

**WHO USES RESIDENTIAL HOSPICE IN ONTARIO?**

**By**

**Ruth Evelyn Fuller Forbes**

**A thesis  
submitted to the Faculty of D'Youville College  
Division of Academic Affairs  
in partial fulfillment of the requirements  
for the degree of**

**Master of Science**

**in**

**Nursing**

**Buffalo, NY**

**October 23, 2013**

Copyright © 2013 by Ruth Evelyn Fuller Forbes. All rights reserved. No part of this thesis may be copied or reproduced in any form or by any means without written permission of Ruth Evelyn Fuller Forbes.

*THESIS APPROVAL*

**Thesis Committee Chairperson**

Name: \_\_\_\_\_ *J* \_\_\_\_\_

Discipline: \_\_\_\_\_ *J* \_\_\_\_\_

**Committee Members**

Name: \_\_\_\_\_ *J* \_\_\_\_\_

Discipline: \_\_\_\_\_ *Nursing* \_\_\_\_\_

Name: \_\_\_\_\_ \_\_\_\_\_

Discipline: \_\_\_\_\_ *J* \_\_\_\_\_

Name: \_\_\_\_\_ \_\_\_\_\_

Discipline: \_\_\_\_\_ *J* \_\_\_\_\_

**Thesis defended**

**on**

**October 23, 2013**

### Abstract

This retrospective case study was designed to describe the characteristics of individuals who use residential hospice for end of life care and death. Historical usage and demographic information for patients who used one Ontario hospice over a seven-year period was evaluated. Comparison was made with data collected by the provincial hospice organization from 17 hospices in Ontario for a three year period. Interviews with hospice administrators revealed contextual elements. The results indicated that the characteristics of hospice users studied were homogeneous for age groups, predominance of malignant diagnoses, few live discharges, and declining mean lengths of stay; and differed in the characteristics of bed usage, occupancy rates, and previous location of care. This initial examination established a base line for further study of patients who use freestanding hospice care at end of life, and identified important gaps in data elements to be collected.

### Acknowledgement

Mrs. Barbara Loomis and Dr. Genevieve Farrell provided initial support to the author for graduate work. The author benefited from the guidance and efforts of each of her thesis committee members, Dr. Tina Sinatra-Wilhelm, Dr. Mark Garrison and Mrs. Kathleen Baba Willison (McMaster University), but in particular from Dr. Eileen Nahigian (Committee Chair). Mr. Dana Bagwell assisted with statistical advice. Two administrators, one from the provincial hospice organization and one from Hospice A, willingly shared their expertise in hospice care. Dr. James W. Forbes offered unflagging encouragement and wisdom.

## Table of Contents

List of Tables .....	viii
List of Figures .....	ix
List of Appendices .....	x
 Chapter	
I. INTRODUCTION .....	1
Statement of Purpose .....	3
Conceptual Framework .....	3
Public health perspective .....	3
Nursing paradigm perspective .....	5
Human caring science perspective .....	5
Significance and Justification .....	7
Assumptions .....	8
Research Questions .....	9
Definition of Terms .....	10
Variables .....	12
Limitations .....	14
Summary .....	15
II. REVIEW OF THE LITERATURE .....	16
International Emergence of Freestanding Hospice .....	17
Preferences for Location of Care and Death .....	20
Development of Hospice Services in Canada .....	22
Policy Influences .....	24
Hospice Care in Ontario .....	25
Gaps in Data Collection .....	28
Conclusion .....	29
Summary .....	29
III. PROCEDURES .....	30
Introduction .....	30
Setting .....	30
Population and Sample .....	31
Data Collection Methods .....	31
Human Rights Protection .....	33
Tools and Treatment of Data .....	34
Conclusion .....	37
Summary .....	38

<b>IV. RESULTS</b>	<b>39</b>
Description of the Sample.....	40
Research Questions .....	41
Tools .....	41
Findings .....	41
Case Study .....	42
Research question .....	42
Monitoring context.....	43
Age .....	44
Gender.....	44
Male and female users by age group.....	46
Male users by age group .....	46
Female users by age group.....	46
Male and female users by age group.....	49
Male users by age group .....	49
Female users by age group.....	49
Admitting diagnoses .....	49
Malignancies .....	50
Non-malignant diagnoses.....	55
Unknown diagnosis.....	57
Bed usage.....	57
Length of stay .....	62
Discharge disposition.....	64
Primary residence.....	64
Provincial Reporting of User Characteristics .....	67
Research question .....	67
Monitoring context.....	67
Provincial patterns .....	69
Age .....	70
Admitting diagnosis .....	70
Bed usage.....	70
Length of stay .....	71
Discharge Disposition.....	71
Comparison of hospice A and provincial characteristics.....	71
Age .....	72
Gender.....	72
Admitting diagnosis .....	72
Bed usage.....	73
Length of stay .....	73
Discharge Disposition.....	74
Residential location.....	74
Interview Summary.....	75
Research question .....	75
Impacts on hospice use .....	75
Demand for residential hospice care.....	75

Resource use .....	77
Service responsiveness.....	77
Models.....	79
Complexities of diagnosis.....	81
Barriers.....	82
Perspective .....	84
Potential solutions.....	85
Research and data collection.....	85
Awareness .....	87
Funding .....	88
Other solutions.....	90
Summary .....	91
<b>V. DISCUSSION.....</b>	<b>92</b>
Summary .....	92
Conclusions .....	93
Relationship of the results to the conceptual framework.....	93
Relationship of the results to the literature .....	95
Relationship of the results to the research questions .....	99
Age and gender .....	100
Diagnosis.....	101
Bed usage.....	102
Length of stay .....	102
Discharge disposition.....	104
Residential location.....	104
Relationship of the results to the study design and data collection methods	110
Relationship of the results to the tools and instruments used .....	113
Relationship of the results to the data analysis methods.....	115
Implications for Practice .....	118
Implications for Policy.....	122
Implications for Education.....	124
Recommendations for Future Research.....	126
References .....	131
Appendices .....	139



## List of Tables

## Table

1.	Comparison of Admissions to Hospice A by Gender and Three Age Categories for Years 2006-2013 ( $N = 744$ ) .....	45
2.	Comparison of Admissions to Hospice A by Gender and by Age Stratified in Ten Year Increments for Years 2006-2013 ( $N = 744$ ).....	47
3.	Comparison of Malignant Cancer and Non-Malignant Diagnosis Among All Users Admitted to Hospice A by Gender for Years 2006-2013 ( $N = 744$ )	51
4.	Percentage Frequency of Twenty Most Common Malignant Diagnosis Among All Users Admitted to Hospice A by Gender for Years 2006-2013 .....	52
5.	Percentage Frequency of Six Most Common Non-Malignant Diagnosis Among All Users Admitted to Hospice A by Gender for Years 2006-2013 .....	56
6.	Percentage Frequency of Non-Malignant Diagnosis Among All Users Admitted to Hospice A by Age Group and Gender for Years 2006-2013 ( $N = 51$ ).....	58
7.	Bed Usage for Hospice A ( $N_1 = 389$ ) and Other Hospices Reporting Provincially ( $N_2 = 6789$ ) for Years 2010-2013 .....	59
8.	Comparison of Hospice A and Provincial User Characteristics by Age, Group Diagnostic Category, and Previous Location of Care for Years 2010-2013 .....	61
9.	Mean Length of Stay for Users of Hospice A and Other Hospices Reporting Provincially for Years 2010-2013.....	65
10.	Primary Residence of Users Admitted to Hospice A in 2012-2013 ( $N = 124$ )	66

## List of Figures

## Figure

1.	Comparison of Hospice A Admission Numbers by Gender and Fiscal Year .....	160
2.	Hospice A Residents Grouped by Age (Years) as a Percentage of Total Number for Years 2006-2013.....	161
3.	Year to Year Comparison of Percentage Admission to Hospice A by Gender .....	162
4.	Comparison of Percentage of Hospice A Users by Diagnostic Category By Year and Total.....	163
5.	Mean Length of Stay for Hospice A Users for Years 2006-2013.....	164
6.	Mean Length of Stay with Standard Deviations at Hospice A for Years 2006-2013 .....	165
7.	Annual Discharge Disposition for Hospice A Users in 2006-2013 .....	166

## List of Appendices

## Appendix

A	IRB Full Approval Letter from D'Youville College .....	139
B	Letters Requesting Institutional Permission .....	141
C	Redacted De-Identified REB Approval Letter from Participating Institutions	146
D	Participant Consent Forms .....	148
E	Interview Guide .....	153
F	IRB Description of Procedures .....	155
G	Human Subject Research Proposal .....	157

## **Chapter I**

### **Introduction**

Hospices are charitable, community, not-for-profit or faith-based organizations developed and governed by community palliative care (PC) activists, volunteers, foundations or faith organizations. In the province of Ontario, there are 27 freestanding residential hospices that provide end of life (EOL) care for adults over the age of 18 (Cuiker, 2012). Their service mandate is to serve the local community in which they are located. According to an administrator from the provincial hospice organization (personal communication, May 25, 2012), in addition to the funded 259 beds in these residential hospices, there are several independent hospices that do not receive provincial funding from the Ministry of Health and Long Term Care (MOHLTC). This care setting and service provides alternatives to hospital or home for EOL care and death. Some patients and families prefer these smaller, 6 to 10 bed, home-like facilities over larger acute care or long term care institutions. Other families choose residential hospices because they are unable to care for their loved ones at home.

The first hospice in Ontario was opened in 1997; by 2002, there were four residential hospices in Ontario. The recent increase in the number of hospices over the past fifteen years reflects the cost conserving move away from government funded health care institutions towards community based care (Fassbender, Fainsinger, Brenneis, Brown, Braun, & Jacobs, 2005). This movement toward community based PC is in keeping with the trend of service developed in response to local needs (Williams, 1999).

The MOHLTC does not directly regulate hospices. According to Hirst (2011), the impact of this care setting on the health care system is not yet acknowledged by the government. Standards and protocols for the establishment of a hospice facility are available from the government and the provincial hospice oversight organization. Accreditation is achieved through provincial hospice organization voluntary membership and compliance to the provincial hospice organization Community Residential Standard. Accountability is to the individual hospice voluntary Boards of Directors, Community Care Access Centres (CCAC) and the Local Health Integration Network (LHIN). The LHIN administers federal health dollars, transferred through the provincial Ministry of Health and Long Term Care to CCAC. This funding was increased in 2005 (Towns et al., 2012) and supports nursing care provided in the hospice setting. Hospices also rely on private funds and volunteers. Nevertheless, people living within a community might not be aware of hospice care until a family member living with a life threatening illness is in need of residential care.

Availability of service, beds and access to care in freestanding residential hospices varies across Ontario. Planning for more residential hospices is underway in the province. Variations in demand, accessibility, inequity for certain social groups and unevenness in this resource distribution exist for rural, remote and isolated communities, as well as within urban locations. Eligibility, waitlists, capacity, occupancy rates, user fees, transportation, programming, staffing mix and lengths of stay vary among hospices. The interplay of these factors sometimes results in hospice bed blockages and perceived unresponsiveness to demand by both community and hospital stakeholders. The question

of who presently uses residential hospice is not well understood. Clarification of the desire and demand for such care could help to inform the planning process.

### **Statement of Purpose**

The purpose of this qualitative, descriptive research was to discover who uses residential hospice care in Ontario. The case study of one urban six bed hospice illuminated the characteristics of the actual population served. This actual use was considered revealed accessibility (Gatrell & Wood, 2012). Revealed accessibility differs from potential accessibility, which describes supply and distribution of service (Gatrell & Wood, 2012). This investigation lays the groundwork for identification of underserved segments of the population who would benefit from hospice care and outreach.

### **Conceptual Framework**

Care of the dying can be described with human rights and public health frameworks (Gwyther, Brennan, & Harding, 2009), the nursing paradigm (Fawcett, 1984) and the nursing theory of Human Caring Science (Watson, 2012).

#### **Public health perspective.**

The population of Ontario is aging. The large baby boomer cohort is experiencing multiple health challenges, while they are living longer. They are developing chronic illnesses with comorbid conditions. This growing demographic sector is creating pressure for changes in planning, delivery and improvement of palliative and EOL care (Williams et al., 2010). The *Advancing High Quality, High Value Palliative Care in Ontario- Declaration of Partnership and Commitment to Action* (Declaration of Partnership) states that people have a right to quality PC in their home

community (Paetkau, Switzer, Kasperski, Seow, & Firth, 2011). Internationally, PC is increasingly viewed as a human right (Gwyther et al., 2009).

Caring for dying individuals is a social (community, family, professional), political and moral responsibility. Gwyther et al. (2009) state this inevitably needed care is a public health issue “which stands equal to all other public health issues” (p. 267) and needs development and advancement world-wide. PC is a philosophy/approach to care based on management of symptoms and relief of suffering, regardless of care setting. It is responsive to patient and family needs and preferences. According to Wright, Wood, Lynch and Clark (2008) and the World Health Organization (WHO) (2012), PC should begin at the time of diagnosis of life threatening illness. The nature and amount of PC intervention fluctuates along the disease trajectory. Hospice palliative care is part of the continuum of PC needed in a community.

Access is a PC outcome that is person centered and indicative of quality of care. It can optimize the ability of individuals to “live well with a progressive, life-limiting illness wherever they reside or receive care” (Paetkau et al., 2011). In Ontario in 2009, 61.4% of all deaths occurred in hospital and 38.6 % occurred in non-hospital settings (<http://www.statcan.gc.ca>). Many people would prefer to die at home but are unable to do so for a variety of reasons (Thomas, Morris & Clark, 2004). Freestanding residential hospice care provides an alternative to home, hospital or long term care home for location of care and place of death, and does so at a per diem cost of approximately half that of an acute care bed (Cuiker, 2012). Improved access to hospice beds could ensure PC by the right staff at the right time and place, while accommodating family and patient preferences and readiness for this final move. Care in this setting can relieve the

caregiving burden from the primary caregiver, lessen the burden of the patient's illness and enhance the quality of life (QOL) close to death and the quality of death. These are desirable population outcomes (Paetkau et al., 2011). Transition to hospice beds in a timely fashion has the potential to lessen acute care bed blockage and acute care costs.

#### **Nursing paradigm perspective.**

Nursing care of dying individuals and their families is conceptually grounded in the nursing metaparadigm. The framework's basic concepts are the person, family or community who is the target of the care; the external environment that influences the individual; health as the goal of the care; and nursing as caring (Fawcett, 1984).

Palliative care nursing requires specialized PC knowledge, development of respectful, caring relationships, ethical decisions, and compassion. Restoration or maintenance of health is not the focus of care. Collaborative caring actions support the dying person and his/her family so that the healing context is relief of symptoms and ease of suffering. The process of caring occurs in the physical, psychological, social and existential dimensions of dying, a universal and inevitable human experience.

#### **Human Caring Science perspective.**

Watson's nursing theory of Human Caring Science (2012) was the philosophical underpinning of this research. Caring theory allows for the understanding of the human experience of healing and health on the individual, community and global level. The dying have a basic relational and human need for care. Caring for the ill other is a social and moral obligation to protect human dignity in all societies. Caring actions provide for the comfort, wellbeing and welfare of the whole person at the end of their life. Caring is an attitude, intentional will, and presence that translates into intentional action that honors



the whole person and self (Watson, 2012). The value of caring can be passed on in the caring moment to the recipient of care.

Watson's ten Caritas processes are

- the practice of compassion and equanimity with the self and other;
- authentic presence, which enables belief systems;
- nurturing spiritual practices, which allow transpersonal presence;
- sustaining a loving, trusting caring relationship;
- allowing for expression of feelings, listening to the other's story;
- engaging in creative solution seeking;
- coaching in teaching and learning for wellness;
- creating a multilevel healing environment;
- respectful assistance with basic needs; and
- attending to spiritual and existential dimensions of life, death, suffering, pain, joy

and transitions (2012, p. 47).

Many of these Caritas processes are intertwined and important in PC nursing in the hospice setting. The attitude and stance of respect, honor and loving kindness for the whole patient is only possible and sustainable if the nurse is also attuned to her own needs, care and beliefs. As the patient transitions to hospice, the transpersonal caring relationship is established and maintained within the deep trusting and compassionate interchange between the nurse and the dying person. These opportunities for connectedness, sharing and healing can teach both the patient and nurse about themselves. This new relationship augments but does not supersede the preexisting caring relationship of the person and his/her family. As the nurse listens to the patient's

story, encourages expressions of emotion, and attends to bodily and existential needs, these dynamic exchanges can foster comfort, pain control, spiritual support and well-being. Dying patients could benefit from this care.

### **Significance and Justification**

Dying people use residential hospices. Although the first freestanding hospices have been built in Ontario over the past sixteen years, the characteristics of actual hospice users have not yet been scrutinized. Examining the characteristics of those who use residential hospice care and identifying patterns or trends of use could inform hospice personnel, funders and health policy planners.

The poorly understood question of hospice utilization is worthy of investigation because the Ministry of Health is poised to operationally fund more hospices, yet communities must grasp the benefit of hospice care for patients, families and the whole community. Leadership, vision, finances and personnel are needed to build hospice residences and programs. A community should have a clear understanding of the target population and of the required critical mass for advocacy, fundraising, human resources, and delivery of service.

Ideally, all persons, regardless of race, ethnicity or socioeconomic status, should have equitable and timely access to hospice care within their own community, if so desired. Persons with vulnerabilities or disabilities should have the same opportunities as any other, regardless of diagnostic differences, mental health issues, behavioral issues, memory impairment or issues of incarceration or hard to serve conditions. The dignity of the individual, non-discrimination and universality are principles that support equitable

access and opportunity for hospice care (Gwyther et al., 2009). Equity, justice, and beneficence must be considered in health service delivery.

An initial literature scan revealed no published research that documents who is being served by hospice in Ontario. Addressing this gap could contribute to new explanatory knowledge, which could inform policy related to larger palliative care practice issues. This descriptive research could influence the public policy issues of resource planning, utilization and accountability as more hospices are being planned and funded. Ontario's health policy for EOL location should be based on definitive, known criteria about population preferences for type and location of care and death.

This evidence-based research has implications for informing the public specifically about their choices for health care delivery. The question about hospice users is answerable and measurable with descriptive statistical analysis of data available from a representative hospice and from the public domain. The regional health authority (LHIN) might be interested in the demographic analysis for local level development and planning of location of outreach teams and advocacy for location of future hospices. The data sets are at the aggregate level making data access feasible. Deeper understanding of this issue will allow validation or disproof of this researcher's clinical observations working as a Registered Nurse in community-based palliative care. Based on this researcher's observations, there are inequities in hospice bed utilization within certain segments of the population.

### **Assumptions**

1. All human beings require care by others at end-of-life (EOL). The dying person is vulnerable. Charity toward the other is an act of selfless love. Caring for the

dying helps the carer as well as the dying person. The process of dying is a social, emotional and existential experience with medical implications.

2. Hospice is a desirable location for EOL care and death. Ontarians want access to freestanding residential hospice beds. Hospice care provides a measurable good to the community, families and individuals.
3. Communities, volunteers and advocates will mobilize to build hospice structures. As hospices are built, people will become aware of this care opportunity and use this location for dying.
4. Individual choice, opportunity for hospice access, and hospice-related factors influence location for care and death. Use of hospice beds requires cooperation and communication between the hospice agency, funder, home care programs, and medical community for allocation, priority determination and usage parameters. This interaction can be politicized.
5. Socialized medicine provides care from the cradle to the grave. Federal government health funding will continue to flow through provincial coffers to support nursing and medical care of dying patients in the location of their preference. Residential care in a hospice is less expensive than using acute care beds for dying patients.

### **Research Questions**

This study was conducted to find answers to three specific research questions:

1. What are the characteristics of dying patients in a medium sized urban setting in Ontario who use hospice?

2. How does this hospice use compare with provincially collected hospice use data?

3. What data about hospice users would hospice administrators find useful?

### **Definition of Terms**

The terms in the research questions were defined theoretically and operationally.

#### *End-of-Life*

**Theoretical definition:** End-of-life (EOL) is the final stage in a person's lifespan.

**Operational definition:** EOL is the period of time from the final six months of a person's life to the moment of death. The noun or adjective term is used broadly, encompassing PC issues as well as social, cultural and legal issues, such as Advanced Care Planning. The MOHLTC uses the service recipient code (SRC) of 95 to indicate an individual requires increased community health care services and interventions in this six month time period. All persons admitted to hospice could be described with SRC 95.

#### *Hospice*

**Theoretical definition:** Hospice is a "community-based inpatient facility with a primary focus of providing hospice community care to individuals facing end-of-life" (HPCO, 2011). A hospice is a charitable organization with public and/or private funding sources. Many hospices conform to the provincial hospice organization Community Residential Standard and belong to this umbrella organization (HPCO, 2011). The number of beds is 3, 6 or 10, with 10 beds being the most common and desirable size.

**Operational definition:** The hospice is a freestanding, residential and independent setting for EOL care that is not attached or part of a hospital, retirement home or nursing home, and is located in Ontario, Canada. Hospices that receive funding from the

provincial government are required to report demographic and usage information annually to the provincial hospice umbrella organization.

### *Hospice Bed Blockage*

Theoretical and operational definition: A hospice bed is occupied by a person who is not at end of life, or is occupied for a period longer than 3 months. Hospice bed blockage occurs if the demand for residential care exceeds the hospice's capacity; or if lengths of stay are prolonged because of prognostication misjudgments or inappropriate timing of referrals and admissions of people with chronic illnesses.

### *Hospice Care*

Theoretical definition: Hospice care is PC care received by patients residing in any residence or other location of care. Hospice care includes community, outreach, freestanding residential, clinic or inpatient hospital hospice programs (as found in Canada, England, the United States of America, and other countries). The forms of care encompass residential use, respite use, day hospice programs, volunteer visiting programs, outpatient clinics and bereavement services for families.

Operational definition: Hospice care is EOL residential care received in a freestanding hospice in Ontario, Canada.

### *Hospice Use*

Theoretical definition: Actual use of hospice beds is an example of revealed accessibility as defined by Gatrell and Wood (2012). Per diem use, length of stay, census and annual occupancy rate are aspects of actual use.

**Operational definition:** Hospice use refers only to in-patient residential care by individuals at EOL. The anticipated length of stay at hospice would not be longer than three months.

### *Palliative Care*

**Theoretical definition:** In Canada, hospice palliative care is an approach to and philosophy of care focused on relief and prevention of suffering, improvement of quality of life and comfort at end-of-life (CHPCA, 2012). The term hospice palliative care is frequently used interchangeably with palliative care. Ideally, palliative care begins at diagnosis and is offered to patients and families throughout the disease trajectory, including the bereavement phase (WHO, 2012). It is “whole-person health care that is multi-disciplinary in nature, [and] can happen in any care setting” (Carstairs, 2010).

**Operational definition:** Palliative care, hospice care and hospice are separate terms and will have different meanings in this thesis. Palliative care is the philosophical and practical relief of suffering at end of life.

### **Variables**

The variables in this research were specified characteristics of patients admitted to and utilizing residential hospice care at the end of their lives. These categories included age, gender, admitting diagnosis, previous location of care, bed usage, length of stay, discharge disposition, and primary residence prior to hospice admission, all of which were determined from the data files used at the target hospice. Age was the lifespan of the user in years as recorded upon admission to hospice. Gender of the user was classified according to sex as male or female. The admitting diagnosis was the primary diagnosis of the user as recorded by the registered nurse upon admission to hospice. The

previous location of care of home, hospital or other was the patient location at time of admission (not time of referral and not necessarily residential location). Bed usage included available bed days, bed days used, occupancy rate, and evaluation of usage by previous location of care. The numbers of admissions, which stand for the number of clients served by the hospice, were those individuals who used residential hospice for end of life care. Discrete admissions included repeat admissions of those users who were admitted, stabilized and then discharged. Upon return to hospice, these users were considered as new admissions because there was no method to reliably verify the user identity in the retrospective census record. Length of stay was similarly considered per admission, and not merely length of time from admission to death. The definition of LOS used was an internationally accepted definition by which the admission day was day 0 and the day of death was not counted as a day. If the user's stay carried over into the next fiscal year, the count of the number of days continued, without reassignment of the user as a new client with a stay beginning on the first day of the fiscal year. The LOS was considered in the fiscal year in which it began. Discharge disposition was determined by death or survival, and included location for live discharges. The primary residence of users was the usual, census, and legal residential location, and might or might not have been the same as previous location of care.

Characteristics of interest were also elicited during interviews with the hospice administrators for consideration for analysis. The datasets were examined for relationships between these variables. Subsets of these characteristics were generated (for example, number of patients referred with a particular diagnosis). Group



characteristics were reported including occupancy rates, number of bed days provided per annum and number of persons served per annum.

### **Limitations**

The sample was a retrospective convenience sample of records from one hospice in Ontario. This geographic setting was primarily urban with a catchment area that encompassed a census metropolitan area (100,000 population, plus at least 50,000 in the city core), 2 census agglomerations (population of at least 10,000) and small town and rural areas (outside of the census metropolitan area and census agglomerations) (<http://www.statcan.gc.ca>). The data obtained might not be generalizable to other decedents at other residential hospices, urban and rural settings, or hospices with ten beds. Outpatient and inpatient access to physician and clinical nurse specialist services in the case study hospice might represent confounding influences to categorization of some variables. Differences in statistical recording by the physicians, clinical nurse specialist and outreach nurse could contribute bias in the data. Accuracy of statistical reporting from year to year might be unreliable because of staff changes, upgrading to the reporting system, technological upgrades, and limitations of the statistical programs for both Hospice A and the provincial organization. The data presented refer only to users of the target hospice and hospices reporting provincially, but not to all hospice users in Ontario. The viewpoints of the interviewees do not necessarily represent those of all hospice administrators, nor do they necessarily reflect predominating opinion in the hospice sector.

**Summary**

Chapter I presented the Statement of Purpose, a conceptual framework using principles of public health and human rights, the nursing metaparadigm and Watson's caring theory, significance and justification for this research about hospice utilization, and assumptions made by the researcher. Three research questions are posed, with terms, variables and study limitations delineated. Chapter II will present the Literature Review, followed by Chapter III Procedures. Chapter IV will present the Results and Chapter V the Discussion.

## **Chapter II**

### **Review of the Literature**

The purpose of this literature review was to identify the existing body of work published since the year 2000 about use of residential hospice care in Canada, and specifically the province of Ontario. Since the emergence of the residential hospice movement in the last fifteen years, there has been little research published about hospice use in Ontario communities and about persons who use this location for place of death. This literature gap identified the need for basic description of hospice usage, characteristics of users and practical information desired by stakeholders. The literature review also provided historical contextual information, descriptive methodologies, and justification for the research study.

A comprehensive literature review focusing on hospice practices was performed using CINAHL and Medline databases for peer-reviewed national and international articles published from 2000 onward. The search terms used were hospice, hospice and grounded theory, freestanding hospice, residential hospice, hospice and Ontario, and then revised to include access, hospice and Canada, and hospice movement. The literature search yielded 36 articles that were then reduced to 29. Eliminated articles were those that defined hospice as a service program delivered in home or virtually in hospital or did not separate out hospice care provided in home, acute care hospital, palliative care unit in

hospital, skilled nursing facility, nursing home and freestanding hospice care in their statistical analysis.

A secondary hand search for relevant seminal articles published in the 1990s was completed based on frequent citations found within the first group of publications. Gray literature was examined next. Government and MOHLTC websites were contacted for sourcing government publications about palliative care, resulting in 5 reports. Website search and personal contact were made with the provincial hospice association, Hospice Palliative Care Ontario. Data were obtained from searches of Statistics Canada, Canadian Institute for Health Information, Canadian Institute for Health Research, Canada Post, and the Canadian Hospice Palliative Care Association. Identification of the leading Canadian palliative care researchers yielded 5 more publications for review.

### **International Emergence of Freestanding Hospice**

Historically, hospices were places of refuge and respite for weary travelers, the sick and dying. During the Crusades (1095-1270), hospices were begun by religious organizations in many European countries. England and Sweden were among the first to open hospices in the modern hospice movement. Dame Cicely Saunders pioneered hospice care in the United Kingdom where St. Christopher's Hospice opened in 1967. Rapid growth and the development of diverse settings for hospice care followed. Despite the large body of literature describing the longstanding British experience with hospice, no pertinent articles on user characteristics were located. Saunders influenced Florence Wald, who is credited with the introduction of hospice care in the late 1960s in the United States. Palliative care in Canada began in the mid 1970s under the aegis of Dr. Balfour Mount, the father of palliative care, who was also mentored by Saunders. The

first Swedish hospice was opened in 1982. The hospital remains the predominant location for most decedents in developed countries (Gomes & Higginson, 2004; Seale, 2000).

Wright et al. (2008) have categorized the development of palliative care globally. There is a wide international variation in service provision, emphases, government supports, and education. These researchers have identified Canada as a country where PC services are approaching integration with mainstream service providers. This means that there are PC activists, multiple service providers and types of service, awareness among health professionals and local communities, availability of opioids for EOL pain management, policy supports, education and training centers with academic input, and a national PC association (Wright et al., 2008). Hospice service types and settings include hospital, home care, residential hospice, day care (Towns et al., 2012; Wilson et al. 2009) and respite (Taylor, Ensor & Stanley, 2011). Some countries have targets to have a hospice facility in every city with a population larger than 100,000 (Wright et al., 2008).

The emergence of PC and concomitant residential hospice use has been subject to a number of pressures. The emphasis on rescue medicine, conflict between cure and care, overuse of life extending treatments, and rise in the number of interventions in the last 3 months of life is set within a death-denying culture. Life-sustaining or palliation decisions are affected by predominant practices, cultural beliefs, confidence and education for symptom management, quality of communication, lack of advance directives, fear concerning the intent and use of written documents for advance directives, concerns about not wanting to offend participants, engagement in shared decision making, and prior preparation for EOL decision making (Tilden & Thompson, 2009). Such concerns pose barriers which, along with problems of access and resources, can

delay referral and transfer to hospice. Furthermore, professionals, patients and families can be reluctant to stop treatment (“give up”) and imbue meaning to the transfer to hospice that signifies abandonment. Some lack the emotional resilience and communicative ability to transform hope and acceptance.

The National Hospice Palliative Care Organization in the United States of America reports the median hospice stay in days was 21 (2006), 21.1 (2009) and 19.7 (2010) but over one third of referrals were made in the last seven days of life (NHPCO, 2011). However, these data do not refer specifically to residential hospice programs and they might not represent the Canadian residential hospice experience. If too short a time, hospice care may not make a difference in quality outcomes (Tilden & Thompson, 2009).

Within countries, regional variability in intensity of EOL health care is revealed by the number of hospice beds (McNamara & Rosenwax, 2007; Prigerson & Maciejewski, 2012). Supply side characteristics of 189 adult hospices in England and Wales included geographic proximity to hospice, accessibility, unevenness in resources, inequity or disadvantage of social and ethnic groups, affordability and number of hospice beds (Gatrell & Wood, 2012). However, this study did not discuss actual use of hospice residential beds (Gatrell & Wood, 2012).

The function and timing of PC can be misunderstood by both the public and professionals. Although the ideal introduction of supportive care and symptom management is at the time of diagnosis, many people understand PC as services offered when treatment is stopped. In their systematic review of internationally comparative studies of palliative care services’ effectiveness, Critchley, Jadad, Taniguichi, Woods, Stevens, Reyno, and Whelan (1999) identified one study from the 1980s that found pain

and symptom control were slightly better in residential hospices as compared to other settings (Greer, Mor, Morris, Sherwood, Kidder, & Birnbaum, 1986). The piecemeal and slow development of PC practices globally (Wright et al., 2008) results from societal death anxiety, lack of government support and emphases, lack of policies and national guidelines, deficiencies in opioid availability, and uncertain funding. There are gaps and lags in education and training, including only recent establishment of PC medicine and nursing specialties, pain management teams, and consultation services (Wright et al., 2008).

### **Preferences for Location of Care and Death**

Many researchers have examined location of death, preference of location for care and death, congruence and setting trends. Twelve relevant articles were found that included residential hospice as a choice. Holdsworth and Fisher (2010) distinguished between location for care and death, and identified achievement of preferred place of death as a desirable PC outcome. Appropriate locations for care and death are viewed differently by patients, family carers and professionals. Ward and Gordon (2006) raised the question whether death is a medical event with psychosocial components or an existential experience with medical implications.

Macrosocial, dynamic influences on preferred place of care include health policies, national and regional stages of development of PC, cultural beliefs, and attitudes about place of death and dying at home (Gomes & Higginson, 2006). Dissemination of sufficient information to help individuals choose a preferred location is important for all racial and ethnic groups (Johnson, Kuchibhatla, & Tulsky, 2009; Koffman & Higginson, 2004; Rhodes, Teno & Welch, 2006).

Preferences might change as disease progresses or circumstances change.

Although many people might cite home as their preferred location for care and death, adequate community and family supports are needed to accomplish this wish. Some people select hospice as a default location in order not to burden their family, or because of lack of family support, or out of fear of hospital care. Caregiver burden, capability, willingness, health and preferences, service familiarity and proximity, community resources, and other demographic and contextual factors affect family decision making (Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005; Thomas, Morris, & Clark, 2004). Many people and circumstances influence care decisions.

Thomas, Morris and Clark (2004) examined preferred location for death in a small sample ( $n = 41$ ) of persons diagnosed with cancer and a prognosis of less than 3 months. This longitudinal study revealed a preference of 29% of respondents for hospice compared to 36% who preferred home. The survey participants lived in north-west England, which has a large number of hospice beds. Actual residential hospice use was 33 %. Important factors that influenced patient and family preferences were attitude toward hospice, previous experience with hospitals, community services and dying, and ability to exercise self-determination to the last possible moment (Thomas et al., 2004). Higginson and Sen-Gupta (2000) reported hospice as the second most preferred site (next to home) for EOL care and death.

In the United Kingdom in 2000, 16.5 % of cancer deaths occurred in residential hospice (versus 55.5 % in hospital, 23 % at home and 5% elsewhere) (Thomas et al., 2004). Gomes and Higginson (2008) presented population projections for increasing numbers of deaths and deaths at increasingly older ages in England and Wales and the



world after 2012. This demand could drive an increase in the number of institutional beds (including those in residential hospices) or result in more deaths at home and nursing homes. The responsibility for expansion to accommodate these increases could be assumed by the government, private, or voluntary sector or a combination of these sectors (Gomes & Higginson, 2008). Similar questions of responsibility and planning should be raised in the Canadian context.

### **Development of Hospice Services in Canada**

Over sixty percent of Canadians die in inpatient settings (Townsend et al., 2012). The Canadian Hospice Palliative Care Association has identified five types of locations for PC delivery - hospital/ acute care, residential hospice, long term and continuing care, shelters/street and homes (2012). Palliative care programs were initiated in 1974 in St. Boniface General Hospital, Winnipeg and at the Royal Victoria Hospital in Montreal. Utilization research by Fassbender et al. (2005) demonstrated that the introduction of comprehensive, integrated, coordinated and community-based PC services (which included residential hospices) in the province of Alberta was cost neutral and decreased the use of acute care beds. Residential hospice care accounted for 8 per cent of the cost of care for cancer patients in their final year of life (Fassbender et al., 2005) with an average per diem cost of \$230 (compared to acute care costs of \$791(in Canadian dollars). Recent Ontario hospice costs of \$439 per day were contrasted with acute care costs of \$850 per day (provincial hospice association administrator, personal communication, May 25, 2012).

In their study of location of death in Canada, Wilson et al. recognized that “The place where end of life care occurs is significant, as the location influences in large

measure the type and manner of care provided.” (2009, p. 1752). Self-control, autonomy and choice support dignity and individual preference. These factors must be in balance with caregiver burden and ability of the community to respond (Brazil et al., 2005). The ideal balance of such factors makes the hospice option attractive for various reasons for some patients, caregivers, families, community and acute care providers, and government funders and policy makers. Yet, “Canada has few free-standing hospices and an almost negligible number of deaths occurring in them” (Wilson et al., 2009, p. 1756).

The Canadian situation is one of an aging population, rising incidence and prevalence of chronic illnesses, longer life expectancy, deinstitutionalization of health care services for cost management, and devolution of the care of dying to community, home and families (Fassbender et al., 2005; Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000; Williams et al., 2010). Sustainable funding, geography and access to the hospice setting are challenges in Canada. Other barriers to PC, which incorporates hospice care, are human resource issues of specialist, advanced and continuing PC educational opportunities, specialized training in symptom management, and opportunities for access to palliative consultative multidisciplinary teams. Issues specifically related to the health care team include prescriptive authority for opioids; primary care physicians and nursing shortages; geographic location of workers and jobs; size of workforce pool related to population; worker aging; volunteer engagement; and recruitment, remuneration and retention of doctors, advanced practice nurses, nurses and personal support workers (Carstairs, 2010; Towns et al., 2012).

There is a growing social expectation for the availability of residential hospices as part of the continuum of PC. Senator Sharon Carstairs championed PC as the right of

every Canadian. In her third report, Carstairs (2010) states that 90 % of Canadians can benefit from PC but 70 % do not have access. In 2008, 16 to 30 % of Canadians were estimated to have access to PC, mostly in urban locations (Carstairs, 2010). The first Canadian freestanding hospice (built without provincial funding) was established in Winnipeg, Manitoba in 1985. Presently, there are 60 Canadian hospices with 27 in Ontario, 18 in British Columbia, 10 in Alberta, two in Manitoba, and one each in Saskatchewan, Yukon, and New Brunswick (Cuiker, 2012). The first hospice in New Brunswick was established in 2010. Advocates for the introduction of residential hospice care in Nova Scotia are currently working to gather funding support. As the hospice movement gathers support, there will be a corresponding demand and expectation for available hospice beds.

### **Policy Influences**

Health care policies have influenced the emergence of freestanding hospices. The Canada Health Act (1984) does not provide PC policy direction. Federal health funding is provincially disbursed. There are different PC emphases province to province. Palliative care is usually delivered and funded within hospitals, long term care homes or home care settings with no dedicated, ongoing funding for hospice care within these sectors (Williams, Crooks, Whitfield, Kelley, Richards, DeMiglio, & Dykeman, 2010). Independent volunteer hospices were developed in some Canadian regions as an alternative way to overcome gaps in PC. They operate outside the formal health care system, and are funded by donations, gaming receipts or hospice societies (Williams et al, 2010). Since sustainability of residential hospice programs is vital, secure funding by tax dollars is a needed solution (Williams et al, 2010).

Rural, remote and isolated communities do not have the PC infrastructure and hospice options that urban centers enjoy. First Nations, prisoners, refugees and street people in need of PC are governed by differing policies and legislation. Opportunities for access differ for specific sub populations (Paetkau et al., 2011).

Regionalization, designation of PC as a core service, the establishment of federal caregiver benefits and national advocacy efforts also affect PC development, including the trend for residential hospice (Williams et al, 2010). The Canadian government focused on capacity building by adding 16.5 million PC research dollars over 2005-2010 through the Canadian Institutes for Health Research, which resulted in a sharp increase in PC academic publications (Carstairs, 2010). In June, 2012, the Minister of Health and the Minister of State for Seniors announced three million dollars in one-time funding for the Canadian Hospice Palliative Care Association. The funds were intended to support the development of community-integrated palliative care models, provider education, EOL information and provision in broader range of settings (<http://www.hpco.ca>, 2012).

### **Hospice Care in Ontario**

Statistics Canada data reveal that there were 84,000 deaths in 2006 among the province's 12.5 million people (Seow, Barber, Howell, & Sydney, 2010). In 2009, there were 88,468 deaths, of which 61.4 % occurred in hospital and 38.6 % occurred in locations other than hospital (<http://www.stat.can>, 2013). The first hospice was built in Oakville in 1997. The 18 provincially funded and operational hospices in Ontario have either three, six or 10 beds each, with 10 being the ideal and most common size. Two more hospices are under construction, with 17 in planning stages (Administrator, provincial hospice organization, personal communication, May 25, 2012). The

anticipated but not yet realized total of 346 hospice beds still does not meet the target of 910 beds provincially, which is based upon the Fraser Health Authority benchmark of 7 beds per 100,000 population (Bodell & Tayler, 2007; Cuiker, 2012). The provincial hospice organization administrator indicated that Ontario ideally needs 1300 to 1500 beds based on the Fraser Health Authority or on the Australian (Gow & Dempster, 2009) models for hospice development (Administrator, provincial hospice organization, personal communication, May 25, 2012). At least three non-conforming, privately funded or faith-based hospices in the province do not belong to the provincial hospice organization nor follow the provincial hospice organization Community Residential Standard.

The option of hospice was not mentioned as a potential location for delivery of community palliative care services in Niagara (Williams, 1999) because freestanding hospices were not yet common provincially or locally. However, Williams did identify that palliative care services develop to meet local needs and have to respond to complex, co-morbid conditions in the elderly (1999). The Niagara region now has two residential hospices built in 2007 and 2008. The Ontario End-Of-Life Care Strategy increased MOH funding for residential hospices in 2005 and required accountability agreements with Community Care Access Centres (MOHLTC, 2006; Seow, King, & Vaitonis, 2008).

A single, recent study was identified that addressed hospice care in Ontario. Towns et al. (2012) surveyed 21 residential hospices in Ontario during 2008-2009 for comparison of medical services, procedures, complementary therapies, and spiritual support programs as part of a larger inpatient PC study. Location of the hospices was categorized as urban or rural based on population. Questionnaires were returned by only

13 out of 21 hospices. Results described admission criteria, number of beds, procedures and services offered (inpatient and outreach), PC specialist staff, and barriers to quality PC provision. Description of residential eligibility was limited to admission criteria for age, diagnosis, and presence of Do Not Resuscitate orders. While most hospices had no diagnostic restrictions for admission, one hospice accepted only patients with cancer. Information about services offered at these hospices allows insight into potential residents, such as those with nephrostomy or feeding tubes, pain pumps, oxygen or hydration requirements, and other palliative interventions. However, this service information reveals little about the people actually served by hospices.

Barriers to hospice use include difficulties with prognostication, transportation, continuity of care during transition to hospice, and late referrals that result in patients using a bed for only a few days (Towns et al., 2012). The average length of stay in hospice is 18 days (www.hpco.ca, 2012). Many patients already had home care services coordinated through the Community Care Access Center. The availability and experience of home care services can be a driver for hospice use, as reported by Gomes and Higginson (2004), Thomas et al. (2004), and Heyland et al. (2000), or a barrier to hospice use. The desire for death at home might continue to be a patient's first choice, with reluctance or inability to change this decision hampering consideration of a move to hospice (Brazil et al., 2005; Gomes & Higginson, 2004).

Hirst (2011) reported that Ontario hospices have common admission criteria: a life expectancy of less than 3 months and residential location in the hospice catchment area (or having relatives residing in the area). Ninety per cent of those admitted to hospice have a cancer diagnosis (<http://www.hpco>, 2010). There are service gaps for

diagnoses with uncertain prognoses, such as congestive heart failure, chronic obstructive pulmonary disease and dementia. Quality of life for more hospice patients could be enhanced by early integration of PC through PC outreach teams and out-patient clinics located in the residential hospice (Towns et al., 2012). Less aggressive treatments can result in longer median survival (Temel et al., 2010). In the hospice, the stage is set for fewer life-prolonging medical interventions, which could result in improvements in quality of life and patient and family satisfaction. No literature was found that addressed the hidden difficulties of caring for patients with disruptive behaviors with or without mental health diagnoses in Ontario hospices.

### **Gaps in Data Collection**

There is a need for the collection of common data sets in Canadian palliative care programs, including demographic, death, program, support and clinical data elements. Because place of death can be considered as reflective of PC capacity, tracking the number of deaths in residential hospice could be used to drive change (Paetkau et al., 2011). The *Declaration of Partnership* recognizes residential hospices as part of a comprehensive continuum of PC, and prioritizes optimization of residential hospices and review of client profiles and needs (Paetkau, et al., 2011). Kuziemy and Lau (2008) commented on the implications of surveillance data collection for the development of national practice and policy standards and the links between patient preferences and service delivery. A national common PC tool, based on a theoretical framework with consensus definitions and elements, is needed to monitor outcomes, access, and user characteristics; to conduct comparative analysis; and to inform policy decisions and coordination of care (Kuziemy & Lau, 2008). A basic understanding of who is

accessing care, who is not accessing care and why, is required for all palliative care services before service delivery is addressed (Kuziemy & Lau, 2008). This would include residential hospice care.

### **Conclusion**

Broad searching for publications since the year 2000 that specifically dealt with residential hospice yielded little information about the characteristics of hospice users. Basic admission information collected by Towns et al. (2012) and Hirst (2011) included age, residential location, diagnosis, and presence or absence of DNR orders. The scarcity of information reflected the organic emergence of residential hospice as a response to community PC needs, which, in turn, parallels the development of PC. Even so, PC “remains at the margins of the health care system” (Williams et al., 2010, p. 1). Pressures from advocates, policy supports for residential hospice expansion and establishment of academic interest will facilitate further research about this location of care. Description of the features of those who use hospice is a place to begin.

### **Summary**

Chapter II has presented the Review of the Literature, with emphasis on work published since 2000. The development of residential hospice use internationally, nationally and provincially, preferences for location of care and death, PC policy influences, and gaps in information about hospice users were addressed. Chapter III will present Procedures. Chapter IV will present the Results, followed by the Discussion and Implications of Results in Chapter V.



## **Chapter III**

### **Procedures**

#### **Introduction**

In-depth analysis of one hospice (Hospice A) as a case study was undertaken to offer insight into the actual population served by hospice, determine important variables for this care setting, inform evidence-based practice for PC clinicians, identify related issues for research opportunities, and uncover relationships heretofore not understood. Hospice A user data was compared with provincially collected user information. Subsequent interviews with one hospice administrator and one hospice association administrator were conducted to provide contextual and interpretive discussion elements. Description of this sample of residential hospice users allowed characterization of extant patient users, contribution to the knowledge surfacing about hospice users, and background for further exploration about hospice users.

#### **Setting**

Demographic and usage data that had been collected historically were received from one urban, freestanding residential hospice located in southern Ontario. This census information included number of deaths, length of stay, location prior to admission, priority/urgency of admission, discharges, diagnoses, age group, gender, specialty of physician, Palliative Performance Scale on admission, location of primary residence, and out of region admissions. In addition to this data source, databases from the Ontario

oversight hospice organization provided aggregate information for 18 hospices in Ontario (including Hospice A) for the years 2009 to 2012-2013.

### **Population and Sample**

The social unit of interest in this descriptive case study was adult patients who used in-patient residential hospice care in the years from March 1, 2006 to March 31, 2013, most of whom experienced expected death in the hospice setting. The population served by Hospice A comprised adults living in the province of Ontario in a particular urban and rural geographic area of population approximately 232,419 (2011 Census, <http://www.statscan.gc.ca>). The records reviewed constituted a convenience sample drawn from former patients who had voluntarily self-selected this hospice location for end of life care and death, or whose Substitute Decision Maker had selected this care location. This case study described aspects of demographics, hospice use, and discharge disposition for these patients. No attempt was made to determine if the sample served was representative of the larger urban population. Former adult users of 17 other RH across the province of Ontario were described in aggregate form for similar characteristics using data reported by each of the funded hospices to the provincial oversight organization.

### **Data Collection Methods**

The mixed method procedures for this study were descriptive and qualitative, non-experimental and exploratory. Following approval from the D'Youville College Institutional Review Board (IRB), the researcher sought written permission for access to statistical databases from two sources: the target hospice and the provincial hospice

organization for annual aggregate data. Interviews with hospice or hospice association administrators were used for qualitative elaboration.

Following IRB approval from D'Youville College (Appendix A), an initial inquiry Letter of Institutional Permission (Appendix B) was sent to Hospice A and Hospice Palliative Care Ontario. IRB Approval from the governing body of Hospice A was then sought (Appendix C). Permission to access documentation of clientele information (for example, Hospice Census, Residential Hospice Quarterly Statistical Reports, and Annual Reports) was obtained from the administrators of the hospice and provincial hospice association. Data collection methods included audiotaped interviews with two administrators, review and collection of de-identified data from documents and records in both print and computerized forms, and analysis of data. The de-identification process was accomplished by temporary collection of deceased patients' hospice census records and assignment of individual codes. The code list was retained at hospice with the administrator until all information about user characteristics was verified. The code list was subsequently destroyed. Neither the institutions, nor the researcher, nor anyone else received remuneration for participation in this study. The study was conducted from May 2013 through August, 2013.

After they signed the consent forms (Appendix D), the administrators of Hospice A and of the provincial hospice association were interviewed individually, using an interview guide (Appendix E), designed to capture their experiential understanding, opinion and perceptions about this study's reported characteristics of hospice users and about important data elements for collection and review. Single interviews were conducted in the hospice and in the provincial association setting, lasting a maximum of

two hours. Field notes were documented at the time of interview and transcribed immediately following the interview. This narrative, anecdotal information was examined for identified patterns and trends of hospice usage and administrator perceptions of data utility, gaps in data collection, and policy recommendations based on the data.

Request for record access was made to Canadian Institute for Health Information, Canadian Institute for Health Research, and the Ontario Ministry of Health, Health Analytics Branch, Vital Statistics – Mortality registry (from the Office of the Registrar General) and Discharge Abstract Database (DAD) for inpatient discharges to obtain disposition status, transfer to institution, and disposition location.

### **Human Rights Protection**

Human Rights Protection for privacy and confidentiality of patient identifiers was assured by use of de-identified data that were stored securely in the researcher's private personal computer protected by a log-in password. The researcher did not have access to identifying patient information. There was no recruitment of subjects. No individual hospice client informed consent was obtained because all data were gathered from census records of deceased hospice patients and / or reported in aggregate form. No risks to patients were identified. Two hospice administrators were approached directly by telephone to participate in the interview process. Each signed an Informed Consent (Appendix D) for the researcher prior to the interview process and was provided a copy of that form.

There might be no direct benefit from this study to any hospice or institution. A pseudonym for the hospice ("Hospice A") was employed to protect the identity of the

participating institution. Summary information about the study was reported to Hospice A. This information will be securely stored and maintained for a period of 6 years, with access restricted to the researcher, and will then be destroyed. The provincial hospice oversight organization was not identified by name. This PC organization is a provincial, charitable association, funded by and reporting to MOHLTC. Hospice data collected by the provincial hospice organization are not generally available publicly.

### **Tools and Treatment of Data**

Following retrieval of stored computer files and print reports of individual and aggregate retrospective data, the variables of interest were organized using descriptive statistics. The individual variables of interest were age, diagnosis, length of stay (LOS), gender, discharge disposition, and postal code. The aggregate data extracted included age, diagnostic category, number of referrals, assessments and admissions, previous location of care, bed usage, LOS, deaths prior to admission, discharge disposition, number of hospice beds and number of hospices reporting. Once the provincial data were collected, the Hospice A data, which was contained in the aggregate totals, was removed. The remaining provincial data were used for comparison.

De-identified data from the Hospice A Census Record, Hospice A Annual, Financial and Statistical, and Key Performance Indicator Reports for the time period 2006 to March 31, 2013 were made available to the researcher by the administrator. More detailed computerized data about user characteristics from Hospice A were not made available to the researcher. The researcher extracted data for six data elements of interest from the available records, which were recorded on an Excel spreadsheet using code numbers to de-identify patient record numbers. Age, diagnosis, LOS and discharge

disposition (death or live to a particular location) were recorded as they appeared in the records. Because gender was not assigned upon original entry of the census record, examination of the client names was done while the researcher was present at the hospice and in the company of an administrator or a designated staff member. The researcher then assigned gender based on first/given name, in consultation with the administrator or staff member. Gender was coded as 0 (Male) and 1 (Female).

Diagnosis was recorded by letter abbreviations for primary diagnosis and then further assigned coding as malignant (0), non-malignant (1) or unknown (2). For those 16 clients who had two unrelated diagnoses listed, the first one recorded was used for coding purposes. Discharge disposition was coded as death (1), home (2), long term care (3), hospital (4) and unknown (5).

Postal codes were available for only the 2012-2013 year. Once verbal report of location and postal code was received from the administrator, verification of postal codes and location was completed using the Canada Post postal code search tool

(<http://www.canadapost.ca/cpotools/apps/fpc/personal/findByCity?execution=e4s1>).

Place of residence was then recorded by letter abbreviations for the patients' home locales. These abbreviations were further recoded into one of 5 categories - City A in which hospice A is located (1); County A in which hospice A is located (2); town A (3) of greater than 10,000 population, located in County A, out of catchment area (4); and 2 other nearby counties, B and C (5), which are part of Hospice A catchment area. These latter two counties have one town (B) which has a population of greater than 10,000, with the remaining area classified as a Rural Area (<http://www12.statcan.gc.ca/census-recensement/2011/ref/dict/index-eng.cfm>). City A, County A and Town A (Categories 1,

2 and 3) make up a Census Metropolitan Area (which has a population of at least 100,000 with 50,000 living in the core) (<http://www12.statcan.gc.ca/census-recensement/2011/ref/dict/index-eng.cfm>). A second categorization was completed to reduce to 3 classifications – urban (1), rural (2), and out of region (3).

Using a numeric coding reassignment, age was categorized into 8 categories by persons less than 24 years (1), six subsequent 10 year ranges - 25-34 (2), 35-44 (3), 45-54 (4), 55-64 (5), 65-74 (6), 75-84 (7), and those older than 85 years (8). Three groupings (0-17, 18-64, over 65 years) were then created to align with provincial categorization.

Computerized examination of frequencies, distribution and variance using the Statistical Package for Social Scientists (SPSS) Version 21.0 for Windows program (SPSS, Inc., Chicago, IL) and Microsoft Office Excel (<http://office.microsoft.com/en-us/excel>) was completed for the period 2006 through March 31, 2013.

Aggregate provincial data were extracted from the annual RH Usage Reports for 2009, 2010-2011, 2011-2012 and 2012-2013 and recorded in an Excel spreadsheet in a manner similar to the recording of Hospice A data. Comparative statistical analysis of Hospice A to provincial aggregates for a 3 year period was completed to identify any significant differences in usage. Statistical tests used were central tendencies, frequencies, variance, dispersion, and standard deviations for the variables of age, gender, diagnosis, bed usage, length of stay, discharge disposition and primary residence. The variables of age and length of stay were described using mean, median and mode. The researcher had made no hypothesis regarding any variable, but was curious whether differences existed between the means for variables described for Hospice A and other provincial hospices. Tests of significance were attempted for differences between means

for LOS, age groups, diagnostic category, and location of care prior to admission for Hospice A characteristics compared to provincial aggregate data. Because the provincial data had been provided to the researcher as aggregated means, rather than as raw data, it was not possible to run the comparisons with raw data. Therefore, the means for three years for Hospice A and the means for the same three years for the other reporting provincial hospices were entered into EXCEL. Desired significance level was established as  $\leq p 0.05$  for all tests. F tests identified significant/non-significant variances. Separate two-tailed t-tests for means with unequal variances were run for the means with significant F-tests; separate two-tailed t-tests for the means with equal variances were run for means with non-significant F tests.

Field notes from the 11 question interview guide and transcription of the two audiotaped interviews were examined for thematic clustering of responses, contextual elements, consistency, convergence and divergence in hospice usage, perceived service or access gaps, and policy implications for planning and service.

## **Conclusion**

Descriptive statistical analysis of the characteristics of all residents at Hospice A for the years of 2006 to 2013 was completed. Comparative analysis of Hospice A with provincial aggregate data for the years of 2010-2011, 2011-2012 and 2012-2013 was accomplished. No assumptions were made about this self-selected hospice user sample nor the heterogeneity of the urban population from which this sample was derived. The user sample size for Hospice A was  $n = 744$  for the study period of seven years. The provincial aggregate sample for the time period 2009 to 2013 was drawn from user reports provided by 15 to 18 hospices. The provincial aggregate sample, excluding



Hospice A data, used in the comparative analysis was  $n = 6789$  for three years 2010-2013.

### **Summary**

Chapter III has presented the methodology for this mixed methods study. Setting, population, sample, data collection methods, Human Rights safeguards, tools, and data analysis were discussed. Chapter IV will present the Results, followed by the Discussion in Chapter V.

## **Chapter IV**

### **Results**

This mixed methods study examined the user characteristics of one hospice over a seven year period, provincially reported data from 15-17 Ontario hospices over four years, and the expressed opinions and ideas of two administrators about data collection obtained from brief audiotaped interviews.

The case study of one residential hospice described aspects of demographics, hospice use and disposition of adult patients who used in-patient residential hospice care in the years from 2006 to 2013, most of whom experienced expected death in the hospice setting. The former hospice patients whose records were reviewed as a convenience sample had voluntarily self-selected this hospice location for end of life care and death, or their Substitute Decision Maker had selected this care location on their behalf.

Narrative description and quantitative summaries were made of the characteristics, behaviors and conditions of this subpopulation served by hospice. Descriptive variables of age, gender, diagnoses on admission, malignant or non-malignant diagnostic categorization, bed usage, length of stay, discharge disposition, and location of primary residence were examined. For fiscal year 2012-2013, postal code analysis provided further characterization of residential location as urban, rural or out of catchment region.

The provincially reported user characteristics included age, malignant or non-malignant diagnostic categorization, bed usage, length of stay, and discharge disposition.

These data were examined for trends. Comparison of provincial data to Hospice A user characteristics showed similar patterns in age related trends and the predominance of use by cancer patients. There was variation in previous location of care, bed usage and occupancy rates between Hospice A and the provincial data sets. Both data sets revealed declining LOS over three years and few live discharges.

The interview responses of two administrators, one from Hospice A and one from the provincial oversight organization, were organized according to eleven themes: *perspectives, demand, resources, responsiveness, models, diagnostic complexities, barriers, research, awareness, funding, and other solutions*. The administrators both reported that they valued collection of user characteristics and potential use of statistical evidence as drivers for advocacy and funding.

### **Description of the Sample**

Hospice A admitted 744 clients to residential hospice beds over the seven year period of 2006 to 2013. Hospice A opened one month before the start of the fiscal year. The seven clients who accessed hospice care in this first month of operation were included in the fiscal year April 1, 2006-March 31, 2007. The characteristics of those clients admitted in one fiscal year who died in the next fiscal year were considered in the year of admission. Even though the mandate of Hospice A is to serve the adult population, there were two clients under 18 who received service. Occasionally, clients were admitted, discharged and readmitted. Five clients were readmitted, one of whom was discharged and readmitted twice. These clients were considered as new clients in calculation of  $n = 744$ . The annual total of clients using Hospice A ranged from 69 to 126, with a mean of 106 (Figure 1. *Comparison of Hospice A Admission Numbers by*

*Gender and Fiscal Year* (Appendix H)). Provincially, the sample (n = 6789) consisted of all adult users of 15 to 17 hospices from various Ontario locations, about which aggregate information is submitted annually to the provincial association.

### **Research Questions**

The three questions that guided this research and were used to organize the discussion of results were:

1. What are the characteristics of dying patients in a medium sized urban setting in Ontario who use hospice?
2. How does this hospice use compare with provincially collected hospice use data?
3. What data about hospice users would hospice administrators find useful?

### **Tools**

Data spreadsheets were constructed using both the Statistical Package for Social Scientists (SPSS) Version 21.0 for Windows program (SPSS, Inc., Chicago, IL) and Microsoft Office Excel (<http://office.microsoft.com/en-us/excel>) to facilitate statistical manipulation. The researcher developed an interview guide of eleven questions to facilitate the live interview (Appendix E Interview Guide). Field notes and transcriptions of the two audio taped interviews were examined for thematic clustering of responses and contextual elements.

### **Findings**

Findings are reported according to the research questions. User characteristics are described for a seven year time period from Hospice A. The characteristics are *age*, *gender*, *admitting diagnosis*, *bed usage*, *length of stay*, and *disposition*. For the 2012-

2013 year only, location of primary residence was available and was also examined. Provincially recorded data from 15-17 hospices for the time period 2010-2013 were then used to show comparisons and draw initial conclusions about the characteristics of users of hospice. Review of the two interview transcripts revealed the administrators' opinions about data collection, which were then clustered according to 11 underlying themes. The two administrators expressed similar thoughts about six of the themes; and they expressed different emphases for five themes.

Census information about population, mortality and disease frequencies were accessed from Statistics Canada (<http://www.statcan.gc.ca>). Searches of the Mortality Registry and Discharge Abstract Data Base (Office of the Registrar General; Ontario Ministry of Health, Health Analytics Branch, Vital Statistics) did not yield any disposition information concerning residential hospice locations. Information about deaths at hospice was not monitored by the Canadian Institute for Health Information or the Canadian Institute for Health Research.

### **Case Study**

#### **Research question.**

*1. What are the characteristics of dying patients in a medium sized urban setting in Ontario who use hospice?*

Since its 2006 opening, Hospice A has been tracking usage statistics and has shared its data collection experience and technology with newer hospices and with the provincial organization. Since 2008, Hospice A's monitoring of key performance indicators has included percentages of malignant and non-malignant diagnoses, average LOS, total number of bed days, average occupancy rate, complaints about nursing and

personal support worker staff, and number of referrals by month (new and waiting for bed). The researcher surveyed these data elements from a variety of Hospice A financial, statistical, and key performance indicator reports, and from Hospice A Census and provincial reports. Although Hospice A has collected data on most responsible physician, previous location of care and other program participation, these data were not available for all years and were excluded from this study.

#### **Monitoring context.**

All hospices funded by the MOHLTC are required to report prescribed information from the onset of funding. The Ministry of Health and Long Term Care flows residential hospice funding through Community Care Access Centers (MOHLTC, 2006). Since 2006, the funding agencies have required the individual hospice agencies to individually report actual bed days, occupancy rates, LOS, number of admissions, referrals and other key performance indicators to CCAC. The CCAC and provincial data reports differ in part by the type and number of indicators reported. Fewer and different indicators are reported to the funder than to the provincial hospice organization. Thus, only the Hospice A Census Record and provincial reports that included detailed information about hospice profile, patient demographics and bed usage were utilized as source documents.

Admission data and the characteristics of interest to the researcher about Hospice A users are summarized in Figures 1 to 7 (Appendix H ) and Tables 1 to 9 for age, gender, diagnosis on admission, diagnostic classification, bed usage, LOS, discharge disposition and residential location. Admission data for Hospice A are included in Figure 1. *Comparison of Hospice A Admission Numbers by Gender and Fiscal Year* (Appendix

H) indicating the total admissions for each of seven years (2006-2013) and the breakdown of admissions by gender. The total number of users admitted to Hospice A was 744.

**Age.** Over the seven years of data studied, the mean age of all Hospice A users was 70.1 years, the median 72.0, and the mode 79 years, with a standard deviation from the mean of 13.09 years. For females, the mean age was 69.7, the median 72.0, the mode 74, and the standard deviation was 13.43 years. For males, the mean was 70.4, the median 72.0 years, the mode 80 and the standard deviation 12.71 years. When the ages of users were stratified by ten year increments, as shown in Figure 2, *Hospice A Residents Grouped by Age as a Percentage of Total Number for Years 2006-2013* (Appendix H), usage patterns appeared higher in the 75- 84 years (30.5 %) and 65-74 years (26.2 %) age groups. Another 18.8 % of users of Hospice A were accounted for in the 55-64 year age group. Provincial hospice data are aggregated into three groups: 0-17, 18-64, and over 65 years. When aggregated into the same three groups (0-17, 18-64 and over 65), the over 65 age group represented the largest group of hospice users (68.0 %).

**Gender.** Over the seven year period studied, more females (n=391, 52.6 %) than males (n = 353, 47.4 %) used Hospice A for EOL care, reflecting an apparent increasing trend for more female usage than male usage as illustrated by the trend lines in Figure 3. *Year to Year Comparison of Percentage Admission to Hospice A by Gender* (Appendix H).

Table 1. *Comparison of Admissions to Hospice A by Gender and Three Age Categories for Years 2006-2013* presents gender information according to the three age categories that are also used provincially.

Table 1

*Comparison of Admissions to Hospice A by Gender and Three Age Categories for Years 2006-2013 (N = 744).*

Age Group		Male	Female	Total
1.	Over 65 years Count	250	256	506
	% within Category	49.4	50.6	100.0
	% within Gender	70.8	65.5	68.0
2.	18 to 64 years Count	102	135	237
	% within Category	43.0	57.0	100.0
	% within Gender	28.9	34.5	31.9
3.	0-17 years Count	1	0	1
	% within Category	100.0	0.0	100.0
	% within Gender	0.3	0.0	0.1
	Total Count	353	391	744
	% Overall	47.4	52.6	100.0



***Male and female users by age group.*** Of all Hospice A users in the over 65 year age group in the time period studied, 49.4 % were male and 50.6 % were female. In the 18-64 year age group, 43.0 % were male and 57.0 % were female. In the 0-17 year age group, 100.0 % were male and 0.0 % were female.

***Male users by age group.*** Of the male users of Hospice A during the study period, 70.8 % were over age 65 years, 28.9 % were aged 17-64 and 0.3 % were aged 0 to 17 years.

***Female users by age group.*** Of the female users of Hospice A during the study period, 65.5 % were over 65 years of age, 34.5 % were aged 18- 64 years, and there were none in the 0 to 17 years age group.

Table 2. *Comparison of Admissions to Hospice A by Gender and by Age Stratified in Ten Year Increments for Years 2006-2013* presents further breakdown about gender in Hospice A users. If age is reclassified into groups of less than 24 years, 25-34, 35-44, 45-54, 55-64, 65-74, 75-84, and over 85 years, there are some noticeable patterns within each gender. Five categories (45-54, 55-64, 65-74, 75-84, and over 85 years) were examined.

Table 2

*Comparison of Admissions to Hospice A by Gender and by Age Stratified in Ten Year Increments for Years 2006-2013 (N = 744).*

Age Group		Male	Female	Total
1.	Over 85 years Count	33	51	84
	% within Category	39.3	60.7	11.3
	% within Gender	9.3	13.0	
2.	75-84 years Count	119	108	227
	% within Category	52.4	47.6	30.5
	% within Gender	33.7	27.6	
3.	65-74 years Count	98	97	195
	% within Category	50.3	49.7	26.2
	% within Gender	27.8	24.8	
4.	55-64 years Count	60	80	140
	% within Category	42.9	57.1	18.8
	% within Gender	17.0	20.5	
5.	45-54 years Count	34	44	78
	% within Category	43.6	56.4	10.5
	% within Gender	9.6	11.3	
6.	35-44 years Count	5	6	11
	% within Category	45.5	54.5	1.5
	% within Gender	1.4	1.5	

---

	Age Group	Male	Female	Total
7.	25-34 years Count	3	3	6
	% within Category	50.0	50.0	0.8
	% within Gender	0.8	0.8	
8.	Under 24 years Count	1	2	3
	% within Category	33.3	66.7	0.4
	% within Gender	0.3	0.5	
	Total Count	353	391	744
	% of Total	47.4	52.6	100.0

---

***Male and female users by age group.*** Of all Hospice A users in the time period studied in the 45-54 year age group, 43.6 % were male and 56.4 % were female. In the 55-64 year age group, 42.9% were male and 57.1% were female. In the 65-74 year age group, 50.3 % were males and 49.7% were female. In the 75-84 year age group, 52.4 % were male and 47.6 % were female. In the over 85 years age 39.3 % were male and 60.7 % were female. Large gender differences, with more female than male users of hospice, were found in three categories - the 45-54 years, 55-64 years and over 85 years age groups.

***Male users by age group.*** Males aged 45-54 correspond to 9.6 % of all males admitted to Hospice A; males aged 55-64 correspond to 17.0 % of all males admitted to Hospice A; males aged 65-74 correspond to 27.8 %; and males aged 75-84 correspond to 33.7 % of males admitted to Hospice A. As male age increased, a steady rise in the percentage of male admissions occurred, until a rapid drop after age 85 years (9.3 %).

***Female users by age group.*** In contrast, females aged 45-54 represent 11.3 % of all females admitted to Hospice A; females aged 55-64 represent 20.5 % of all females admitted to Hospice A; females aged 65-74 represent 24.8 %; and females aged 75-84 represent 27.6 %. Women older than 85 years represented 13.0 % of all females admitted to Hospice A. The trend for women also appeared to steadily increase but the percentage increase was spread over more age groups.

***Admitting diagnoses.***

Figure 4. *Percentage of Hospice A Users by Diagnostic Category by Year and Total* (Appendix H) presents the comparative percentage of malignant, nonmalignant and unknown diagnoses illustrating the consistently high frequencies of malignant diagnoses

in Hospice A users, with considerably smaller nonmalignant frequencies. The numbers of unknown diagnoses are very small.

*Malignancies.* The majority of clients admitted to Hospice A had a malignant or oncology diagnosis as recorded by the admitting registered nurse in the census book (Figure 4. *Comparison of Percentage of Hospice A Users by Diagnostic Category by Year and Total* (Appendix H)). Metastatic spread was inconsistently listed. Of a total of 744 users, 690 users had malignant diagnoses corresponding to 92.7 % of total admissions over the 7 year study period. The minimum percentage (88.1 %) of malignant diagnoses occurred in 2006-2007 and the maximum percentage (96.6 %) occurred in 2008-2009. There has been little variation in this category since 2009-2010.

An admission diagnosis of malignancy occurred with similar frequency in male hospice users (93.2 %) and female hospice users (92.3 %) over the seven year period (Table 3. *Comparison of Malignant and Non-malignant Diagnoses Among All Users Admitted to Hospice A by Gender for Years 2006-2013*).

Men over 65 years had a higher percentage (70.0 %) of malignant diagnoses than did women over 65 years of age (63.9 %). In the 18-64 year age category, 29.7 % of men aged 18-64 had malignant diagnoses, whereas 36.1 % of women had malignant diagnoses. In the 0-17 year age group, 0.3 % of males had malignant diagnoses. There were no females in this age group.

Table 3

*Comparison of Malignant Cancer and Non-Malignant Diagnoses Among All Users  
Admitted to Hospice A by Gender for Years 2006-2013 (N =744).*

Diagnostic Category		Male	Female	Total
1.	Malignant			
	Count	329	361	690
	%	93.2	92.3	92.7
2.	Non-malignant			
	Count	23	28	51
	%	6.5	7.2	6.9
3.	Unknown			
	Count	1	2	3
	%	0.3	0.5	0.4
	Total			
	Count	353	391	744
	%	47.4	52.6	100

**Table 4. *Percentage Frequency of Twenty Most Common Malignant Diagnoses Among All Users Admitted to Hospice A by Gender for Years 2006-2013*** summarizes the more frequently occurring admitting diagnoses.

**Lung cancer:** Lung cancer was the most common diagnosis overall, representing 26.9 % of the total hospice user clientele, and 25.8 % of male and 27.9 % of female diagnoses. Lung cancer was the most frequent diagnosis across all years among those patients admitted to Hospice A. When year to year comparisons of lung cancer frequencies were made, the lowest lung cancer frequency was 22.9 % in 2008-2009 and the highest was 33.3 % in 2006-2007 and 2007-2008. This category included “lung”, “small cell”, “non-small cell”, “bronchus”, and “bronchogenic” cancers.

**Colorectal and related cancers:** The second most frequent diagnosis was colon cancer at 12.0 % of total admission diagnoses, and 14.7 % of male and 9.5 % of female diagnoses. Year to year frequency comparisons revealed the lowest frequency of colorectal cancer in clients admitted to Hospice A in 2008-2009 (8.5 %) and the highest frequency was in 2010-2012 (14.5 %). This category included census labels of “anal”, “bowel”, “cecum”, “colon”, “rectal”, “sigmoid”, and “GI malignancy”.

**Pancreatic cancer:** Pancreatic cancer was the third most frequent diagnosis at 8.7 % of admission diagnoses, and 9.1 % of male and 8.4 % of female diagnoses among clients admitted to Hospice A. Year to year variation in the percentage of Hospice A users with this diagnosis ranged from a low of 7.7 % in 2010-2011 to a high of 15.3 % in 2008-2009.

Table 4

*Percentage Frequency of Twenty Most Common Malignant Diagnoses among All Users Admitted to Hospice A by Gender for Years 2006-2013.*

	Cancer Diagnosis	Male	Female	Total
	N = 690	N = 353	N = 391	N = 744
1.	Lung	25.8	27.9	26.9
2.	Colorectal	14.7	9.5	12.0
3.	Pancreatic	9.1	8.4	8.7
4.	Breast	0.6	14.8	8.1
5.	Prostate	6.8	—	3.2
6.	Liver	4.5	1.8	3.1
7.	Ovary	—	5.6	3.0
8.	Glioblastoma	2.8	2.6	2.7
9.	Kidney	2.3	2.6	2.4
10.	Myeloma	3.4	1.5	2.4
11.	Esophagus	3.7	1.3	2.4
12.	Melanoma	3.7	0.8	2.2
13.	Gastric	1.7	2.3	2.0



14.	Lymphoma	1.7	0.3	0.9
15.	Leukemia	1.7	1.8	1.7
16.	Bladder	3.1	0.8	1.7
17.	Gall bladder	1.1	1.8	1.5
18.	Uterine	—	2.6	1.5

	Cancer Diagnosis	Male	Female	Total
	N = 690	N = 353	N = 391	N = 744
19.	Cervix	—	1.5	0.8
20.	Unknown	1.7	1.0	1.3

---

Other cancers: Breast and prostate cancers represented 8.1 % and 3.2 % respectively of admission diagnoses. Liver and ovarian cancer presented similar percentages (3.1%, 3.0 %). Glioblastoma and other brain or meningeal tumours, esophageal, gastric, hepatocellular, kidney, melanomas and myelomas each contributed 2 to 3 % of overall diagnoses. Leukemias accounted for 1.7 % of admissions. Cancers of the uterus and gall bladder each represented 1.5 % of all diagnoses and unknown primary diagnoses accounted for 1.3 % of all admissions. Cervical cancer represented 0.8 % of all diagnoses on admission.

*Non-malignant diagnoses.* Of the 744 Hospice A users, 51 had a non-malignant diagnosis corresponding to 6.9 % of total admissions over the seven year study period. Admission of patients with non-malignant diagnoses declined from 11.9 % in Hospice A's first year of operation (2006-2007) to 4.3 % in 2007-2008 and 1.7% in 2008-2009. Over the next four fiscal years (2009-2013), there has been little variation (6.6 %, 7.7 %, 7.9 %, and 8.1 %) in this category (Figure 4. *Percentage of Hospice A Users by Diagnostic Category by Year and Total* (Appendix H)).

The non-malignant diagnostic group encompassed chronic obstructive pulmonary disease (COPD), including pulmonary fibrosis and pulmonary hypertension; cerebral vascular accident and intracranial bleed; congestive heart failure (CHF); cirrhosis; amyotrophic lateral sclerosis (ALS); and end stage renal failure (Table 5. *Percentage Frequency of Six Most Common Non-Malignant Diagnoses Among All Users Admitted to Hospice A by Gender for Years 2006-2013*). COPD represented 1.9 % of all admitting diagnoses; CVA 1.3%; and CHF, cirrhosis and amyotrophic lateral sclerosis 0.7 to 0.8%

each. The aggregation of failure to thrive, Huntingdon's chorea, hydrocephalus, Creutzfeldt-Jakob Disease (CJD), and pleural effusion results in another 1.1 %.

An admission diagnosis of non-malignancy was recorded for 6.5 % of males and 7.2 % of females who were admitted to Hospice A over the seven year period (Table 3. *Comparison of Malignant and Non-malignant Diagnoses Among All Users Admitted to Hospice A by Gender for Years 2006-2013* (p. 51). Occurrence of non-malignancies was higher for the over 65 year age group for women (85.7 %) than men (78.3 %), whereas in the 17-64 year age group, 14.3 % of women and 21.7 % of men had non-malignant diagnoses (Table 6. *Percentage Frequency of Non-Malignant Diagnoses Among All Users Admitted to Hospice A by Age Group and Gender for Years 2006-2013* (N = 51). There were no non-malignant diagnoses in the 0-17 year age group. All non-malignant diagnoses, except ALS, CVA and end stage renal failure, were found to be higher in men than women admitted to Hospice A.

Table 5

*Percentage Frequency of Six Most Common Non-Malignant Diagnoses Among All Users Admitted to Hospice A by Gender for Years 2006-2013.*

Non-malignant Diagnosis N=51		Male N=353	Female N=391	Total N=744
1.	COPD	2.0	1.8	1.9
2.	CVA	1.1	1.5	1.3
3.	CHF	1.1	0.5	0.8
4.	Cirrhosis	1.1	.05	0.8
5.	ALS	0.3	1.0	0.7
6.	End Stage Renal Failure	0.3	0.3	0.3

Table 6

*Percentage Frequency of Non-Malignant Diagnoses Among All Users Admitted to Hospice A by Age Group and Gender for Years 2006-2013 (N = 51).*

	Non-malignant Diagnosis N = 51	Male N=353	Female N= 391	Total N=744
1. 0-17 years		0	0	0
2. 18-64 years		21.7	14.3	1.2
3. Over 65 years		78.3	85.7	5.6
4. Total		6.5	7.2	6.9

***Unknown diagnoses.*** Three indeterminate labels (gluteal mass, bowel obstruction, unknown diagnosis) were considered non-malignant but separately coded as unknown. This group represented only 0.4% of the total diagnostic categories. 0.3% of males and 0.5 % of females had an unknown diagnosis.

***Bed usage.*** Hospice A has collected bed usage data since 2009. Because the bed usage data were not available from the Hospice A Census Record, the researcher extracted this usage data from the provincial records. Provincial bed usage data also included identification of where patients had previously received care. Any data reported on previous location of care (PLC) for Hospice A was obtained from provincial reports in aggregate form for three fiscal years. Table 7. *Bed Usage for Hospice A (N1 = 389) and Other Hospices Reporting Provincially (N2 = 6789) for Years 2010-2013* presents bed usage data for Hospice A.

Table 7

*Bed Usage for Hospice A (N1 = 389) and Other Hospices Reporting Provincially (N2 = 6789) for Years 2010-2013.*

Fiscal Year	2010-2011		2011-2012		2012-2013	
Location	Hospice A	Ontario	Hospice A	Ontario	Hospice A	Ontario
Beds	6	131	6	138	6	144
Admissions	128	2170	131	2184	130	2435
Available Bed Days	2190	31769	2190	48840	2190	52560
Bed Days Used	2010	20638	1964	39592	1927	43614
Occupancy Rate %	91.8	65.0	89.7	81.1	88.0	83.0
Bed Usage by PLC						
%	44.7	86.1	36.8	53.1	68.2	54.3
Home	49.8	8.2	59.7	44.0	17.6	44.1
Hospital	5.5	5.7	3.5	2.9	14.6	1.6
Other						
Discharge	120	1551*	126	2038*	124	2292*
Disposition	3	23	1	73	5	94
Deaths						
Discharge						

*Note.* There was variation in the number of hospices reporting provincially each year (16 in 2010-2011, 17 in 2011-2012, and 18 in 2012-2013. All raw data were obtained from provincial organization reports.

There were 2190 available bed days each year at Hospice A. Hospice A had a high occupancy rate for each of the three recorded years (91.8 %, 89.7 %, 88.0 %). PLC was more likely to be home (53.9 %, 49.6 %, 66.9 %) than hospital (39.8 %, 45.8 %, 25.4 %) with less than 8 % of clients admitted from other locations (6.3 %, 4.6 %, 7.7%) (Table 8. *Comparison of Hospice A and Provincial User Characteristics by Age Group, Diagnostic Category and Previous Location of Care for Years 2010-2013*). The percentage of bed days used according to previous location of care did not reveal discernible trends over the three years (Table 7. *Bed Usage for Hospice A (N1=389) and Other Hospices Reporting Provincially (N2= 6789) for Years 2010-2013* (p. 53)). For patients coming from home, hospital and other locations, the bed usage was respectively 44.7 %, 49.8, 5.5 % (2010-2011); 36.8 %, 59.7 %, 3.5% (2011-2012); and 68.2%, 17.6%, 14.6 % (2012-2013). The apparent disparate changes in usage frequency for the last recorded year are puzzling.

***Length of stay.*** The mean, median and modal LOS for Hospice A were 18.2 (SD 25.9), 9.0 and 4.0 days for the 2006-2013 seven year period. The range was 264, with the minimum stay less than one day and the maximum stay 265 days. Ninety seven point eight percent (97.8%) of stays were less than 90 days; 1.6% were 91-180 days; and 0.5% exceeded 180 days. There is a difference in the LOS for males (mean 15.7 (standard deviation (SD) 20.82), median 8.0, mode 3,) and females (mean 20.4 (SD 29.61), median 10.0, mode 4). As Figure 5. *Mean Length of Stay of Hospice A Users for Year 2006-20013* (Appendix H) shows, the mean LOS varied by fiscal year from a high of 28.0 days (2007-2008) to a low of 15.2 days (2011-2012). than 180 days.



Table 8

*Comparison of Hospice A and Provincial User Characteristics by Age Group, Diagnostic Category and Previous Location of Care for Years 2010-2013.*

Fiscal Year	2010-2011		2011-2012		2012-2013	
Location	Hospice A	Ontario	Hospice A	Ontario	Hospice A	Ontario
Percentage						
Age Group						
0-17	0.8	4.0	0.0	3.9	0.0	0.0
18-64	32.0	31.2	32.8	25.3	28.5	24.7
65	67.2	64.8	67.2	70.8	71.5	75.3
Diagnostic Category						
Malignant	90.6	75.6	92.4	83.8	91.5	83.8
Non-malignant.	9.4	24.4	7.6	16.2	8.5	16.2
Admissions by PLC					—	
Home	53.9	59.8	49.6	54.9	66.9	52.7
Hospital	39.8	37.6	45.8	41.4	25.4	45.4
Other	6.3	2.6	4.6	3.7	7.7	2.2

*Note.* Number of hospices varied year to year.

There were a greater percentage of females (11/391) than males (5/353) with LOS longer than 90 days. There were five males who had a LOS greater than 90 days and 11 females with LOS greater than 90 days. Four of the 11 females had stays longer than 180 days. No males stayed longer

In the first two years of Hospice A operation, the means for LOS (24.5 and 28.0 days respectively) were higher than that of the overall 7-year mean LOS (18.2 days) (Figure 5. *Mean Length of Stay for Hospice A Users for Years 2006-2013* (Appendix H)). These longer lengths of stay appeared to be explained by eight stays longer than 60 days, four of which exceeded 90 days, in 2006-2007; and six stays longer than 60 days, four of which exceeded 90 days, in 2007-2008. For the entire seven year period, there were 16 Hospice A users (11 females and five males) whose stays were over 90 days, which represented 2.2 % of all users. Four female users (0.5% of all users) were at Hospice A longer than 180 days; one each in years 2006-2007, 2007-2008, 2009-2010, and 2011-2012. The mean LOS for Hospice A has leveled off over the five years 2008-2009 to 2012-2013 to between 15.2 and 17.8 days.

The mean LOS at Hospice A for each of the seven years are illustrated in Figure 6. *Mean Length of Stay with Standard Deviations at Hospice A for Years 2006-2013* (Appendix H). Because the mean LOS over the last five years had leveled off to between 17.8 and 15.2 days, the longer lengths of stay were examined more closely to determine how much the outliers in the first two years of operation might explain the higher overall mean. One SD above the mean of 18.2 days occurred at 44.1 days and two SD above the mean occurred at 70.0 days (at a 95% confidence level). The researcher therefore removed all LOS data for users whose stays were greater than 90 days, which is the

residential hospice standard for maximum LOS. The standard deviations below the overall mean of 18.2 days were not considered because two SDs below the mean would have resulted in negative numbers, well below the mode of four days, which would not then provide meaningful information. For only users with LOS 90 days or shorter, the mean LOS is 15.4 for the seven year period (compared to a mean LOS of 18.2 for all users); and more closely resembles the LOS for 2008-2009 to 2012-2013 (17.8 to 15.2 days).

From the provincial hospice organization usage reports, Hospice A mean LOS was also tracked according to previous location of care for fiscal years 2010-2011, 2011-2012, and 2012-2013 (Table 9. *Mean Length of Stay for Users of Hospice A and Other Hospices Reporting Provincially for Years 2010-2013*). The mean LOS for 2010-2011 was 15 days; for 2011-2012, 14 days; and for 2012-2013, 17 days. For the same three time periods, the mean LOS for those admitted from home was 17, 11, and 15 days; for those admitted from hospital, 20, 19 and 10 days; and for those admitted from other locations, none recorded, 11 and 27 days.

**Discharge disposition.** In the beginning of Hospice A's service provision, there were more live discharges than in later years. Discharges other than death ( $n = 29$ ) were to home, hospital, long term care home and unknown locations. Home was the most frequent destination (58.6%). Live discharges represented 4.3 % or fewer of all dispositions, with the exception of the hospice's first year of operation (2006-2007) in which they were 10.7%. Percentages of deaths while at hospice per total admissions ranged from 89.2 % to 98.4 % over seven years of provision of service (Figure 7. *Annual Discharge Disposition for Hospice A Users in 2006-2013* (Appendix H)).

Table 9

*Mean Length of Stay for Users of Hospice A and Other Hospices Reporting Provincially for Years 2010-2013.*

	2010 - 2011	2011 - 2012	2012 - 2013
	Hospice A	Hospice A	Hospice A
Mean LOS			
(days)	15	14	17
PLC			
Home	17	11	15
Hospital	20	19	10
Other	8	11	27

*Note.* \*2010-2011 LOS from hospital was reported as 19.6 from Emergency and 23.6 from an acute ward. The recorded LOS is an average of these 2 numbers.

Table 10

*Primary Residence of Users Admitted to Hospice A in 2012-2013 (N = 124).*

Location	Percentage of total admissions
1. City A, the Census Metropolitan Area (CMA) in which Hospice A is located	61.3
2. Town D, a Census Agglomeration of greater than 10,000 within County A, and part of the CMA	12.9
3. County A, exclusive of City A and Town D, but part of the CMA	11.3
4. Other Counties B and C, comprised of one town E (a Census Agglomeration of greater than 10,000 population) and Rural Areas	8.9
5. Out of Region	5.6

*Note.* Town E, County B and County C are not part of a CMA or population centre.

When grouped as urban, rural, and out of region, 85.5 per cent of 2012-2013 users were urban dwellers, 8.9 per cent were rural or small town residents and 5.6 per cent resided out of the catchment region.

### **Provincial Reporting of User Characteristics**

#### **Research question.**

*2. How does this hospice use (that is, Hospice A) compare with provincially collected hospice use (that is, all other reporting hospices) data?*

User data were accessed from two resources: a) Hospice A Census Report and b) the provincial hospice organization. Since 2009, all funded hospices have been requested to report usage data every 6 months to the provincial hospice organization. The provincial reports included detailed information about hospice profile, patient demographics and bed usage. The domains presently tracked annually (fiscal year) by the provincial organization are hospice name, LHIN name and number, number of beds, target population, admission, age groups, diagnostic category, number of referrals, number of assessments, deaths prior to admission, location of care prior to admission, bed usage (bed days available, bed days used, bed days according to previous location of care, occupancy rate), length of stay, LOS separated by PLC, bed turnover, and discharge disposition. The provincially collected hospice data reported in this study excludes Hospice A data.

#### **Monitoring context.**

The CCAC flows funding from the Ministry of Health and Long Term Care (MOHLTC, 2006). Since 2006, the funding agencies have required the individual hospice agencies to individually report actual bed days, occupancy rates, LOS, number of

admissions, referrals and other key performance indicators. The hospices report to a variety of Community Care Access Centers, but without consistency in reporting from hospice to hospice and funding organization to funding organization. The CCAC and provincial data reports differ in part by the type and number of indicators reported, with fewer and different indicators reported to the funder than to the provincial hospice organization. Although the researcher had access to the CCAC reports, the level of data did not add to the purposes of this particular study. For this reason, the researcher chose to concentrate only on the provincial reports.

Information not recorded in either database included LHIN name, hospice residential location, gender or specific diagnoses of users, marital status, presence of medical director or physician on site, available type and usage of other RH programs (day, volunteer, counseling/psychosocial support, therapies, bereavement). Calculation of the ratio of admissions to applications was not presented consistently.

Provincially, hospice user information has been tracked only since 2009. Voluntary submission began with 13 criteria in calendar year 2009 because many hospices opened that year. However, annual data were incomplete because some hospices were open only for few months in their first and/or final years of operation. Fourteen hospices initially reported on eight categories of user information and 15 hospices reported on 13 categories. Subcategories considered number of admissions, number of bed days, and length of stay according to the user's previous location of care, thus expanding monitoring to 16 categories.

The current provincial organization is an amalgamation of two hospice palliative care organizations; it has tracked user data since 2011 for the purposes of advocating for

hospice resources. Beginning in 2010, there has been a growing expectation that all hospices should submit data annually to the provincial body. After province-wide agreement among hospice administrators about the need, utility and desired characteristics for usage monitoring, reporting was switched from calendar year to fiscal year. Because the whole reporting process has continued to evolve, this researcher had no way to confidently verify or validate data entered by any hospice or hospice organization. For this reason, the researcher chose to concentrate only on the aggregate provincial reports.

Four reports of provincial data were accessed for this research study. The source of the reports for fiscal years 2010-2011, 2011-2012, and 2012-2013 was the provincial umbrella organization. The report for 2010-2011 actually predated the formation of the present provincial association. The number of hospices serving adults with submitted data varied from 14 in 2009, 16 in 2010-2011, 17 in 2011-2012 to 18 in 2012-2013. Although the provincial report for calendar year 2009 included important aggregate bed usage information, it lacked individual hospice data elements that would have allowed for comparison. Thus, the 2009 report was not included in this study.

#### **Provincial patterns.**

Over the three year period 2010-2011 to 2012-2013, the number of available RH beds grew from 137 to 150. The characteristics of users that are monitored province-wide are number of admissions, referrals and assessments; user age groups; diagnostic categories; bed usage, including bed days available and used, previous location of care, occupancy rate, and length of stay according to previous location of care; deaths prior to admission; deaths and discharges. The data elements discussed in this section are age,



diagnostic category, bed usage, including previous care location and occupancy rates, LOS, and discharges.

**Age.** Three age categories are reported among all users of residential hospice in the province. Of the three age categories, the over 65 year age group represented 64.8 % (2010-2011), 70.8 % (2011-2012) and 75.3 % (2012-2013). The 18-64 years age group represented 31.2 % (2010-2011), 25.3 % (2011-2012) and 24.7 % (2012-2013). The 0-17 age group represented 4.0 % (2010-2011), 3.9 % (2011-2012) and 0.0 % (2012-2013).

**Admitting diagnoses.** Two diagnostic labels (malignant and non-malignant) have been recorded since 2010-2011. Malignant diagnoses were recorded as 75.6 %, 83.8 %, and 83.8 % for the years 2010-2011, 2011-2012 and 2012-2013 respectively. Non-malignant diagnoses were recorded as 24.4%, 16.2 %, and 16.2 % for the years 2010-2011, 2011-2012 and 2012-2013 respectively. Provincially reported data did not include specific diagnoses so the researcher could not make comparisons with Hospice A diagnoses.

**Bed usage.** Overall occupancy rates were 65.0 % (2010-2011), 81.1 % (2011-2012) and 83.0 % (2012-2013). Although more referrals were made than assessments done, there were too few records of admission to referral and admission to assessment rates to be useful to this researcher. However, the previous location of care did appear to be useful. There was year to year variation in bed usage for those admitted directly from home and from hospital over the three years of available data. The percentages of users admitted from home were 59.8 %, 54.9 % and 52.7 %, whereas from hospital, they were 37.6 %, 41.4 % and 45.1 %. Total bed days used was reported for 2010 to 2013. Hospice users admitted from home had more total bed days (86.1 %, 53.1 % and 54.3 %) than did

persons admitted from hospital (8.2 %, 44.0 % and 44.1 %) of total bed days used.

Persons admitted from other locations used 5.7 %, 2.9 % and 1.6 % of total bed days

(Table 7. *Bed Usage for Hospice A (N1 = 389) and Other Hospices Reporting*

*Provincially (N2 = 6789) for Years 2010-2013* (p. 53).

***Length of stay.*** The average LOS has declined from 23.5 days (2010-2011) to 17.4 (2011-2012) and 19.4 days (2012-2013). Users admitted from home had a declining length of stay over time, as did those admitted from other locations. In contrast, users admitted from the hospital continued to have slightly higher LOS than those from home. See Table 9. *Mean Length of Stay for Users of Hospice A and Other Hospices Reporting Provincially for Years 2010-2013.* (p. 56).

***Discharge Disposition.*** The number of live discharges remained at or less than four percent of admissions for the three year reporting period. Although the provincial hospice organization is tracking number of deaths at hospice and number of deaths occurring following referral but prior to admission to hospice, these numbers are not verifiable because the number of hospices reporting user data has varied each year.

#### **Comparison of Hospice A and provincial characteristics.**

Both administrators acknowledged difficulty in consistently obtaining user information from all hospices, technological reporting challenges, and the need for awareness efforts to enhance hospices' knowledge of data utility, conviction to dedicate time and staff for data collection and entry, and development of expertise in collection techniques. Because of reporting inconsistencies and reliability issues, comparison between Hospice A and provincial user characteristics was made for only three years, namely, 2010-2011, 2011-2012 and 2012-2013.

The comparative results for age group, admitting diagnostic category, previous location of care, bed usage, LOS and disposition are presented in Table 8. *Comparison of Hospice A and Provincial User Characteristics by Age Group, Diagnostic Category and Previous Location of Care for Years 2010-2013* (p. 54); and two previously cited tables: Table 7. *Bed Usage for Hospice A (N1 = 389) and Other Hospices Reporting Provincially (N2 = 6789) for Years 2010-2013* (p. 53), and Table 9. *Mean Length of Stay for Users of Hospice A and Other Hospices Reporting Provincially for Years 2010-2013* (p. 56).

**Age.** The age group profiles for Hospice A showed more year to year consistency than the provincial data (Table 8. *Comparison of Hospice A and Provincial User Characteristics by Age Group, Diagnostic Category and Previous Location of Care for Years 2010-2013* (p. 54)). The two tailed independent t tests for differences in means with equal variances ( $p = 0.15$ ,  $p = 0.18$  and  $p = 0.65$ ) were not statistically significant at  $p \leq 0.05$  for any of the three age groups. The over 65 year class represented the majority of admissions both locally and provincially. However, separation of Hospice A users into ten year groupings showed the majority of users were 65-74 and 75-84 with approximately equal distribution in both age periods (Table 2. *Comparison of Admissions to Hospice A by Gender and Ten Year Age Category for Years 2006-2013*) (p. 44).

**Gender.** Gender was not monitored by either Hospice A or the provincial body.

**Admitting diagnosis.** Comparison of diagnostic classification revealed lower percentages of users with non-malignant diagnoses (9.4 %, 7.6 % and 8.5%) at Hospice A than occurred provincially (24.4 %, 16.2 % and 16.2%) (Table 8. *Comparison of Hospice A and Provincial User Characteristics by Age Group, Diagnostic Category and Previous*

*Location of Care for Years 2010-2013* (p. 54)). The two-tailed independent t tests for differences in means with equal variances were statistically significant for both malignant ( $p = 0.02$ ) or non-malignant diagnoses ( $p = 0.02$ ) at  $p \leq 0.05$ . Classification by primary disease diagnosis was not recorded provincially.

**Bed usage.** Hospice A trends in location of care prior to admission are mirrored by provincial trends, with more users admitted from home to hospice than from hospital to hospice (Table 8. *Comparison of Hospice A and Provincial User Characteristics by Age Group, Diagnostic Category and Previous Location of Care for Years 2010-2013* (p. 54)). The two-tailed independent t test for differences in means with equal variances was not statistically significant for previous location of care from home ( $p = 0.87$ ) or hospital ( $p = 0.53$ ) but was significant for previous locations other than home or hospital ( $p = 0.03$ ) at  $p \leq 0.05$ . Occupancy rates at Hospice A are notably higher than provincial averages (91.8 %, 89.7 %, 88.0 % compared to 65.0 %, 81.1%, 83.0 %). The provincial percentage of total bed days used in 2010-2011 was appreciably higher (86.1%) for those users who came from home compared to those from hospital (8.2 %) and was in contrast to similar percentages for home (44.7%) and hospital (49.8%) for Hospice A.

Calculation of rates of admission compared to assessment showed provincial reporting problems in 2010-2011. Where the data were available, there were consistently high rates of admission to assessment for 2011-2012 (88.2%) and for 2012-2013 (72.0%). There were consistent rates of admission to assessment of 55.2%, 51.0 % and 55.1% percent for Hospice A.

**Length of stay.** Length of stay for Hospice A is trending downwards, regardless of PLC, except for hospice users admitted from locations other than home and hospital

(LOS = 27 days, 2012-2013) (Table 9. *Mean Length of Stay for Users of Hospice A and Other Hospices Reporting Provincially for Years 2010-2013* (p.57)). In Hospice A, the mean LOS over seven years of recordkeeping is 18.19 days, with 15.66 days being the norm over the last three year period (2010-2013) (Figure 5. *Mean Length of Stay for Hospice A Users for Years 2006-2013*). For the three comparison years, provincial LOS for all users was higher at 23.5, 17.5 and 19.4 days, irrespective of PLC being home or hospital. However, the provincial trend in mean LOS from locations other than home or hospital was lower (15.2, 9.1, 9.8 days). For PLC other than home or hospital, Hospice A LOS rose to a notable 27 days in 2012-2013.

For the three comparison years, overall mean LOS at Hospice A was 15, 14, 17; and for other provincial reporting hospices, 23.5, 17.5, 19.4. The two tailed independent t test for differences in means of equal variance was non-significant ( $p = 0.07$ ) at  $p \leq 0.05$ .

**Discharge Disposition.** Most users of Hospice A and of all other reporting hospices died while under hospice care. The total number of deaths at hospice increased in both Hospice A and the province over the three comparison years. Live discharges were higher provincially in 2011-2012 than at Hospice A. Although the total percentage of live discharges remained low both for Hospice A and for the other reporting hospices, they did increase to a high of 4% in 2012-2013 (Table 7. *Bed Usage for Hospice A (N1 = 389) and Other Hospices Reporting provincially (N2 = 6789) for Years 2010-2013* (p. 53).

**Residential location.** Primary residential location of users was not reported provincially so no comparisons could be made between urban or rural users of Hospice A and other reporting hospices.

## **Interview Summary**

### **Research question.**

#### ***3. What data about hospice users would hospice administrators find useful?***

Brief interviews, using an 11 question interview guide, were conducted in June, 2013 with two administrators working in hospice care in Ontario. The administrators identified bed usage, length of stay, diagnosis, previous residential location, culture, ethnicity and religion as data points of interest. As the interviewees elaborated their thoughts about issues associated with accessing necessary data, 11 themes emerged from the discussions. When the interview transcriptions and field notes were examined, the interview responses were organized into six themes related to hospice use (*demand, resources, responsiveness, models, complexities of diagnosis, barriers*); and four themes of solutions (*research, awareness, funding, and other solutions*). *Local versus provincial perception* was an interwoven theme. The perspectives of the administrators at times seemed to reflect each one's immediate areas of concern or job responsibilities. Both expressed similar opinions about demand for residential hospice care, inconsistent resource use, service responsiveness, residential models, funding, and the complexities of diagnoses (that is, the complex intersection of chronic disease and palliative care). Differing perspectives surfaced about data collection, barriers, awareness and other solutions.

### **Impacts on hospice use.**

***Demand for residential hospice care.*** The interviews uncovered several concerns related to, but not directly addressed by data collection. Both hospice administrators identified an unequivocal, increasing demand for residential hospice beds. They spoke of

the demographic pattern of the large aging population and the resultant strain on the health care system. “We see the aging population, then how do we service everyone in the future that is going to need this care?” (administrator, Hospice A). Once community members are familiar with hospice, they might request hospice care for subsequent family members who are dying, thus increasing the demand by word of mouth. Hospice A has a “philosophy of whole person care that we give to support the person emotionally, spiritually, and the family support that they need.” (administrator, Hospice A).

The administrator from Hospice A cited that agency’s increase in annual number of referrals and number of annual admissions for residential care and outreach programs as indicators of bed need. The administrator from the provincial organization quoted provincial population forecasts, disease statistics, and lack of an accurate hospice bed census. The provincial administrator referenced the Australian and Fraser Health Authority hospice models that provide benchmarks for RH bed numbers based on population. According to the provincial administrator, Ontario would need 1300 or 1500 beds based on these models. Currently there are 215 RH beds throughout Ontario. Even considering the addition of 320 other palliative beds in acute settings and 335 in complex continuing care, the resources do not approach the need. The demand could actually be greater than this because these numbers are estimated. For example, beds in other settings designated and funded for other purposes, such as overflow or post-surgery, are sometimes used for palliation. Alternately, beds designated and funded for palliative care are sometimes used for other purposes. The provincial administrator commented at one point “Either way you look at it, we don’t have enough palliative beds.” and at another time, “The need is only going up.”

**Resource use.** According to both administrators, there are many resource issues. In discussing the inadequacy of resources for palliative care, the provincial administrator noted that sub-groups within the province do have particular needs for EOL care. Developmentally delayed adults need palliative care within their group home or institution according to the administrator from the provincial hospice organization. First Nations (both rural and urban) want hospice care that will accommodate their cultural beliefs. Patients with non-malignant diagnoses, dementia, the frail elderly, those without family, and long stay palliative patients experience challenges just accessing palliative care. “The hospices are not the place because the cost of care for long stay would be as prohibitive as in hospital” (administrator, provincial hospice administrator). Neither can small hospices with only one Registered Nurse manage this care. Although discharge of stable patients from hospice to long term care could be a solution, there is no streamlined process to quickly facilitate this. When discharge is not possible, at least two negative management options occur: a) prolonged use of the hospice bed with resultant bed blockage or b) return to home with the possibility that the hospice user would again have to access acute care.

**Service responsiveness.** Hospices admit based on service referrals, priority of need, staffing complement, and discretion of the hospice admission staff. Residential hospices presently receive referrals from within their local catchment areas and also respond as needed to individual and family needs for care across Local Health Integration Network boundaries. Hospice A provides onsite overnight accommodation for the family, some of whom must travel up to 2.5 hours to visit their loved ones in the nearest hospice. Hospice A has also provided EOL care for children because there is no



children's hospice in the region. Both administrators described instances of Ontario hospices providing sentient, culturally competent care to people of various ethnicities and belief systems and facilitation of life review, family celebrations, and death rituals. In the context of the hospice organizational belief that no-one should be left uncared for, the Hospice A administrator described an occasional need for care for individuals without valid provincial health cards (for example, new Canadians, persons from other provinces, and employees of federal jurisdictions).

The administrator from the provincial hospice organization described the impact of the move to hospice on the dying individual and his/her family. For some of these patients, "Two things happen on admission: There is a reduction in stress because they are no longer a burden to the caregiver. The care expertise is high. They get the right pain and right symptom management. The quality of life improves."

Despite this responsiveness, hospice admission decisions are complicated by a number of factors. The Hospice A administrator identified wait list problems. Some new clients present with immediate admission needs but have not been on the wait list nor provided any previous community outreach or support. Others have had their names placed on the hospice list too early in their disease trajectory. Eligibility decisions are made externally by the Community Care Access Center but admission decisions are made collaboratively. Improved coordination and communication of status and changing user needs among all caregivers is needed to prevent bed blockages and to encourage responsiveness to community, emergency department and hospital patients. As an example, palliative physicians in County A have improved access to care in the right place because they are able to work in all care settings. When there is competition for the

next available bed, the Case Manager, physician and hospice admission coordinator “ask who can receive more care at home” or they move a patient from the hospital palliative bed to hospice so the hospital bed is free for someone to access from the emergency department. Such flexibility in response is an important component of access to care because “nothing is black and white at EOL” (administrator, Hospice A).

The hospice wants to neither rush nor delay a patient’s admission. Hospice A admits on any day at any time but the downsized ambulance service is only available during 7am to 7 pm daily. When a need arises outside of these hours, Hospice A responds to arrange alternate transportation that is charged to the family. There are unpredictable, urgent changes in a patient’s health status, such as thrombosis causing dyspnea. Behaviors, such as agitation with brain metastases, can be difficult for families to manage at home. Family coping and psychosocial issues also can impact demand for admission to hospice. The administrator of Hospice A described a patient’s personal struggle with what it meant for him/her to accept a bed: “I don’t want to come in here. I know what coming into one of these beds means”. Recognizing this struggle when the patient becomes ready to move, the hospice needs to respond appropriately. The offer “needs to be done gently” (administrator, Hospice A).

**Models.** Geography and local needs influence present and proposed hospice models of care. According to the administrator of the provincial organization, two Local Health Integration Networks in Ontario do not have any residential hospices. This ED reported that most Ontario hospices are six or ten beds, with several being three bed models. They are freestanding, community built charities that receive partial government funding for nursing services. New models being discussed are co-locations or cottage

hospices attached to hospitals, central hubs for all hospice services, early intervention and hospice outreach teams, and hospices with several satellite sites in smaller or rural communities with shared administration staff.

Rural areas and large geographical service areas face particular challenges related to access, delivery of care, and model of care. As an example of access challenges, some families have to drive up to 2.5 hours to place and visit a loved one in the nearest hospice. Delivery of care is challenged by cultural and individual needs. Within each community, there can be specific needs, such as that associated with very short end of life stays. For example, one cultural group does not want death to occur at home and prefers to use one Ontario hospice only for the last few hours or days of life.

A stakeholder survey conducted prior to building Hospice A identified needs not only for support of patients at EOL, but also for caregiver and family support, and attending to the needs of patients with cancer and dementia. The administrator from Hospice A acknowledged that patients with dementia in their service area experience service delivery challenges.

Patient input continues to be important in the delivery of care especially when the patient's needs might differ from the service delivered or envisioned by hospice providers. Polling patients for what they want from hospice might uncover differing definitions of quality of care. For example, the hospice might focus on the number served and length of stay but the patient's quality concern is "What are you doing for my family?" (administrator, provincial hospice organization). The definition of quality of care might differ from the patient and provider perspective. Although the provincial administrator is aware of beginning research by one Ontario hospice about reduction in

pain and psychosocial stress with hospice admission, there is not research about quality of life experience in hospice.

Responsive models of care have included psychosocial support and trained hospice volunteers. Both of the administrators interviewed valued the importance of uncompensated hospice volunteers, who contribute significantly by their expenditure of time, and their individual and program support. The Hospice A administrator emphasized “the most successful part of our [residential] program and Outreach is that a human being answers the phone” to help those in need who are frightened. Staff at this hospice were described as persons who take the time to sit with, touch and listen to clients. The administrator from Hospice A commented “We’re not afraid to ask those questions” about fears and unresolved relationships. “Those people for the first time in their lives are able to unload some of those things that they’ve never, ever been able to talk to someone about. It’s very helpful in their death.”

*Complexities of diagnosis.* Both administrators described trends in increasing acuity of patients at EOL, which impacts length of stay. “Our length of stay is relatively low, which speaks to the acuity, and how close they are to EOL, but our acuity and complexity have gone up dramatically in the last 5 years” (administrator, provincial hospice organization). There have been consistent, high percentages of malignant diagnoses in users of RH care. The administrator of Hospice A commented “We have been so focused on cancer.”

By contrast, persons with other diagnoses also could benefit from hospice care. For example, the person with end stage renal failure, congestive heart failure or chronic obstructive pulmonary disease lives with end of life uncertainty. Optimization of service

for persons with chronic, multiple comorbidities and nonmalignant diagnoses is an emergent need. “Our population now has ...the highest percentage of those with COPD” (administrator, provincial hospice organization).

Both interviewees identified the unique concerns of the frail elderly. Location for care and determining how best to serve this group when they have multiple comorbidities or require long stays are problematic issues. Another example is patients with amyotrophic lateral sclerosis. The provincial ED described an ALS client without family who required a long stay in hospice and used this case to illustrate comparisons about best care location, cost and sustainability in hospice, hospital or long term care.

The care needs of Ontarians with chronic illness overlap with and are analogous to the needs of persons receiving palliative care. Nevertheless, patients with end stage chronic illness might not receive palliative care or residential hospice care. Part of this disparity in care can be explained by the lack of understanding among primary care physicians of the complex intersections of chronic illness and palliative management (administrator, provincial hospice organization). According to the provincial administrator, the provincial government has identified a need to develop and track outcome measures for quality improvement for chronic illness.

**Barriers.** In addition to the need for research to verify barriers to hospice use, the interviewees identified common barriers to hospice users. Barriers affect the hospice provider and professional caregivers, as well as patients and their families. Unchanging attitudes, lack of information, taboos, and lack of conversations about death and dying occur within families and among professional caregivers. Evolving issues concern both

the hospice and the family. For example, Hospice A has to consider current patients' care needs and staffing workloads when making admission decisions.

Hospice providers lack understanding of the needs of ethnic, religious, disabled and marginalized socioeconomic groups in their community. As the provincial hospice organization administrator commented, "We won't know unless we collect some of the data." Lack of specialized training in cultural competence for local community practices is a barrier for the psycho social spiritual team. If financial restraints occur, funding of these support staff might be at risk. "While that may not have an immediate impact on the person dying, it may have a huge impact on the family" (administrator, provincial hospice organization). Care provided for families, which might be placed at risk, involved "how the family is cared for, return to work, the complexity in grief" (administrator, provincial hospice administrator).

The increasing incidence of chronic illness and nonmalignant diagnoses in the aging Ontario population creates barriers for access and planning appropriate access to hospice care. The Hospice A administrator commented on the difficulty of predicting an illness trajectory:

You can know when someone had lung cancer with spread to bone or brain their length of end of life isn't going to be so long, whereas with congestive heart failure it can be years. They can be this close to end of life, a hair away, and the next day they are out shopping. We struggle with this.

Hospice users and their families might profit from a clearer understanding of what to expect after their loved one has been admitted. If a patient rebounds, he/she might need to be discharged. At such times, families might feel that their loved one "is not

dying fast enough” when discharge is suggested. A small number of stabilized patients are discharged to their homes, to family residential locations, or to retirement homes. Because there is no service delivery mechanism to fast track these stable patients into a long term care home, if LTC is the desired discharge location, a small number of residents must still be discharged to home. Following discharge, the patient may choose readmission to hospice or to the hospital or he/she can choose to die at home when further decline occurs. However this choice is not available to those who are discharged to LTC. A move to LTC precludes readmission to hospice. These difficulties create pressures for bed flow throughout the care delivery system.

Another issue arises for communities planning to build new hospices. The provincial administrator found LHINs across the province continue “doing the exact same thing, putting the same amount of resources into development with really no information sharing,” and without assistance from older and experienced sector participants.

*Perspective.* Two different layers of experience are represented by the Hospice A administrator and the provincial administrator. The local response emerged over time according to specific community needs for support for EOL, caregivers and families. The Hospice A administrator cited an example of one spouse who recognized that “OK, I know I don’t have to do this alone.” Barriers were identified incrementally. Hospice A developed an interdisciplinary outreach team for round the clock symptom management, psychosocial spiritual support, volunteers, clinical navigation, and satellite clinics. The Hospice A administrator identified the rigidity of the system, which impacts the ability of all hospices to respond (for example, eligibility determination, access to transportation,

wait listing, and fees). The provincial administrator described gaps in palliative care provision across the province. There are different kinds and occurrences of barriers to system responsiveness issues for rural communities, large geographical catchment areas, the long stay palliative client, children, cultural groups, the homeless and disenfranchised. Stumbling blocks in thinking were identified by the provincial administrator (that palliative care means imminent death, that treatment and palliation cannot occur simultaneously, and that advanced care planning conversations can be delayed). The provincial administrator alluded to hospice as a second choice, stating “The residential hospice system is very important and is an integral part of delivery of palliative services. But I am constantly reminding people that the first location of choice is the home.”

**Potential solutions.**

***Research and data collection.*** Basic user characteristics from each Ontario funded hospice are voluntarily submitted annually to the provincial organization. The two hospice administrators wanted continued user surveillance and indicated interest in expansion of data collection. Both interviewees spoke to the utility of research to demonstrate the impact and value of their services for individuals, families and the community.

The provincial organization administrator commented that “It is evident to me that there is immense potential for research within the sector.” and “What is the story we need to tell? What data do we need to collect...How do we use the data to tell the story?” This administrator was interested in user characteristics concerning location of “home”, details about diagnosis and concomitant disease, language, ethnicity and religion, and the



impact of the move to hospice on caregiver coping and the patient and caregiver relationship. At present, there is no measure of caregiver burden that can be considered during admission decisions. "I'd like to see more data collected on the family and the impact of residential care on the family caregiver." The provincial organization administrator observed that one woman appreciated "spending their final days as man and wife, rather than patient and caregiver". This care of the family, quality of death, and grief support has important societal health impacts. This administrator understood that the value and system impact of residential hospice could be derived from research. Purposeful research would allow presentation of concrete outcomes, such as decreased emergency room and alternative levels of care bed usage, to government funders.

The Hospice A administrator advised caution about invasive surveys that might "bombard patients and families" at a vulnerable time. The administrator expressed particular concern about timing of survey administration, staff acceptance, survey language and sensitivity to ethnicity and religion. The Hospice A administrator was interested in knowing how to improve the process of identifying potential users, how to determine priority of need for admission, and bed flow. This administrator reported having spoken directly to the Minister of Health about the impact of end of life care and the need for high standards of care at hospice. For the Hospice A administrator, data collection was important "to change practice and to get the Ministry to understand" hospice care.

Both administrators agreed that research on the impact of hospice care on the caregiver is urgently needed as a quality of care indicator. Hospice A administrator stated that "People can die well at home, in the hospital and the hospice. But I don't

believe any other setting provides the care we wrap around the family with that anticipatory loss. We're here 24/7." The provincial administrator suggested a unified provincial survey post death to validate the type and quality of care from the patient's and family's perspectives. The MOHLTC has a task group to develop outcome measures for "the quality of care through the lens of the patient and caregiver" (administrator, provincial hospice administrator). More research might convince government funders to increase operational funding, identify underserved and unserved populations and support alternative models of hospice care. Presently, hard data are not available.

*Awareness.* Although raising awareness of hospice care occurs provincially, locally and individually, awareness had different meanings for the 2 administrators. The administrator of the provincial organization addressed broader issues. This administrator identified that, although provincial campaigns have a high cost, current initiatives have targeted discussion about Advanced Care Planning with all Ontarians and education of primary care doctors about PC philosophies and their intersection with chronic disease. "The public dialogue around death and dying needs to shift" (administrator, provincial hospice organization). On demand mentoring and support initiatives have been planned for physicians. The provincial organization continually seeks to support the front line and sector engagement by offering an annual hospice conference, newsletters, networking, brochures, workshop materials and teaching training for advanced care planning awareness, pilot workshops for physicians, advocating for communities wanting to establish hospices, and political activism for increased hospice funding. "We set up a policy advisory group to help guide the public policy dialogue and launched a new publication...its really a relay publication... about innovations on the frontline..."

The ED of the provincial hospice organization spoke of declaration of priorities for equitable access for hospice services. Access depends on awareness of cultural and socioeconomic barriers for marginalized, urban and rural First Nations, Muslim, Hindu and other religious or ethnic groups. One response to access barriers would be to develop more cultural competence education for hospice staff.

Both administrators agreed that substantiation of the system impact of hospice was imperative. The Hospice A administrator discussed the MOHLTC's need for awareness of hospice's high standards of care, pursuit of accreditation, and impact on Emergency Room and Alternate Level of Care bed use. The provincial administrator was outspoken about the need to identify actual system outcomes and cost savings of hospice beds versus diversion of dollars. "The hospitals are writing letters of support saying 'we desperately need this hospice because its having this direct impact on my ER and ALC'."

Describing awareness as "a hard sell", the administrator of Hospice A focused on local awareness of hospice programming for potential users, the hospice's history within the community, and the ongoing need for lessening people's discomfort about talking about dying. The Hospice A administrator felt strongly that awareness through public speaking about hospice programs and benefits is an ongoing need. Community members, including new Canadians, might not be aware of the hospice option until a family member is dying. For some people, there is a cultural expectation for EOL care of their loved one at home.

**Funding.** There is lack of hard data about bed usage for palliation in acute settings, inconsistent use of beds that are funded or designated for other purposes, uncertainty in reporting bed usage and lack of monitoring of bed usage (administrator,

provincial hospice organization). However, all beds (acute, palliative, alternate level of care, long term care, and residential hospice) are funded through MOHLTC but at different per diem rates. When an acute care bed is occupied by a palliative client, cost savings are not realized. When clients are transferred to hospice, cost savings are not monitored across the care settings. Furthermore, the cost impact only represents diversion of costs, not cost savings (administrator, provincial hospice organization).

There is no cost for residential hospice care to patients or families. Fifty six percent of operational funding for nursing services is presently provided by the Ontario MOHLTC. Both administrators remarked that fundraising for capital campaigns and other hospice programs (wellness, therapy, volunteer, outreach, bereavement) is challenging for these charitable organizations and their communities. Provincial lobbying efforts for an increase to 80 % of operational funding are underway using statistical monitoring of outcome measures such as bed usage and per diem bed costs. Securing a greater percentage of operating costs from government funding would make supportive care less vulnerable.

Funding for beds encompasses other issues. The idea of what hospice care could and should be can vary among patients, families, providers and funders. There are community fundraising challenges for the other hospice based programs, such as, bereavement support, therapies, and outreach. Government recognition of the importance and outcomes from these supportive programs and their funding would make these user programs more secure. However, studies of the impact of such programs on user quality of life have not yet been done. Funding for capital costs for new beds or expansion in bed capacity is a community responsibility. The administrator of Hospice A wants to

serve more than six families at a time. A satellite model might provide savings from shared administrative staff and back office costs.

***Other solutions.*** The interviewees recognized the value of research to substantiate their experiential understandings of hospice impacts on users, families and communities. In addition to their desire for data collection, the interviewees proposed other responsive solutions to barriers, funding and awareness issues.

There are developing opportunities for novel partnerships, hubs with satellites or collocation of hospice beds as expansion of services occurs. These are being explored locally and provincially. Rural and large geographic service areas present particular challenges for site location, staffing and community fundraising. The provincial administrator suggested a need for different funding models for rural communities. The administrator of Hospice A has willingly shared experiential learning with emergent hospices, has provided collaborative support and has engaged in development through partnering. This administrator envisions hospice as a “center of expertise and excellence” in palliative care through which an interdisciplinary team, both in house and in outreach, would manage symptoms early, assist more people to die at home if they prefer, and staff other hospice programs and clinics physically located at the hospice hub. To reach particular communities, such as First Nations, the administrator of Hospice A expressed the belief that more geographically accessible hospices are needed.

The provincial administrator identified information sharing as a way to minimize resource expenditures for assessment of need, site location, and new model development, and to foster agency engagement across the province. The new sector newsletter has the goal “to share information across the geographies.” An annual hospice conference is held

in the province. The provincial hospice organization administrator stated that committees have been struck to revise the Standards for Residential hospice, develop an accreditation package for hospices and review data collection. There is a task force led by Cancer Care Ontario that will look at outcome measures for quality of care from the patient and family's perspective, across the full spectrum of illnesses.

The provincial organization has focused educational efforts for all Ontario residents about end of life discussions and advanced care planning. The provincial administrator wants earlier conversation about dying, earlier interventions and clear understanding that palliative care in itself does not indicate a short prognosis. Several physician education and support solutions have been launched. "We are developing a pilot workshop for primary care physicians about the intersection of chronic care and PC to demonstrate the impact of early introduction on patient outcomes" with further plans for on demand mentoring and on demand support for physicians.

### **Summary**

Chapter IV has presented the results for this mixed methods study. The description of the sample, research questions, tools and findings were discussed. The research findings were organized in three sections according to the research questions. The characteristics of users from Hospice A were described using descriptive statistical analysis. Next, comparisons were made with Hospice A and provincially collected hospice user data. Following qualitative review of transcripts of brief interviews with two hospice administrators about the utility of data collection, their responses were organized thematically into 11 themes to amplify issues related to data collection. Chapter V will present the Discussion.

## **Chapter V**

### **Discussion**

#### **Summary**

The characteristics of residential hospice users in Ontario were examined quantitatively and qualitatively using a mixed methods design. This retrospective, exploratory research utilized Watson's theory of Human Caring Science as the foundational premise for quality of life, dignity, and caring at end of life in the residential hospice location. Three research questions were addressed. Data about user characteristics were obtained from one Ontario hospice and from the provincial hospice organization. Statistical analyses of frequency, central tendency and variance compared user characteristics. Age groups, diagnostic category, length of stay, and disposition were found to have similar patterns. Location of care prior to hospice admission, bed usage, and occupancy rates exhibited dissimilar trends between the case study hospice (Hospice A) and the provincial aggregate experience. Gender was not intentionally tracked by either Hospice A or the provincial hospice organization. Results for previous residential location, which was only available from Hospice A, showed users of hospice care lived proximally to the hospice site. Interviews with two hospice administrators revealed their continued interest in data collection about user characteristics, as well as their impressions about barriers to hospice use and solutions to usage issues.

**Conclusions**

This exploration of hospice user characteristics uncovered patterns of usage unique to Hospice A, and others that were similar to hospice use across the province. Hospice A user characteristics were collected over a seven year period, a sufficient time frame to establish trends and to discount early variations. The sample size was large (n = 744). Provincially, consistent data were available for only three years; data collection and reporting problems from non-profit hospices were evident to the researcher and were also noted by the provincial hospice administrator. More provincial data are needed to consider irregularities in reporting and to accurately describe trends across the province.

Demographic patterns of Hospice A users revealed that the majority of users were over 65 years of age, came to hospice directly from home, and had a malignant diagnosis. Slightly more females than males were admitted to Hospice A. Neither gender nor marital status data were collected or reported by Hospice A or by the other provincially reporting hospices. Mean length of stay hovered around 15 days, with longer stays observed among users who were admitted directly from a hospital. Demand for hospice beds was signified by high bed usage rates and few live discharges.

Differences in local and provincial experiences of users of hospice care and contextual influences were anecdotally described by the two hospice administrators. These differences might account for some of the study findings, but no conclusions can be drawn about differences in user characteristics without further research.

**Relationships of the results to the conceptual framework.**

Jean Watson's Theory of Human Caring Science (2012) provided direction for this research. Caring for the vulnerable dying person admitted to residential hospice



allows the caregiver to attend to what Watson (2012) described as the person's human need for love, caring interactions, positive regard, acceptance, understanding, appreciation and value, even to the end of life. Caring moments and caring events between the nurse and dying individual can take place in any location, but residential hospice brings together professional caregivers with experience. "Every member of the hospice staff team is a palliative care specialist, trained in pain and symptom management and the specific needs of the dying" (Southlake Regional Health Centre, 2011, p. 13). Compassionate and complex interpersonal interactions between users of hospice, their families and interdisciplinary caregivers allow the development of authentic, nurturing and trusting relationships with supportive care provided according to individual needs.

From the contextual illustrations presented by the administrators, it was evident that hospice staff was unafraid to talk about dying. Watson (2012) explained that conscious, intersubjective connections are made when entering into the experience of another person. Particularly at end of life, professional caregivers use transpersonal caring to create quality of life for the dying person. Just as Watson has described, hospice users felt safe to express their feelings and tell their stories. They were able to create opportunities, such as Watson (2012) described, for transpersonal caring moments, meaning making, restoration of personal harmony and transcendence in journeying through experience together into the future. The interviewed administrators also expressed that hospice caregivers understood the importance of the restoration of dignity and the relief of burdens for both the dying individuals and their families. Their stories

especially underscored that the work of caring requires the whole family and caregiving team, plus advocates, funders, policy makers and political will.

Caring at the system level was a specific interest of the two administrators interviewed. Examples of system level caring have occurred when these administrators engaged in speaking out, advocacy, novel problem solving, calling for high standards of care, encouragement of new hospices, networking and addressing education needs. The provincial administrator also expressed a need to know about ethnicity, culture or religious beliefs so that equitable access to residential hospice beds in an appropriate setting can be ensured for all Ontarians. The emergence of more hospices in the province illustrates a societal commitment to quality of life at the end of life, which is a particular end for transpersonal caring. However, the lack of an evident patient/family voice about why they choose hospice and what they expected, appreciated, or found missing in hospice care, presents a huge gap when viewed from the public health, nursing paradigm and Watson's Human Caring Science perspectives that grounded this research study.

#### **Relationships of the results to the literature.**

The body of literature about users of freestanding hospice and how hospice care is used is quite small. Little has been published about the characteristics of actual users of residential hospice in Ontario or Canada. This initial research contributes new knowledge about revealed accessibility (actual use) not previously described. These results address the need to establish and disseminate baseline data in this emerging field. They also add to the body of hospice palliative care literature by describing usage of residential hospice as part of the continuum of care in Canada at end of life. The results point to the pressing need to collect further data that will more fully describe

characteristics of hospice users, identify individuals and groups who are not served by this option for EOL care, and assist in developing quality outcome measures for hospice care. However, “. . . there remains a dearth of evaluative research on HPC service delivery in Canada, thus resulting in a lack of data and, consequently, lack of traceability and evidence specific to best practices.” (Williams et al., 2010).

From the provincial hospice organization’s reports, approximately 2300-2500 persons per year in Ontario access residential hospice for care at EOL. Because this number of people did not die in a hospital or at home, health care costs have been redistributed. From a calculation based on information from the 2012 Census of the Ontario population of 13,505,900 and a mortality rate of 398.8 per 100,000 population, there was an estimated 53,861 deaths that occurred in the province in 2012 (<http://www.statcan.gc.ca>). The number of residential hospice users per year represents only 4 % to 5 % of deaths occurring per year in Ontario. This finding substantiated comments made by Wilson et al. (2009) that there are very few deaths in free standing hospices.

Cuiker (2012) identified that there are 27 hospices in Ontario, two under construction, and planning for more underway. These numbers were verified by the provincial association’s administrator who provided more detailed information about hospice development. According to the administrator, 17 hospices are in planning stages in addition to the two being constructed. There are still 2 LHINs in the province without any RH. As described by Brazil et al. (2005) and the provincial hospice administrator, there are problems in rural geographies related to access, resources, partial program funding, fundraising issues, the ability of the community to respond, the need for

community champions and volunteers, and lack of information about hospice access by various cultural groups. The provincial administrator confirmed the LHIN reports of regional engagement in population projections, forecasting, and planning for future palliative care needs, with RH as an integral component of the delivery of care especially for seniors.

A number of research studies described psychosocial attributes of hospice users that might characterize users of hospice. Holdsworth and Fisher (2010) discussed the achievement of hospice admission as an outcome measure of preferred location for care and death. Higginson and Sen-Gupta (2000) measured decision making of hospice users who chose hospice as their first or second preference or in order to avoid another location. Others further developed the idea of decision making by examining the reasons for a move to hospice by individuals and their caregivers (Brazil et al., 2005; Thomas et al., 2004); caregiver preferences and burden (Brazil et al., 2005); and attitudes about hospice as a place of death (Gomes & Higginson, 2006). Although the provincial organization administrator briefly mentioned the choice of hospice as a location for care (secondary to home), the current research did not describe any of these cognitive or behavioral characteristics of hospice users.

In their systematic review of palliative care services, Critchley et al. (1999) found one study that reported better pain and symptom management in residential hospice than in other types of hospice programs, which benefited hospice users. Although this outcome measure for quality of life of hospice users has not yet been monitored in Ontario, both hospice administrators described anecdotes of the impact of expert symptom management, supportive care, and relief of existential suffering.

From the interviews with the administrators, it was clear that more conversations are needed about advanced care planning and death and dying with individuals, families and the community. As Wright et al. (2008) also identified, the administrators recognize that more awareness about these specific issues is needed among health professionals.

Both administrators discussed funding and geographic issues as potential impediments to hospice construction and models of hospice care, as well as to individual access and usage. The survey done by Towns et al. (2012) found geography created barriers for only a few PC organizations, which included hospices. Towns et al. (2012) identified lack of fiscal resources and late referrals as barriers to providing quality palliative care in hospices. The ED of Hospice A believed that both the wait listing and the live discharge process were not streamlined, creating barriers to usage. Towns et al. (2012) also pointed to human resource issues, which were not identified in either administrator interview.

Rhodes et al. (2006) commented that potential users need sufficient information to help them choose a preferred location for care and this desire for information is important across all racial and ethnic groups. Koffman and Higginson (2004) called for improvement in communication skills of professionals with patients from diverse backgrounds, including their discussions about EOL care location choices. The provincial organization administrator identified the link between the need to examine user ethnicity and religion and the extent to which all socioeconomic and cultural groups in the community were accessing hospice care. The provincial administrator recognized that more questions need to be asked, data collected, and research conducted about persons and groups who do and do not use hospice. In contrast, the Hospice A

administrator's perspective was that their local community lacked diversity and that the community was aware of Hospice A and understood that hospice services were available when needed. Because it was well established in that community, Hospice A had provided care for more than one member of a family on numerous occasions.

This beginning research addressed a gap in the literature. Both limited literature and data deficits, as mentioned by Kuziemy and Lau (2008), shaped this research. The present study was based on hospice datasets that were available to the researcher. The study itself was limited by deficits in the original data collection by some or all of the reporting hospices. Kuziemy and Lau (2008) suggested that research is first needed to determine what purposes will be served by data collection and what type of data to collect. These authors recommended a common Canadian palliative care tool for collection of clinical, program, and surveillance data. Development of electronic data collection technologies, theoretical frameworks, and methods for specific research purposes will influence data quality and support timely collection, analysis and dissemination of results (Kuziemy and Lau, 2008).

#### **Relationships of the results to the research questions.**

The research questions were threefold:

1. What are the characteristics of dying patients in a medium sized urban setting in Ontario who use hospice?
2. How does this hospice use compare with provincially collected hospice use data?
3. What data about hospice users would hospice administrators find useful?

*1. What are the characteristics of dying patients in a medium sized urban setting in Ontario who use hospice?*

The first research question examined characteristics of users from one Ontario residential hospice. From the results, a detailed picture of users emerged. Descriptions of age, gender, diagnoses, bed usage (including previous location of care prior to admission), length of stay, discharge disposition, and primary residential location established baseline information about user characteristics that might also draw attention to the need for further research.

**Age and gender.** Persons with a wide range of ages were admitted to Hospice A. The mean age of all users was 70.1 years, with slight difference when described by gender (70.4 years for males and 69.7 years for females). Median age was the same regardless of gender (72.0 years). As might be expected at end of life, the majority of hospice users (68%) were over 65 years of age and fewer than 1 % were under 18 years.

Hospice A admitted more females than males. The separation by gender and stratification of age by ten year increments revealed similar percentages of male and female users in 65-74 year and 75-84 year age group. These two ten year age groups represented the majority of all users. Users over 85 years of age were predominantly females. The under 65 year age group had a predominance of female users, regardless of the sorting choice (18-64 years or 55-64, 45-54, 35-44 years). From available data (Table 2. *Comparison of Admissions to Hospice A by Gender and by Age Stratified in Ten Year Increments for Years 2006-2013*), it appears that men who use hospice are dying within a narrow age range, but female deaths at hospice are spread over a wider age range.

**Diagnoses.** The majority of Hospice A users had malignant diagnoses. Over seven years, no gender difference was seen in this category. The most frequently represented cancers among Hospice A users were lung, colorectal, pancreatic, and female breast. County A Public Health Unit records both cancer incidence and mortality rates. The incidence rates per 100,000 listed in order of occurrence are prostate, breast, lung, and colon cancers (<http://www.statcan.gc.ca>). The death rate per 100,000 listed in order of occurrence are lung, colorectal, female breast and prostate cancers (<http://www.statcan.gc.ca>). The mortality rates for these four cancers in County A are higher than the provincial mortality rates for these same cancers. Although represented among Hospice A users, pancreatic cancer does not appear among the four most frequent cancers for County A incidence or mortality.

Within the 200 users who had lung cancer, there were slightly more females (54.5%) than males (45.5%). There were a higher percentage of males than females among the 89 users who had colorectal cancers. Within the 65 users who had pancreatic cancers, there was equal percentage distribution between males and females. Of all 60 users with breast cancer, a higher percentage of female users had breast cancer than did males. More male users than female users over 65 years of age had malignant diagnoses. In contrast, in the 18-64 years group, a higher percentage of women than men had malignant diagnoses. While no clear conclusions can be drawn about these age disparities related to malignancies, the administrator of Hospice A was of the opinion that the caregiver's capacity to provide care at home influenced hospice admission timing and that admission decisions were made for different reasons by male and female caregivers.



The researcher speculates that this age-related trend might be due to gender associated malignancies, but further research is needed.

The frequency of non-malignant diagnoses among users of Hospice A is low and has stabilized with time. For the most commonly represented non-malignant diagnoses (COPD, CHF and cirrhosis), there were a higher percentage of men than women in all age groups with these diagnoses. The frequency of non-malignant diagnoses overall was higher in older women over 65 years than men over 65 years, but this trend was reversed in the 17-64 year age group. COPD, the most common non-malignant diagnosis, appeared at higher levels within the Hospice A community than in the province as a whole (<http://www.statcan.gc.ca>).

Unknown diagnoses represented a very small number of users and did not appear to be important contributors to user characteristic description.

***Bed usage.*** Bed usage patterns were available for only three years of Hospice A's operation. High occupancy rates of over 88 % were noted for each of the three years at this six bed hospice. Previous location of care before admission was more likely to be home than hospital, with few users being admitted from other care locations. The examination of percentage of bed days used did not show trending according to previous location of care.

***Length of stay.*** Scrutiny of lengths of stay over seven years uncovered information about access to and actual use of Hospice A beds. The mean LOS over seven years is 18.2 days. The most frequently occurring length of stay (mode) was short at four days. Over the past five years, the mean LOS has hovered around 15 to 17 days. Female users had longer mean LOS than males by almost five days and longer median

stays by two days. The overall median LOS of nine days suggests more users had stays shorter than the mean than those who had stays longer than the mean. Ninety eight percent of all stays at Hospice A were less than 90 days. This LOS aligns with the desired residential hospice standard in Ontario that fosters equity of access without causing bed blockage.

The mean LOS was affected by longer stays in the first two years of Hospice A operation. Justification for the removal of long stay outliers was provided by consideration of two standard deviations above the overall mean LOS (18.2 days). When only stays of less than 90 days are considered, the mean LOS for the seven year period (15.4 days) resembles the mean LOS for the most recent five year period (15.2 to 17.8 days). Two explanations for long stays surfaced. The administrator of Hospice A postulated that, because more women had longer stays than did men, the women with long stays might be widowed, or their male spouse might be frail or unable to sustain caregiving at home. Because the long stays primarily occurred in the first two years of Hospice A operation, they might have reflected a lack of discharge protocols and inexperience to guide management.

Length of stay according to previous location of care was available for only the most recent three years. When mean length of stay was considered according to PLC (Table 9. *Mean Length of Stay for Users of Hospice A and Other Hospices Reporting Provincially for Years 2010-2013*) (p. 56), LOS for users admitted directly from hospital was longer than for those admitted directly from home for two of the three years. The long mean LOS (27 days) in 2012-2013 from locations other than home or hospital appears unusual and is unexplained.

***Discharge disposition.*** The majority of Hospice A users died while Hospice A residents, as would be expected. Live discharge accounted for fewer than 4 % of all Hospice A users. Most of these users had been discharged to home. There were no follow up data available about these users discharged to home.

***Residential location.*** Postal codes for the primary residence of hospice users were reviewed to ascertain usage patterns by geographic location. Postal codes were available only for users in 2012-2013. The large city in which Hospice A is located was the most common residential location of hospice users. The majority of users dwelt in population centers or proximal to the large, urban area. Fewer than 9 % of Hospice A users resided in rural areas. This hospice also served a few out of region residents, all of whom had family members residing in the catchment area.

*2. How does this hospice use compare with provincially collected hospice use data?*

The second research question addressed the comparison in demographic profile and hospice usage between Hospice A and the provincially collected aggregate data from 15 to 17 Ontario hospices, excluding Hospice A. Before this comparison could be made, the researcher had to examine the available provincial reports. The researcher confirmed one provincial administrator's opinion that data collection has been inconsistent with regard to characteristics tracked, hospices that submit usage data, accuracy of data, and completeness of submitted data. According to both hospice administrators interviewed, these problems might be due to varying familiarity with data recording and technology use, reporting procedures still under development, time constraints, and staff

inexperience in newly established hospices. Three available annual reports for years 2010-2013 provided the most useful data sets for comparison.

Five characteristics (age category, diagnostic category, bed usage, average LOS and discharges) were consistently monitored provincially. Gender, marital status, specific age, specific diagnosis, ethnicity, religion, and residential location prior to admission were not tracked provincially. The provincial reports showed an increase in the number of available hospice beds over the 3 years. For each year reviewed, the majority of hospice users in the province were over 65 years (65 % to 75 % of all users), and 26 % to 32 % were in the 18-64 years age group. Fewer than 4 % of users of these adult hospices were under 18 years of age. (The pediatric hospice data was outside of the scope of this research.) Provincial data reported a predominance of malignant diagnoses, fewer than 1 % live discharges, variable occupancy rates, more admissions from a previous location of home, and longer lengths of stay for users admitted from hospitals. Provincial LOS ranged from 17 to 23 days for the three year period. Occupancy rates fluctuated as new hospices began operations and others closed.. Awareness grew within communities when each new hospice opened and referrals from professionals gradually increased.

Similarities were evident for several demographic characteristics when Hospice A was compared to the other hospices reporting provincially. High proportions of malignant diagnoses, few live discharges, more admissions of users coming directly from home, and longer lengths of stay for users admitted directly from hospital were found in Hospice A and all other hospices reporting provincially over three comparison years. Both Hospice A and the other hospices reporting provincially revealed variable

occupancy rates. However, Hospice A's occupancy rate was higher and more consistent than the other hospices reporting provincially. The more consistent occupancy rate might be expected in an established agency.

Hospice A's age group profile was more consistent year to year than was the provincially reported age profile. Stratification of age by ten year increments yielded a more detailed picture of age at which death occurred than did stratification into three age groups of 0-17, 18-64 and over 65 years.

Gender, residential location, and individual diagnoses were not collected by the province so comparisons could not be made.

Comparison of bed usage over three years showed that Hospice A followed provincial trends concerning usage according to previous location of care. More than half of all hospice users were admitted from home, as reflected in both Hospice A data and provincially reported data. Hospice A had higher rates of admissions from locations other than home or hospital than did the other hospices reporting provincially. No explanation was provided for Hospice A's lower rate of admission directly from a hospital in 2012-2013.

The provincial mean LOS were higher (17 to 23 days) than at Hospice A (15 to 17 days) over three years, for users whose PLC had been home or hospital. The provincial LOS was shorter than the Hospice A LOS for users who previous location for care was other than home or hospital. One explanation for this discrepancy is that the previous location might not have been a discharge option, requiring some users to remain at hospice. If the person is admitted from a retirement home, shelter, or the street and then stabilizes, the possibility of discharge and return to hospice decreases if the previous

location is no longer available. The available options for discharge locations might differ across the province compared to the Hospice A community, which is a smaller urban and rural setting. Care by the Outreach team at Hospice A prior to admission might have contributed to shorter LOS than occurred provincially. Good symptom management by the team possibly allowed people to stay at home longer. Hospice staff respond to the increasing and intensive care needs of dying persons in the last few weeks of life.

Overall, the comparison of Hospice A user characteristics with the provincially reported aggregate characteristics revealed regional differences in bed usage, higher occupancy rates and lower LOS and similarities in age groups served, preponderance of malignant diagnoses, previous location of care prior to admission, and few live discharges. The LOS is declining in both Hospice A and other reporting hospices.

These findings establish new baseline information about hospice user characteristics and hospice use in Ontario. Monitoring of more demographic characteristics could expand this initial research. The need for data collection and analysis continues to evolve.

### *3. What data about hospice users would hospice administrators find useful?*

The third research question addresses qualitative information about data collection gleaned from interviews with hospice administrators. The interviews tapped into two administrators' extensive knowledge of residential hospice use as an integral part of the continuum of care at EOL. The interviews provided many descriptive, rich, contextual elements about hospice use and users from both micro and macro perspectives. In particular, the interview with the provincial hospice administrator provided substantive elaboration on the provincial circumstance, which also affects the

local hospice experience. Both hospice administrators identified the importance of understanding more about user characteristics and hospice usage, difficulties with data collection and research, and the application of results from data analysis.

Both administrators were aware of increasing demand, insufficient resources, and piecemeal access across the province for hospice care. Geographic proximity to hospice was a concern identified by both administrators for potential users and their families. The two administrators described difficulties in admitting specific types of people to hospice, such as users with non-malignant diagnoses, dementia, mental health co-morbidities, those needing long stays, or those with no family. Neither administrator clearly understood how or to what extent particular social, ethnic or disadvantaged groups within communities accessed hospice care. They recognized that hospice access problems might represent a health disparity. Discharge problems could also surface when users stabilized after admission to hospice.

Cultural competence was seen as a way of supporting diverse and marginalized users of hospice. Staff education was viewed as essential to helping staff develop these cultural competencies. During the interview, the Hospice A administrator introduced innovative models for delivery of care as a solution to access, staffing and funding issues. No conclusions could be made about ideal models of hospice care nor did the researcher's review of 2000 to 2013 literature reveal recent articles about models of hospice care.

The administrators identified the need for more research about the impact of hospice care on the quality of life for residents and their families. They understood anecdotally about the relief of caregiver burden, reduction in stress, and societal benefits

of hospice care. The provincial administrator expressed interest in learning more empirically about the effect of a move to hospice on caregiver coping and on the patient and caregiver relationship. Psychosocial and spiritual support for users of hospice has not been funded. Verification of the impact of this funding for this critical role could be established through research. Evidence of the benefit of psychosocial spiritual support on user quality of life could be utilized for planning purposes and for advocacy with funders about the system impact of hospice care. The provincial administrator identified a related gap in understanding how patients define quality of care and their needs. Exploration of what is important for patients and caregivers could further guide hospice in EOL planning.

Data collection about service responsiveness included admission counts, bed usage, occupancy rates, LOS, and admission to assessment rates. Hospice A's administrator expressed concerns about waitlist management, admission decision timing, and inadequate expedited processes for discharge to LTC. The provincial administrator expressed an interest in how residential location of users might inform hospice planning and delivery. Although the provincial administrator expects expansion of monitoring criteria, there remain pragmatic and technological barriers to data recording that need resolution. The hospice organization is engaged in committee work to discuss data collection issues.

Although both administrators remarked on the acuity and predominance of malignant diagnoses among hospice users, the provincial administrator was interested in knowing more about individual diagnosis, comorbidities and what collection of this type of information would reveal about hospice users. Having made the connection between



acuity and decreasing LOS, the administrator was then curious about complexities.

During the interview, the administrator discussed the overlapping care needs of persons with chronic illness and palliative diagnoses and commented on the need to develop chronic illness outcome measures.

Limited awareness and inadequate funding are barriers to access and service delivery. Partnerships, information sharing, and education about death, dying and choices for EOL for all stakeholders could improve resource use and consequently, the experience of hospice users.

The hospice administrators' views about data collection encompassed themes of *demand, resources, responsiveness, models of care, diagnostic complexities, barriers affecting use, awareness, funding and other solutions*. This background information raised additional questions about residential hospice research needs. In the words of the provincial administrator, "there is immense potential for research within the sector."

#### **Relationships of the results to the study design and data collection methods.**

The exploratory, mixed methods study examined the characteristics of dying persons who use residential hospice care at end of life in Ontario. This retrospective design allowed investigation of both quantitative and qualitative aspects of user characteristics. Following D'Youville College IRB approval and institutional REB approval, a sample of deceased persons who had self-selected hospice for end of life care were identified. Quantitative data were gathered from a number of datasets from census records, statistical and key performance indicator reports for the funder, publicly available hospice reports and the provincial hospice organization reports. The characteristics of users admitted to residential hospice were manually gathered from two

sources, the Hospice A census for years 2006 to 2013 and provincial organization annual reports for years 2010-2013. Eight characteristics of users admitted to the case study hospice, Hospice A, were first described. Hospice A data were extracted from the provincial datasets for 2010-2011, 2011-2013, and 2012-2013. Five user characteristics from the revised provincial datasets were compared to Hospice A. Qualitative data was obtained from the 2 hospice administrators through their participation in brief individual interviews about data collection and factors influencing hospice use. Open-ended interview guide questions allowed the natural flow of the administrators' ideas and opinions. The interviews provided rich contextual elements that complemented the descriptive analysis of eight characteristics of hospice users. The study design facilitated the uncovering of new information about demographics of hospice users and bed usage.

The Hospice A census report did not contain all of the provincially required user characteristics. However, these missing data concerning bed usage, occupancy rates and previous location of care for Hospice A users were collected from the provincial organization residential hospice annual reports. The computerized Hospice A database was not made available to the researcher. As a result, data about a smaller number of user characteristics was collected than the researcher had anticipated. This limited the reach of the findings.

Data collection limitations might have affected the results. There was no way to verify the accuracy of user data recorded by many different individuals in Hospice A and other hospices that had submitted provincial data. Retrospective user data from Hospice A was collected for seven years, allowing inspection for longitudinal trends, discounting possible aberrations during hospice start up, and providing possible explanations for

variations in usage. The Hospice A sample size was large ( $n = 744$ ). However, data collected from one hospice location cannot be generalized to other hospices and geographic areas. Provincially, only three years of consistent data was available, with data collection and reporting problems noted by the provincial hospice administrator. The researcher purposefully excluded early provincial reports because of incomplete data, few reporting hospices, fewer data elements, and differing time frames for reporting (calendar year versus fiscal year).

Concerns about reporting consistency in the recording for specific data points arose prior to data collection. For example, the admitting nurse might have documented age in the census record incorrectly copying from a medical record or by miscalculating day, month or year. Characteristics were omitted from the census record for a few individuals (age, diagnosis, postal code). The staff responsible for the recording of user information varied by shift and position (charge nurse, clinical nurse specialist or administrator). Any record might have been entered in the census book by the admitting nurse on admission or completed on death or discharge by another nurse.

Attribution of gender relied on the researcher's knowledge of first names and the recall of long time hospice employees familiar with the names. Gender assignment was done at a date later than the user's admission, by the researcher, and not by the admitting nurse who had recorded other user characteristics. Even with this consideration of possible bias affecting classification of users by gender, the analysis of gender information reveals that more females than males are admitted to Hospice A. This finding generated questions about connections to population or diagnostic trends. The administrator from Hospice A offered two explanations of this phenomenon: Men might

not be able to care for their wives or women might have been widowed and have no caregiver. Because data about marital status was not recorded or collected by either Hospice A or the provincial hospice organization, the administrator's hypothesis could not be validated.

The provincial hospice organization did not collect aggregate data about specific diagnoses as Hospice A did. Thus, no comparisons could be made between Hospice A and provincial diagnoses or disease prevalence within the population. This study highlighted important gaps in the categories of data being collected, as well as in the reliability of recorded data. Improved data management will be necessary before research can effectively ground government policies or justify funding requests for growth and development of residential hospices and related services.

#### **Relationships of the results to the tools and instruments used.**

Spreadsheets using both the Statistical Package for Social Scientists (SPSS) Version 21.0 for Windows program (SPSS, Inc., Chicago, IL) and Microsoft Office Excel (<http://office.microsoft.com/en-us/excel>) allowed organization of user characteristics for 744 cases collected from the case study hospice and aggregate user data from the provincial hospice yearly usage reports. Demographic and bed usage information was used to establish an initial understanding of user characteristics. The power of the SPSS computer program permitted multi-level layering of the variables of interest, which provided opportunities for comparison of 2 or more characteristics simultaneously.

Population characteristics were sought from various government statistical databases by searching and email requests. Neither method of inquiry yielded any disposition information about deaths at residential hospices. The researcher postulated

that this location for death was not monitored because of the small numbers of deaths that occur in this location, the emergent nature of this location across the country and the provincial variation in definitions of hospice.

The eleven question interview guide was used to elicit the hospice administrators' opinions about data collection concerning hospice usage. Bias could have been introduced in the data collection and analysis in several ways. A limitation in the use of this guide is that the questions were not pretested or validated to pre-determine if the questions would yield the desired information. The visual or aural cues provided by the researcher while asking these questions of the interviewees, or indeed the presence of the researcher who was known to the interviewees as a professional familiar with aspects of hospice care, could also have introduced distortion in the responses. The researcher's prior knowledge of provincial hospice care might have biased her direction of questions and interpretation of data. The interviewees, themselves, might have held known or unrecognized biases about hospice care and reporting requirements.

The interview tools facilitated the collection of a broad variety of contextual elements that support, alter or present barriers to hospice use. The researcher made every effort to understand the potential for biases and to protect against them during data collection and analysis. The researcher reviewed the audiotapes and field notes five times to ensure accuracy. The audiotape transcription and field notes might have been compromised by transcriber error. The field notes might not have captured all contextual information pertinent to each interviewee's responses.

**Relationship of the results to the data analysis methods.**

Quantitative data were analyzed using both SPSS and Excel computer programs. Both programs facilitated descriptions of central tendency, frequency, and variance of both individual and aggregate data.

Most of the data elements were already classified in the source documents. However, the researcher made judgments about classifications of several data points within demographics. In the startup year of Hospice A, seven persons were admitted in the month prior to the beginning of the fiscal year. The researcher combined the data for these seven users with the data for all users in fiscal year 2006-2007. For Hospice A users who were admitted in one fiscal year and died in the subsequent fiscal year, the researcher chose to record only the admission count and length of stay in the fiscal year of admission. This meant that the number of users reported by Hospice A in census did not match those reported to the provincial organization. It is not known if all reporting hospices had recorded these overlapping stays in the same manner prior to submission of their annual aggregate data to the provincial hospice organization.

The age of one user had not been recorded. The researcher assigned an age of 70 years, similar to the mean age. By re-categorizing age data from Hospice A, more detailed information was obtained than was immediately available from the data file. Original categorization of age had been done to match the provincial groupings of 0-17, 18-64 and over 65 years so that comparison was possible. A second classification into ten year age groups provided more detailed information related to admissions and gender. Mean, median and modal scores for Hospice A user characteristics provided more

detailed information from that sample than did the aggregate group data reported provincially.

Gender classification was not tracked by either Hospice A or the provincial organization. From the Hospice A census record, the researcher assigned gender based on reported first names. This action might have introduced error. However, this effort captured more detailed information for description and comparison. The researcher was mindful of the limitations of gender assignment based on first names. The data sets considered according to gender included admissions, age, age groupings, admitting diagnosis, diagnostic category, age groupings, and length of stay.

For diagnosis, the researcher followed traditional coding groupings, such as classifying small cell and non-small cell lung cancers together. The broad classification of malignant and non-malignant was used to follow the provincial categorization. There were several data limitations identified. Hospice A's allocation of diagnosis to these 2 groups (which was reported to the provincial hospice organization) was not available to the researcher for confirmation. The diagnosis was recorded without metastatic spread or co-morbidities listed. It is not known if the diagnosis was related to cause of death. Several data sets were incomplete. One diagnosis recorded with a question mark was assigned to the unknown and non-malignant categories. Gluteal mass and pleural effusion were assigned to the non-malignant category. These 3 data points were a small percentage of the total ( $n = 744$ ) and should not skew the data. The data set considered according to diagnosis and diagnostic category was gender.

For length of stay, the internationally accepted definition of length of stay was used, that is, day of admission is day zero and day of death is not counted as a day. This

created a difficulty when reporting data for users who are admitted and die on the same day. The LOS for these users was recorded by the Hospice A staff as one day, the same as a user who would have been admitted and then died the following day. There are 27 users of Hospice A whose LOS is recorded as one day, representing 3.6% of all users. It is not known if users whose LOS overlapped fiscal years were reported consistently among all reporting hospices. (There were two possible recording strategies a) recording the user's LOS only in the fiscal year of admission, and b) ending the LOS at the end of the fiscal year and reassignment of that person as a new user with admission day at the first day of the new fiscal year). Discrete admissions encompassed repeat admissions for users who stabilized, were discharged and then returned to hospice. Because the five repeat admissions represented a small percentage of total admissions ( $n = 744$ ) and repeat admissions were not captured provincially, the researcher chose to treat these five as discrete admissions.

For residential location, one user, a homeless person, had no postal code recorded. Because the Hospice A administrator knew that this person was known to be living in City A, the researcher assigned residential location to City A and urban groupings.

Descriptive statistics were used to quantitatively compare the demographic and usage characteristics of people admitted to Hospice A and all reporting hospices across the province. Although the two populations of hospice users were convenience samples and not randomized, the separate two tailed t test was applied to the available aggregate means to determine any significant differences ( $p \leq 0.05$ ) in the means of four characteristics descriptive of Hospice A and other reporting provincial hospices over the three-year period 2010-2013. When tested in this way, only frequency of non-malignant



and malignant admission diagnoses, and prior location of care which was not home or hospital appeared to be significantly different for the comparison groups. The means for LOS, age groups, prior location of care of home, and prior location of care of hospital did not appear to be significantly different. Further investigations with randomized samples and with access to all pertinent raw data are needed to affirm or dispute these findings.

Even with mostly non-significant statistical differences in the two samples, questions arise about clinical significance. For purposes of planning and delivery of care, mean length of stay information may impact services offered to clients and bed usage. Age of clients seeking admission, current location of care, and diagnostic category are of interest to decision-makers in individual hospices and at development and planning tables.

The researcher then analyzed qualitative data from the interview transcripts thematically to understand the views of experienced hospice administrators about desirable information, data collection issues and hospice use barriers and solutions. Analysis of the administrators' comments might have been compromised by its subjective nature. However, the comments and analysis were reviewed multiple times by the researcher and two other experienced registered nurse academics for validation. The derived themes provided another level of critical evaluation.

### **Implications for Practice**

Kuziemy and Lau (2008) pointed to the importance of structured palliative care data collection at clinical, program and surveillance levels in order to first understand who uses care options, who does not, and the reasons for these choices, before service delivery is examined. Although more hospices are being built, the required research is

lagging behind. This initial inquiry into users of hospice care in Ontario illuminates the need for improved monitoring and data collection of user characteristics. Many characteristics were not tracked. Monitoring of 10 year age groups, gender, marital status, ethnicity, religion, and residential location would yield a more fulsome picture of hospice users. This would require consensus about data collection, participation of all funded hospices, technological support, financial commitments, and monitoring by the provincial hospice organization. Understanding service delivery gaps and description of value could arise from broader data collection. The provincial hospice administrator identified these two practice implications as being of interest.

The findings about the characteristics of Hospice A users cannot be extrapolated to other users in the province. It is not known why the mean age is 70 years at this hospice. The expectation that older persons use hospice aligns with the evidence from this study. Stratification of age groups provided broader information about the ages of Hospice A users than was available from provincial data that had been categorized by only three age groups. Stratification of age in ten year increments could inform the provincial campaign about advanced care directives to target younger age groups, such as adults aged 55-64 years. Because younger persons do use hospice, early education might be helpful to initiate conversations about death and dying. Advanced practice nurses working in palliative care are uniquely situated to coach, guide, inform and educate individuals, families and communities about advanced care planning.

Evaluating current hospice palliative care practice, interpreting research and using research data to improve service delivery are additional responsibilities of the advanced practice nurse. From the provincial database, some observations can be made that raise

practice questions. Because deaths at residential hospice represent only a small percentage of all deaths in Ontario, issues surface concerning awareness of hospice, reasons for the choice of this location, community care service delivery, and accessibility. Kuziemyk and Lau (2008) have called for research to uncover links between preferences for care and service delivery. Not all dying persons or their families want residential hospice care. As the provincial organization administrator stated, hospice might be a default location, second to the choice for dying at home. For both Hospice A and all other provincially reporting hospices, persons with cancer more frequently use hospice than do persons with other diagnoses. Consistent low percentages of non-malignant diagnoses were found. This situation raises different questions of accessibility. If this location is not available to potential users of hospice because of uncertain length of prognosis, planners must address where people with non-malignant diagnoses can receive expert EOL care. The mission statements of each hospice could differ from other hospices relative to their target populations. Education of community members and health care professionals can influence service demands. As the provincial administrator identified, the needs and desires of patients and their families for EOL and hospice care must be clarified. The determination of maximum length of stay, the process and criteria for this determination, and the influences on decision makers must be considered from ethical perspectives of justice, equity and the utilitarian use of taxation funds for health care.

Advocacy for equitable access to RH beds in the appropriate PC setting initially stimulated the posing of the three research questions. It has been the researcher's observation that those clients admitted to local hospices are Caucasian, middle or upper

class, older males and females with a variety of predominantly cancer diagnoses, who are able to seek out this option for care, and have involved family members. Visible minorities, immigrants, new Canadians, the poor, persons with dual diagnoses or heart and lung disease or memory impairment are underrepresented in those admitted to hospice. Actual use (the revealed accessibility) of Hospice A and of other reporting hospices within the province did not describe these characteristics. Citing other researchers, Koffman and Higginson (2004) stated that "A greater understanding of the health and social needs of different cultural groups at end of life may lead to improvements in health of patients and post-bereavement outcomes in family members" (p. 629). Questions of equitable access for diverse populations remain. Geographic accessibility also affects hospice use. Both hospice administrators described driving distances and care giver burden within rural communities. Distance affects care continuity for families and professional teams. Trends in family living arrangements, such as adult children at great distances from elderly parents, alone can influence the choice of institutional care (including hospice) over the home setting (Grundy et al., 2004, as cited in Gomes & Higginson, 2008). Accessibility for users includes both services and facilities that can satisfy preferences for care. Tang (2003) emphasized that dying in the place of choice is recognized as an indicator of quality. If there is no hospice site in the community, quality of care cannot be achieved for those who want this option. Convenient residential hospice care needs to be part of the continuum of EOL choices. Alternate interpretations and manifestations of hospice care and its quality might develop in communities without the capacity to establish these physical locations.

Finally, the thematic analysis of the interviews in this research revealed aspects of the impact of hospice on the dying person, the caregiver, and family. Nelson-Becker (2006) discussed resilience as a characteristic of older adults living with life-threatening illness and receiving hospice care. Both administrators described the psychological relief and unburdening of families at admission such that the family member can attend to the relationship and not just caregiving tasks. This builds an environment of wellness in the family, community, and society when the inevitable, universal experience of death is accepted (Nelson-Becker, 2006). Nursing in the hospice setting creates opportunities for the conscious integration of charity and caring, as described by Watson (2012).

Just as the hospice administrators presented differing perspectives, the advanced practice nurse can participate in higher level advocacy opportunities as local communities and the province collaboratively develop hospice care. From this basic research, a few characteristics of hospice users have been illuminated. The continuation of nursing research about hospice use could contribute further knowledge to this emerging field of residential hospice care.

### **Implications for Policy**

Supporting quality of life becomes an increasingly pressing health care policy issue along with the generational shift toward more deaths occurring at advanced ages (Carstairs, 2010). Residential hospice care can contribute to QOL at EOL. *Advancing High Quality, High Value Palliative Care in Ontario - Declaration of Partnership and Commitment to Action* (Paetkau et al., 2011) addressed palliative care delivery in Ontario. In the provincial environmental scan by Paetkau et al. (2011), place of death was considered as an element of capacity, but no information is presented about deaths in

hospice. However, the policy document identifies improved quality of life preceding death, quality of death, improved quality of experience, and reduction of unmet health care needs as desirable population health outcomes. Hospice use can decrease these disparities in population health outcomes for persons at the end of life. Residential hospice is commonly considered an essential part of the new community based paradigm for integrated HPC. However, without pertinent data, its benefit cannot be documented. Numerous questions might be posed related to diagnoses and timeliness of access. For instance, how can planners ensure people with non-malignant diagnoses and uncertain length of prognoses receive quality EOL care? Why, when, and how do individuals choose hospice (or avoid hospice)? How many people die while waiting hospice admission? What is the referral to admission ratio?

More research is needed to uncover which individuals and groups of people want and are best suited to use hospice care, why they choose hospice, and the particular benefits provided to them by hospice care. Kuziemy and Lau (2008) recommended policy decisions for service delivery that are outcomes-driven and informed by data collection, analysis and development of practice standards. Heyland et al. (2000) suggested that service delivery should be supported by policies that align need with service, and respect patient preferences, values and goals. Paetkau et al. (2011) identified the right of dying persons to quality care in their home community and the availability of an integrated continuum of care options, which would include residential hospice. Tilden and Thompson (2009) recommended system changes for improvements in coordination of care across settings, implementation of advance care directives, coaching and support for caregivers, and the integration of chronic illness management and palliative care.

Policy should be informed by relevant research. Because residential hospice care is an emergent field in Canada, it is not yet known how many hospice beds are needed. The Fraser Health benchmark of 7 beds per 100,000 population (Bodell & Tayler, 2007) might not be applicable to the Ontario experience. The Ottawa Champlain benchmark is 65 beds per million population (Barkey et al., n.d.). Rural locations are looking to Australian guidelines for 65-85 beds per million population (Gow & Dempster, 2009). A number of Ontario LHINs are engaged in research based on horizon and environmental scans, population growth and aging projections, and forecasting to substantiate regional residential plans and rationales for service development (Southlake Regional Health Centre, 2011; Barkey et al., n.d.). In communities with established residential hospices, research into symptom management, psychosocial support, and emergency room diversion rates could validate the impact of residential hospices on costs, system functioning, and on the community's wellbeing.

Both hospice administrators addressed funding levels and sustainability. As Williams et al. (2010, p. 14) stated, "Having residential hospice programs securely funded by Canadian tax dollars will ensure their ongoing existence."

### **Implications for Education**

Awareness and education about hospice is needed to inform the public about the viable alternative choice of residential hospice as a location for EOL care and death. Development of outreach programs might be necessary to inform diverse communities of potential users so that they can access hospice services and locations. A person's knowledge, attitudes and experience of community services, including hospice, influences the person and caregiver's preference for location of death (Thomas, Morris &

Clark, 2004). Health care planners ought to know whether or not there are individuals and / or groups being excluded from receiving hospice care. The question of equity should be examined regarding access or disparity in service provision for individuals and / or groups within communities already served by hospice. Programs and service for the hard-to-serve dying people must be addressed.

The provincial hospice administrator explained that there is a need to dispel fear by speaking out about death and dying, changing the death experience into a healthy part of living, and building an environment of wellness. Advanced care planning education for consumers, the public, and professionals is one solution discussed by the provincial administrator. Health professional education about the intersection of PC and chronic illness, up-skilling, and development of referral pathways for patient centered, timely, specialist care could foster responsive, supportive care. Knowledge translation and exchange among hospice sector partners is needed for quality improvement and system change. The provincial organization presently supports its members through newsletter dissemination, offering of workshops and an annual conference, linking novice stakeholders with experienced partners for development, participation at government discussion tables, and government and public presentations to influence policy. Each hospice needs to provide continuing education for its staff about best practices in symptom management, culturally competent and culturally safe EOL practice, and development of innovative responses to particular identified needs within each community.



**Recommendations for Future Research**

This beginning demographic analysis is the starting point and foundation for further research on hospice usage and population outcomes. A number of immediate questions deserve attention, including:

1. Is there worth and benefit of having a hospice in each community?
2. When hospices exist in communities, whom should they serve and how?
3. What data sets are essential for all hospices to gather to best inform health care delivery at end of life?
4. How does or could government collected hospice usage information influence community capacity development, location of new hospices or public policy for funding?
5. How best can the voice of actual and potential clients and families be heard and implemented in hospice care?

Reporting on outcomes about usage can be used as drivers for change in service provision, policy and funding (Paetkau et al., 2011). Hospice facilities should consider correlating analyzed data with needs analyses, internal review for service goals related to quality, sustainability and value, funding requests, and comparison with public perception of use.

Although Kuziemy and Lau (2008) described the need for data collection for electronic health records and health information systems in general, their comments are also applicable to data collection about users of hospice. They suggested that data collection requires foresight. Hospice palliative care “is in danger of missing its opportunity to influence the design of information and communication technologies that will shape how data is collected and disseminated in future healthcare delivery”

(Kuziemy & Lau, 2008, p.6). Because reporting, collection and technology use are uneven across the province, a business case should be developed to scope hospice data collection needs and the feasibility of common data base development. Seow et al. (2008) also suggested a common data management system in the community. The Canadian Hospice Palliative Care Association report, *The Way Forward* (2013) proposed that all programs gather demographic and clinical data that are used to track and improve services. This could be done internally and provincially.

This exploratory research contributed to understanding baseline, actual use, revealed accessibility of historical usage, and demographic information for decedents at certain Ontario hospices. From this initial retrospective analysis of hospice users, there are a number of recommendations for further research. Such research needs funding.

Although there might be an expectation that most deaths in Ontario occur in older persons over 65, broad age categories seem to miss details about age and cause of death in younger age categories. These categories do not tell as much of a story compared to the narrow ten year stratification that uncovers specific characteristics. Individual variation is obscured and differences cannot be accounted for when only the aggregate analysis is available. However, convincing hospices to report using ten year categories might be problematic because of attitudes toward data collection, technology and time requirements.

Too short a stay might not provide the hospice user with all available benefits (such as symptom management) from accessing the interdisciplinary team for EOL care. Late referrals to hospice have been identified as a barrier to providing good care (Towns, et al., 2012), but this view should be examined from the perspective of the patient and

caregivers. Any speculation about acuity or disease progression in users from a particular care location that influence length of stay would require more investigation. LOS data with consideration about previous location of care over longer periods than three years could yield stronger conclusions. The provincial administrator raised the question of determining an appropriate, accessible, and desirable location for care for long stay PC patients. Examination is needed to follow discharged patients to determine readmission to hospice or death in other locations (for example, Long Term Care homes). Residential location of hospice users warrants further study to be able to identify any service patterns and service gaps over time.

Collection of user data should use standardized tools and technologies across the province to report and analyze domains that have been consensually examined and agreed upon for their utility. In the researcher's opinion, the characteristics should include non-aggregated data on actual age, gender, marital status, co-morbid diagnoses, cultural identification, religious affiliation, socioeconomic indicators, residential location, assessment of symptoms on admission and caregiver demographic information. Verifiable research requires that raw data is available to the individual researcher(s) and to those who would later critique and validate the research.

Further research is needed to reveal the multifactorial reasons for choosing residential hospice in Ontario. More work needs to be done to evaluate the impact and value of hospice care at the individual, family, and societal level. These research results could then inform the direction and development of residential hospice care within the local and provincial EOL care context, and its integration within the larger continuum of health care delivery specifically and generally. Next, there is an opportunity for

translational research. Hospices are aware of the demand for their services. Service delivery to a disadvantaged or marginalized group, cultural safety within the hospice, best models of service provision, the impact of psychosocial support, structural models for hospices in rural areas, and cost sharing in satellites are ideas presented by the hospice administrators which require further study. Developmental research into residential hospice emergence is needed from advocacy, resource management, and PC models. Mapping of hospice development would add to present understandings of hospice capacity building and population needs provincially and nationally. Residential hospice care for the population with non-malignant disease could be examined as an example of the intersection of chronic disease management, public health policy and human rights perspectives (as described by Gwyther et al., (2009). Sociological perspectives of hospice use, such as wealth management, identity politics or emotional labor, could also be examined.

“Although national initiatives in Canada are advocating for increased HPC delivery we first need to be able to answer basic questions such as who is not accessing HPC and perhaps, more importantly, why are patients not accessing HPC?” (Health Canada Surveillance Data Set, 2002, p. 6, <http://www.statcan.gc.ca>). Understanding the reality of who uses hospice will introduce further questions about service. Hospices should learn whether or not they are caring for the people they intend to serve. Hospices should identify individuals and groups who are not accessing hospice and why. They should ask whether or not use reflects need, and how hospices can better serve the community.

This study was motivated by practical concerns and by the researcher's awareness of gaps in providers' knowledge about users of hospice. This is an emergent field with stakeholders resolving issues as they arise and responding organically to user care needs. Additional research can be used to ascertain the value of hospice to users, their families and community; to urgently prove the case and value of hospice to funders and society; and to move into the future with sufficient options to care for those living with life limiting illness. Further investigation needs to be pursued to broaden this initial baseline information and develop clarity in the picture of who uses hospice.

## References

- Barkey, V., Conacher, M., Hong, E., Laughlin, T., Robertson, G., Owens., Chamberlain, K., Sunderland, L., & Zawierzeniec, D. (n.d.). For consideration in the Central East Local Health Integration Network IHSP: A strategy for residential hospice development. Scarborough: CE-LHIN Residential Hospice Working Group.
- Bodell, K., & Tayler, C. (2007). *Fraser Health Hospice Residences – Creating a healing and caring environment at end of life: Standards and guidelines for planning, development and operation*. Surrey, British Columbia: Fraser Health Authority.
- Brazil, K., Howell, D., Bedard, M., Krueger, P., & Heidebrecht, C. (2005). Preferences for place of care and place of death among informal caregivers of the terminally ill. *Palliative Medicine*, 19, 492-499. doi: 10.1191/0269216305pm1050oa
- Canada Post, 2013.
- (<http://www.canadapost.ca/cpotools/apps/fpc/personal/findByCity?execution=e4s1>)
- Canadian Hospice Palliative Care Association. (2012). Fact sheet: Hospice palliative care in Canada. Retrieved from [http://www.chpca.net/media/7622/fact\\_sheet\\_hpc\\_in\\_canada\\_may\\_2012\\_final.pdf](http://www.chpca.net/media/7622/fact_sheet_hpc_in_canada_may_2012_final.pdf)
- Canadian Hospice Palliative Care Association. (2013). Innovative models of integrated Hospice Palliative Care, The Way Forward Initiative: An integrated palliative approach to care. Retrieved from [www.hpcintegration.ca](http://www.hpcintegration.ca)

- Carstairs, S. (2010). *Raising the bar: A roadmap for the future of palliative care in Canada*. Ottawa: Senate of Canada. Retrieved from <http://www.sharoncarstairs.ca/RaisingtheBarJune2010.pdf>
- Critchley, P., Jada, R., Taniguchi, A., Woods, A., Stevens, R., Reyno, L., & Whelan, T. (1999). Are some palliative care delivery systems more effective and efficient than others? A systematic review of comparative studies. *Journal of Palliative Care*, 15(4), 40-47.
- Cuiker, A. (June 28, 2012). Hospice care saves money, frees acute care beds. *Hamilton Community News*. Retrieved from <http://www.hamiltonnews.com/news/hospice-care-saves-money-frees-acute-care-beds/>
- Fassbender, K., Fainsinger, R., Brenneis, C., Brown, P., Braun, T., & Jacobs, P. (2005). Utilization and cost of the introduction of system-wide palliative care in Alberta, 1993-2000. *Palliative Medicine*, 19, 513-520. doi: 10.1191/0269216305pm1071oa
- Fawcett, J. (1984). The Metaparadigm of nursing: Present status and future refinements. *Image: The Journal of Nursing Scholarship*, 16(3), 84-87.
- Gatrell, A.J., & Wood, D. J. (2012). Variation in geographic access to specialist inpatient hospices in England. *Health & Place*, 18, 832-840. doi: 10.1016/j.healthplace.2012.03.009
- Gomes, B., & Higginson, I. (2004). Home or hospital? Choices at the end of life. *Journal of the Royal Society of Medicine*, 97(9), 413-414.

- Gomes, B., & Higginson, I. (2006). Factors influencing death at home in terminally ill patients with cancer: Systematic review. *British Medical Journal Online*, 1-7.  
doi:10.1136/bmj.38740.614954.55
- Gomes, B., & Higginson, I. (2008). Where people die (1974-2030): Past trends, future projections and implications for care. *Palliative Medicine*, 22, 33-41.  
doi:10.1177/0269216307084606
- Gow, T., & Dempster, D. (2009). *Residential Hospices in the area served by the Central East LHIN: Planning, building, operating and sustainability. Final Report to the Central East Residential Hospice Working Group*. Scarborough: CE-LHIN Residential Hospice Working Group.
- Greer, D.S., Mor, V., Morris, J., Sherwood, S., Kidder, D., & Birnbaum, H. (1986). An alternative in terminal care: Results of the National Hospice Study. *Journal of Chronic Disease*, 39(1), 9-26.
- Gwyther, L., Brennan, F., & Harding, R. (2009). Advancing palliative care as a human right. *Journal of Pain and Symptom Management*, 35(5), 767-774.  
doi:10.1016/j.painsymman.2009.03.003
- Health Canada Surveillance Data Set. (2002). Retrieved from: <http://www.statcan.gc.ca>
- Heyland, D.K., Lavery, J.V., Tranmer, J.E., Shortt, S.E., & Taylor, S.J. (2000). Dying in Canada: Is it an institutionalized, technologically supported experience? *Journal of Palliative Care, Supplement: Palliative Care in the Intensive Care Unit*, S10-16.



- Higginson, I.J., & Sen-Gupta, G.J. (2000). Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. *Journal of Palliative Medicine*, 3, 287-300.
- Hirst, L. (2011). Which home care experiences result in transfer to hospice? The experience of family members of patients that expressed a preference to die at home. (Unpublished master's thesis). Newcastle University, Newcastle, United Kingdom.
- Holdsworth, L., & Fisher, S. (2010). A retrospective analysis of preferred and actual place of death for hospice patients. *International Journal of Palliative Nursing*, 16 (9), 424-430.
- Hospice Palliative Care Ontario. (2011). [www.hpcoco.ca](http://www.hpcoco.ca)
- Johnson, K., Kuchibhatla, M., & Tulsky, J. (2009). Racial differences in self-reported exposure to information about hospice care. *Journal of Palliative Medicine*, 12, 921-927.
- Johnston, C., & George, M. (2012). *A Residential hospice plan for the South East LHIN: Report and recommendations of the Southeastern Ontario Palliative and End-of-Life Care Network Residential Hospice Work Group*. Belleville: SEO PEOLCN.
- Koffman, J., & Higginson, I. (2004). Dying to be home? Preferred location of death of first-generation black Caribbean and native-born white patients in the United Kingdom. *Journal of Palliative Medicine*, 7(5), 628-636.
- Kuziemy, C., & Lau, F. (2008). A comparative analysis of computer based hospice palliative care datasets in Canada. *BMC Palliative Care*, 7(6), 1-8.  
doi:10.1186/1472-684X-7-6

- McNamara, B., & Rosenwax, L. (2007). Factors affecting place of death in Western Australia. *Health and Place*, 13, 356-367. doi:10.1016/j.healthplace.2006.03/001
- Ministry of Health and Long Term Care. (2006). Residential Hospices. In *Client Services Policy Manual, CCAC Home Care Services*. Retrieved from [http://www.health.gov.on.ca/english/providers/pub/manuals/ccac/cspm\\_sec\\_7/7-8.html](http://www.health.gov.on.ca/english/providers/pub/manuals/ccac/cspm_sec_7/7-8.html)
- National Hospice and Palliative Care Organization. (2011). *NHPCO Facts and figures: Hospice care in America*. Retrieved from [http://www.nhpco.org/files/public/Statistics\\_Research/2011\\_Facts\\_Figures.pdf](http://www.nhpco.org/files/public/Statistics_Research/2011_Facts_Figures.pdf)
- Nelson-Becker, H.B. (2006). Voices of resilience: Older adults in hospice care. *Journal of Social Work in End-of-Life & Palliative Care*, 2(3), 87-106. doi:10.1300/J457v02n03\_07
- Paetkau, S., Switzer, G., Kasperski, J., Seow, T., & Firth, R. (2011). *Advancing high quality, high value palliative care in Ontario. Declaration of partnership and commitment to action*. Toronto: Coalition of Hospice Interests and Ministry of Health and Long Term Care. 1-72. Retrieved from [www.hpco.ca](http://www.hpco.ca), 2012.
- Prigerson, H.G., & Maciejewski, P.K. (2012). Dartmouth Atlas: Putting end-of-life care on the map but missing psychosocial detail. *Journal of Supportive Oncology*, 10(1), 25-28.
- Rhodes, R.L., Teno, J.M., & Welch, L.C. (2006). Access to hospice for African Americans: Are they informed about the option of hospice? *Journal of Palliative Medicine*, 9(2), 268-272.

- Seale, C. (2000). Changing patterns of death and dying. *Social Science & Medicine*, 51, 917-930.
- Seow, H., Barber, L., Howell, D., & Dy, S. (2010). How end-of-life home care services are used from admission to death: A population-based cohort study. *Journal of Palliative Care*, 26(4), 270-278.
- Seow, H., King, S., & Vaitonis, V. (2008). The impact of Ontario's End-of-Life care strategy on end-of-life care in the community. *Healthcare Quarterly*, 11(1), 56-62.
- Southlake Regional Health Center. (2011). *Residential Hospice – The need for residential hospice on Southlake campus to support a comprehensive health system, population growth demand, regional programs and exemplary end-of-life care options*. Newmarket: Author.
- Statistics Canada Community Profiles. (nd). Retrieved from: <http://www.statcan.gc.ca>
- Taylor, E.J., Ensor, B., & Stanley, J. (2011). Place of death related to demographic factors for hospice patients in Wellington, Aotearoa, New Zealand. *Palliative Medicine*, 26(4), 342-349. doi:10.1177/0269216311412229
- Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., . . . Lynch, T.J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, 363(8), 733-742.
- Tilden, V., & Thompson, S. (2009). Policy issues in end-of-life care. *Journal of Professional Nursing*, 25(6), 363-368.

- Thomas, C., Morris, S.M., & Clark, D. (2004). Place of death: Preference among cancer patients and their carers. *Social Science & Medicine*, 58, 2431-2444. doi: 10.1016/j.socscimed.2003.09.005
- Towns, K., Dougherty, E., Kevork, N., Wiljer, D., Seccareccia, D., Rodin, G., . . . Zimmermann, C. (2012). Availability of services in Ontario hospices and hospital providing inpatient palliative care. *Journal of Palliative Medicine*, 15(5), 527-534. doi:10.1089/jpm.2011.0453
- Ward, E.G., & Gordon, A.K. (2006). Looming threats to the intimate bond in hospice care? Economic and organizational pressures in the case study of a hospice. *Omega: Journal of Death and Dying*, 54(1), 1-18.
- Watson, J. (2012). *Human caring science - A theory of nursing*. Sudbury, MA: Jones & Bartlett.
- Williams, A. (1999). An assessment of community palliative care needs: The case of Niagara. *Journal of Palliative Care*, 15(2), 45-52.
- Williams, A., Crooks, V., Whitfield, K., Kelley, M., Richards, J., Demiglio, L., & Dykeman, S. (2010). Tracking the evolution of hospice palliative care in Canada: A comparative care study analysis of seven provinces. *BMC Health Services Research*, 10, 147-162. doi: 10.1186/1472-6963-10-147
- Wilson, D.M., Truman, C.D., Thomas, R., Fainsinger, R., Kovacs-Burns, K., Froggatt, J., & Justice, C. (2009). The rapidly changing location of death in Canada, 1994-2004. *Social Science & Medicine*, 68, 1752-1758. doi: 10.1016/j.socscimed.2009.03.006

- Wright, M., Wood, J., Lynch, T., & Clark, D. (2008). Mapping levels of palliative care development: A global view. *Journal of Pain and Symptom Management*, 35(5), 469-485. doi: 10.1016/j.jpainsymman.2007.06.006
- World Health Organization. (2007). WHO Definition of palliative care. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>

**Appendix A**

**IRB Full Approval Letter from D'Youville College**



D'Youville  
COLLEGE

(716) 829-8000  
FAX: (716) 829-7790

TO: Ruth Evelyn Fuller Forbes  
FROM: Dr. Roger Fiedler *RF*  
Institutional Review Board  
DATE: November 2, 2012  
SUBJECT: IRB FULL APPROVAL

I am pleased to inform you that your application to the D'Youville College Institutional Review Board entitled: *"Who Uses Residential Hospice In Ontario?"* has been granted **FULL APPROVAL** with respect to the protection of human subjects. This means that you may now begin your research unless you must first apply to the IRB at the institution where you plan to conduct the research.

Please note that you are required to report back to this IRB for further review of your research should any of the following occur:

1. a major change in the method of data collection
2. unanticipated adverse effects on the human subjects
3. unanticipated difficulties in obtaining informed consent or maintaining confidentiality
4. the research has not been completed one year from the date of this letter

Congratulations and good luck on your research!

jjg

cc: Director of Graduate Studies  
Dr. Eileen Nahigian  
file

**Appendix B**

**Letters Requesting Institutional Permission**



Ruth E. Forbes  
15 Glenron Road, R. R. # 2  
Campbellville, Ontario  
Canada L0P1B0  
March 15, 2013

[REDACTED], Executive Director  
[REDACTED]  
[REDACTED]  
[REDACTED], Ontario  
Canada [REDACTED]

Dear [REDACTED]

I am writing to request permission to conduct a research study at your institution. I am Ruth E. Forbes, a graduate student in the Master's of Science in Nursing (Clinical Focus – Palliative Care) program at D'Youville College in Buffalo, New York. The study I am proposing is *"Who Uses Residential Hospice in Ontario?"*

The purposes of this descriptive case study are to determine the characteristics of patients using freestanding residential hospice care at a single location in Ontario and to explore hospice or hospice association administrator views about desirable data, utility, gaps in collection and possible influences on policy recommendations. This investigation could allow for identification of underserved segments of the population that might benefit from outreach about hospice services. It might further public education about this available option for end of life care and place of death. My data analysis could help the hospice establish a baseline understanding of actual service provided and verify the population served. Public policy issues of resource utilization and accountability might be informed by this study as more hospices are built.

The goals of this research are: 1) to present findings that describe past users of hospice care in one Ontario location; 2) to identify patterns or trends occurring within these data; and 3) to compare this individual hospice data to that from other Ontario hospices in the province according to common characteristics (length of stay, number of bed days, total number served annually, and others; and 4) to explore what data hospice or hospice association administrators believe are appropriate to collect and why.

Your permission to conduct this research will allow me to accomplish the following: 1) gain access to review official institutional documents that relate to the characteristics of former patients who have used hospice; 2) gain access to review the Residential Hospice Statistics

Reports from 2008 to date; and 3) accomplish comparative review with provincially collected demographic data about hospice care. Data collection methods at your site will include an audiotaped interview with the Executive Director, observation and analysis of documents, data, and records of the characteristics of patients who have used residential hospice care. The institutions will not receive remuneration for their cooperation in this study. Expected study duration is September 2012 through May 2013.

The mixed methods procedures for this study are quantitative and qualitative, non-experimental and exploratory. No risks to patients are identified. There might be no direct benefit from this study to any hospice or institution. A pseudonym for Stedman Community Hospice will be employed to protect the identity of the institution. Neither your organization, your patients, nor anyone associated with your organization, will be identified in any reports of the study. Data will be reported and discussed in aggregate form. Summary information about the study will be reported. The information will be securely stored and maintained, with access restricted to the researcher. All data will be destroyed after 6 years according to Canadian protocols for research.

For further questions related to this research study and process, please contact me directly at 905-659-2221 or [forber05@dyv.edu](mailto:forber05@dyv.edu) or my thesis director, Dr. Eileen Nahigian at 716-829-8379 or at [nahigian@dyv.edu](mailto:nahigian@dyv.edu).

Your signature below will indicate that you give institutional permission and limited access to Ruth E. Forbes to conduct this study at your institution, and agree to allow the researcher to present her findings publicly or privately, orally or in written form, while maintaining confidentiality.

  
Executive Director,  Hospice

March 31, 2013  
Date

\_\_\_\_\_  
Researcher

March 18, 2013  
Date

Yours truly,

Ruth E. Forbes BScN, MScN (candidate)

Ruth E. Forbes  
15 Glenron Road, R. R. # 2  
Campbellville, Ontario  
Canada L0P1B0  
November 26, 2012

[REDACTED], Executive Director  
[REDACTED]  
[REDACTED]  
[REDACTED]  
Canada [REDACTED]

Dear [REDACTED]

I am writing to request permission to conduct a research study at your institution. I am Ruth E. Forbes, a graduate student in the Master's of Science in Nursing (Clinical Focus – Palliative Care) program at D'Youville College in Buffalo, New York. The study I am proposing is *"Who Uses Residential Hospice in Ontario?"*

The purposes of this descriptive case study are to determine the characteristics of patients using freestanding residential hospice care at a single location in Ontario and to explore hospice or hospice association administrator views about desirable data, utility, gaps in collection and possible influences on policy recommendations. This investigation could allow for identification of underserved segments of the population that might benefit from outreach about hospice services. It might further public education about this available option for end of life care and place of death. My data analysis could help the hospice and HPCO establish a baseline understanding of actual service provided and verify the population served. Public policy issues of resource utilization and accountability might be informed by this study as more hospices are built.

The goals of this research are: 1) to present findings that describe past users of hospice care in one Ontario location; 2) to identify patterns or trends occurring within these data; and 3) to compare this individual hospice data to that from other Ontario hospices in the province according to common characteristics (length of stay, number of bed days, total number served annually, and others; and 4) to explore what data hospice or hospice association administrators believe are appropriate to collect and why.

Your permission to conduct this research will allow me to accomplish the following: 1) gain access to review official institutional documents that relate to the characteristics of former patients who have used hospice; 2) gain access to review the Residential Hospice Statistics Reports from 2008 to date; and 3) accomplish comparative review with provincially collected

demographic data about hospice care. Data collection methods at your site will include an audiotaped interview with the Executive Director, observation and analysis of documents, data, and records of the characteristics of patients who have used residential hospice care. The institutions will not receive remuneration for their cooperation in this study. Expected study duration is November 2012 through May 2013.

The mixed methods procedures for this study are quantitative and qualitative, non-experimental and exploratory. No risks to patients are identified. There may be no direct benefit from this study to any hospice or institution. A pseudonym for Stedman Community Hospice will be employed to protect the identity of the institution. Neither your organization, your patients, nor anyone associated with the organization will be identified in any reports of the study. Data will be reported and discussed in aggregate form. Summary information about the study will be reported. The information will be securely stored and maintained, with access restricted to the researcher. All data will be destroyed after 6 years according to Canadian protocols for research.

For further questions related to this research study and process, please contact me directly at 905-659-2221 or [forber05@dvc.edu](mailto:forber05@dvc.edu) or my committee chairperson, Dr. Eileen Nahigian at 716-829-8379 or at [nahigian@dvc.edu](mailto:nahigian@dvc.edu).

Your signature below will indicate that you give institutional permission and limited access to Ruth E. Forbes to conduct this study at your institution, and agree to allow the researcher to present her findings publicly or privately, orally or in written form, while maintaining confidentiality.

\_\_\_\_\_  
Executive Director, \_\_\_\_\_

\_\_\_\_\_  
Date

*Dec 23, 2012*

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

*December 28, 2012*

Yours truly,

Ruth E. Forbes BScN, MS (candidate)

**Appendix C**

**Redacted De-Identified REB Approval Letter from Participating Institutions**

## RESEARCH ETHICS BOARD

[REDACTED], ONTARIO, CANADA [REDACTED]

Tel. [REDACTED] Fax: [REDACTED]

March 11, 2013

Research Ethics Board  
Membership

[REDACTED], MB, BS, MD, PhD,  
Chairperson  
[REDACTED], BSc, MA, PhD  
Psychology, Vice Chair  
[REDACTED], MA, PhD  
Ethicist  
[REDACTED], MD, FRCSC,  
General Surgery  
[REDACTED], MB BCh, MSc,  
FRCPC Nephrology  
[REDACTED], MD, Diagnostic  
Imaging  
[REDACTED], MD, FRCPC Internal  
Medicine/Critical Care  
[REDACTED], BA, MA Community  
[REDACTED], MSc, MD, PhD,  
Medicine/Respirology  
[REDACTED], JD, Research  
Officer/Legal  
[REDACTED], MD, PhD, FRCPC  
Psychiatry  
[REDACTED], BA, Community  
[REDACTED], RN, BScN, MScN,  
MEd - Clinical Nurse Specialist  
[REDACTED], BA, MA, PhD  
Neuropsychology, Ethics  
[REDACTED], BA, PhD  
Biostatistics  
[REDACTED], MA, BM BCh,  
FRCPC Respiratory  
[REDACTED], BA, MA, LLB  
Legal, Community  
[REDACTED], BSc, MSc, PhD  
Biostatistics  
[REDACTED], BScPhm, Pharmacy  
[REDACTED], MB, BCh, MRCPI,  
FRCPC President (Ex officio)

The [REDACTED] REB operates in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans; the Health Canada / ICH Good Clinical Practice: Consolidated Guidelines (E6); the Health Ethics Guide (CHAC); and the applicable laws and regulations of Ontario. The membership of this REB also complies with the membership requirements for REBs as defined in Canada's Food and Drug Regulations (Division 5: Drugs for Clinical Trials Involving Humans Subjects).

Ms. Kathleen Baba Willison  
St. Joseph's Healthcare Hamilton  
Palliative Care  
Fontbonne Building, Room F803

RE: R.P. #12-3795  
Study Title: Who uses hospice in Ontario?  
Local Principal Investigator: Ms. Kathleen Baba Willison  
Received date: 26 November, 2012  
Review type: Expedited  
Initial Approval: 14 December, 2012  
Final Approval: 11 March, 2013

## All Received Enclosures:

Application Form - General Research Application  
Protocol - Study Protocol undated - REB date stamp NOV 26 2012  
Consent Form (Main) - Informed Consent  
Interview Guides - Interview Guide  
Application Form - D'Youville College Institutional Review Board  
Application Oct 23, 2012  
Approval Letter from Other REB - D'Youville College Institutional  
Review Board approval dated November 2, 2012  
Letter of Support - [REDACTED] letter of support  
Other - NIH Certificate for Ruth Forbes dated 07/08/2012  
Other - TCPS 2:core Certificate for Kathleen Willison  
dated 22 November, 2012  
Other - Letter of Permission to [REDACTED]  
dated November 26, 2012  
Other - Draft Letter of Permission to [REDACTED]  
PI Letter - Letter dated February 24, 2013 responding to conditions  
Consent Form (Main) - Informed Consent ver: 2 23 February, 2013

## Approved Enclosures:

Application Form - General Research Application  
Protocol - Study Protocol undated - REB date stamp NOV 26 2012  
Interview Guides - Interview Guide  
Other - Letter of Permission to [REDACTED]  
dated November 26, 2012  
Other - Draft Letter of Permission to [REDACTED]  
Consent Form (Main) - Informed Consent ver: 2 23 February, 2013

Ms. Kathleen Baba Willison

Page 2 of 2 Pages

March 11, 2013

**Acknowledged Enclosures:**

Application Form - D'Youville College Institutional Review Board Application Oct 23, 2012

Approval Letter from Other REB - D'Youville College Institutional Review Board approval dated November 2, 2012

Letter of Support - [REDACTED] letter of support

Other - NIH Certificate for Ruth Forbes dated 07/08/2012

Other - TCPS 2:core Certificate for Kathleen Willison dated 22 November, 2012

PI Letter - Letter dated February 24, 2013 responding to conditions

Dear Ms. Willison:

Please be advised that a member of the Research Ethics Board's Subcommittee reviewed R.P. #12-3795 on 14 December, 2012 and approved it with some conditions. Those conditions have now been met. You have final approval to commence your research.

This approval will be for a period of 12 months ending 11 March, 2014. We will request a progress report at that time.

If your project is terminated, it is your responsibility to notify the REB. Any changes or amendments to the protocol or consent form must be approved by the Research Ethics Board prior to implementation.

Please ensure that all study personnel are familiar with the REB requirements on the appended page.

Please reference R.P. #12-3795 in any future correspondence. Please note that all study related correspondence must be signed by the local principal investigator.

We wish you well in the completion of this research.

Sincerely yours,

[REDACTED]  
[REDACTED], MB, BS, MD, PhD  
Chairperson, Research Ethics Board  
RR:ah

cc: Prof. Eileen Nahigian (Study Co-ordinator)  
M. Fletcher - E. Kapetanovic - Pharmacy  
Append.

**Appendix D**

**Participant Consent Forms**





## Who Uses Residential Hospice in Ontario?

### INFORMED CONSENT

#### Introduction

You are being invited to participate in a research study conducted by Ruth Evelyn Fuller Forbes, a graduate Nursing student at D'Youville College, Buffalo, New York, because, as administrators, you have knowledge of residential hospices. The study is entitled, "Who Uses Residential Hospice in Ontario?" Its threefold purpose is to: 1) determine the characteristics of people who use a residential hospice for end-of-life care, 2) to gather and compare one hospice's data with information that is collected provincially, and 3) to explore hospice or hospice organization administrators' views about user characteristics, data utility, gaps, and policy recommendations.

The investigator team consists of the following:

**Ruth Evelyn Fuller Forbes:** Master's in Nursing Graduate Student Researcher, School of Nursing, D'Youville College, Buffalo, NY.

**Dr. Eileen Nahigian:** Thesis Director, School of Nursing, D'Youville College, Buffalo, NY.

**Kathleen Baba Willison:** the Local Principal Investigator, School of Nursing and Division of Palliative Care, St. Joseph's Healthcare Hamilton and McMaster University, Hamilton, ON.

Consent:Version 2:February 23, 2013



1

Consent:Version 2:February 23, 2013



#### Participant Role

You will be one of two administrators within the hospice system, whose information will contribute to part 3 of this study. Your participation will involve one audiotaped interview session, lasting a maximum of two hours. Results from the residential hospice (part 1), as well as results from the provincial hospice organization (part 2) and information from the annual reports will be shared with you. Following this, you will be asked a series of questions about your perceptions, observations, and opinions about the summary data, its utility, and any noticeable gaps or policy recommendations that might arise from these findings. You will then be asked to identify additional data sets that might be useful for analysis and for hospice planning.

#### Risks and Benefits

The procedures in this study are not considered experimental. There are no more risks or discomforts associated with the procedures involved in this study than those ordinarily encountered in daily life or during any interview. There might be no direct benefits to you for participating in this research, but your participation could be helpful in contributing to new understanding about patients who have chosen to use residential hospice in the past, identifying population segments underserved by hospice, which may ultimately contribute to planning for future service.

#### Privacy and Confidentiality

Any information you provide during the course of the study will be recorded and given the limited number of participants, the recording itself may be identifiable. However, the recording will be transcribed and your name will not be revealed. The transcript will be assigned

Consent: Version 2: February 23, 2013



a number and information abstracted from the transcript will only be referred to in this way. No one but the researcher will have access to the information, and the transcripts will be securely stored in a locked cabinet in the researcher's private home office for ten years and then destroyed. Your identity and your hospice name will never be revealed in any report of this study.

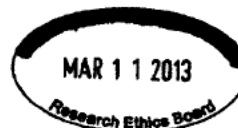
#### Voluntary Participation

Your participation in this study is completely voluntary. If you choose to participate, you may change your mind at any time up to 7 days after the interview session and withdraw your consent by notifying Ruth Forbes at 905-659-2221. There is no penalty or loss of any of the above mentioned potential benefits if you withdraw from the study. If you do choose to withdraw following any interview session, all recordings of the interview will be destroyed and will not be used in the study reports.

#### Monitoring

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the Hamilton Integrated Research Ethics Board (HIREB) may consult the research data. If, during the course of the study you have questions, you may contact Dr. Eileen Nahigian, the thesis director at D'Youville College (1-716-829-8379), or Kathleen Baba Willison, the local principal investigator at St. Joseph's Healthcare Hamilton (905-522-1155 x 33704). If you have any questions about your rights as a research participant, you may contact the Office of the Co-Chair of the Hamilton Integrated Research Ethics Board, (905-521-2100 x 42013) or the Office of the Chair of the Institutional Review Board, D'Youville College, Buffalo, at (1-716-829-7790).

Consent:Version 2:February 23, 2013



3

Consent:Version 2:February 23, 2013

**Signatures**

You are receiving two copies of this form. If you agree to participate, please return the signed copy to Ruth Forbes in the stamped self-addressed envelope provided and keep the other for your future reference. If you would like to receive a summary of the results of the study upon its completion record your full address on the request form included for this purpose.

My signature below indicates that I understand the procedures to be employed in this study, all my questions concerning the study have been answered to my satisfaction, and I agree to participate in this study. I understand that my identity and the identity of my institution will be maintained confidentially and not revealed in any reports connected to this research study. I also agree to allow the researcher to present her findings publicly or privately, orally or in written form.

Participant Name Participant's Signature 

Date

Mar. 31/13Researcher's Name Ruth FORBES

Researcher's Signature \_\_\_\_\_

Date

March 18, 2013

Consent: Version 2: February 23, 2013



4



Request for Summary of Research Results from the study

"Who Uses Residential Hospice in Ontario?"

By Ruth E. Forbes

Name

[Redacted]  
[Redacted]  
[Redacted]

Address

Date

April 4/13





## **Who Uses Residential Hospice in Ontario?**

### **INFORMED CONSENT**

#### **Introduction**

You are being invited to participate in a research study conducted by Ruth Evelyn Fuller Forbes, a graduate Nursing student at D'Youville College, Buffalo, New York, because, as administrators, you have knowledge of residential hospices. The study is entitled, "Who Uses Residential Hospice in Ontario?" Its threefold purpose is to: 1) determine the characteristics of people who use a residential hospice for end-of-life care, 2) to gather and compare one hospice's data with information that is collected provincially, and 3) to explore hospice or hospice organization administrators' views about user characteristics, data utility, gaps, and policy recommendations.

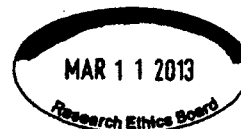
The investigator team consists of the following:

**Ruth Evelyn Fuller Forbes:** Master's in Nursing Graduate Student Researcher, School of Nursing, D'Youville College, Buffalo, NY.

**Dr. Eileen Nahigian:** Thesis Director, School of Nursing, D'Youville College, Buffalo, NY.

**Kathleen Baba Willison:** the Local Principal Investigator, School of Nursing and Division of Palliative Care, St. Joseph's Healthcare Hamilton and McMaster University, Hamilton, ON.

Consent: Version 2: February 23, 2013





### Participant Role

You will be one of two administrators within the hospice system, whose information will contribute to part 3 of this study. Your participation will involve one audiotaped interview session, lasting a maximum of two hours. Results from the residential hospice (part 1), as well as results from the provincial hospice organization (part 2) and information from the annual reports will be shared with you. Following this, you will be asked a series of questions about your perceptions, observations, and opinions about the summary data, its utility, and any noticeable gaps or policy recommendations that might arise from these findings. You will then be asked to identify additional data sets that might be useful for analysis and for hospice planning.

### Risks and Benefits

The procedures in this study are not considered experimental. There are no more risks or discomforts associated with the procedures involved in this study than those ordinarily encountered in daily life or during any interview. There might be no direct benefits to you for participating in this research, but your participation could be helpful in contributing to new understanding about patients who have chosen to use residential hospice in the past, identifying population segments underserved by hospice, which may ultimately contribute to planning for future service.

### Privacy and Confidentiality

Any information you provide during the course of the study will be recorded and given the limited number of participants, the recording itself may be identifiable. However, the recording will be transcribed and your name will not be revealed. The transcript will be assigned

Consent: Version 2: February 23, 2013



a number and information abstracted from the transcript will only be referred to in this way. No one but the researcher will have access to the information, and the transcripts will be securely stored in a locked cabinet in the researcher's private home office for ten years and then destroyed. Your identity and your hospice name will never be revealed in any report of this study.

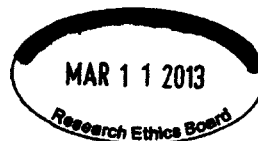
#### Voluntary Participation

Your participation in this study is completely voluntary. If you choose to participate, you may change your mind at any time up to 7 days after the interview session and withdraw your consent by notifying Ruth Forbes at 905-659-2221. There is no penalty or loss of any of the above mentioned potential benefits if you withdraw from the study. If you do choose to withdraw following any interview session, all recordings of the interview will be destroyed and will not be used in the study reports.

#### Monitoring

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the Hamilton Integrated Research Ethics Board (HIREB) may consult the research data. If, during the course of the study you have questions, you may contact Dr. Eileen Nahigian, the thesis director at D'Youville College (1-716-829-8379), or Kathleen Baba Willison, the local principal investigator at St. Joseph's Healthcare Hamilton (905-522-1155 x 33704). If you have any questions about your rights as a research participant, you may contact the Office of the Co-Chair of the Hamilton Integrated Research Ethics Board, (905-521-2100 x 42013) or the Office of the Chair of the Institutional Review Board, D'Youville College, Buffalo, at (1-716-829-7790).

Consent: Version 2: February 23, 2013





Signatures

You are receiving two copies of this form. If you agree to participate, please return the signed copy to Ruth Forbes in the stamped self-addressed envelope provided and keep the other for your future reference. If you would like to receive a summary of the results of the study upon its completion record your full address on the request form included for this purpose.

---

My signature below indicates that I understand the procedures to be employed in this study, all my questions concerning the study have been answered to my satisfaction, and I agree to participate in this study. I understand that my identity and the identity of my institution will be maintained confidentially and not revealed in any reports connected to this research study. I also agree to allow the researcher to present her findings publicly or privately, orally or in written form.

Participant Name



Participant's Signature

June 4, 2013  
Date

Researcher's Name Ruth E. FORBES

Researcher's Signature

June 4, 2013  
Date

Consent: Version 2: February 23, 2013





Request for Summary of Research Results from the study

"Who Uses Residential Hospice in Ontario?"

By Ruth E. Forbes

  
Name

  
  
  
Address

Date June 4, 2013



**Appendix E**  
**Interview Guide**

### Interview Guide

Date

Interviewee's Role/Position

Location    A    B

1.    What defines your service area? How do you define your catchment area? What is the greatest distance your patients reside from the hospice?
2.    What is your perception of your region's needs and demand for hospice beds?
3.    This study found that previous hospice patients at your site were A, B, C, etc. How does that compare with what you believed about your residents?
4.    How would you interpret x phenomenon/trend/pattern? For example, I found that more (women) than (men) were served in 2011. Is this important?
5.    How representative are your patients of your local population? What are your communities' dominant ethnic groups / language groups / religious groups? How appropriate or useful is it for this kind of information to be collected?
6.    What has been your experience having patients who are new Canadians? First Nations? Have ESL? Francophone? Physically Disabled? Mentally Challenged? How appropriate or useful is it for this kind of information to be collected? What do you understand from these observations about your residents?
7.    What groups would benefit from hospice EOL care who do not presently access care and would be well served by hospice?
8.    How does your organization currently engage the population to raise awareness for residential care at hospice? Where would you focus your next outreach efforts to increase awareness of residential hospice care?
9.    How does current funding policy affect users of hospice?
10.   What information would you like to know about hospice users?
11.   How would you collect and use this information?

**Appendix F**

**IRB Description of Procedures**

### **IRB Description of Procedures**

The research is to be conducted using data from an urban 6 bed freestanding residential hospice in Ontario, the oversight organization , located in . , Ontario; and Vital Statistics for mortality from the Office of the Registrar General. The population served by hospice is adults living in the province of Ontario who experience expected death in the residential hospice setting. Use of a specific hospice is voluntarily made by the patient, or the patient's Substitute Decision Maker, usually within the same geographical location as their residence. Following approval by the Institutional Review Board from D'Youville College, an initial inquiry Letter of Institutional Permission will be sent to the target hospice and . IRB approval from the governing body of the target hospice and will be sought. Permission to access documentation of clientele information (for example, Hospice Census, Residential Hospice Quarterly Statistical Reports, and Annual Reports) will be sought. The researcher will seek permission to access and record de-identified data. The researcher will conduct a computerized data analysis of central tendencies, frequencies and variance using the Statistical Package for Social Scientists (SPSS) Version 21.0 for Windows program (SPSS, Inc., Chicago, IL). As available, hospice statistics will be examined from 2008 through 2012. Following signing of consent forms, audiotaped interviews of two administrators from hospice or hospice associations will be conducted, with field notes recorded concurrently. After sharing of the study results, the researcher will use an interview guide to capture the administrators' experiential understanding, opinions and perceptions of the characteristics of residential hospice users; value of data collection about residents, and policies about hospice use. Human Rights Protection for privacy and confidentiality of patient identifiers will be ensured by use of aggregate data, which will be stored securely in a private personal computer under password protection. The tools for data collection will be analytic and statistical computer programs. No recruitment of subjects will be done. No informed consent will be obtained because patients are post mortem and data will be de-identified.

**Appendix G**

**Human Subject Research Proposal**

**HUMAN SUBJECTS RESEARCH PROPOSAL EVALUATION**

HUMAN SUBJECTS RESEARCH - D'YOUVILLE COLLEGE INSTITUTIONAL REVIEW BOARD

Researcher: Ruth Evelyn Fuller ForbesDate: 21-Sep-2012

1. Are subjects exposed to any possibility of:

Risk:

Discomfort:

	Y:	N:
physical	<input type="checkbox"/>	<input type="checkbox"/>
psychological	<input type="checkbox"/>	<input type="checkbox"/>

	Y:	N:
physical	<input type="checkbox"/>	<input type="checkbox"/>
psychological	<input type="checkbox"/>	<input type="checkbox"/>

If yes, describe how subjects are exposed, the methods to be used to protect subjects, and what will be done to restore physical and psychological homeostasis.

2. What are the possible benefits that can be derived by subjects who participate in the research?

Possible benefits to interview subjects could be satisfaction from contributing to hospice research through the interview process itself, allowing their opinions about hospice care to be expressed and heard, and potentially shaping the course of policy for data collection, hospice service, educational programs and outreach efforts to new patients.

3. What are the possible benefits that can be derived from the research?

The possible benefits include gaining a retrospective understanding of the characteristics of people living in Ontario who use hospice as a location for care and end of life. This addresses a gap in the hospice palliative care literature. This unique population data could potentially influence hospice care planning and policy. It may direct hospice outreach to under serviced populations. Valuing of individual choice and client preference for location of care could be affirmed.

4. Please indicate below whether subjects are members of a vulnerable population. If yes, explain why the research is not conducted with members of less vulnerable populations, and what special protections or safeguards will be used to protect the welfare of members of a vulnerable population. Check all that apply.

☒ No, subjects are not members  
of a vulnerable population

Y: N:

<input type="checkbox"/>	<input type="checkbox"/>	children
<input type="checkbox"/>	<input type="checkbox"/>	economically disadvantaged
<input type="checkbox"/>	<input type="checkbox"/>	educationally disadvantaged
<input type="checkbox"/>	<input type="checkbox"/>	institutionalized persons

Y: N:

<input type="checkbox"/>	<input type="checkbox"/>	mentally disabled
<input type="checkbox"/>	<input type="checkbox"/>	pregnant women
<input type="checkbox"/>	<input type="checkbox"/>	prisoners
<input type="checkbox"/>	<input type="checkbox"/>	other (specify)



**HUMAN SUBJECTS RESEARCH PROPOSAL**  
**D'YOUVILLE COLLEGE INSTITUTIONAL REVIEW BOARD**

5. Are subjects exposed to deception? If so, explain how, why it is necessary, and possible risks or discomforts for subjects.

Y: ☐ N: ☒

6. Are subjects exposed to coercion? If so, explain how, why it is necessary, and possible risks or discomforts for subjects.

Y: ☐ N: ☒

7. If either question 5 or 6 was answered yes, explain debriefing procedures to be used to desensitize, dehoax, or otherwise inform subjects of the true intent of the research and why deception and/or coercion was necessary.

8. What is the relationship between the researcher and the potential subjects? Explain how the potential subjects will be protected from coercion during the recruitment and research processes based on this relationship.

There is no relationship between the researcher and the interview subjects, who are executive directors of residential hospices or associations. Participation would be free and voluntary, without compensation.

9. How will subjects' data be maintained?

☐ anonymous  
☒ confidential

10. How long will subjects' data be stored?

☐ 3 years  
☒ 6 years

11. Where and how will subjects' data be securely stored and maintained?

Confidential data will be stored and maintained in a password protected, private computer database in a locked office in the researcher's residence for a period of six years.

12. How will research findings be disseminated to subjects?

A summary of research findings will be shared with the Executive Directors. Analysis will be reported in aggregate without naming the source or the locations.

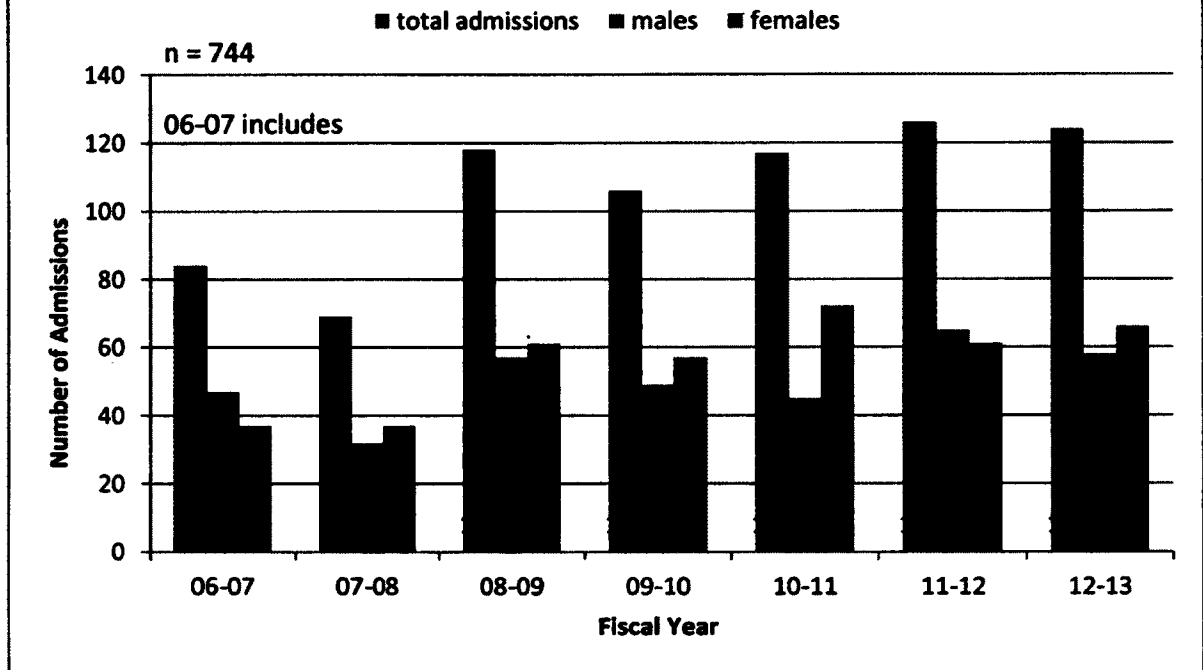
13. How will subjects' voluntary informed consent be obtained and documented? Specify any accommodations made to the consent form or consent process for special populations.

Informed consent will be obtained by direct ask for willingness to participate in an interview with minimal risk to subjects and protection of confidentiality. It will be documented in written form requiring both researcher and participant signature, inclusion of waiver of confidentiality, disclosure of any relationship between researcher and subject and protection of confidentiality of data. No accommodations will be used.

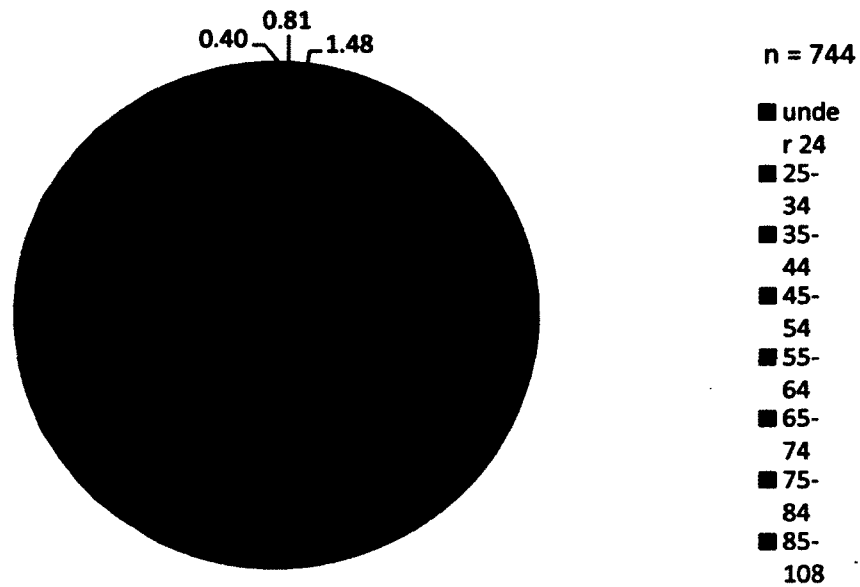
## Appendix H

### Figures

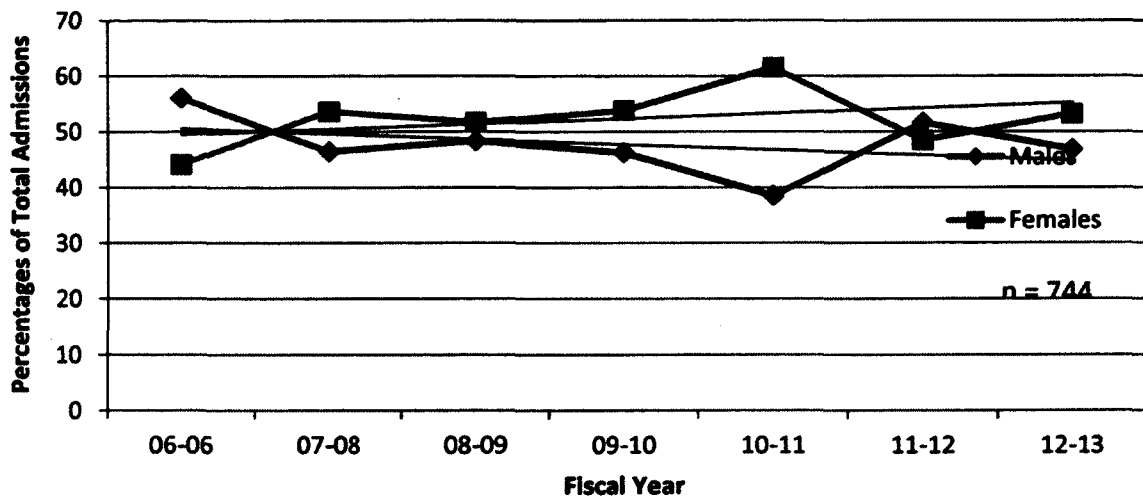
**Figure 1. Comparison of Hospice A Admission Numbers by Gender and Fiscal Year**



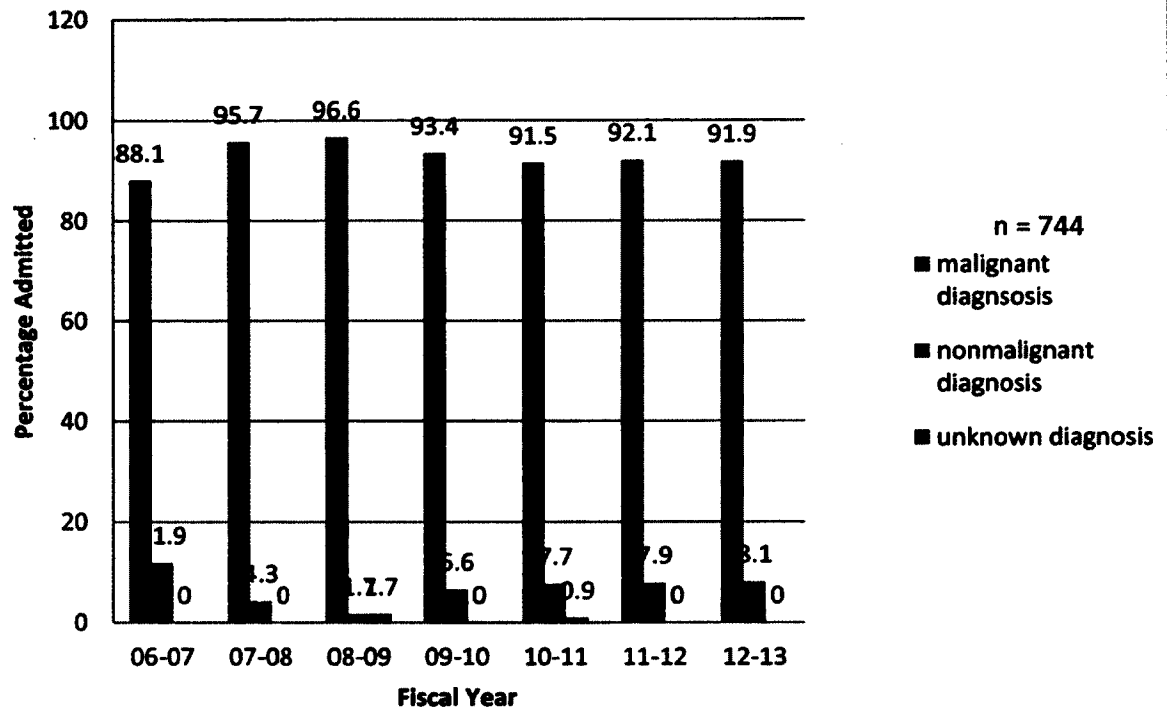
**Figure 2. Hospice A Residents Grouped by Age (Years) as a Percentage of Total Number for Years 2006-2013**

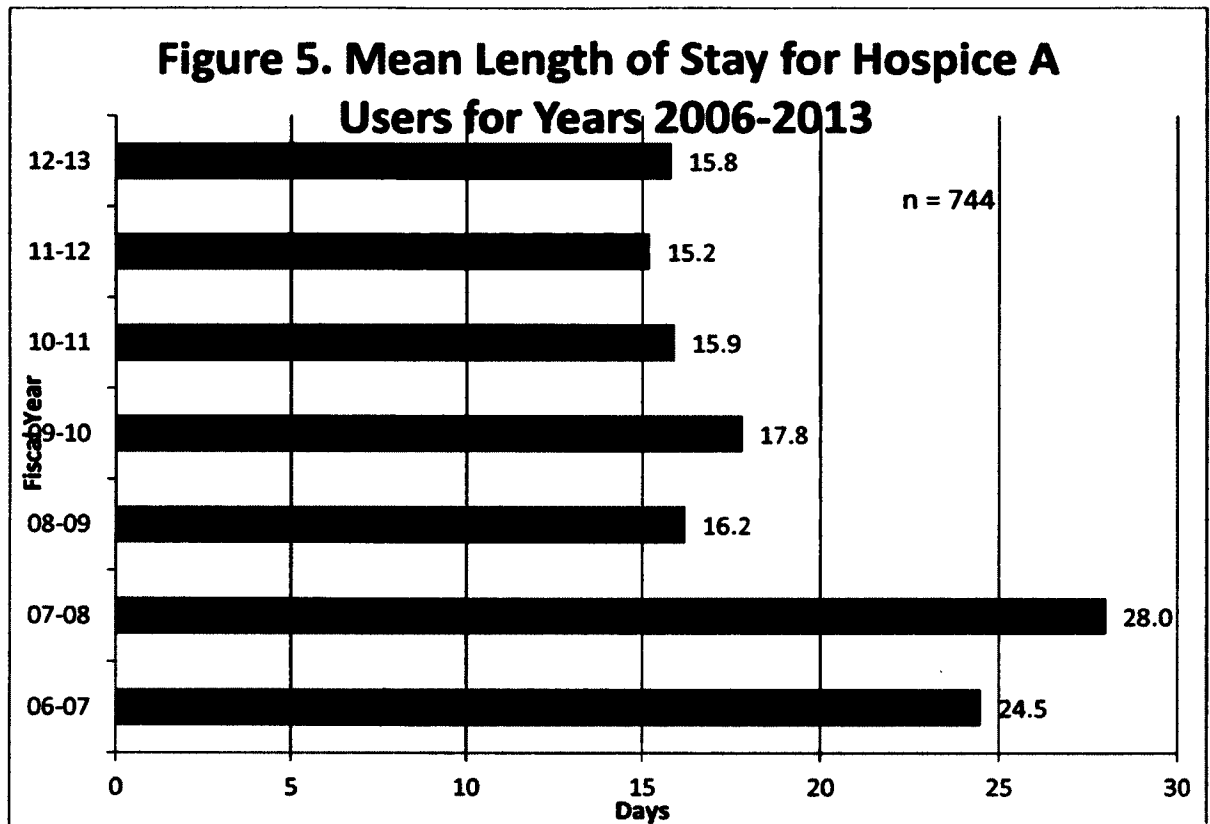


**Figure 3. Year to Year Comparisons of Percentage Admission to Hospice A by Gender**

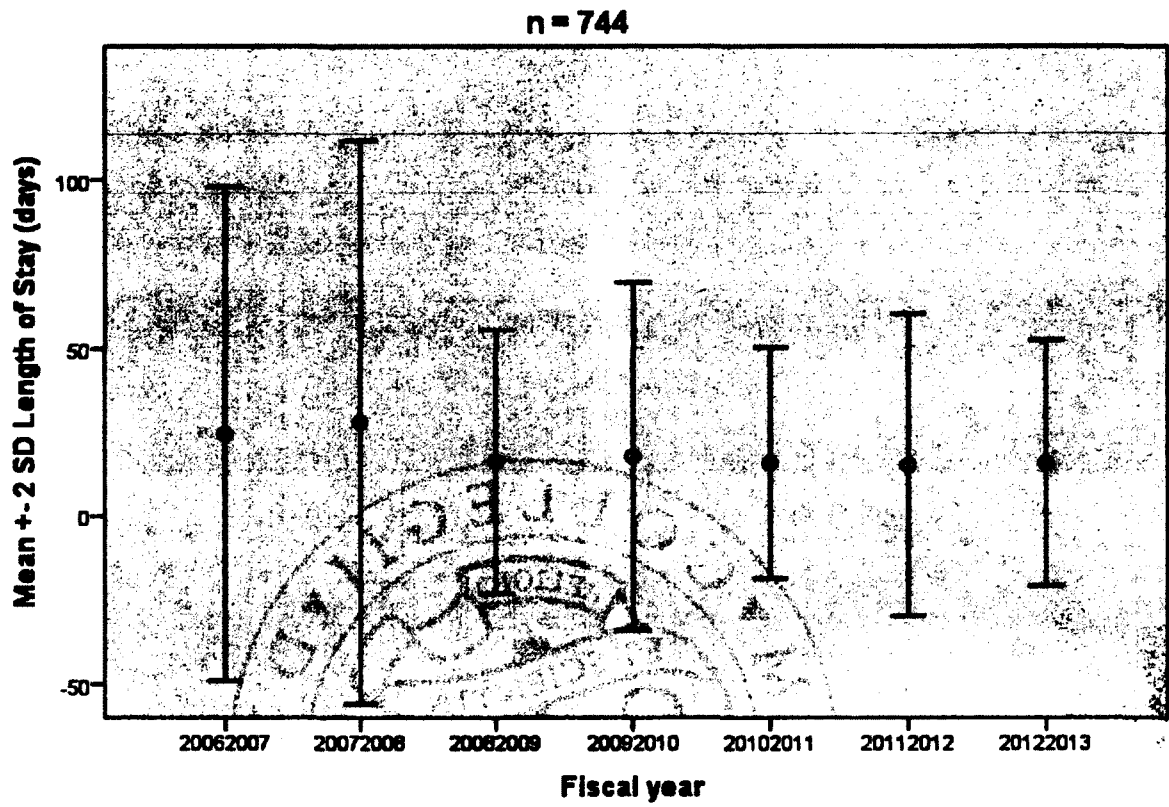


**Figure 4. Comparison of Percentage of Hospice A Users by Diagnostic Category by Year and Total**





**Figure 6. Mean Length of Stay with Standard Deviations at Hospice A for Years 2006-2013**





**Figure 7. Annual Discharge Disposition for Hospice A Users in 2006-2013**

