discussed under these headings: utilization of services, preferred location for death, hospital deaths, emergency departments and hospital admissions, chemotherapy and/or radiation therapy treatment and methods. Limitations of the study and implications for practice, research, policy, and education conclude the chapter.

The research questions that guided this study were as follows:

1. What palliative care services were utilized during the last month of life?
2. Where did the clients die?
3. Is there a relationship between the quantity of palliative care services utilization and location of death?
4. Is a greater quantity of CCAC palliative care services related to the proportion of time palliative clients spent at home?
5. Was the location of death the clients' preferred location of death?

Andersen's Behavioral Model of Health Services Utilization (2008) (Adapted)

The benefits of applying Andersen's (2008) model as adapted for this research study were many. The use of the model informed instrument development, data collection, and categorization of the data. The use of the adapted model facilitated the process of answering the research questions and examining the relationship between the services used and the location of death.

Through the adaptation of the model, it became a system's model rather than a behavioural model. Examination of individual variables such as satisfaction, decision-making processes, and cultural influences were no longer included in the adapted model.

Andersen's (2008) model adapted for this study provided structure and context to this study. In the adaptation of Andersen's model used in this study, the 'Health Care System' and 'External Environment' components of the model were explored in the examination of palliative care at the national, provincial, regional and local levels in Canada. The 'Environment' category that encompasses the components, 'Health Care System' and 'External Environment', offered a broad perspective of palliative care before focusing on the details of services utilization in a specific community. Use of the model to develop the data collection tool and focusing the data collection on population factors (socio-demographic data, physician services, treatments, diagnoses and health profiles) and health behavior factors (health services used) highlighted the value of this adapted model for this study. The predisposing factors, enabling resources, need factors, and health behaviors were the categories used to examine who used the CCAC services, what the need was for services and lastly, what CCAC services were used (Klinkenberg et al., 2005). The outcome or findings of CCAC services used by clients in each location of death provided the data that were analyzed for patterns and trends in services utilization for clients who died at home, in a hospice, a hospital or a palliative care unit.

Andersen (2008) identified economics or funding as an 'Enabling' factor in both the 'Contextual Characteristics' and 'Individual Characteristics' of his model.

The adapted model used in this study did not include the financial implications of services utilization. The cost of services was beyond the focus of this study where the objective was to study the types of services and quantity of the services.

The adapted model's outcome, the location of death, was specific to this study's research questions and objectives. This outcome differed from Andersen's (2008) outcomes that he identified as 'Consumer Satisfaction', 'Perceived Health', and 'Evaluated Health'. Andersen's outcomes are consistent with behavioral variables rather than system factors that were the subject of this study.

Andersen's (1995) initial versions of his model focused on 'system' factors. In the final version of his model, he recognized the need to combine the 'system' factors with the 'individuals' characteristics' when examining services utilization (Andersen, 2008). The analysis of the data in this study generated a greater understanding of the use of palliative care services and their impact on location of death. The adaptation of the model proved to be useful in answering the research questions because the categories and indicators related to palliative care from the federal (Canada), provincial (Ontario), regional (Champlain Health Integration Network), and local (Champlain CCAC Ottawa Palliative Care Program) levels of palliative care services utilization and provision. The chart audit tool was developed directly from the 'Population Characteristics, 'Health Behaviour' and 'Outcomes' categories and the specific indicators identified from the adapted the model were used for collection of the data from charts.

Adaptation of this model was effective for this study on palliative care services utilization and location of death. Similar modifications to Andersen's model (2008), reflecting specific factors for particular conditions or situations can be developed to

collect data in other areas of health services research. Klinkenberg et al. (2005) used Andersen & Newman's (1973) model in a palliative care study by extrapolating the part of the model that was relevant for their research – predisposing factors, enabling resources and need factors. The application of the model as a whole, with the adaptations made for this study, enabled a view of palliative care services utilization from a broad context and the local perspective.

Utilization of Services

The purpose of this study was to investigate the utilization of palliative care services, acute services, and location of death for palliative CCAC clients during their last month of life. Patterns of services utilization were evident in the findings and the quantity of services used changed depending on the location of death. When examining services utilization in the four locations of death, home, hospice, hospital and a palliative care unit, it is important to consider not only the services that were used but the number of clients who used the services.

The clients who died at home used the greatest number of visits and/or hours of service and the number of visits/hours of service increased weekly as death approached. More clients who died at home used CCAC services, so not only were there high numbers of visits and/or hours provided, a larger number of clients received services than clients at other locations of death.

In recent studies by Seow, Barbera, Howell and Dy (2010a, 2010b) they demonstrated that when visit nursing, shift nursing, and personal support services increased as death approached, and particularly in the last month of life, the odds of death at home increased. The findings in the present study further support the

research conducted by Seow et al. as the results showed the higher the services utilization, the greater the number of clients who died at home.

As the clients' need for skilled assessment of pain and symptom management, and bedside palliative care increased, the end-of-life personal support services provided by unregulated health care workers decreased and the shift nursing services, provided by licensed professionals, increased. This pattern of services utilization allowed the clients to continue to have their increasing and changing palliative care needs met at home and enabled them to attain their goal of dying in their preferred location.

There are some understandable reasons for variations in services utilization for clients who died in a hospice, hospital, or palliative care unit. As services utilization increased the closer to death for clients who died at home, the services utilization decreased for the clients who died in the hospice or palliative care unit. The decrease in services used was expected because, as death approached, the clients moved into the facility where they died. The services used by clients who died in a hospital did not show a consistent pattern of increasing or decreasing visits and/or hours during their last month of life. Services used by those who died in hospital fluctuated weekly depending on how many clients were hospitalized during a particular week. Clients who had multiple admissions to a hospital during their last month of life had less time at home to be able to use the services. Although a small number of clients who died in a hospital or palliative care unit used a large quantity of services, it was not documented why they died where they did. None of the clients had expressed a wish to die at either of these locations.

Another consideration for variation of services utilization in the four locations in which death occurred was contextual differences. Theoretically, hospitalized clients may have greater or easier access to services such as chemotherapy or radiation treatments. Although clients in the community receive similar services as clients in a hospital, (e.g. nursing, physiotherapy) the hospital setting may facilitate a faster response to the service request. Accessing chemotherapy or radiation treatments for the client who is dying and living in the community places a greater demand on the client and/or caregiver in terms of energy and participation to get to the hospital than that of hospitalized clients. Although the effort to get to a hospital for these treatments can be extreme, a community setting does not negate, for example, radiation treatment for pain management when appropriate. Clients who reside in a hospice or palliative care unit do not receive active or aggressive chemotherapy or radiation. The focus is palliation that includes symptom management, comfort measures and quality of life.

In this study it was not possible to explain why; overall, the clients who died in a hospice, a hospital, or palliative care unit used fewer visits and/or hours of service while they were at home when compared to the quantity of services used by those who died at home. It has been identified in the study that community palliative care physician services in Ottawa are an important component to supporting death at home. The study's findings demonstrate that the combination of all the services from CCAC and medical care at home are required to support death in home or hospice.

There are several points to consider that may influence why some clients do not remain at home. Utilization of services, for clients who are palliative, at home depends on the clients and/or caregivers acceptance of the services in the home. If

open discussion regarding palliative care needs and expectations has not occurred, the clients and/or caregivers may not understand and accept the need for increased services at home. This lack of knowledge may influence why some clients do not remain at home.

Although a client may decide where he or she would prefer to die at one point in time, this preference may change as symptoms increase, the caregiver becomes exhausted or for other personal reasons. The availability of human resources and possible shortages of service providers may be factors in where clients die but this information was not documented in the clients' charts.

Preferred Location for Death

In this study, a large number of clients were successful in dying in their preferred location. They received the palliative medical care and services needed to remain at home and die where they wanted to die.

The results in this study found that almost 60% of the clients died in their preferred location of home or hospice, indicating that the services utilized by these clients met their needs and provided the appropriate care to die in their chosen location. The high percentage of clients fulfilling their wish to die at home or in a hospice in this study is higher than in previous studies reporting preferred location of death. The Canadian Hospice Palliative Care Association Gold Standards (2006) found that more than 56% of patients with cancer die in acute care hospitals. Another study identified that 25% of deaths in Canada occur at home (Wilson et al., 2009). In the present study, high uses of CCAC services and physicians who home visit have been shown to support death at home. Several studies name services utilization and physician services as predictors of home deaths (Masucci, Guerriere,

Cheng & Coyte, 2010; Seow et al., 2010a, 2010b; Seow, King & Vaitonis, 2008; Wilson et al., 2009).

Another predictor of dying at home, expressing a preference for a location of death (Fukui et al., 2003; McWhinney, et al., 1995; Teno, 2005; Van den Eynden, 2000; & Wijk & Grimby, 2008), was supported by this study. A large number (81%) of the clients that were missing documentation of their preferred location for death, died in a hospital or a palliative care unit. The lack of documentation of a clients' preferred location for death provides evidence that it is important to ask clients where they want to die.

The Role of Community Palliative Care Physicians

The high number of clients in this study who received their medical care from community palliative care physicians demonstrates the value of this model of medical care for people who wish to die at home. Medical crises such as unmanaged symptoms or not having the appropriate medication can result in emergency department visits and/or hospital admissions, but could be avoided when medical care is provided by physicians with an expertise in palliative care and 24/7 availability to clients and health care professionals.

Burge, Lawson and Johnston (2003b) identified that dying in a hospital could be prevented through continuity of care by family physicians. A study by Brazil, Bedard and Willison (2002) found that home visits by physicians were necessary for home deaths to occur. In this study, all of the clients who died at home and 88.8% of the clients who died in the hospice were cared for by physicians who home visited.

Residents of Ottawa are fortunate to have access to specialized physicians who support clients in their wish to be cared for and die in their preferred location.

This model of community palliative care physician services is not available in most Ontario towns and cities. One of the reasons cited for the lack of physicians' providing palliative care in the community is the way payment for physicians' home visits for palliative care services is managed by Ontario Health Insurance Plan (OHIP – a universal provincially funded health care program). In the past year, there has been announcement by the Ontario government that “the new billing codes of the Ontario Ministry of Health and Long Term Care for providing palliative care by family physicians have addressed previous concerns of inadequate remuneration for family physicians for this type of care” (Champlain Hospice Palliative and End of Life Care Network, 2010, p.4). Although this is a positive move by the Ministry, there remains a question about whether the remuneration is adequate, based on challenges family physicians have in managing overcrowded practices, scheduling home visits and being available on call. More palliative care specialists and family physicians with expertise in palliative care and the ability to make home visits are needed to meet the demands of the increasing numbers of an aging population who need palliative care.

A plan was developed by the Champlain Hospice Palliative and End of Life Care Network (2010), entitled *Regional Hospice Palliative Care Program for the Champlain LHIN*. It identified the need to increase primary level medical palliative care, noting, “Most of the primary palliative care in the community is delivered by a small group of family physicians who do only palliative care” (p. 3). Implementation of the plan's recommendation “to increase the number of family physicians and primary health teams actively involved in providing palliative patients to increase the

long term sustainability and access of [hospice palliative care] to patients” (p. 3) will be important to improve palliative care in Ottawa.

Hospital Deaths, Emergency Departments and Hospital Admissions

The charts indicated that no one reported hospital as his or her preferred location to die. It is well documented in the palliative care literature that dying in hospitals is costly to the health care system and rarely the location people with a terminal illness wish to die (Barbera, Paszat, & Chartier, 2005; Brazil et al. 2005; Seow, King, & Vaitonis, 2008). There are circumstances and situations when hospital care is the most appropriate location for people at the end stage of a life-threatening illness. Valid reasons for a hospital admission include spinal cord compression, uncontrolled pain and symptom management, the lack of a caregiver or a caregiver who is no longer able to manage the required care at home, or lack of available, the community health care resources.

In this study, 25% of the clients died in a hospital and half of this group had not expressed a preferred location for death. In findings by Cancer Care Ontario (2009b), dying in a hospital is contrary to the research that supports the desire of individuals with life-threatening diseases to experience ‘a good death,’ with quality palliative care that includes pain and symptom management, in their location of choice. Barbera, Paszat & Chartier (2006) reported that one indicator of poor quality of palliative care is death in a hospital. In their 2006 study of Ontario patients with cancer, Barbera et al. found that home care, outpatient palliative assessments, and physicians who home visit were associated with decreased odds of emergency department visits, ICU admissions, and receiving chemotherapy during the last two weeks of life. In Barbera et al.’s study, the clients who used the least amount of

CCAC services, were those who died in a hospital or palliative care unit, made more trips to an emergency department, had a higher number of hospital admissions and were the clients who died in an emergency department or an ICU. In Barbera et al.'s study 28% of the sample died in an emergency department or an ICU and used few CCAC services.

It was not within the realm of this study, nor did the chart audits identify the reasons clients were admitted to various facilities, including hospitals. It was not possible to determine if the reasons or causes for hospital admissions could have been met or addressed from home. It is likely that the disease progression among the clients, in this study, with a cancer diagnoses (>88%) followed similar trajectories, as has been reported in the literature (Fassbender, Fainsinger, Carson & Finegan, 2009; Lunney, Lynn, Foley, Lipson & Guralnik, 2003; Seow et al., 2010a, 2010b). The clients who died at home probably experienced similar symptoms, issues, or crises to those of the clients who died elsewhere. This study showed that the CCAC services used by the clients and the community palliative care physicians' services provided the resources to support people at home. The clients who died in a hospital or a palliative care unit did not use the same quantity of services and they needed other resources to meet their needs.

One possible explanation why some clients died in a hospital is that these clients were often middle-aged and perhaps not ready to 'give up' or perhaps in some circumstances, the clients had not been informed how far their disease had progressed. If clients did not know they were at the end stage of their illness, they might not have been prepared to request or accept additional services from the CCAC Palliative Program or a community palliative care physician. Improved

communication from health care professionals concerning the individual's disease progression and prognosis could provide the client with the opportunity to make choices when planning the time they have left.

There are a number of strategies that could prevent or lower hospital use by clients who are palliative. As noted above, communication is important when providing care to clients with life-threatening diseases (Field & McGaughey, 1998; Larson & Tobin, 2000; Middlewood, Gardner & Gardner, 2001). Health care professionals are not always comfortable or experienced in telling patients they will soon die or helping them explore their options.

Along with improving the educational curriculum at professional schools, the physicians and nurses currently working in hospital settings require opportunities to increase their knowledge and skills to care for individuals with end stage diseases. Hospital staff have a different working definition of palliative care than those who provide palliative care in the community (Gott, Ahmedzai & Wood, 2001; Pastrana, Jünger, Ostgathe, Elsner & Radbruch, 2008). In a hospital, someone is considered 'palliative' when he/she is actively dying, rather than the definition used within the palliative care community that asks the question "Would you be surprised if this person is still alive in 6 months?" (Champlain Hospice Palliative and End of Life Care Network, 2010). This difference in understanding when someone is palliative leads to confusion and at times inappropriate care for individuals who have a life threatening illness. Therefore, to improve palliative care in hospitals and transitions from a hospital to the community, hospital staff needs to align their understanding of what it means for a client to be considered palliative, using the Champlain Hospice Palliative and End of Life Care Network (2010) definition. This improved

understanding may help to identify when to put the CCAC services in place and decrease hospitalizations, emergency department use, and the number of deaths that occur unnecessarily in hospitals.

Another strategy to reduce the use of hospitals is to give clients and their caregiver's clear information and direction on how to manage situations at home and who to contact when problems arise, instead of calling an ambulance. This strategy will be successful only when there are enough available and knowledgeable community physicians to provide medical palliative care at home along with adequate CCAC services to meet the changing needs of clients who are palliative at home.

Emergency department staff needs education and support to recognize clients who arrive in an emergency department that are at the end stage of their disease. This recognition would enable the emergency department staff to identify the appropriate resources for the client and to direct the resources and client to more suitable locations. With increased CCAC support, the appropriate location might be home or admission to a palliative care bed in a hospital, a hospice, or palliative care unit – not the ICU.

Chemotherapy and/or Radiation Therapy Treatment

As discussed earlier, if clients were better informed about their disease progression and the pros and cons of treatment at the end stage of their illness, the number of clients in this study receiving treatment might have been lower. Lowering the number of clients who receive active treatment is of particular concern with the palliative population (Asola, Huhtala & Holli, 2006; Harrington & Smith, 2008). The goal of active treatment for cancer is understood to mean cure. Careful consideration

and discussion regarding the purpose and toxicity of chemotherapy and/or radiation treatment could provide clients with choices and options about how they wish to live until death occurs. The reduction in the number of people receiving treatment in their last month of life could decrease health care costs and more importantly, provide an improved quality of life for these clients.

The highest proportions of clients receiving treatment during their last month of life were the clients who died at the hospice or a hospital. Some of the clients who died at the hospice were transferred directly from the hospital. The information about who made the treatment decision when the disease is incurable - the oncologist or the client - was not available in this study.

Methods

Many studies have used large databases to examine home care services for clients who were palliative in the community (Brazil et al., 2002; Bruera et al., 1999; Burge et al., 2003a; Burge et al., 2008; Constantini et al., 2003; Seow et al., 2010a, 2010b; Seow et al., 2008). Although the sample size in this study was small compared to those of researchers using regional or provincial databases, the data collected were at the individual client level. This individual level data was more detailed than can be collected from large databases and provided new information (e.g. identification of the primary medical provider, which clients received chemotherapy, the relationship of the caregiver to the client) that advances the knowledge of the provision of community palliative care and services utilization that support clients in dying in their preferred location.

Chart audits, the method used in this study, allowed gathering relevant information that was located in the individual clients' chart notes and was not

available in the CCAC database. Whether the client had a community palliative care physician is an example of information found in the notes and not present in the database. The name of a client's family physician could be found in the database and if a community palliative care physician had assumed responsibility for clients' medical services, it was only documented in the clients' chart notes. This is an example of information that is lost when large databases are used as the only source of data in palliative care research.

One of the data sources for this study was the Chart in the Home. This binder is kept in the client's home and used for documentation by all those who provide care to the client. Unfortunately, the return rate for these binders to the CCAC after the clients die was very low. Although the case managers document their contacts with service providers in the chart notes, information documented by service providers, physicians and family members in the Chart in the Home is often lost. Since the completion of the data collection for this study, the Ottawa CCAC has improved the process for having the Chart in the Home returned.

Limitations

There are several limitations to consider in this study. The data that was collected was limited to the information that was available through the paper charts and electronic databases.

Due to the descriptive type of data collected and exploratory nature of this study, inferential statistics could not be used. Comparative data would need to be collected to determine if statistical significance was possible.

The sample used for this research only represented clients of the Champlain CCAC Ottawa Palliative Program. Although comparative data was not available, this

was not the focus of the research questions. The 14 CCACs in Ontario offer services to clients who require palliative care services at home but there can be local variations in the implementation of these services. Because of local differences, some of the findings in this study might not generalize to other CCAC Palliative Care Programs.

Individual preferences of clients and/or caregivers influence decisions related to location of death and use of services. Data on personal preferences were not recorded in the charts and databases. Investigation of individual influences on the location of death decision-making would add to the knowledge in the field of palliative care. This study did not address if or how the preferred location of death may have changed from the client's and/or caregiver's initial expression of their preference as symptoms changed and death approached.

This research does not consider economics, funding, and cost of services utilization. Exploration of financial implications will be required before implementation of policy changes.

The community palliative care physicians model is unique in Ottawa and had a positive impact on clients remaining at home to die, if they so desired. This medical service increased the numbers of clients who died at home and may be responsible for the higher number of deaths at home compared to similar studies in places without this type of community medical palliative care. The model of community palliative care medical services limits the generalization of the study results to other palliative care settings.

Implications for Practice

As this study demonstrated, the greater the use of CCAC services the more likely it is that people with life-threatening illnesses will die in their preferred location, home or the hospice. To meet the increasing numbers of people who will die over the next decades, it will be important for case managers and service providers to encourage and assist CCAC clients to accept services at a level that will support their death in their preferred location. Use of services at the optimal level allows service providers to identify potential problems and complications appropriately so they can be addressed, and if feasible, prevent unnecessary emergency department visits and hospital admissions. If the reasons and rationale for emergency department visits and hospitalizations were documented by case managers and service providers, then, if gaps in services exist, they could be tracked and consideration given to changes in practice that would reduce these costly occurrences.

To help clients make informed decisions related to their palliative care, community health care providers need to encourage questions from clients about the extent of their disease, prognosis, death and dying. When these difficult topics are discussed, it makes it easier to provide appropriate services and support so the clients can die in their preferred location.

When the preferred location for death was documented in the clients' charts, death usually occurred in their location of choice. As noted in the literature, the expression by clients of their desire to die at home is one of the factors that support death at home (Brazil et al., 2002; Karlson & Addington-Hall, 1998; McWhinney et al. 1995). Attention to asking clients their preferred location for death and

documentation of their responses is important and may influence the number of clients who die at home. Notation of this discussion, when it occurred and if it changed during the time of receiving CCAC services, will add useful information for future planning.

Case managers who work in hospitals could take a more proactive role in planning hospital discharges of clients who are palliative and in ensuring adequate services are arranged to support the care needs at home. Providing palliative care in the home environment is more challenging than in an institution such as a hospital and it is critical that adequate and appropriate services are in place for a smooth transition from hospital to home.

Implications for Research

This study was not able to determine if hospitalizations and emergency department visits would decrease for clients who died in the hospital or palliative care unit if they had a higher level of CCAC services utilization and a community palliative care physician providing the medical care at home. Further research in this area would be useful to identify the causes of emergency department visits and hospitalizations for the CCAC palliative population.

Investigation to determine who makes treatment decisions when clients have end stage disease might inform palliative care versus treatment rationale and protocols. Research in the area of informed consent for treatment when the client is palliative might clarify who makes the treatment decisions and how knowledgeable the client is about his or her disease when making these decisions. Perhaps this research information would decrease the number of people who receive chemotherapy and/or radiation therapy in the last month of life.

Other possible future research related to this study include investigation of clients' and caregivers' acceptance of CCAC services at home, whether the preferred location of death changes over time, and if CCAC services are available when needed, particularly shift nursing and EOL PSS. Individual behavioral variables were out of the scope of this study. Exploration of the influence of behavioral concepts on services utilization would be an interesting topic for future research. These issues might have influenced the services used by the sample in this study and the chart audits and databases did not reveal details or information on these areas of interest.

The role of the CCAC Ottawa Palliative Program case managers was not part of this study because every client had a case manager. The case management role is vital to the co-ordination and provision of CCAC services. Future investigation of services utilization with the community palliative care population would benefit from examination of the case manager's role and if case management practices have an influence on the location of death.

Implications for Policy

Implementation of the plan developed by the Champlain Hospice Palliative and End of Life Care Network (2010) to improve palliative care for the Champlain Region requires policy- and decision-makers to collaborate and develop policies that will move the plan to reality. As palliative care expands in the community, there will be a need for an increase in services. An increase in community palliative services has financial ramifications that need consideration along with implementation of policy changes. The decision-makers need to include this growth in their plans.

Current policies require that referral to community palliative care physicians must come from another physician. This policy requires review by the decision-makers and medical community to avoid situations where a client does not have a physician to make the referral or the client's physician refuses to make the referral, to a palliative care physician and the patient is therefore denied appropriate medical care.

The demand for palliative home care services are growing and an increase in services will be required. It will be necessary for government policy-makers to address the need for additional services and the required resources to support them.

Implications for Education

University programs in health care are continuously updating their curricula and are now including classes on palliative care, a positive move forward for people with a life-threatening illness (Matzo et al., 2003). The time dedicated to palliative care in courses is brief and requires more attention in the educational environment. Incorporating communication strategies into these classes, to develop skills and comfort when discussing difficult topics like death and dying, would provide clients who are palliative opportunities to make choices when planning the rest of their lives. Additional education would increase the confidence of the health care professionals to help initiate these difficult conversations.

Ongoing education and in-services for practicing health care professionals, to increase their knowledge and comfort level when working with people who have life-threatening diseases cannot be neglected. Because of the rapidly aging population, changes need to take place now. Physicians and nurses need to acquire skills to

open discussions on prognoses, treatment options, and care choices when patients have life-threatening illnesses.

Conclusion

It is possible to die in a chosen location when CCAC Palliative Care Program services are provided at a level that meet the needs of clients and when physicians who are experienced in palliative care provide medical care at home.

There are several ways in which the findings from this study may be generalized to other settings. Cancer Treatment Centres may re-examine the provision of chemotherapy and radiation to individuals whose disease is no longer curable, particularly as they approach the end of their lives. The 13 other CCACs in Ontario may benefit from the greater understanding of the use of palliative care services and location of death as larger centres in Canada have similar options for location of death. Differences may exist nationally or internationally in how home-based palliative care services are provided yet the type of services remain the same. Adaptation of Andersen's model to a health care system focus may be useful for others conducting services utilization research in the health care environment.

Most of the clients who used a high level of CCAC services were able to die at home. This study investigated the utilization of palliative care services, acute care services, and location of death, during the last month of life, for CCAC clients who were palliative. The evidence indicated that adequate resource allocation for clients requiring palliative care, while living in the community, enabled them to die in their preferred location. The use of costly acute care services can be minimized when the appropriate services are provided to CCAC clients who are palliative and at home.

An increase of palliative care information and related topics in the curriculum for future health care professionals will benefit the students and patients. Further education of health care professionals in the area of palliative care will advance their knowledge and skills and improve their practice to be able to meet the palliative care demands of the aging population.

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Appendix A

Data Collection Tool Headings

Demographics

Gender
Age range
Marital status
Informal caregiver
Languages spoken
Postal code
Residence

Physician Services

Family physician HV
PPSMCS
Community palliative care physician

Health profile

Diagnosis (1^o site if cancer)
Co-morbidities
Has private insurance for nursing
Wait period for hospital, hospice or PCU
Preferred location of death
Actual location of death
Date of admission palliative program (dd/mm/yyyy)
Last month of chemo or rads
Trips to emergency departments
Ambulance use
Hospital admissions
Hospital days
MIS d/c
Hospital d/c location
Diagnosis on discharge/cause of death
Date of death (dd/mm/yyyy)

Services

Nursing

Nursing visits week 5 before death
Nursing visits week 4 before death
Nursing visits week 3 before death
Nursing visits week 2 before death
Nursing visits week 1 before death (week of death)

Shift nursing available
Shift nursing hours week 5 before death
Shift nursing hours week 4 before death
Shift nursing hours week 3 before death
Shift nursing hours week 2 before death
Shift nursing hours week 1 before death (week of death)
Same nursing agencies
Private /insurance shift nursing hours used

Personal support services

PSS hours used week 5 before death
PSS hours used week 4 before death
PSS hours used week 3 before death
PSS hours used week 2 before death
PSS hours used week 1 before death

PSS EOL hours available
PSS EOL hours used week 5 before death
PSS EOL hours used week 4 before death
PSS EOL hours used week 3 before death
PSS EOL hours used week 2 before death
PSS EOL hours used week 1 before death
Same PSS agencies

Therapy

Physio visits
Occupational therapy visits
Nutrition visits
Social work visits
Speech therapy visits

Equipment