

**PREVALENCE OF PALLIATIVE PATIENTS AND THEIR
HEALTH SERVICES UTILIZATION IN THE
REGINA QU'APPELLE REGIONAL HEALTH AUTHORITY**

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in Partial Fulfillment of the Requirements
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by

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ABSTRACT

This population-based, retrospective descriptive analysis was conducted to study a cohort of decedents who died between January 2004 and December 2005 who were referred to the Regina Qu'Appelle Palliative Care Services (RQPCS). Demographics, diagnostic information and palliative service utilization were collected and analyzed.

The first step of the analysis included interviewing the program director and clinical consultant of the RQPCS. They provided the program vision and philosophy of the RQPCS as well as a comprehensive description of the program, including descriptions of the services offered and the staff of the palliative care team.

The second step of the research described in detail the demographics, palliative care service use and diagnostic background of the patients of the RQPCS. The variables of interest were age, gender, marital status, living arrangements, area of residence and diagnosis. Analysis also included determining which services the decedents accessed and how many of the services were used by each decedent. Timing of referrals and location of death were also analyzed. Frequencies and percentages were used to describe categorical variables. Means, median and range were used for continuous variables.

The third step of this thesis tested for associations between patient attributes and palliative care services utilization, timing of referral and location of death using chi-square analyses.

This research determined each of the patient characteristics under investigation to be associated with palliative care utilization. Similar findings were also evident in the literature. In particular, age, marital status, living arrangements, area of residence and diagnosis appeared to be significantly associated with accessing palliative care services.

When analyzing the associations between patient attributes and timing of referrals for the RQPCS, no significant results were found. Previous research indicated strong associations between marital status and diagnosis on the timing of referrals into hospice and palliative care programs.

Finally, there were two significant associations found between location of death and patient characteristics (gender and living arrangements). However, no clear conclusion could be reached on whether age, gender, marital status, living arrangement, area of residence or diagnosis had any effect on place of death in previous literature.

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DEDICATION

I dedicate this thesis to my parents, Jene and Susan Porter.

Mom and Dad, while I am proud of this work, I am more proud to be your daughter.
Thank you for all your love, support and belief in me.

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LIST OF ABBREVIATIONS

RQHR	Regina Qu'Appelle Health Region
RQPCS	Regina Qu'Appelle Palliative Care Services
WHO	World Health Organization
CVH	Canadian Virtual Hospice
PC	Palliative Care
PCU	Palliative Care Unit
ACU	Acute Care Units
LOS	Length of Stay
SWADD	System Wide Admission/Discharge Department
PCS	Palliative Care Services
SK	Saskatchewan
RCT's	Randomised Control Trials

Chapter 1 Introduction

1.1 General Background

1.1.1. Definition of Palliative Care

Palliative care is an approach that aims to maintain the quality of life of terminal patients and their families at the end of life by focusing on their physical, mental, emotional, social and spiritual well-being.¹ Palliative care, as defined by the World Health Organization (WHO):

- “Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness.”¹

1.1.2. History of Palliative Care

In 1967, the first modern research and teaching hospice, St. Christopher’s Hospice, opened near London, England.² When St. Christopher’s Hospice was founded, their view was “that people should be helped not only to die peacefully, but to live until they die with their needs met as fully as possible.”² The success of St. Christopher’s Hospice in helping dying patients resulted in the growth of palliative care programs worldwide. Palliative programs can be found throughout the world and most noticeably in the United Kingdom, Sweden, Italy, Germany, Spain, Belgium, and the Netherlands, as well as in Canada, the United States, and Australasia.^{3,4}

1.2 Problem Statement

According to Gaudette et al., “Canadians know very little about either the characteristics of patients or the nature of the care they receive near the end of their lives.”⁵ This lack of knowledge is due in part because formal palliative care surveillance has yet to emerge in Canada. Currently, Canada lacks a national database and tracking system, and no provincial-level databases exist.⁶ Therefore, it is difficult to characterize and estimate the prevalence of palliative patients in Canada, and to evaluate the health services they used or failed to access. Canada’s palliative care information shortage “impedes our ability to plan, develop, implement, and evaluate palliative care programs.”⁵

1.3 Rationale

Despite the internationally accepted WHO definition and the successful establishment of palliative care programs worldwide, there still appears to be a lack of a common interpretation, terminology, and practice among the health care providers who deliver palliative services.⁷ Consequently, several problem areas in the implementation of proper palliative care for palliative patients exist throughout the world and in Canada. For example, a wide range of referral patterns and practices are occurring with no consensus on who should be recognized as palliative, when the designation should occur, or what constitutes effective and comprehensive palliative care services. In Canada, it is not clear what current end-of-life programs offer, where improvement is needed, or how to consolidate and lessen the disparity among the various programs that are provided. Analysis of health care services use or program evaluations allow researchers “to determine over-utilization and under-utilization of services, to determine

costs associated with a particular provider's care, to uncover problems related to efficiency and quality of care, and to assess provider performance.”⁸

The Regina Qu'Appelle Health Region (RQHR) has developed an integrated palliative care program including a comprehensive database containing the numbers of palliative patients it assists and which palliative care services these patients have received. To better understand palliative care in one Saskatchewan health region, a descriptive analysis of the services provided and characterization of decedents who accessed the RQPCS was undertaken. Use of the 2004/2005 decedent database compiled by the RQPCS, allowed the researcher to explore what type of palliative patients accessed certain services, which services were used, discover when referrals occurred and analyze place of death. This analysis was the first step toward a provincial-level database and to understanding which individuals access palliative care and how palliative care is delivered in the province. In the future, it may be possible to evaluate unmet need within Saskatchewan palliative cohorts in future studies by linking individual palliative care program databases with Saskatchewan Health administrative databases.

1.4 Objectives

The purpose of this research was to better understand the range/scope of palliative care services in the Regina Qu'Appelle Health Region and to determine who is referred to the RQPCS, which services are accessed and where RQPCS patients are dying.

The specific study objectives were to:

1. Describe the palliative care services provided by the Regina Qu'Appelle Palliative Care Services program.
2. Characterize the 2004/2005 palliative decedent cohort who accessed the services of the RQPCS and describe their utilization of palliative care services, timing of referrals and places of death.
3. Compare services received, number of services accessed, location of death, timing of referral according to patients' attributes (age, gender, marital status, living arrangements, residence, diagnosis).

Research questions will include the following:

- a. What services are provided by the RQPCS to palliative individuals?
- b. How is the cohort that received a referral to the RQPCS characterized? Which services did these palliative individuals access? What was the time interval between referral and death? In which settings do patients die?
- c. Are certain patient attributes associated with palliative care services use, location of death, and timing of referral?

Chapter 2 Literature Review

2.1 Canadian Health Care System and Palliative Care

Following a visit to St. Christopher's, the founders of Hospice, Inc. of New Haven, Connecticut had begun a home-care program in 1974 that offered services to palliative patients.^{2,9} Also in 1974, a New York hospital implemented roving teams offering palliative services to terminal patients.² In the mid-1970's, Dr. Balfour Mount and Dr. Paul Henteleff, of Canada, followed suit and set up the first inpatient care units within the teaching hospitals of McGill University and the University of Manitoba, where consultations took place in hospital as well as in patients' homes.^{2,3}

Since the mid-1970's, advancement of palliative care in Canada has been facilitated by several important proceedings and reports. See Table 2.1 for list of key national events since 1992.¹⁰

1992	Palliative Care 2000 for the Cancer 2000 Task Force
June 1995	"Of Life and Death," Report of the Special Senate Committee on Euthanasia and Assisted Suicide ¹¹
June 2000	Quality End-of-Life Care: The Right of Every Canadian, Sub-committee to update of "Of Life and Death" of the Senate Committee on Social Affairs, Science and Technology ⁶
December 2000	Creation of the Quality End-of-Life Care Coalition of Canada (QELCC) and working document entitled Blueprint for Action by the National Stakeholder/Quality End-of-Life Care Coalition ¹²
February 2001	Canadian Strategy for Cancer Control Consultation Conference (Working Group on Palliative Care)
March 2001	Senator Sharon Carstairs appointed Minister with special responsibility for Palliative Care and an Advisor to the Minister of Health on Palliative Care
June 2001	Secretariat on End-of-Life and Palliative Care established within Health Canada
January 2002	Steering Committee meets to plan for National Action Plan on End-of-Life Care Workshop
March 2002	- Invitational workshop: National Action Planning Workshop on End-of-Life Care, March 2 nd -4 th , Winnipeg - National Action Planning Workshop on End-of-Life Care: Workshop Report, March 26 th ¹³
June 2004	Dying for Care – Quality End-of-Life Care Coalition: Status Report ¹⁴
September 2004	CIHR announces 16.5 million dollars funding for research in Hospice Palliative Care
June 2005	Still Not There – Quality End-of-Life Care: A Progress Report released by Senator Sharon Carstairs ¹⁵
September 2005	Framework for a National Strategy for Palliative and End-of-Life Care

Despite the attention and recognition of provincial and national government on the importance of palliative care, there is still no national palliative care database, funding for hospice palliative care services is still quite varied, inconsistent access to hospice palliative care and respite care services is still occurring, no standard drug plans are in place across the provinces and research funding capacity is still not clear per province.¹⁴

2.2 Palliative Patients

In reviewing the literature which studied and described palliative patients, many of the articles tended to be retrospective in nature and usually focused on chart reviews or linking of databases. The strengths of these studies were they provided comprehensive demographic and clinical information on a variety of palliative patients. Many studies also exposed inconsistent referral patterns, outlined possible barriers to appropriate care for palliative individuals, and determined general predictors of enrolment into the varied types of palliative programs.

2.2.1 Characteristics of Palliative Care Patients

2.2.1.1 Age

“75% of all deaths occur in people over 65 years of age.”⁶ Therefore, it might be assumed that people aged 65 years and older are more likely to need and/or use palliative care services than younger terminal patients. However, this is a false assumption and can lead to unmet need in younger palliative patients. Throughout the literature it was evident that patients of all ages were suitable for and could benefit from some form of palliative care service. For instance, the age range of patients in an

investigation into current acute care hospital use by terminally ill and dying persons ranged from newborn to 107.¹⁷ Furthermore, the age range of patients who were referred to a specialized palliative care unit in Sweden was 29-91 years.¹⁸

The literature also highlights palliative care as an appropriate option for children with terminal illnesses. For instance, Kopecky et al. determined that children ranging in age from 1 day to 23 years (mean age at admission = 4.8 years) with malignant and non-malignant diseases were suitable candidates to receive home-based palliative care services.¹⁹ Similarly, dying children ranging in age from 1-18.6 years were managed in the Pain and Palliative Care Service of the Children's Hospital at Westmead, Sydney, Australia.²⁰

Even though it has been acknowledged that palliative individuals of all age groups could benefit from palliative care, elderly patients (65 years and older) still occupy the majority of the available hospital and respite palliative beds. For instance, the average age of palliative patients in the Vancouver General Hospital was 67 and the median age of patients enrolled in a hospital-based palliative care service was 71.2 (range = 20-101).^{21,22} Comparable findings revealed similar median ages of palliative patients of the acute care hospital wards of the Royal Alexander Hospital and St. Boniface General Hospital, 70 years and 69 years, respectively.⁵

The research indicated that, "People over 65 years of age are less likely than younger people to want to die at home."⁶ For example, Hunt and McCaul found that people in the 40-59 age group were more likely to access home hospice than people in the 60-79, and 80+ age groups.²³ And, in a study of terminal HIV patients (n=261) who received home care services near death, the mean age was 39.25.²⁴

Finally, studies show that palliative patients in long-term care residences tended to be older than patients at home, in hospices or in acute care wards. The results of a chart audit of five long-term care facilities in Ottawa, Canada revealed a mean age 86.2 for palliative decedents.²⁹ Evers et al. found that decedent patients with and without dementia who received palliative care measures within 30 chronic care facilities had mean ages of 82.4 and 76.9, respectively.²⁵ Similarly, in a study describing the palliative care needs of dying nursing home residents, their average age at death was 82 years.³¹

2.2.1.2 Gender

In the literature, the proportion of men to women throughout various palliative care settings was not significantly different, except in long-term care (LTC) facilities. One study which reviewed referral patterns to three different palliative care centres, found that 51% of the patients referred were male and no significant differences in sex arose regarding patients seen in the community, in hospice, or at outpatient departments.²⁶ Similarly, in a study of community-based palliative patients where 47 males (53.5 %) and 41 (46.5%) females were analyzed, gender was not significantly different between the decedents.²⁷ Once more, in a study of 13,577 Houston area cancer decedents, 53.3% were male and 46.7% were female, resulting in similar gender dispersion when compared to other studies.²⁸

When comparing by gender, proportional differences were only evident in long-term care facilities. Hall et al. established that out of 185 terminal patients in five long-term care facilities, 62% were palliative females and 38% were palliative males.²⁹ Similarly, when profiling palliative residents admitted to Missouri LTC facilities in

1999, Porock et al. found that 40% were male and 60% were female.³⁰ Furthermore, in a study of nursing home decedents, women made up two-thirds of the terminal population.³¹ A longer life expectancy in women is thought to be the reason behind the ratio of women to men found in chronic care facilities and also explains the proportional difference in gender found in the terminal population of these LTC facilities.

2.2.1.3 Marital Status

According to the literature, patients' marital status is quite varied but sample majorities were generally married or common law couples or widowers. For example, married couples comprised 48.4% of the sample when studying the correspondence between patients' preferences and surrogates' understanding of these preferences.³² Similarly, Singer et al. discovered that a homecare sample consisted mostly of widowers (56.6%) and married persons (30.3%), which was similar to the non-homecare sample of 44.6% widowers and 39.6% married persons.³³ In another study focusing on palliative care units, the marital status breakdown was 57% married or common-law, 25% widows, 10.5% single, 7.5% divorced.³⁴

2.2.1.4 Living Arrangements

Like the marital status of palliative patients, the types of informal caregivers and living arrangements also varied in the literature. Most often the caregiver's relationship to the patient was spousal, but other caregiver's consisted of the patients' children, other family members, or friends. In one study, the primary caregiver sample was comprised of spouses (43.5%), adult children (38.0%), other family members (8.7%) and friends (9.7%).³² In another study of homecare palliative patients, a similar breakdown of informal caregivers occurred with spouses making up 53.9% of the sample followed by

son or daughter (30.3%), parent (7.9) and other family (1.3%).³³ Again, similar results were found in a study of 3013 palliative patients in 21 European countries, where more than half the sample lived with a spouse (55.4 %), 28.8% patients lived alone, and 15.8% lived with another relative.³⁴

2.2.1.5 Area of Residence

Area of residence of palliative patients' varied from centre to centre. Generally, it was established that rural patients were less likely to access palliative care services than their urban counterparts. For example, patients living close to a county hospital had more admissions during the last 6 months than those who lived more than 40 km away.³⁵ Similarly, "people who lived in rural areas were less likely to be involved in hospice care than people living in the metropolitan area."²³ Tong et al. discovered similar results with Vancouver residents accounting for 76% of the palliative population in the Palliative Care Unit of the Vancouver General Hospital.²¹ Johnston et al. found 76.9% of the patients registered to the Halifax-based Palliative Care Program were resident's of Halifax County.³⁶

It is important to note that when urban patients outnumbered rural patients, the distribution of urban to rural was dependent on where the palliative care centre of interest was located. Generally, the palliative population in an urban centre will consist mostly of urban residents and the palliative population in a rural centre will consist mostly of rural residents.

2.2.1.6 Diagnosis

"About one quarter of the total deaths in Canada are related to cancer, but cancer patient's account for more than 90% of those receiving palliative care."⁶ Cancer

was the diagnosis in 85% of patients seen by hospital-based palliative care programs throughout the United States.³⁷ Similarly, Gaudette et al. determined the majority of palliative care episodes in six palliative care programs across Canada involved patients with cancer (92%).⁵ Likewise, in a retrospective review of 400 referrals to three different palliative care centres, 5% of patients had a non-cancer diagnosis.²⁶ This highlights the predominance of palliative care services' involvement with patients who have malignant disease.

The most common cancer diagnoses included lung, prostate, breast, gastrointestinal tract, head-neck, haematological, and female genital tract. According to the report entitled, *Toward a Healthy Future: Second Report on the Health of Canadians*, lung cancer incidence in men is declining while increasing in women, but lung cancer deaths are still the leading cause of cancer death in both women and men.³⁸ 26.2% of cancer deaths in Nova Scotia, from 1992-1997, were lung cancer deaths followed by breast (10.2%), prostate (9.4%) and colorectal (8.5%) cancer deaths.³⁹ In the Vancouver General Hospital palliative care program, lung carcinoma (27.5%) was the most frequent diagnostic site, followed by breast (14.3%), colon/rectum (12.2%), and prostate (8.0%).²¹ Lung cancer was also the most common diagnostic site or leading cause of cancer deaths in males and females in Saskatchewan, Houston, Italy, and the UK.^{40,28,41,27}

Even though cancer was the predominant diagnosis among palliative patients, several other non-malignant diagnoses were also treated in the various palliative care settings. Generally, the primary non-malignant diagnoses could be broken down into six different categories, which included: pulmonary diagnoses, neurologic diagnoses,

musculoskeletal diagnoses/auto-immune diseases, cardiovascular diagnoses, organ failure, and HIV/AIDS.⁴² The pulmonary diagnoses included chronic obstructive pulmonary disease, acute respiratory failure, pneumonia, and pulmonary fibrosis. The neurologic diagnoses included, dementia, neuromotor degenerative disorders, and spinal cord disorders. The musculoskeletal diagnoses/auto-immune diseases included degenerative joint disease, osteoporosis, multiple sclerosis, and rheumatoid arthritis. The cardiovascular diagnoses included coronary artery disease, cerebral vascular accidents, congestive heart failure, and hypertension. Organ failure included liver, multi-system, and kidney. The major cause of death in Canada is cardiovascular disease.³⁸

2.3 Palliative Care Utilization

Healthcare use can be measured several different ways depending on the information collected. Admissions, type of service used, lengths of stay, number of procedures performed, and antibiotic use are a few of the more common categories studied in palliative care.

There are several different settings in which palliative care is offered; therefore, it is appropriate to break down palliative care services utilization by setting. Palliative care is offered in specialized palliative care units within hospitals, in hospices, by home care, and in chronic care settings. The variations in provision of services and lengths of stay observed in the literature were due to the different program philosophies of each palliative setting.

2.3.1 Palliative Care Settings

As previously noted, Canadian palliative care began in two hospitals in the mid-1970's. Since that time, palliative care has expanded across Canada and now a variety of palliative care settings have emerged. Integrated programs are located across the country and palliative care programs and resources are available in inpatient and outpatient palliative care units, hospices, home care, and continuing care facilities.

2.3.1.1 Palliative Care Units (Acute Care)

Palliative Care Units (PCU) are usually located within hospitals. These units specialize in palliative care and are intended to provide short term hospitalization for relief of pain and other distressing symptoms like nausea, anxiety, and restlessness. The goal is often successful discharge of patients back to home or into hospice. PCU's also provide temporary respite for patients and patients' caregivers. Often times, PCU's provide end of life care when care at home is no longer appropriate or safe. Finally, spiritual care and bereavement services are offered to patients, family and friends in the PCU.

2.3.1.2 Hospices

Hospices differ from palliative care units in that these settings are geared toward providing long term care rather than short term stays. Hospices provide active compassionate care in home-like environments when staying at home or in a hospital is no longer an option. Like the PCU, hospice staff provides symptom management and pain control for patients and offer spiritual care and psychosocial support to both patient and family.

2.3.1.3 Home Care

Palliative home care is a specialized team of health care providers whose support enables patients to remain at home. Nurses provide supervision of symptoms, pain management and support to the client and family. Home care nursing is available on a 24 hour basis. Home health aides give personal care and support to the client, respite to care providers and assist in home management and meal preparation.

2.3.1.4 Continuing Care Facilities

“Nursing homes and residential homes provide intermittent or continuous respite and continuing care.”⁴³ Long term care facilities do not have the specialist facilities of hospices or palliative care teams, rather support teams, palliative home care nurses and home health aides can work with chronic care facilities and residential homes (as they work with hospitals or in patients’ own homes) to assist and advise in the care of patients who need palliative care.⁴³ The support teams offer and provide symptom and pain management and personal care services.

2.3.2 Types of Palliative Care Services/Resources

The services and resources offered and the staff available in palliative care programs varies across settings, but generally include terminal care, respite care, bereavement care, pain and symptom management, spiritual care, music therapy, palliative home care nursing, home health aides, occupational therapists, volunteers, and social workers. Palliative care resources are also available on the internet.

2.3.2.1 Terminal care

“Terminal care is an important part of palliative care and usually refers to the management of patients during their last few days or weeks or even months of life from a point at which it becomes clear that the patient is in a progressive state of decline.”⁴³

2.3.2.2 Respite care

Respite literally means a period of rest or relief. Therefore, respite care provides a caregiver temporary relief from the responsibilities of caring for a palliative family member.

2.3.2.3 Bereavement care

The grief from the anticipated and resulting death of a special person can be devastating. Bereavement counsellors offer a variety of options to help patients and family members understand more about anticipated loss, grief and bereavement including bereavement support groups for adults, teens and children, as well as individual counselling and resource materials.⁴⁴

2.3.2.4 Music Therapy

“Music has the capacity to stimulate memories, modify mood, soothe pain, address fears, express feelings, calm and relax.”⁴⁵ Music therapy for individuals or group sessions includes listening to music, singing and making music, relaxation exercises and composing music. Music therapy is offered to help patients and family to cope with terminal illness.

2.3.2.5 Canadian Virtual Hospice (CVH)⁴⁶

The Canadian Virtual Hospice is an interactive online network designed to facilitate information exchange, communication, and mutual support between and

among patients, their friends and family, health care providers and palliative care volunteers and does not offer direct medical advice or clinical care. It was created due to the need for more information and support for people with life-threatening illness and their families. The website offers information and resources that may help people better understand the physical, emotional, and spiritual aspects of their experiences. The CVH is intended to be used as a supplement to the palliative care provided by specialized palliative care professionals.

2.3.3 Length of Stay (LOS)

The length of stay is a commonly used calculation for palliative care service utilization. The LOS, or time from referral to discharge/death, is a good indicator of the timeliness and appropriateness of referrals into a palliative program or service. LOS allows programs to track cost and utilization outcomes, too.

Again, the LOS per setting varied depending on referral times and the type of setting, whether an acute care unit or a long term setting.

2.3.3.1 Acute Care Units (ACU)

15.4 days was the average length of stay in acute care hospitals for all Albertans in 1996/97.¹⁷ The average length of stay at the Massachusetts General Hospital was 6.0 days.⁴⁷ The mean length of stay for the Queen Elizabeth II Health Sciences Centre (QE-II) in Halifax was 24 days and 16 days reflects the mean length of stay for palliative patients of the Royal Alexandra Hospital in Edmonton.⁵

2.3.3.2 Palliative Care Units (PCU)

The Palliative Care Unit of Vancouver General Hospital observed a mean length of stay of 17.9 days.²¹ The Sisters of Charity Of Ottawa Health Service (SCOHS)

observed an average length of stay of 21 days.⁵ Lower means were seen at the QE-II and the PCU of Linköping University Hospital in Sweden where 10 days was the average length of stay for both units.^{5,18}

2.3.3.3 Home Care

The average length of stay in Home Care palliative programs varied widely in the literature. In Halifax, the mean length of stay was 88 days for palliative care home care.⁵ The Hospital for Sick Children in Toronto revealed 124.3 days as the average number of days on the Home-based palliative care program.¹⁹ Finally, the hospital based home care program of Sweden observed a mean length of stay of 60 days.⁴⁸ The differences observed between the different Home Care programs may be a reflection of the varying referral practices seen in palliative care around the world and in Canada.

2.3.3.4 Hospices

The mean length of stay for the Maison Michel Sarrazin in Quebec City was 25 days.⁵ Constantini et al. found that the median survival time was significantly lower for hospice patients (22.5 days) compared to patients in Home PCUs (35 days) or patients in Mixed PCUs (42.0 days).⁴¹

2.3.3.5 Chronic Care Facilities

Gaudette et al. noted a difference in length of stay for two chronic care centres in Canada where the SCOHS reported a mean LOS of 80 days and the QE-II reported a mean LOS of 10 days.⁵ Another long term care facility revealed a median survival time of 33 days for the patients who actually died in the facility.³⁰ Many times palliative care residents of long-term care facilities are discharged to an acute care setting where

death occurs. As a consequence, a difference in length of stay for chronic care facilities was observed in the literature.

2.4 Location of Death

Throughout the literature the preferred place of death among terminally ill patients was at home without life-sustaining treatments.^{33,49,50} According to Burge et al., 28% to 47% of Canadians referred to a specialized palliative care program died at home.^{51,52} While patients prefer to die at home, many are still dying in hospital, but the rate of in-hospital deaths is declining.⁵³

Most specialized palliative care programs recognize the importance of patient personal choice and this may be one reason why home deaths are on the rise.⁵¹ Another reason for the trend toward home deaths may be the reduction of hospital bed availability.⁵¹ Sometimes informal caregiver's are unable or unequipped to offer the proper support for a home death and patients end up at hospital.

Several randomised controlled trials sought to discover if the type of care had an impact on place of death. Two studies evaluated the impact of specialized palliative care services versus conventional care on the likelihood of home deaths. Grande et al. compared hospital at home with standard care and found no significant difference in the place of death.⁵⁴ On the other hand, Jordhoy et al. determined patients in formal comprehensive palliative care programs were more likely to die at home, if that was their preference.⁵⁵

The literature lacks conclusive evidence on why people are not dying at home if that is their preference.

2.5 Predictors of Palliative Care Use

Several demographic variables have been studied to determine if they influence referral patterns. Gender, by itself, was not found to be a significant predictor of palliative care referral. Hunt and McCaul reported that sex was not a significant predictor of hospice involvement and Johnston et al. reported that sex, by itself, was not a predictor of referral to a Palliative Care Program^{23,36}

On the other hand, age was found to be a significant predictor of palliative care referral and/or use. Older people (85 years or older) were less likely to be referred to a palliative care program at all and were more likely to be referred late than were younger people.³⁶ In Sweden, admissions into the county hospital of Jämtland were more frequent among patients younger than 70 years during the last 6 months of life (median-3), compared with those older than 70 years (median-1).³⁵ Bird et al. in a study of age and gender differences in health care utilization for patients in their last years of life discovered, in their age-specific analyses, total Medicare expenditures were 70% higher for the youngest decedents (65-69) than for the oldest (85 and above).⁵⁶ Again, age was a significant predictor for involvement with a hospice service where people aged 40-59 were more likely to use a hospice than were people aged 80 or older.²³ Finally, a significantly higher percentage of younger inpatients than retirement-age (65+) inpatients died in special care units (26.6% versus 11.8%) in Alberta hospitals.¹⁷

Another significant predictor of palliative care use was area of residence. In Sweden, the patients living outside the 40km radius of the specialized hospital unit spent more days in a nursing home (15.6) and fewer days in the hospital (15) in the last 6 months of life compared to the patients living closer to the county hospital (24

hospital days, 8.4 nursing home days).³⁵ “People who lived in rural areas were less likely to be involved in hospice care than people living in the metropolitan area” of Southern Australia.²³ Among other variables, Johnston et al. found that residence within Halifax County was a statistically significant predictor of PCP referral.³⁶ Accessibility and proximity appear to be important determinants for palliative care use between rural and urban patients.

A third predictor of palliative care referral, and seemingly most obvious predictor, is a diagnosis of cancer. Cancer diagnoses account for more than 90% of palliative care episodes in Ireland and the United Kingdom and for 70% to 90% of palliative care in Australia.^{57,58,59} In a study conducted by Gaudette et al., the authors found that 92% of all care episodes in six different settings involved patients with cancer.⁵

The reasons for referral vary across settings. Some of the more common reasons for referral into palliative care programs are symptom control, pain management, special treatment and investigations, rehabilitation, terminal care, and respite care.¹⁸ Many times there is weak agreement between the stated reason for referral and actual content of care usually due to the difficulty with accurate prognostication in the palliative population.¹⁸

2.6 Barriers to Referral into Palliative Care

Aside from the demographic and diagnostic determinants listed above many studies revealed a list of barriers to appropriate care for palliative individuals. Ahmed et al. noted physician and nurse related issues as possible barriers to timely referral into hospice.⁶⁰ For instance, physician specialty, physician prognostic accuracy, board

certification, physician knowledge level about hospice and previous experience with hospice patients have been found to be associated with patient referral into hospice.^{61,62,63} Nurses' inconsistent knowledge regarding hospice referral criteria was also found to be a barrier to enrolment into hospice care.^{60,64}

Other barriers contributing to late referrals are associated with patients and families. Misconceptions about palliative care, lack of knowledge about hospice, lack of awareness of options, cultural and spiritual beliefs, denial of death, lack of experience with death, stress of health care decisions and unwillingness or unlikelihood of pursuing treatment options not recommended by family physicians are barriers which have been found to hinder earlier enrolment into hospice.^{60,65,66}

Finally, organizational barriers such as inter-organizational conflicts between providers and settings, hospice staff turnover, the shortage of nursing professionals and the lack of bilingual and culturally competent staff have been found to hinder access to palliative care.⁶⁶

Despite the proven benefits of palliative care, too many people are referred to palliative services in the last days of life. Ethical dilemmas⁶⁷, culture⁶⁸, ineffective interagency and inter-professional collectives⁷, management focus⁶⁹, troublesome prognostications⁷⁰, timing of referrals⁷¹ and socio-demographic characteristics of patients and families⁷² have all been listed as potential barriers to accessing palliative care services. Short lengths of stay are associated with less satisfaction with palliative care by family caregivers, possible poor symptom control and probable, yet unnecessary, suffering.^{65,73,74}

2.7 Components of a Good Death

Steinhauser et al. identified six components of a “good” death which include good quality pain and symptom management, excellent communication to aid in decision making, adequate time to prepare for death, “completion” which encompasses meaningful time with family and friends and includes religious and spiritual beliefs, allowing the patient to participate in activities and engage in interactions which allow him/her to contribute to others, and constant affirmation of the patient as a whole person, not simply as a disease or case.⁷⁵ Earlier referral combined with the previous six components may help to provide an initial framework for addressing the needs of patients and families at the end of life and may improve the quality and delivery of palliative care, too.

2.8 Summary

After reviewing the literature it is apparent that Canadian palliative care focuses on providing comprehensive physical, psychological, emotional and spiritual care and support to patients and families regardless of disease across many different settings. Palliative populations are highly heterogeneous and therefore services should be offered to accommodate a variety of patients.

In the literature there were many descriptive and comparative non-randomised studies which focused on palliative care and provided information on the characteristics of individuals who access palliative care services at the end of life. The strengths of these retrospective, descriptive studies were they provided comprehensive demographic and clinical information on a variety of palliative patients. Many studies exposed inconsistent referral patterns, outlined possible barriers to appropriate care for palliative

individuals, and determined general predictors of enrolment into the varied types of palliative programs. However, it must be noted there were very few successful prospective or randomised control studies which analyzed palliative care populations. Possible reasons for the lack of randomised control trials (RCT's) included problems of recruitment and attrition, difficulty in predicting prognosis, unexpected inpatient admissions and patients' and carers' frequent inability to complete measures.⁵⁴ Despite the lack of RCT's in the palliative literature, the demographic and clinical information reported was useful for administrative planning, as well as tracking and reporting on the quality of palliative care services and patient outcomes.

Canada currently has no national palliative care database. Surveillance has been identified as a priority area by the National Action Committee for Palliative Care and the Cancer Control Strategy for Cancer Control.^{13,76} The status report entitled Dying for a Cure also identified the need for provincial and territorial governments to create systems that track what services and programs are available throughout their province or territory in order to move toward a national tracking system.¹⁴ The RQPCS databases includes demographic and diagnostic information as well as service utilization information which can all be used as tracking palliative care within the RQHR. The RQPCS information in conjunction with Saskatchewan Health data could possibly provide a more comprehensive tracking system and may be an important aspect of a national palliative care database. By gathering, describing and analyzing key demographic, diagnostic and palliative care utilization information this research may prove an important first step toward a provincial palliative care surveillance program.

Chapter 3 Methodology

3.1 Research Design

3.1.1 Descriptive Design

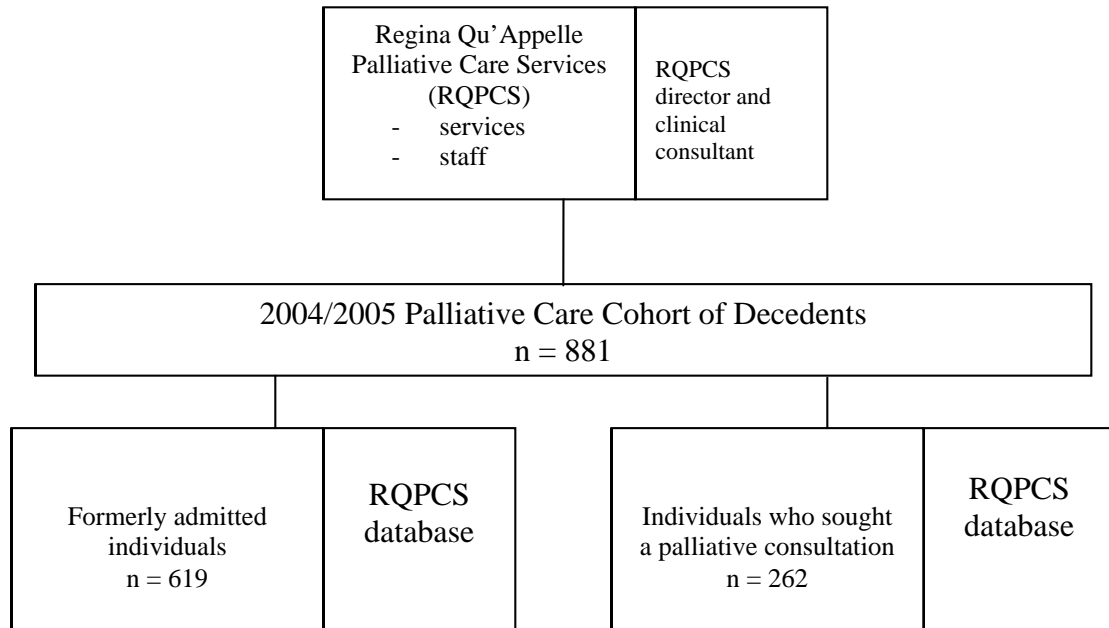
The research design that was used is commonly referred to as a descriptive design.⁸ This study examined and described the differences within a palliative decedent cohort on select variables. First, patient demographics, disease characteristics, and palliative service utilization data were gathered for the cohort. Second, comparisons of service use, number of palliative care services used, timing of referral, and location of death were examined according to population characteristics such as gender, age, marital status, living arrangements, area of residence and diagnosis. Finally, it was possible to develop hypotheses for future palliative investigations into palliative health service utilization, which will further our understanding of palliative care in Canada.

3.2 Study Sample

The project sample consisted of palliative individuals who died in 2004 and 2005 and who had a residence within the RQHR. The individuals were required to have undergone a formal intake assessment by a System Wide Admission/Discharge Department (SWADD) Palliative Care Coordinator or receive a consultation with a member of the RQPCS palliative care team.

Figure 3.1 is a diagram representing the study sample.

Figure 3.1 Regina Qu’Appelle Palliative Care Services Study Sample



3.3 Data Collection

The present study was retrospective in nature, given that the RQPCS administrative health database was the main data source.

3.3.1 Interview

In order to gather a description of the services offered by the RQPCS, the director of palliative care (PC) services and the clinical consultant were interviewed. The interviewees answered questions regarding program goals and objectives, the types of services offered, and admission procedures. The interview took place in the primary centre of the RQPCS located in the Pasqua Hospital. With the permission of the Director of PC services, the interview was tape-recorded and handwritten notes were also taken. The interview guide can be found in Appendix I.

A more in depth description of the RQPCS follows in the results section.

Objective #1 was fulfilled by the use of this interview.

3.3.2 RQPCS Database

The RQHR has developed a palliative care program that offers an array of services. The Regina Qu'Appelle Palliative Care Services provides support and care to patients, their families and friends who are dealing with a terminal illness where treatment has shifted from curative care to palliative care. Their palliative care philosophy is that patients should receive the highest level and best quality of care to ensure comfort and compassion while maintaining dignity and quality of life. The services provided include music therapy, occupational therapy, social work, spiritual care, volunteers, educational programming, a resource centre and bereavement care for caregivers after the death of a loved one. Due to the concern about offering the highest quality care possible, the RQPCS established a comprehensive database, which contains the numbers of palliative patients it assists and records which palliative care services these patients receive.

For the present study, with the collaboration of the PC program director and the data entry manager, those patients who accessed the RQPCS at least once were identified and a database was constructed of palliative decedents who died in 2004 and 2005. Relevant demographics and palliative care services utilization data per individual were entered into the database.

3.4 Defining Study Variables

A database was created using the data which described the 2004 and 2005 palliative decedents who accessed the palliative care services of the RQPCS. The following is an explanation of the study variables included in the database.

3.4.1 RQPCS Study Variables

In order to characterize the 2004/2005 palliative decedents who accessed the services of the RQPCS and describe their usage of palliative care, demographics, disease characteristics and utilization data were collected.

Table 3.1 lists the demographic variable names and their assigned categorization for entry into SPSS.

Table 3.1 RQPCS Patient Demographics

Variable Name	Values
Sex	1 – Male 2 – Female 9 - Unknown
Date of Birth	MM/DD/YYYY
Date of Death	MM/DD/YYYY
Residence (Res) Codes	1 – Regina 2 – Rural RQHR 9 – Unknown
Marital Status	1 – Single/Never Married 2 – Married/Common-Law 3 – Divorced/ Separated 4 – Widow/er 9 - Unknown
Primary Language	1 – English 2 – French 3 – Eastern European 9 - Unknown
Living Arrangements	1 – Lives Alone 2 – Spouse Only 3 – Spouse and Others 4 – Other Family 5 – Others 9 - Unknown

Table 3.2 lists the health services utilization variables and their assigned values for data entry and Table 3.3 lists the disease characteristics variables and their subsequent values for SPSS.

Table 3.2 RQPCS Palliative Care Services Utilization

Variable Name	Values
Date of Admission /Transfer to Palliative Care Program	MM/DD/YYYY
Referral Source	1 – Allan Blair Cancer Clinic 2 – Family Doctor 3 – Palliative Care Physician 4 – Self 5 – Family/Friends 6 – Palliative Care Unit 7 – Pasqua Acute Care Facility 8 – Regina General Acute Care Facility 9 – Pasqua Hospital Ward 10 – Regular Home Care Program 11 – Regina General Hospital Ward 12 – Clinical Consultant 13 – Doctor 14 – Out of District 99 - Unknown
SWADD Assessment	1 – Yes 2 – No
Home Services Use (Home Health Aide)	1 – Yes 2 - No
Nursing Use	1 – Yes 2 - No
Occupational Therapy Use	1 – Yes 2 - No
Social Work Use	1 – Yes 2 - No
Music Therapy Use	1 – Yes 2 - No
Spiritual Care Use	1 – Yes 2 - No
Palliative Care Physician Use	1 – Yes 2 - No
Location of Death	1 – Specialized Palliative Care 2 – Home 3 – Hospital 9 – Out of District 99 - Unknown

Table 3.3 RQPCS Disease Characteristics

Variable Name	Values
Initial Diagnosis	Valid ICD-10CA code or diagnosis explanation
Diagnosis Group	1 – Neoplasms 2 – Certain Infectious & Parasitic Diseases 3 – Endocrine, Nutritional & Metabolic Diseases 4 – Mental & Behavioural Disorders 5 – Diseases of the Nervous System 6 – Diseases of the Eye & Adnexa 7 – Diseases of the Circulatory System 8 – Diseases of the Respiratory System 9 – Diseases of the Digestive System 10 – Diseases of the Musculoskeletal System 11 – Diseases of the Genitourinary System 12 – Congenital Malformations, Deformations, Chromosomal Abnormal 13 – Symptoms, Signs & Abnormal Clinical and Lab Findings 99 - Unknown
Cancer Sites	1 – Lung 2 – Colorectal 3 – Bladder 4 – Lymphoma 5 – Leukemia 6 – Kidney 7 – Stomach 8 – Melanoma 9 – Pancreas 10 – Breast 11 – Uterus 12 – Ovary 13 – Prostate 14 – Other

3.4.2 Comparable Study Variables

Once the entire cohort of palliative individuals had been described, comparisons within the cohort occurred by analyzing differences in health services utilization, timing of referral and location of death between patient groups based on age, gender, marital status, living arrangements, area of residence and diagnosis. In total, there were six separate patient groups chosen, based on the above attributes, and four different comparison variables.

For the patient cohorts, the initial age strata were dichotomized into people = 70 and people > 70, based on distribution pattern. Originally, marital status was categorized into one of four groups which included single/never married, married/common-law, divorced/separated, or widow/er. Again, the four groups were

consolidated into two categories. The single/never married, divorced/separated and widow/er groups were merged together to form one group and group two consisted of the married/common-law decedents. At first, the data collected by the RQPCS indicating a person's living arrangement was categorized into five groups: lives alone, lives with spouse only, lives with spouse and others, lives with other family or lives with people other than family. Then, based on the literature, living arrangements was split into two categories, lives alone and lives with spouse/others. The data collected on gender, area of residence and diagnosis were already defined and ready for analysis.

Type of services accessed included home services, nursing, occupational therapy, social work, music therapy, spiritual care and palliative care physician. There were 7 services a patient could access, but for the comparison analysis number of services accessed was dichotomized into 3 or fewer services used and 4 or more services used, based on the distribution pattern. Timing of referrals was recoded from a continuous variable into early referrals and late referrals. Any person with a program admit date which occurred 8 days prior to death or earlier was considered an early referral and any program admit date which occurred less than 7 days prior to death was considered a late referral. This definition of late referrals was also evident in the literature. Location of death was analyzed twice. The first analysis categorized location of death into two groups, deaths within specialized palliative care settings versus hospital deaths. The RQPCS requested location of death be dichotomized in this manner stating as long as a person is admitted into the RQPCS the services delivered are equal across all settings and place of death should reflect where the services are or are not offered. The second analysis of location of death saw a restructuring of the

variable into home deaths versus all other places of death and this dichotomization was based on the literature.

Table 3.4 lists the comparison variables of interest that were analyzed between the different cohorts.

Table 3.4 Variables of Interest used for Comparison

Patient Characteristics			Comparison Variables	
Group 1	Age = 70 > 70		C	Type of Service Accessed
Group 2	Gender Male Female	M		
Group 3	Marital Status Sing, Never, Div, Wid* Married/Common-Law	P	Number of Services Accessed	
Group 4	Living Arrangements Lives Alone Spouse/Others ⁺	A		
Group 5	Area of Residence Regina Rural RQHR	R	Timing of Referral	
Group 6	Diagnosis Cancer Non-Cancer	E		
		D	Location of Death	
		B		
		Y		

* Sing = Single, Never = Never Married, Div = Divorced/Separated, Wid = Widow/er
+ Spouse/Others includes Spouse Only, Spouse and Others, Other Family, and Others

3.5 Data Analysis

The descriptive nature of this study allowed the researcher to examine and describe the variables of the palliative decedent cohort but also analyze and compare several smaller groups within the larger cohort. The first step of the analysis involved the gathering of descriptive statistics. Analysis of the continuous variables was completed and included measuring the central tendency of these variables. Also, percentage distributions of the categorical variables took place. Descriptive statistics allowed the researcher to examine the data to gain more information about the characteristics within the cohort.

Step two of the analysis involved comparing the palliative service utilization, referral patterns and location of death differences between groups within the main cohort. For comparisons between the study groups, chi-square analysis was used for

categorical variables. Despite discovering differences between the groups, the differences identified are only associated with the sample under study. Also, even though differences were indicated, the specific differences among variables remain unknown. Further inferential statistics were not attempted due to missing data causing small cells within some variables.

This research made no attempt to establish causality. The researcher merely wanted to provide a concise description of the decedent palliative population of the RQPCS and the palliative care services that they used. This research was completed with the intent to further facilitate research into planning, developing, implementing and evaluating palliative care. With further study and analysis, it may be possible to identify gaps in current practice, recognize strengths and weaknesses in the provision of palliative services, and finally improve the experiences of palliative patients at the end of life.

3.6 Ethics Approval

Ethics approval was sought and granted from the University of Saskatchewan's Behavioural Research Ethics Board as well as the Regina Qu'Appelle Health Region Research Ethics Board. See Appendix II for the ethics approval from the University of Saskatchewan and Appendix III for the ethics approval from the Regina Qu'Appelle Health Region.

Chapter 4 Results

4.1 Objective 1: Description of the Regina Qu'Appelle Palliative Care Services⁷⁷

4.1.1 Program Vision

According to the director, the RQPCS team “strives to provide comprehensive and coordinated care to terminally ill clients and their families and to address the diverse physical, psychological, social, and spiritual needs that accompany the dying process.”⁷⁸ The RQPCS is prepared to provide care in any setting, whether in an institution or at home and is provided to all dying clients regardless of disease.⁷⁸ Finally, the PCS is “committed to public and professional education and to research in caring for the dying.”⁷⁸

4.1.2 Goals

The RQPCS program goals were defined with the Canadian Hospice Palliative Care Association (CHPCA) National Standards Document in mind.⁷⁹ (See Appendix IV for the guiding principles of the CHPCA.) The director of the RQHR Palliative Care Services listed timely access to information and services, appropriateness, providing care in the best location without discrimination, bringing the services to the patient and family, ethics and absolute clinical competence as qualities that define optimal palliative care.⁷⁷ The Clinical Consultant added palliative care is directed towards meeting the physical, social, psychological and spiritual expectations/needs of every client and family “with sensitivity to their personal, cultural and religious values, beliefs and practices,…”^{77,78}

4.1.3 Admission Criteria and Focus of Care

Any person who has been diagnosed with a progressive disease leading to death will be admitted to the program. The focus of care will be on comfort and improving

the patient's quality of life. The team will be required to alleviate distressing symptoms related to physical, emotional, social, and spiritual needs.

4.1.4 Referrals

Referrals to the RQPCS program are permitted from any source, including the patient, family members, friends, or family doctor. The RQPCS receives two different types of referrals.

The first type of referral is for formal admission into the PCS. These referrals are assessed by a System Wide Admission/Discharge Department (SWADD) Palliative Care Coordinator.

The second type of referral is for consultation.⁷⁸ These referrals are not considered as admission into the program. A referral for consultation can be directed to any member of the palliative care team and/or palliative medical director.

4.1.4.1 Referrals to System Wide Admission/Discharge Department (SWADD)

SWADD palliative care coordinators assess all referrals for admission received by the PCS. Within two or three days of receiving the referral, one of three coordinators will visit the person's home. The intake coordinator will evaluate the needs of the person and if the person meets the criteria for admission he/she will officially be considered a client of the RQPCS and a formal needs assessment will be formulated. Based on the needs assessment, a comprehensive care plan will be implemented and will coordinate all appropriate services and ensure a continuum of care that will meet the needs of the client and his/her family.

If the person does not meet the criteria for admission the coordinator will refer the person to the most appropriate setting of care to meet his/her needs.

4.1.4.2 Referrals to Palliative Consultative Service

A referral for consultation is appropriate when physical pain and symptoms are unrelieved or pain of a spiritual or psychosocial nature is present.⁷⁸ A referral for physical pain can be directed to any member of the palliative care team and/or palliative medical director and a referral for spiritual or psychosocial pain can be referred to the palliative care chaplain, social worker, music therapist, or bereavement counsellor.⁷⁸

“Access to palliative care services will be determined and/or authorized by the palliative care medical director and/or designate and/or SWADD palliative care coordinator.”⁷⁸ A person who receives services via consultation will not be considered a formal client of the RQPCS.

4.1.5 Palliative Care Services Offered

Every client of the RQPCS program has access to the services offered by the palliative care team. The following is a list of the palliative care services offered by the RQPCS interdisciplinary team, consisting of SWADD coordinators, home health aides, nurses, clinical consultant, palliative care physician, volunteer manager and volunteers, chaplain, social workers, music therapist, and occupational therapist⁸⁰:

- **Palliative Home Care** – provides management of pain and symptoms, ongoing assessment, personal care, a liaison between client and doctor, and professional/interdisciplinary support to clients and families in their own home setting.
- **Palliative Care Unit** – located at the Pasqua Hospital, the nine-bed palliative acute care unit provides short term hospitalization for patients needing management of pain and symptoms such as nausea, anxiety and restlessness. The environment of the PCU is one of serenity and comfort, designed to meet the needs of the individual, family and friends.
- **Regina Wascana Grace Hospice** – provides a home-like environment with stimulating recreational programs such as entertainment, games, music and outings for clients who cannot be cared for at home and require longer term supportive care.

- **Medical Care** – the family physician is considered the primary medical caregiver. However, consultative pain and physical symptom support is provided by the Palliative Care Medical Director and Clinical Consultant in the acute care facility, the long term care special care home and at the residence.
- **Social Work** – assists patients and families to cope with the emotional, physical, social and financial implications of a life-limiting illness and future loss. The client may feel overwhelmed with fears and uncertainty. The social worker also assists with reactions to losses being experienced such as losses of health, mobility and future plans.
- **Volunteer Program** – consists of 65 trained volunteers who provide sensitive and skilled care, at no charge, in the setting most appropriate – in the acute care facility, the long term care special care home or at the residence.
- **Spiritual Care** – when facing a life-limiting illness, clients may be thinking about such things as the meaning of life, hope, fear, guilt, abandonment or faith. Whether or not they are religious, they may want to experience a greater measure of peace, contentment and harmony as the end of life approaches. The Chaplain is available to assist no matter what religious background or philosophy of life.
- **Occupational Therapy** – will help make the most of a client’s capacity and independence in the areas of self-care (activities of daily living), work (making a productive contribution to life – domestic duties, employment or volunteer activities) and leisure (activities of enjoyment and renewal).
- **Music Therapy** – is available to assist clients and families to stimulate memories, modify mood, soothe pain, address fears, express feelings, calm and relax. Music as a therapeutic tool addresses spiritual, physical, and psychosocial needs.
- **Bereavement Care** – a variety of care to help clients and families understand more about imminent loss, grief and bereavement. This care includes resource materials, bereavement support groups for adults, teens and children, or individual counselling. The adult bereavement support group meets three times a year and the childhood/teen grief support group meets twice a year. Plus, other support groups are offered.
- **Resource Centre** – available for loan are a variety of current books, journals, magazines, videos and tapes on palliative care topics. Information is relevant to all ages, including children.

See Appendix V for a graphical representation of the Regina Qu’Appelle

Palliative Care Services.⁸¹

4.1.6 Coordinated Care

The RQPCS recognizes the importance of continuity of patient care in meeting the needs of their clients. In order to ensure that each client is benefiting from the

program the team regularly follows client outcomes to evaluate whether or not a client's needs are being properly and efficiently met.

All staff members of the PCS are trained to assess the needs of their clients. The PCS team regularly meets to discuss client care plans. Also, formal rounds are conducted within the palliative care unit and hospice and informal rounds are performed within the other care settings to ensure appropriate care for every client. If a client's needs change, his/her case manager will coordinate and implement a new care plan that ensures continuity of care across all settings.

4.1.7 Summary

In keeping with the aims of hospice palliative care, the aim of the RQPCS is to relieve suffering and improve the quality of living and dying of their palliative population. The RQPCS strives to help patients and families address all aspects of the dying process which includes physical, psychological, social, spiritual and practical issues as well as address their expectations, needs, hopes, fears, feelings of loss and grief. The RQPCS recognizes that palliative care is appropriate for any patient or family living with a life-limiting illness. They provide services that neither hasten nor postpone death in any setting to all dying clients regardless of diagnosis or prognosis and without discrimination. In order to provide effective, comprehensive and coordinated care, the RQPCS delivers its services using an interdisciplinary team approach. Finally, the RQPCS is dedicated to providing the best quality of care and is constantly striving for new knowledge to further strengthen the program.

4.2 Objective 2: Characteristics of the RQPCS Cohort

4.2.1 Demographic Characteristics

In total, the RQPCS database included information on 881 decedents who died between January 2004 and December 2005 of which 619 were formally admitted and the other 262 patients received a palliative consultation. Table 4.1 displays the demographic characteristics of the RQPCS decedents.

The majority (77.0%) of the decedents fell within the 60 – 69, 70 – 79, and 80 – 89 year groups. The RQPCS assisted patients ranging in age from 1–99 years old. The overall mean age of the RQPCS decedents was 71.75 years.

The overall sample was made up of 48.7% males and 51.4% females. These proportions are similar to what was found in the literature. Generally, gender is not significantly different throughout different palliative care settings.

648 patients identified English as their primary spoken language while 6 clients spoke French and 3 patients identified Eastern European as their language of preference. The RQPCS true to their goals provided information and services in languages that each of the decedents could understand.

59.0% of the sample were married or in a common-law relationship. 7.7% were single or never married and 19.1 % were divorced or separated. 87 decedents (14.1%) were widowed.

271 (50.1%) decedents lived with a spouse only. 27 decedents lived with a spouse and others comprising 5.0% of our RQPCS sample. The rest of the decedents lived alone (22.0%), lived with other family (10.5%), or lived with others (12.4%).

88.1% of the decedents who accessed the RQPCS were Regina residents. 11.9% of the decedents were considered rural RQHR residents.

Table 4.1 Descriptive Statistics of Demographic Variables

Variable	Sample n = 881				
	Formally Admitted n = 619		Palliative Consultation n = 262		
	Frequency	%*	Frequency	%*	
Age Group (years)					
	= 49	37	4.3	13	1.5
	50 – 59	78	9.0	26	3.0
	60 – 69	129	14.8	53	6.1
	70 – 79	191	22.0	66	7.6
	80 – 89	153	17.6	77	8.9
	= 90	31	3.6	16	1.8
	Missing	0		11	
Gender					
	Male	287	33.3	133	15.4
	Female	331	38.4	112	13.0
	Missing	1		17	
Primary Language					
	English	605	92.1	43	6.5
	French	6	0.9	0	0.0
	Eastern European	3	0.5	0	0.0
	Missing	5		219	
Marital Status					
	Single/Never Married	44	7.1	4	0.6
	Married/Common-Law	349	56.6	15	2.4
	Divorced/Separated	107	17.3	11	1.8
	Widow/er	83	13.5	4	0.6
	Missing	36		228	
Living Arrangements					
	Lives Alone	111	20.5	8	1.5
	Spouse Only	260	48.1	11	2.0
	Spouse and Others	26	4.8	1	0.2
	Other Family	52	9.6	5	0.9
	Others	60	11.1	7	1.3
	Missing	110		230	
Area of Residence					
	Regina	563	79.4	62	8.7
	Rural RQHR	55	7.8	29	4.1
	Missing	1		171	

* Percentages are computed from non-missing data

4.2.2 Disease Characteristics

According to the Carstairs report, cancer patients account for more than 90% of those receiving palliative care even though only one quarter of total deaths in Canada are related to cancer.⁶ Despite the RQPCS' ability to offer services to all dying clients

without being disease specific, the proportion of decedents with cancer diagnoses at admission comprised 87.3% of the total population who died in 2004 and 2005.

Table 4.2 shows the diagnoses breakdown separated into cancer and non-cancer diagnoses.

Table 4.2. Diagnoses

Variable	Sample n = 881			
	Formally Admitted n = 619		Palliative Consultation n = 262	
	Frequency	%*	Frequency	%*
Cancer Diagnosis	521	67.5	153	19.8
Non- cancer Diagnosis	71	9.2	27	3.5
Missing	27		82	

* Percentages are computed from non-missing data

4.2.2.1 Malignant Diagnoses

The rationale for choosing the cancer groupings in Table 4.3 was based on the Saskatchewan Cancer Control Report from the Saskatchewan Cancer Agency, which identified these sites as the top sites for mortality in men and women from 1997-2001, with lung cancer being the top site for both genders.⁴⁰

Similar to the mortality findings in the report of the Saskatchewan Cancer Agency, lung cancer was the most common malignant diagnosis of the decedent cohort of the RQPCS. Lung cancer was followed by colorectal, breast, prostate and pancreas cancer in the RQPCS cohort.

Table 4.3 demonstrates the malignant diagnoses by site.

Table 4.3 Cancer Diagnoses

Site	Sample n = 674			
	Formally Admitted n = 521		Palliative Consultation n = 153	
	Frequency	%	Frequency	%
Lung	155	23.0	46	6.8
Other	115	17.1	25	3.7
Colorectal	63	9.3	22	3.3
Breast	40	5.9	12	1.8
Prostate	21	3.1	15	2.2
Pancreas	28	4.2	5	0.7
Lymphoma	22	3.3	7	1.0
Bladder	14	2.1	6	0.9
Stomach	15	2.2	3	0.4
Ovary	16	2.4	1	0.1
Melanoma	10	1.5	2	0.3
Kidney	8	1.2	3	0.4
Leukemia	5	0.7	5	0.7
Uterus	9	1.3	1	0.1

4.2.2.2 Non-malignant Diagnoses

Almost a quarter of the decedents with a non-cancer diagnosis were diagnosed with a disease of the circulatory system such as cerebral vascular accident, congestive heart failure, cardiomyopathies, acute myocardial infarction, etc.

The second highest group of non-malignant diagnoses consisted of diseases of the genitourinary system (18%) of which the majority of decedents were diagnosed with renal failure.

Diseases of the nervous system (12.2%), which included A.L.S., Alzheimer's disease, Parkinson's disease, cerebral ischemia, etc. was the third highest occurring group of non-cancer diagnoses.

Diseases of the respiratory system and digestive system were next in succession, representing 11.2% and 10.2% of the 98 decedents respectively, making up the top five non-cancer diagnosis groups of the 2004 and 2005 decedent cohort.

Table 4.4 is a breakdown of non-malignant diagnoses for the decedent cohort by SWADD admissions.

Table 4.4 Non-Cancer Diagnoses

Diagnosis	Sample n = 98			
	Formally Admitted n = 71		Palliative Consultation n = 27	
	Frequency	%	Frequency	%
Diseases of the circulatory system ^a	16	16.3	8	8.2
Diseases of the genitourinary system ^b	11	11.2	7	7.1
Diseases of the nervous system ^c	10	10.2	2	2.0
Diseases of the respiratory system ^d	5	5.1	6	6.1
Diseases of the digestive system ^e	9	9.2	1	1.0
Diseases of the musculoskeletal system & connective tissue ^f	8	8.2	1	1.0
Symptoms, signs & abnormal clinical & lab findings ^g	4	4.1	1	1.0
Certain infectious & parasitic diseases ^h	1	1.0	1	1.0
Endocrine, nutritional & metabolic diseases ⁱ	2	2.0	0	0.0
Mental and behavioural disorders ^j	2	2.0	0	0.0
Diseases of the eye & adnexa ^k	2	2.0	0	0.0
Congenital malformations, deformations & chromosomal abnormalities ^l	1	1.0	0	0.0

^a Includes CVA, CHF, cardiomyopathies, acute MI, others

^b Includes renal failure, U.T.I.

^c Includes A.L.S., Alzheimer's disease, Parkinson's disease, cerebral ischemia, others

^d Includes COPD, emphysema, unspecified pleural effusion, pneumonia, other

^e Includes intestinal obstruction, cholangitis, others

^f Includes osteoporosis with pathologic fractures, lupus, arthropathy, others

^g Includes unspecified debility, chronic pain, retention of urine

^h Includes AIDS and H.I.V.

ⁱ Includes type II diabetes mellitus and hypercalcemia

^j Includes organic personality syndrome and mental retardation

^k Includes senile macular degeneration

^l Includes other congenital anomalies of the nervous system

4.2.3 Referrals

4.2.3.1 Source of Referrals

Of the 881 decedents, a SWADD Palliative Care Coordinator formally admitted 619 into the program and the remaining 262 decedents were referred for consultative purposes and were considered informal clients of the RQPCS. Referrals to the program came from multiple sources with nearly half of them made by physicians. The main referral source for formal patients of the RQPCS was the Allan Blair Cancer Clinic which referred just over 25% of the RQPCS cohort. Out of the 262 informal patients referred for consultative reasons, only 129 patients had a record of the referral source. The only referral source for the informal patients of the RQPCS consisted of a broad-spectrum of physicians who were not the decedents' family doctor or the palliative care physician, likely hospital-based referrals.

Table 4.5 indicates the sources which provided referrals to the RQPCS for the 2004/2005 decedent cohort.

Table 4.5 Description of Referral Sources

Referral Source	Sample n = 881			
	Formally Admitted n = 619		Palliative Consultation n = 262	
	Frequency	%	Frequency	%
Allan Blair Cancer Clinic	176	25.8		
Doctor (Hospital-based)			129	18.9
Palliative Care Physician	108	15.8		
Family Doctor	72	10.6		
Pasqua Acute Care Facility	66	9.7		
Family/Friends	51	7.5		
Regular Home Care Program	31	4.5		
Regina General Acute Care Facility	26	3.8		
Pasqua Hospital Ward	8	1.2		
Palliative Care Unit	6	0.9		
Clinical Consultant	4	0.6		
Self	3	0.4		
Regina General Hospital Ward	1	0.1		
Out of District	1	0.1		
Missing	66		133	

* Percentages are computed from non-missing data

4.2.3.2 Timing of Referrals

All decedents who were formally admitted to the program received an official program admit date whereas the patients who received a consultation had no program admit date. Therefore, the average length of stay (LOS) in the program (referral to death) only applies to the formal patients. There were some extreme values found when looking at the distribution pattern of the LOS. The extreme values were calculated using a stem and leaf plot and a box plot, both indicating 67 outliers. Therefore, two separate analyses were conducted when looking at LOS to see how the variable differed, with and without outliers. Before the outliers were removed from analysis, the initial mean length of time between referral and death was 132 days with a range of 0 days to 1091 days (median 62.5 days). While 132 days seems like an unusually long LOS for a palliative care program, it is important to remember the RQPCS offers both

long term help, in chronic care facilities, hospice and home as well as short term aide in the acute/palliative care unit. Therefore, the 132 days is more a reflection of the LOS in the overall program and not reflective of individual settings within the program. After the outliers were removed, the mean time interval between referral and death was 78 days with a range of 0 to 358 days (median 51 days).

In order to better understand the timing of referrals for the formally admitted decedents, the LOS variable was dichotomized into early and late referrals. Based on evidence in the literature, early referrals were defined as any program admit date 8 days prior to death or earlier and late referrals were 7 days prior to death or later.

Table 4.6 shows the majority of the decedents received an early referral (92.4%), which implies these decedents were more likely to experience the benefits of the RQPCS program. Their early referral allowed for the focus of care to be more comprehensive with a focus on comfort and improving the patient’s quality of life as well as alleviation of distressing symptoms related to physical, emotional, social, and spiritual needs.

Table 4.6 Timing of Referrals by Group

Variable	Sample n = 881			
	Formally Admitted n = 619		Palliative Consultation Sample n = 262	
	Frequency	%*	Frequency	%*
Early	556	92.4	0	0.0
Late	46	7.6	0	0.0
Missing	17		262	

* Percentages are computed from non-missing data

4.2.4 Regina Qu’Appelle Palliative Care Services Utilization

4.2.4.1 Palliative Service Usage

Both formal patients and patients seeking consultation were permitted to use home health aides for home services, personal care and respite care, nursing,

occupational therapy, music therapy, and obtain support from the social workers, the chaplain and Dr. Clein. Formal patients differed from patient consults in use of home health aides, nursing, occupational therapy, social work, music therapy and spiritual care as seen by the proportions.

Table 4.7 describes palliative care services utilization of the decedents who were and were not assessed by SWADD.

Table 4.7 Services Use of Formal Patients and Patient Consults

Sample = 881					
Type of Service Accessed	Formally Admitted n = 619		Palliative Consultation n = 262		
	Frequency	%	Frequency	%	
Home Services					
Yes	240	38.8	42	16.0	
No	379	61.2	220	84.0	
Nursing Use					
Yes	534	86.3	0	0.0	
No	85	13.7	262	100.0	
Occupational Therapy					
Yes	506	81.9	9	3.4	
No	113	18.3	253	96.6	
Social Work					
Yes	434	70.1	117	44.7	
No	185	29.9	145	55.3	
Music Therapy					
Yes	213	34.4	26	9.9	
No	406	65.6	236	90.1	
Spiritual Care					
Yes	358	57.8	97	37.0	
No	261	42.2	165	63.0	
Dr. Clein Use					
Yes	438	70.8	190	72.5	
No	181	29.2	72	27.5	

4.2.4.2 Number of Palliative Services Accessed

The average number of services used by the 2004/2005 decedent cohort was 3.63 services. There was a marked difference in the number of services used by the two separate groups. For instance, the formally admitted patients accessed up to seven services with over half of the patients having used between three and five services. In

contrast, 50% of the consultation patients only used one service and others received up to four services.

Table 4.8 reflects the number of services used by the formal and informal groups.

Table 4.8 Number of Services Used by Group

Number of Services Used	Sample n = 881			
	Formally Admitted n = 619		Palliative Consultation n = 262	
	Frequency	%	Frequency	%
0	6	1.0	3	1.1
1	27	4.4	131	50.0
2	55	8.9	51	19.5
3	97	15.7	62	23.7
4	116	18.7	15	5.7
5	142	22.9	0	0.0
6	111	17.9	0	0.0
7	65	10.5	0	0.0

4.2.5 Location of Death

Location of death was collected by the RQPCS and initially coded into three different categories, specialized palliative care, home and hospital. For this research, two separate approaches were used to define location of death; one definition was according to the RQPCS and the other in accordance with the literature. Both definitions were used for the descriptive phase as well as for the chi-square analysis when testing for associations between place of death and patient attributes.

4.2.5.1 Categorization According to the RQPCS

In accordance with the RQPCS, location of death was categorized into two groups, specialized palliative care deaths and hospital deaths. Specialized palliative care deaths included deaths that occurred in the Grace Hospice, the Palliative Care Unit (PCU) of the Pasqua Hospital, long term care facilities and home. The RQPCS offered

and delivered its services in each of the previous palliative care settings. Hospital deaths included any emergency room (ER) deaths or any deaths within a hospital ward other than the PCU of the Pasqua hospital. Table 4.9 demonstrates the places of death of the 2004/2005 decedent cohort, when categorized according to the RQPCS.

It is apparent, the formally admitted decedents were different from the patient consults when comparing place of death. The formally admitted cohort was more apt to die in a location which offered specialized palliative care (90.7%) whereas patients seeking consultation died more often in hospital wards or ER units (58.0%).

Table 4.9 Location of Death by Group (RQPCS)

Variable	Sample n = 881			
	Formally Admitted n = 619		Palliative Consultation n = 262	
	Frequency	%	Frequency	%
Specialized Palliative Care Deaths	556	90.7	103	42.0
Hospital Deaths	57	9.3	142	58.0
Missing	6		17	

* Percentages are computed from non-missing data

4.2.5.2 Categorization According to the Literature

When looking at the literature, previous studies analyzed home deaths separately from other settings of death. This was due to the belief that home deaths are more desirable by palliative patients and their families and are an indication of a “good death.”^{55,82,83} So, for the second descriptive analysis, location of death was dichotomized into home deaths versus specialized palliative care/hospital deaths.

When analyzing home deaths versus all other places of death combined, the formally admitted patients were three times more likely to die at home than the patients who received a palliative consultation. Nearly 90% of all patients who received a consultation died in a setting other than home.

Table 4.10 demonstrates the places of death of the 2004/2005 decedent cohort, when categorized according to the literature.

Table 4.10 Location of Death by Group (Literature)

Variable	Sample n = 881			
	Formally Admitted n = 619		Palliative Consultation n = 262	
	Frequency	%	Frequency	%
Home Deaths	190	31.0	25	10.2
Specialized Palliative Care/Hospital Deaths	423	69.0	220	89.8
Missing	6		17	

* Percentages are computed from non-missing data

4.3 Objective 3: Comparisons Within the RQPCS Cohort

4.3.1 Comparison of Services Received

The RQPCS offers an array of services of which 7 are included in this comparative analysis and include use of home health aides, nursing, occupational therapy, social work, music therapy, spiritual care and palliative care doctor. To observe if age, gender, marital status, living arrangements, area of residence or diagnosis were associated with the type of service patients' received, significance tests were conducted.

4.3.1.1 Age

Initially, age was calculated by subtracting birth dates from death dates, which resulted in a continuous variable. Then, the continuous variable was converted into a categorical variable representing 6 separate age groups. Finally, for the analysis stage, the variable was further examined and based on its distribution pattern resulted in a dichotomous variable of people aged = 70 and people aged > 70.

There was a significant relationship between age and four out of the seven palliative care services offered. People aged = 70 tended to use nursing (p=.002),

occupational therapy (p=.000), social work (p=.000), and music therapy (p=.016) more than people over 70. Similar results were found in the literature.^{56,84}

Table 4.11 shows the results of the chi-squared tests of independence in determining if age is associated with service utilization.

Table 4.11 Independence Analysis between Age Groups and Palliative Services Utilization

Sample n = 870							
Variable	= 70		> 70		Chi-squared test		
	Frequency	%	Frequency	%	X ² ₁	p-value	
Home Health Aide							
Yes	111	31.0	168	32.8	0.316	0.574	
No	247	69.0	344	67.2			
Nursing							
Yes	242	67.6	292	57.0	9.923	0.002	
No	116	32.4	220	43.0			
Occupational Therapy							
Yes	243	67.9	272	53.1	18.982	0.000	
No	115	32.1	240	46.9			
Social Work							
Yes	252	70.4	294	57.4	15.162	0.000	
No	106	29.6	218	42.6			
Music Therapy							
Yes	114	31.8	125	24.4	5.837	0.016	
No	244	68.2	387	75.6			
Spiritual Care							
Yes	187	52.2	265	51.8	0.019	0.890	
No	171	47.8	247	48.2			
PC Doctor*							
Yes	263	73.5	365	71.3	0.496	0.481	
No	95	26.5	147	28.7			

* PC = Palliative Care

4.3.1.2 Gender

When studying the independence analysis between gender and use of palliative care service utilization, it was discovered that women were more likely to access home services (p=.030), nursing (p=.037) and music therapy (p=.004) than men. This study's observed association between gender and service use was not recognized in the literature.^{23,56}

Table 4.12 shows the significant associations between gender and palliative care services usage.

Table 4.12 Independence Analysis between Gender and Palliative Services Utilization

Sample n = 863							
Variable		Male		Female		Chi-squared test	
		Frequency	%	Frequency	%	χ^2_1	p-value
Home Health Aide	Yes	119	28.3	156	35.2	4.702	0.030
	No	301	71.7	287	64.8		
Nursing	Yes	245	58.3	289	65.2	4.356	0.037
	No	175	41.7	154	34.8		
Occupational Therapy	Yes	242	57.6	272	61.4	1.279	0.258
	No	178	42.4	171	38.6		
Social Work	Yes	265	63.1	277	62.5	0.030	0.863
	No	155	36.9	166	37.5		
Music Therapy	Yes	97	23.1	141	31.8	8.233	0.004
	No	323	76.9	302	68.2		
Spiritual Care	Yes	219	52.1	230	51.9	0.004	0.947
	No	201	47.9	213	48.1		
PC Doctor*	Yes	306	72.9	322	72.7	0.003	0.955
	No	114	27.1	121	27.3		

* PC = Palliative Care

4.3.1.3 Marital Status

For the RQPCS, the data gathered on a person's marital status was categorized into one of four groups which included single/never married, married/common-law, divorced/separated, or widow/er. For the significance analysis, the four groups were consolidated into two categories. The single/never married, divorced/separated and widow/er groups were merged together to form one group and group two consisted of the married/common-law decedents. The rationale behind these two groupings was based on the literature which suggests that married/common-law palliative patients differ from non-married palliative patients in terms of utilization of palliative care services.^{23,85}

Table 4.13 shows the results of the chi-squared analysis used to determine if there is an association between marital status and use of palliative care services. Nursing ($p=.001$) and occupational therapy ($p=.000$) use was associated with married people.

Table 4.13 Independence Analysis between Marital Status and Palliative Services Utilization

Sample n = 617

Variable	Sing, Never, Div, Wid [†]		Married/Common-Law		Chi-squared test	
	Frequency	%	Frequency	%	X ² ₁	p-value
Home Health Aide						
Yes	99	39.1	134	36.8	0.341	0.559
No	154	60.9	230	63.2		
Nursing						
Yes	190	75.1	311	85.4	10.455	0.001
No	63	24.9	53	14.6		
Occupational Therapy						
Yes	176	69.6	302	83.0	15.360	0.000
No	77	30.4	62	17.0		
Social Work						
Yes	171	67.6	261	71.7	1.204	0.273
No	82	32.4	103	28.3		
Music Therapy						
Yes	87	34.4	121	33.2	0.088	0.767
No	166	65.6	243	66.8		
Spiritual Care						
Yes	139	54.9	220	60.4	1.855	0.173
No	114	45.1	144	39.6		
PC Doctor*						
Yes	180	71.1	261	71.7	0.023	0.880
No	73	28.9	103	28.3		

[†] Sing = Single, Never = Never Married, Div = Divorced/Separated, Wid = Widow/er

* PC = Palliative Care

4.3.1.4 Living Arrangements

The data collected by the RQPCS indicating a person's living arrangement was categorized into lives alone, lives with spouse only, lives with spouse and others, lives with other family, or lives with people other than family. Based on the literature, the variable was combined into two categories, lives alone and lives with spouse/others. The literature suggests palliative patients who live alone differ from palliative patients who live with a spouse, a family member, or with friends in terms of palliative service usage.^{86,87}

Table 4.14 shows an association between use of nursing services ($p=.005$) and people living with family or friends. According to the significance test, there were no other significant associations between living arrangements and palliative services utilization for this particular population.

Table 4.14 Independence Analysis between Living Arrangements and Palliative Services Utilization

Sample n = 541

Variable	Lives Alone		Spouse/Others ⁺		Chi-squared test	
	Frequency	%	Frequency	%	X ² ₁	p-value
Home Health Aide						
Yes	51	42.9	149	35.3		
No	68	57.1	273	64.7	2.270	0.132
Nursing						
Yes	85	71.4	350	82.9		
No	34	28.6	72	17.1	7.805	0.005
Occupational Therapy						
Yes	84	70.6	330	78.2		
No	35	29.4	92	21.8	2.993	0.084
Social Work						
Yes	87	73.1	279	66.1		
No	32	26.9	143	33.9	2.076	0.150
Music Therapy						
Yes	39	32.8	139	32.9		
No	80	67.2	283	67.1	0.001	0.973
Spiritual Care						
Yes	72	60.5	240	56.9		
No	47	39.5	182	43.1	0.502	0.479
PC Doctor*						
Yes	90	75.6	293	69.4		
No	29	24.4	129	30.6	1.725	0.189

+ Spouse/Others includes Spouse Only, Spouse and Others, Other Family, and Others

* PC = Palliative Care

4.3.1.5 Area of Residence

There is ample evidence in the literature that shows area of residence is significantly associated with palliative service utilization.^{23,88} When a specialized palliative care program is offered in an urban centre, palliative people who live in urban areas tend to use palliative care services more than people who live in rural areas. The same association is evident when the palliative program is offered in a rural setting. Palliative patients living in the rural area will access the rural program more often than their urban counterparts. This is expected and is an issue of accessibility.

Table 4.15 indicates significant associations between people living in Regina and palliative care service usage. People living in Regina accessed home services ($p = .000$), nursing ($p = .000$) and occupational therapy ($p = .000$) more than people living in the rural areas of the RQHR.

Table 4.15 Independence Analysis between Area of Residence and Palliative Services Utilization

Sample n = 709

Variable	Regina		Rural RQHR		Chi-squared test	
	Frequency	%	Frequency	%	X^2_1	p-value
Home Health Aide						
Yes	228	36.5	11	13.1		
No	397	63.5	73	86.9	18.121	0.000
Nursing						
Yes	493	78.9	40	47.6		
No	132	21.1	44	52.4	38.777	0.000
Occupational Therapy						
Yes	468	74.9	43	51.2		
No	157	25.1	41	48.8	20.646	0.000
Social Work						
Yes	430	68.8	65	77.4		
No	195	31.2	19	22.6	2.587	0.108
Music Therapy						
Yes	196	31.4	28	33.3		
No	429	68.6	56	66.7	0.133	0.715
Spiritual Care						
Yes	360	57.6	52	61.9		
No	265	42.4	32	38.1	0.564	0.453
PC Doctor*						
Yes	456	73.0	58	69.0		
No	169	27.0	26	31.0	0.568	0.451

* PC = Palliative Care

4.3.1.6 Diagnosis

The literature shows that palliative patients with cancer diagnoses need more help than patients with non-cancer diagnoses, account for the majority of care episodes within palliative care programs and show a trend associated with increased ER visits, hospitalizations, and ICU admissions.^{87,89} These trends may be due to the higher prevalence of cancer patients in palliative care. So, it was no surprise when the chi-squared analysis in Table 4.16 demonstrated similar findings. Significant associations between diagnosis and palliative services utilization were shown in the 2004/2005 decedent population of the RQPCS. Occupational therapy (p=.041), social work (p=.000), music therapy (p=.019), spiritual care (p=.000) and PC physician use (.000) was associated with cancer patients.

Table 4.16 Independence Analysis between Diagnosis and Palliative Services Utilization

Sample n = 772							
Variable	Cancer		Non-cancer		Chi-squared test		
	Frequency	%	Frequency	%	X ² ₁	p-value	
Home Health Aide							
Yes	229	34.0	37	37.8	0.541	0.462	
No	445	66.0	61	62.2			
Nursing							
Yes	460	68.2	58	59.2	3.185	0.074	
No	214	31.8	40	40.8			
Occupational Therapy							
Yes	449	66.6	55	56.1	4.158	0.041	
No	225	33.4	43	43.9			
Social Work							
Yes	453	67.2	43	43.9	20.280	0.000	
No	221	32.8	55	56.1			
Music Therapy							
Yes	201	29.8	18	18.4	5.525	0.019	
No	473	70.2	80	81.6			
Spiritual Care							
Yes	371	55.0	33	33.7	15.665	0.000	
No	303	45.0	65	66.3			
PC Doctor*							
Yes	505	74.9	56	57.1	13.623	0.000	
No	169	25.1	42	42.9			

* PC = Palliative Care

4.3.2 Comparison of Number of Services Accessed

The RQPCS offers many different services to its palliative population of which up to 7 are included in this comparative analysis. First, the number of services variable was dichotomized into 3 or fewer services used and 4 or more services used. The decision to break this variable into these two categories was based on the distribution of the data. Then, in order to observe if age, gender, marital status, living arrangements, area of residence or diagnosis were associated with the number of services patients accessed, significance tests were conducted.

Table 4.17 shows the younger decedents (≥ 70 yrs) tended to use more services than the older decedents ($p=.001$). Married individuals used more services than single, divorced, or widowed individuals ($p=.013$). It was found that urban decedents were more likely to use more services of the RQPCS than rural decedents, who were likely to use 3 or fewer services ($p = .003$). The proportion of people with a cancer diagnosis used more services of the RQPCS than the proportion of people with a non-cancer diagnosis ($p = .000$).

Table 4.17 Independence Analysis between Number of Services Accessed and Patient Attributes

Variable	3 or fewer services		4 or more services		Chi-squared test	
	Frequency	%	Frequency	%	X^2_1	p-value
Age	n = 870					
= 70	148	35.2	210	46.8	12.107	0.001
> 70	273	64.8	239	53.2		
Gender	n = 863					
Male	209	50.5	211	47.0	1.050	0.306
Female	205	49.5	238	53.0		
Marital Status	n = 617					
Sing., Never, Div., Wid. ⁺	98	48.0	155	37.5	6.234	0.013
Married/Common-Law	106	52.0	258	62.5		
Living Arrangements	n = 541					
Lives Alone	41	21.7	78	22.2	0.016	0.901
Spouse/Others*	148	78.3	274	77.8		
Area of Residence	n = 709					
Regina	224	83.6	401	90.9	8.617	0.003
Rural RQHR	44	16.4	40	9.1		
Diagnosis	n = 772					
Cancer	279	82.1	395	91.4	15.093	0.000
Non-cancer	61	17.9	37	8.6		

⁺ Sing. = Single, Never = Never Married, Div. = Divorced/Separated, Wid. = Widow/er

* Spouse/Others includes Spouse Only, Spouse and Others, Other Family, and Others

4.3.3 Comparison of Timing of Referral

The LOS variable was dichotomized into early and late referrals for the purpose of analyzing the independence between timing of referral and patient characteristics. Early referrals were defined as any program admit date 8 days prior to death or earlier and late referrals were 7 days prior to death or later.

Table 4.18, which includes the outliers, shows there were no significant results when testing for independence. However, it is necessary to discuss the p-values of both marital status ($p = 0.073$) and diagnosis ($p = 0.075$). The p-values are not significant but do indicate a trend which is observed in the literature that timing of referrals is actually associated with some patient attributes, such as marital status and diagnosis.^{63,131,90} But overall, the literature was inconclusive about the significance of the associations between patient attributes and timing of referral.

It was decided to include the outliers in this analysis in order to keep the integrity of the descriptive nature of this study, which was to describe the complete cohort of decedents and existing distribution of variables. However, another analysis was completed in which the outliers were removed and two of the patient attributes were found to be associated with timing of referrals, marital status ($p = 0.048$) and diagnosis ($p = 0.037$).

Table 4.18 Independence Analysis between Timing of Referral and Patient Attributes

Variable	Early Referral		Late Referral		Chi-squared test	
	Frequency	%	Frequency	%	χ^2_1	p-value
Age			n = 602			
	= 70	244	43.9	15	32.6	
	> 70	312	56.1	31	67.4	2.204
						0.138
Gender			n = 601			
	Male	258	46.5	23	50.0	
	Female	297	53.5	23	50.0	0.211
						0.646
Marital Status			n = 566			
	Sing., Never, Div., Wid. ⁺	201	38.5	23	52.3	
	Married/Common-Law	321	61.5	21	47.7	3.216
						0.073
Living Arrangements			n = 492			
	Lives Alone	92	20.4	12	29.3	
	Spouse/Others*	359	79.6	29	70.7	1.773
						0.183
Area of Residence			n = 601			
	Regina	506	91.2	42	91.3	
	Rural RQHR	49	8.8	4	8.7	0.001
						1.000
Diagnosis			n = 577			
	Cancer	476	88.8	32	78.0	
	Non-cancer	60	11.2	9	22.0	4.186
						0.075

+ Sing. = Single, Never = Never Married, Div. = Divorced/Separated, Wid. = Widow/er

* Spouse/Others includes Spouse Only, Spouse and Others, Other Family, and Others

4.3.4 Comparison of Location of Death

4.3.4.1 Deaths within Specialized Palliative Care Settings versus Deaths in Hospital

As indicated by the p-values in Table 4.19, there were no significant results when testing for associations between place of death as defined by the RQPCS and patient characteristics. Even though the p-value (0.060) of the analysis between gender and location of death is not statistically significant it suggests a trend toward statistical significance between place of death and gender. Overall, these results may seem unusual especially when compared with the literature, but are most likely a reflection of how location of death was defined for this independence analysis test.

Table 4.19 Independence Analysis between Location of Death and Patient Attributes (RQPCS)

Variable	Specialized PC Service		Other		Chi-squared test	
	Frequency	%	Frequency	%	X^2_1	p-value
Age	n = 852					
= 70	276	42.0	79	40.5	0.139	0.710
> 70	381	58.0	116	59.5		
Gender	n = 846					
Male	305	46.7	105	54.4	3.533	0.060
Female	348	53.3	88	45.6		
Marital Status	n = 609					
Sing., Never, Div., Wid. ⁺	222	40.0	27	50.0	2.036	0.154
Married/Common-Law	333	60.0	27	50.0		
Living Arrangements	n = 533					
Lives Alone	105	21.6	13	27.7	0.911	0.340
Spouse/Others*	381	78.4	34	72.3		
Area of Residence	n = 698					
Regina	557	88.7	62	88.6	0.001	0.975
Rural RQHR	71	11.3	8	11.4		
Diagnosis	n = 761					
Cancer	523	87.5	140	85.9	0.281	0.596
Non-cancer	75	12.5	23	14.1		

⁺ Sing. = Single, Never = Never Married, Div. = Divorced/Separated, Wid. = Widow/er

* Spouse/Others includes Spouse Only, Spouse and Others, Other Family, and Others

4.3.4.2 Home Deaths versus Specialized PC/Hospital Deaths

Consistent with prior research, the results of the second analysis of location of death determined statistically significant associations between gender ($p=0.024$) and living arrangements ($p=0.000$) on location of death. Throughout the literature patient characteristics such as age, gender and marital status have been recognized as predictors of place of death.^{23,91,92,93} Ahlner-Elmqvist et al. and Chvetzoff et al. reported an association between home deaths and living with someone, but found no such association between gender and place of death.^{94,95}

Table 4.20 Independence Analysis between Location of Death and Patient Attributes (Literature)

Variable	Home		Specialized PC/Other		Chi-squared test	
	Frequency	%	Frequency	%	X^2_1	p-value
Age	n = 852					
= 70	96	44.9	259	40.6	1.199	0.274
> 70	118	55.1	379	59.4		
Gender	n = 846					
Male	89	41.8	321	50.7	5.085	0.024
Female	124	58.2	312	49.3		
Marital Status	n = 609					
Sing., Never, Div., Wid. ⁺	73	40.1	176	41.2	0.065	0.799
Married/Common-Law	109	59.9	251	58.8		
Living Arrangements	n = 533					
Lives Alone	19	11.9	99	26.5	13.973	0.000
Spouse/Others*	141	88.1	274	73.5		
Area of Residence	n = 698					
Regina	174	90.2	445	88.1	0.577	0.447
Rural RQHR	19	9.8	60	11.9		
Diagnosis	n = 761					
Cancer	170	84.2	493	88.2	2.153	0.142
Non-cancer	32	15.8	66	11.8		

+ Sing. = Single, Never = Never Married, Div. = Divorced/Separated, Wid. = Widow/er

* Spouse/Others includes Spouse Only, Spouse and Others, Other Family, and Others

Chapter 5 Discussion

5.1 Summary of Findings

The RQPCS program vision and goals were defined using the Canadian Hospice Palliative Care Association's national model entitled A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice.⁷⁹

In analyzing and comparing the RQPCS vision and goals to the norms set out by the Canadian Hospice Palliative Care Association, it is apparent the RQPCS shares the same vision, values, and guiding principles as the CHPCA. The RQPCS offers an array of programs and services in a variety of settings and has committed to deliver consistent, appropriate, comprehensive and coordinated care to the palliative population of the RQHR.

Of the 2004/2005 decedent cohort, the RQPCS served a vast range of people of varying ages (age range 1-99). The mean age for this study cohort is lower than the mean age of Saskatchewan as a whole (71.75 versus 78.35).⁹⁶ There was an equal distribution between males and females, 48.7% and 51.4%, respectively. The majority of decedents indicated English as their primary language. Consistent with prior research, this study demonstrated the majority of decedents were married and lived with a spouse, 59.0% and 50.1%, respectively.^{32,33,34} Finally, 88.1% of the decedents were Regina residents which is not surprising due to the urban location of the RQPCS program.

87.3% of the decedents had an initial diagnosis of cancer with lung cancer being the most prevalent malignant diagnosis (29.8%). Of the non-malignant diagnoses, 24.5% were diseases of the circulatory system such as cerebral vascular accidents and congestive heart failure.

45.3% of the decedents were referred to the RQPCS by physicians with the majority of the formally admitted patients being referred at least 8 days prior to death (92.4%).

Formally admitted decedents accessed and used more services of the RQPCS than the patients referred for consultations. 57.3 % of the formally assessed decedents used between three and five services whereas 50% of the patients who received a consult only used one service.

The first descriptive analysis of location of death found that 76.8% of the decedent cohort died in settings which provided specialized palliative care services, such as the palliative care unit and home. The second descriptive analysis of location of death found that 25.1% of the cohort had a home death.

Significant associations were observed between age, gender, marital status, living arrangements, area of residence and diagnosis on the types of services the decedents used. Typically, younger patients, women, married people, people living with family or friends, urban residents and people with a cancer diagnosis were apt to access different services than their counterparts.

Age, marital status, area of residence and diagnosis were significantly associated with the number of services patients accessed. Again, younger decedents, married individuals, urban residents and people diagnosed with cancer tended to use more services.

When analyzing whether patient characteristics were associated with the timing of referrals, the chi-squared analysis showed no significant results. Previous research has studied associations between patient attributes and timing of referrals and no clear

conclusions could be reached since a number of studies found significant associations whilst other studies found no significant associations.

Significant associations between location of death and patient attributes were observed when the variable was dichotomized into home deaths and all other deaths but no significant associations were observed when location of death was categorized as specialized PC versus hospital deaths.

5.2 Issues with Accessibility and Utilization

By modelling the program after the norms set out by the CHPCA, the RQPCS offers comprehensive specialized palliative services to the RQHR palliative population. However, accessibility and referrals to the program appear to be troublesome as indicated through the high percentage of cancer patients (88%), occurrence of late referrals and small representation of rural patients (12%).

When a specialized palliative care program is offered in an urban centre, palliative people who live in urban areas tend to use palliative care services more than people who live in rural areas. The same association is evident when the palliative program is offered in a rural setting. Palliative patients living in the rural area will access the rural program more often than their urban counterparts. This is expected and is an issue of accessibility. Research found urban residents to be more likely to access palliative care services; yet, rural residents have more care episodes in small, rural hospitals.^{17,23} This may be an indication of an underserved palliative population.

Within the 2004/2005 RQPCS decedent cohort, there were disproportionate numbers of patients seeking consultations who only accessed one service of the RQPCS (131 out of 262).

Unfortunately, this study was not designed to discern definitively why 50% of the patients seeking consultations only accessed one service out of the many services offered by the RQPCS. One possible explanation may have been due to the timing of the consultation which did not allow enough time for the decedent to access other services. Other reasons for the utilization patterns of the patient consults may have been patient preference, lack of knowledge and education about the services offered by the RQPCS, accessibility issues, availability of patient and organizational resources or the needs of the decedent were being adequately met by an informal caregiver.

5.3 Patient Characteristics and Palliative Care Utilization

Age

Generally, it is thought that older people make greater demands on the health care system. This study found that younger people actually tended to take advantage of more services of the RQPCS than older people. Similar results were observed in the literature, where older people were less likely to access the services of home care than younger patients.⁹⁷ Another study found that patients younger than 70 years had more admissions in the last six months of life (median 3) compared to patients older than 70 (median 1).³⁵ Catt et al. hypothesized the age-related differential in access to hospice and specialist palliative care services are due to possible attitude differences between age groups and attitude shifts over time, as a consequence, older people are less likely to want these services.⁹⁸

Gender

This study found that women were more likely to access home services, nursing and music therapy. However, this apparent association between gender and service use

was not clearly seen in the literature. According to Hunt and McCaul, sex is not a predictor of hospice involvement.²³ Other studies reported no effect of gender on palliative care service utilization.^{57,99,100} Studies which found a gender bias on service use ironically found that females were more likely to be referred to home care than men, yet men were still more likely to die at home than women.⁹⁷ When gender effects on palliative service use were observed, the differences may have been due to the perception that male partners may be less able or less willing to provide care at home and/or the expectation that women outlive their partners leaving less support for home care or a may reflect the traditional caring role of women,^{97,101,102}

Marital Status

This research found married people were more apt to access the services of the RQPCS than the other group. This association was also observed by previous studies. For instance, marital status was significantly correlated to the number of admissions during the terminal 6 months with married patients having a median of two admissions compared to one admission for other groups.³⁵ Similarly, people who died of cancer and were single or widowed were less likely to receive or access specialist palliative care.¹⁰³ Also, it was shown that divorced or separated individuals were less likely to receive hospice services as were unmarried women.¹⁰⁴ Finally, Wachterman and Sommers found that marital status had a significant effect on end-of-life care and service utilization especially when comparing men and women largely due to the disparities in the availability of informal caregiving.¹⁰⁴ Even though there is an association between marital status and palliative care utilization, the marital relationship may not be as important as having an informal caregiver as a support and an advocate.

Living Arrangements

This research found that people who lived with family or friends tended to access nursing services more than people living alone. Some of the previous literature revealed similar results. For instance, it was found that clients living with a caregiver tended to have twice as many visits from home care.¹⁰⁵ Casarett et al. determined people in a bridge program who had more needs also had a caregiver living with them.⁸⁵ In another study, a trend was evident between having a caregiver and using more services.¹²² This association may be a reflection of caregiver burden such as mental and physical health problems as well as financial strain.^{86,106,107} For whatever reasons, the informal caregiver plays a significant role in deciding who will provide palliative care services to meet the needs of the dying person.¹²²

Area of Residence

When hospice is urban centered, utilization patterns reflect an association between decreasing hospice use with decreasing urban influence resulting in lower rates of hospice use in more rural environments.⁸⁸ For example, patients living close to a county hospital had more admissions during the last 6 months than those who lived more than 40 km from the hospital.³⁵ Consistent with prior research, this study found significant differences between rural and urban patients in terms of access to and utilization of palliative care services. Regina residents accessed and used more services than rural residents. Generally, geographic location and population density are important factors influencing access to use of palliative care services, and not patient demographics.⁸⁸

Diagnosis

In this study, of all the patient attributes, diagnosis was more significantly associated with utilization and amount of services accessed, with cancer patients accessing and using more services than non-cancer patients. The relationship between diagnosis and service use was evident in the literature, but was not clear as to who accesses more services. For instance, people who died of cancer were less likely to receive specialist palliative care if they were also single or widowed, over 85 yrs of age or lived in a region other than a major city.¹⁰³ But, cancer patients in higher socioeconomic groups were more likely to access home care.⁹⁷ However, people who were not married and who died of non-cancer conditions were less likely to access specialized palliative care.¹⁰³ Addington-Hall et al. also found that patients with non-cancer diagnoses were less likely to need help than cancer patients especially in the younger population, but the reverse was true in older groups.⁸⁷

No clear conclusion could be reached as to which patients' access palliative care services by diagnosis, but a trend emerged and revealed younger cancer patients and older non-cancer patients seemed to need more palliative services. Also, it was apparent that many other variables play a role in why cancer and non-cancer patients access palliative care services.

5.4 Issues with Referrals

Referrals to the program came from multiple sources with nearly half of them made by physicians and 16.3% of referrals made by hospitals. This is consistent with earlier studies reporting the majority of referrals to specialized palliative care programs come from physicians.^{41,73,85} Massarotto et al. revealed the percentage of hospital

referrals to vary between studies which ranged from 14% to 46% of all referrals to palliative care.^{108,109,110} Knowledge regarding source of referrals is critical to enhancing referrals to palliative care programs.

Even though 92.4% of the referrals were considered to be early referrals, meaning at least 8 days prior to death there still needs to be discussion on why late referrals may be occurring in the RQHR.

Knowledge about Palliative Care

The issue of late referrals may not be directly caused by the RQPCS program itself but may be due to patient, family and physician lack of knowledge about the program and the services it offers. Improving patient, family and physician knowledge about the RQPCS may aid in more equal representations of cancer and non-cancer patients as well as urban and rural patients in the RQPCS population. Also, providing more education about palliative care, in general, and the services offered by the RQPCS may help to reduce patient, family and physician barriers to earlier referral. Due to the lack of knowledge and education about the benefits of palliative care, often times patients, family and physicians only consider palliative care after most curative treatments are exhausted rather than incorporating palliative care at earlier stages of the disease trajectory.¹¹¹ These groups may also perceive palliative care as speeding up the dying process as such they are reluctant to pursue palliative care as a viable and appropriate option.⁶⁵

Difficulty in Determining Prognosis of Non-Cancer Patients

Even though it is widely recognized that palliative care is beneficial to any person with an incurable, progressive illness, cancer patients still represent the majority

of most palliative care programs and settings. The same was true for the 2004/2005 RQPCS cohort, where the majority (87.3%) of decedents had a diagnosis of cancer. Within the malignant diagnoses, lung cancer (29.8%) was the most common diagnosis followed by colorectal, breast and prostate cancer. Lung cancer was also the most common cause of death in Saskatchewan in 2005.⁹⁶ The leading malignant diagnosis of cancer palliative patients in the literature also proved to be lung cancer.^{63,85,112} Consistent with prior research, this study found among the non-malignant diagnoses, congestive heart failure and cerebral vascular accidents (diseases of the circulatory system) were the most common diagnoses of the 2004/2005 cohort followed by renal failure, 24.5 % and 18.3%, respectively.^{131,113,114}

Troublesome prognostications may be delaying non-cancer referrals to the program and one of the reasons why there were disproportionate numbers of decedents with cancer diagnoses, as well. Cancer is a more predictable disease in terms of disease trajectory and therefore physicians are more confident in referring cancer patients to palliative care. Field found greater uncertainty among physicians in identifying non-cancer candidates suitable for specialized palliative care services due to the differing disease progressions of non-cancer diseases.¹¹⁵

5.4.1 Patient Attributes and Referrals

Tests of associations between patient attributes and timing of referrals indicated no significant results when using the complete RQPCS data set. No clear conclusion within the literature was discovered when analyzing the significance of patient attributes on timing of referrals, either.

Age

When analyzing age and timing of referrals, it was discovered in Nova Scotia and England, older people dying of cancer were less likely to be referred to a palliative care program at all and were more likely to be referred late than were younger people.^{36,116} Furthermore, the time interval between palliative care referral and death for patients <65 years old was significantly different than patients >65 years old, 2.1 months versus 1.4 months, respectively.¹¹¹ In contrast, Christakis and Escarce demonstrated that age is not associated with the length of survival after enrolment into a hospice.¹¹³ Even though the significance of age on timing of referrals in the literature is inconclusive, it appears when age is associated to timing of referrals it is the younger palliative patients who are more likely to be referred earlier to a specialized palliative care service than older palliative patients.

Gender

Gender was not statistically significant when analyzing the relationship between sex and timing of referrals. The results of this analysis are consistent with earlier studies. For example, Johnston et al. found that sex by itself was not a predictor of referral into a palliative program.³⁶ Correspondingly, Cheng et al. found that there was no association between gender and the interval between palliative care enrolment and death.¹¹¹ However, one study found that men had a 10 percent higher risk of death than women after enrolment into hospice.¹¹³ Other studies found gender to be significantly associated with timing of referrals, where women were more likely to be enrolled in hospice earlier than men resulting in men having shorter survival times in hospice than

women.^{131,132,113} Whether gender plays a significant role in timing of referrals remains unclear.

Marital Status

There were no significant results when analyzing the association between marital status and timing of referrals. This is contradictory to previous research which determined marital status to be significantly associated with timing of referrals and length of survival in palliative care programs. Lamont and Christakis found that unmarried patients lived 26.4 days longer in hospice compared with married persons.⁶³

Living Arrangements

No significant association was discovered between living arrangements and referral times for the 2004/2005 RQPCS cohort of decedents. Inconsistencies exist in the literature with regards to the significance of living arrangements on timing of referrals. People who lived alone tended to stay in home-based palliative care services longer than people with a caregiver (median 70 days versus 50 days).¹⁰⁵ One study found that living with a caregiver had no significant association with the number of days from referral to death.¹¹⁷ The previous two studies demonstrate the conflicting results in the research as to the importance of living arrangements on referral times.

Diagnosis

The significance test result between diagnosis and timing of referral was insignificant. This is inconsistent with earlier studies which reported strong associations between diagnosis and referral times. One study found that “each additional year the patient had been sick with cancer was associated with a 4.3 day longer survival in hospice.”⁶³ Another study of cancer patients demonstrated that

survival times differ within cancer populations with patients with lung and liver metastasis having shorter survival times than patients with other metastases.⁹⁰ Median length of survival varies substantially according to diagnosis from 17 days for renal failure to 77 days for COPD as do the range of survival times from 39 days for liver or biliary cancer to 349 days for dementia.¹¹³ According to Christakis and Escarce, the length of stay or duration of survival after enrolment into palliative care is an important outcome to measure because it is relevant to the quality of care that patients receive at the end of life.¹¹³

The literature is inconclusive with regards to the importance of patient attributes on timing of referrals, yet it is established that late referrals to palliative care services are unacceptable and highly criticized.^{65,85,113,118} Also, it is recognized that early referral into palliative care programs is paramount to the quality of care a patient receives at the end of life.

5.5 Issues with Place of Death

There was a high number of patient consults dying in settings with no specialized palliative care (142 out of 245). Consistent with prior research, this study demonstrated that many palliative patients die in acute care facilities.^{28,94,119} Unfortunately, this is a trend that contradicts the ideal of a good death, which is described as dying at home surrounded by friends and family offering more autonomy to the dying person.^{120,121}

Again, this research did not aim to discover the reasons for place of death, but rather to find associations between location of death and patient attributes. However, the literature demonstrated reasons for death in hospital to be varied and include patient

preference to die in hospital, change in patient preference of place of death from home death to hospital death when disease progresses, caregiver unable to care for patient at home closer to death or the occurrence of an acute episode leading to hospital admission and eventual death.^{82,122}

5.5.1 Patient Demographics and Location of Death

Since location of death in the literature focuses on home deaths versus other settings, the following discussion refers only to the significant results determined by this research when comparing home deaths versus specialized palliative care/hospital deaths.

Age

This study did not find any patient attributes to be significantly associated with place of death. Conversely, there are numerous studies which have shown that certain demographic factors are associated with location of death. Many studies have found that younger aged patients (50-70 yrs old) were more likely to die at home as opposed to older aged patients (70+).^{92,93,98,101,123} But, there have been studies that found older patients tend to die at home, more so than younger patients who tended to die in hospital.^{124,125} Several studies demonstrated no association between age and location of death.^{94,95} Overall, due to the varied findings on whether age is a predictor of home death suggests that it is not simply age which is important, but other factors such as culture and family context may play a roll, too.

Gender

The literature which analyzed the association of gender on location of death was mixed. Many studies found no relation between gender and place of death.^{94,95}

However, this study along with previous literature found gender to be significantly associated with place of death. Most often men were more likely to die at home compared to women.^{91,92,93} In Australia, females were more likely to prefer death in a hospice facility and were actually more likely to die in these setting than men.^{101,126} However, an Italian study found that women were more likely to die at home which again suggests that gender alone is not an indicator of home death but works in conjunction with family circumstance and differs between cultures.^{104,125}

Marital Status

Similar to this study, when Grande et al. reviewed a study conducted by Axelsson and Christianson they found no effect of marriage on home death.^{97,127} However, there are other studies that revealed significant associations between place of death and marital status.⁹⁵ Many studies found that patients who died at home were significantly more likely to be married, regardless of gender.^{91,125,128} Wachterman and Sommers found that marital status had a significant impact on place of death, with unmarried individuals significantly more likely to die in nursing homes and less likely to die in hospitals.¹⁰⁴ Unfortunately, the conclusiveness of whether marital status has any bearings on place of death is still not fully proven.

Living Arrangements

When reviewing the literature, no clear conclusion could be reached when assessing the association between living arrangements place of death. This and other research found a relationship between living with someone and place of death. Patients who died at home were significantly more likely to live with someone, most likely an informal caregiver.^{94,122} Similarly, when comparing clients living with a caregiver to

clients living alone, it was discovered fewer clients with no caregiver died at home and more died in a hospice or a tertiary hospital.¹⁰⁵ But, Harding and Leam discovered that having an informal caregiver had no bearing on whether the person died in home or not.¹¹⁷

Area of Residence

The relationship between area of residence on place of death was not significant for the RQPCS decedent cohort. This is consistent with previous research which reported residence is not associated with location of death.^{94,95} Then again, one study found that people who lived in a rural setting were more apt to die at home.¹²² Furthermore, in Australia, the preference of metropolitan residents revealed they preferred to die in hospice.¹⁰¹ Again, due to the varied results in the literature no clear conclusion could be reached with regards to the effect residence might have on location of death.

Diagnosis

Most research, including the present study, has found no conclusive evidence that diagnosis, alone, is a predictor of home death.^{94,95} Conversely, Addington-Hall et al. found that place of death differed significantly between cancer and non-cancer patients where non-cancer patients were more likely to die in a hospital or in an institution, regardless of age.⁸⁷ It was also evident that cancer patients in higher socioeconomic groups were more likely to die at home.⁹⁷ The results remain unclear as to the importance of diagnosis on location of death.

The insignificant results found in this study between location of death and patient attributes may be due to the manner in which location of death was

dichotomized. Location of death was broken down by locations in which specialized palliative care was delivered, rather than by preference. It is well documented that dying at home is favoured by the majority of terminally ill patients, caregivers, health professionals and the general public and is an indicator of a good death. In all probability, the reason why the results were insignificant is because patient attributes alone are not true predictors of place of death. More studies have found that palliative home care service use or hospice use to be stronger contributory factors towards home death than demographics.^{23,97}

5.6 Summary

The RQPCS is a well organized, model palliative care program which offers active, supportive and compassionate care. This care is delivered to the dying individual and family and is aimed at improving the quality of life of its patients. The care addresses the physical, psychological and spiritual needs of the patient and family and is delivered by a multidisciplinary care team in the home, long-term care or acute care settings.

This research determined each of the patient characteristics under investigation to be associated with palliative care utilization. Similar findings were also evident in the literature. In particular, age, marital status, living arrangements, area of residence and diagnosis appeared to be significantly associated with accessing palliative care services.

When analyzing the associations between patient attributes and timing of referrals for the RQPCS, no significant results were found. Previous research indicated

strong associations between marital status and diagnosis on the timing of referrals into hospice and palliative care programs.

Finally, there were two significant associations found between location of death and patient characteristics (gender and living arrangements). However, no clear conclusion could be reached on whether age, gender, marital status, living arrangement, area of residence or diagnosis had any effect on place of death in previous literature.

Chapter 6 Conclusion

6.1 Strengths

Burns and Grove state several strengths of descriptive studies. For example, “they may be used for the purpose of developing theory, identifying problems with current practice, justifying current practice, making judgments, or determining what others in similar situations are doing.”⁸ Descriptive studies are the first step in research and are important in providing a foundation for well designed epidemiological studies or in determining the feasibility of future research. They allow the investigator to define a good hypothesis which can then be tested using a better design.

Descriptive studies which use administrative health databases have potential of providing population-based, unbiased, efficient measures of quality of care. This study analyzed an entire cohort of decedents of the RQPCS who died between January 2004 and December 2005 who accessed the palliative care program, which made it population-based. In so doing, a large amount of information was collected and analyzed and more is known about the characteristics of patients who access the RQPCS and which services they access near the end of life.

Defining, measuring and monitoring quality palliative care, or palliative care surveillance, involves collection and analysis and interpretation of outcome-specific data for use in the planning, implementation and evaluation of palliative care programs and services.⁵ This research raised some questions that can be used for future research into understanding palliative care in the RQHR, such as what are the predictors of referral into the RQPCS, what are the determinants of resource utilization, what are the preferences of location of death of the RQPCS population.

6.2 Limitations

This study dealt with data collected retrospectively, which limits the value of its conclusions due to missing data and questionable accuracy of the medical files.^{8,24} Plus the results obtained from this sample are not generalizable to different populations and only produce working hypotheses.^{24,29}

In general, use of administrative databases for conducting research has its limitations and concerns, such as incompleteness and accuracy.^{129,130} The data accumulated by the RQPCS was collected from patient records and the databases were developed previous to the present study. The information collected was for administrative purposes and not collected for the purpose of quality assessment, therefore the completeness and accuracy of the data is questionable.¹³⁰ The variables analyzed for the present study were determined by what was collected and available from the administrative databases of the RQPCS, consequently some important demographics and clinical information was not obtainable and as a result not analyzed.

One of the limitations of this study was the lack of certain demographic and diagnostic data for the decedents of the RQPCS, particularly race and symptoms. The database also lacked information on patient and family preferences for care and do not resuscitate orders and place of death. Consequently, no discussion of the importance of race, patient symptomology or patient preferences occurred. Unfortunately, inaccurate record keeping or incomplete medical records is a problem when conducting a descriptive study that uses administrative databases as the main source of information. The RQPCS could introduce patient race and symptoms into its electronic record keeping in the future.

Information on caregivers as well as referring physicians was not gathered or documented in the patient medical records, therefore not included in the RQPCS database. It is known that patient perspectives can hinder timely enrolment into a palliative service, but family and physician issues are also closely associated to timing of referrals into PCS.^{131,132} Due to the missing information, this study was unable to demonstrate possible familial and physician barriers to accessing the RQPCS in a timely fashion.

Another limitation of this study is that we did not know the reason for referral into the RQPCP. Pain and symptom control is the most common reason for referral into palliative care, but because of the lack of documentation on symptoms this study was unable to analyze symptoms as possible reasons for referral.¹⁸ Unfortunately, reason for referral was not documented in our dataset, so it was not possible for us to report on the strength of agreement between reason for referral and actual content of care. It is important to know why patients are being referred and why they access palliative care services in order to assure proper care and continuity of care across palliative settings.

Finally, it was not possible from the data to determine total admissions or total procedures. Our data did not include how many health care admissions or how many hours an individual patient used certain palliative care services or the procedures performed. Our data only indicated the initial date when a formally enrolled individual was admitted into the RQPCS. Admission data or initial consult date for patient consultations was excluded from the database, as well. Therefore, it was not possible for the researcher to analyze the amount and appropriateness of treatment provided to RQHR palliative individuals at the end of their lives.

6.3 Recommendations for Future Research

The literature concerning the true prevalence of palliative patients is insufficient. Currently, research focuses on palliative patients who access hospice or palliative care services. The knowledge is vast concerning the predictors and barriers of palliative care for patients who use these services. However, there may be a group of patients who have been designated or recognized as palliative based on diagnosis that could benefit from these services and for whatever reasons are being missed by the very health care system that designated them as palliative.

In terms of quantitative research, the next step involves linking the RQPCS database with the Saskatchewan (SK) Health databases. Once the linkage with the SK Health databases is complete, prevalence of palliative care patients, inclusiveness of coverage, patterns of referral and overall health services utilization can be studied for the Regina Qu'Appelle Health Region. The analysis would involve describing the palliative patients who use palliative care services as well as the patients who have been designated as palliative who are not being reached by the RQPCS program or are not using the palliative care services within the provincial health care system such as the palliative prescription drug plan or medical therapies like home oxygen therapy. The final step would include a comparison analysis between the above cohorts on demographics, health service utilization and timing of palliative designation.

Finally, it would be interesting to perform a similar analysis of the remaining health regions of Saskatchewan to better understand the palliative population of and the palliative care services offered throughout the whole province. Gathering palliative care data from each SK Health Region and linking it with the SK Health databases will

provide a more comprehensive look at palliative care in the province. Such an analysis, if successful, may lead to a formal system of palliative care surveillance in Saskatchewan. Problems such as wide ranging referral patterns and practices may be further studied using the surveillance data. Also, it would be useful to study when palliative designations are occurring in the province. Finally, the surveillance data may provide a clearer picture of what services are offered through out the province and may help to consolidate and lessen the disparity among the various programs.

While a provincial palliative surveillance system may be beneficial in terms of quantitative research, it will not benefit researchers who are interested in the quality of the palliative care that is offered in the RQHR. Therefore, future palliative care research should also involve qualitative research which focuses on the quality of care delivered and received in the RQPCS and provincially. In depth interviews with palliative patients, their families and health care professionals will provide insight into the quality of palliative care offered by the RQPCS as well as Saskatchewan.

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Appendix I

Interview Guide

1. Define what optimal palliative care is?
2. What is the overall program goal of the Regina Qu'Appelle Palliative Care Program (RQPCP)?
3. What are the objectives of the RQPCP?
4. How do you measure whether the service objectives are being met?
5. How is palliative designation assigned in the RQPCP?
6. How are palliative individuals referred to the RQPCP?
7. How are palliative patients' needs assessed once referred to the RQPCP? How are appropriate services per individual coordinated?
8. What services are provided by the RQPCP to palliative individuals and families and in which locations are the services provided?
9. In terms of service flow, what is the expected trajectory for each individual?
10. How is the frequency of use for each service determined per individual?
11. How do you track patient outcomes?
12. How is the RQPCP workforce categorized (how many FTE, PTE, casual, nurses, home health aides, volunteers, administrators, specialists, pharmacists, chaplains, etc.)?
13. What is the breakdown of staff in each location where RQPCP services are offered?
14. To what extent do you feel the RQPCP is able to meet the needs of patients and family members in the region?

Appendix II

University of Saskatchewan Ethics Approval



**UNIVERSITY OF SASKATCHEWAN
BEHAVIOURAL RESEARCH ETHICS BOARD**

<http://www.usask.ca/research/ethics.shtml>

NAME: Anne Leis (Julia Porter)
Community Health & Epidemiology

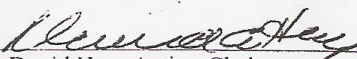
Beh-04-32

DATE: March 4, 2004

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the Application for Ethics Approval for your study "Palliative Patients and Their Health Services Utilization in the Regina Qu'Appelle Regional Health Authority" (Beh 04-32).

1. Your study has been APPROVED.
2. Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Committee consideration in advance of its implementation.
3. The term of this approval is for 5 years.
4. This approval is valid for one year. A status report form must be submitted annually to the Chair of the Committee in order to extend approval. This certificate will automatically be invalidated if a status report form is not received within one month of the anniversary date. Please refer to the website for further instructions
<http://www.usask.ca/research/behavrsc.shtml>

I wish you a successful and informative study.


Dr. David Hay, Acting Chair
University of Saskatchewan
Behavioural Research Ethics Board

DH/ck

Appendix III

**Regina Qu'Appelle Health Region Research Ethics Board
Certificate of Approval**



Certificate of Approval
Research Ethics Board

PRINCIPAL INVESTIGATOR	Dr. Anne Leis	Mailing Address:
APPROVAL DATE	October 5, 2005	Dr. Anne Leis, Associate Professor
RQHR PROJECT #	REB-05-30	Community Health & Epidemiology
TITLE	Palliative patients and their health services utilization in the Regina Qu'Appelle Health Region	University of Saskatchewan 107 Wiggins Road Saskatoon SK S7N 5E5

CERTIFICATION

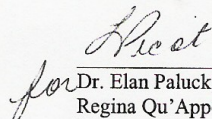
The protocol for the above named project has been reviewed by the Chair of the Regina Qu'Appelle Health Region Research Ethics Board and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

The Regina Qu'Appelle Health Region Research Ethics Board meets the standards outlined by Canada's Tri-Council Policy Statement for Ethical Conduct for Research Involving Humans.

The Regina Qu'Appelle Health Region Research Ethics Board has met the criteria for purposes of Section 29 of the *Health Information Protection Act*.

Please note that all future correspondence regarding this project must include the RQHR project number.

Best wishes in your continuing research endeavours.



Dr. Elan Paluck, Chair
Regina Qu'Appelle Health Region
Research Ethics Board

/lgp
cc. Ms. C. Klassen, Corporate Services, WRC

This Certificate of Approval is valid provided there is no change in the experimental procedures. Any significant changes to the protocol must be reported to the Chair for the Board's consideration, in advance of implementation of such changes. You are required to provide a status report on an annual basis.

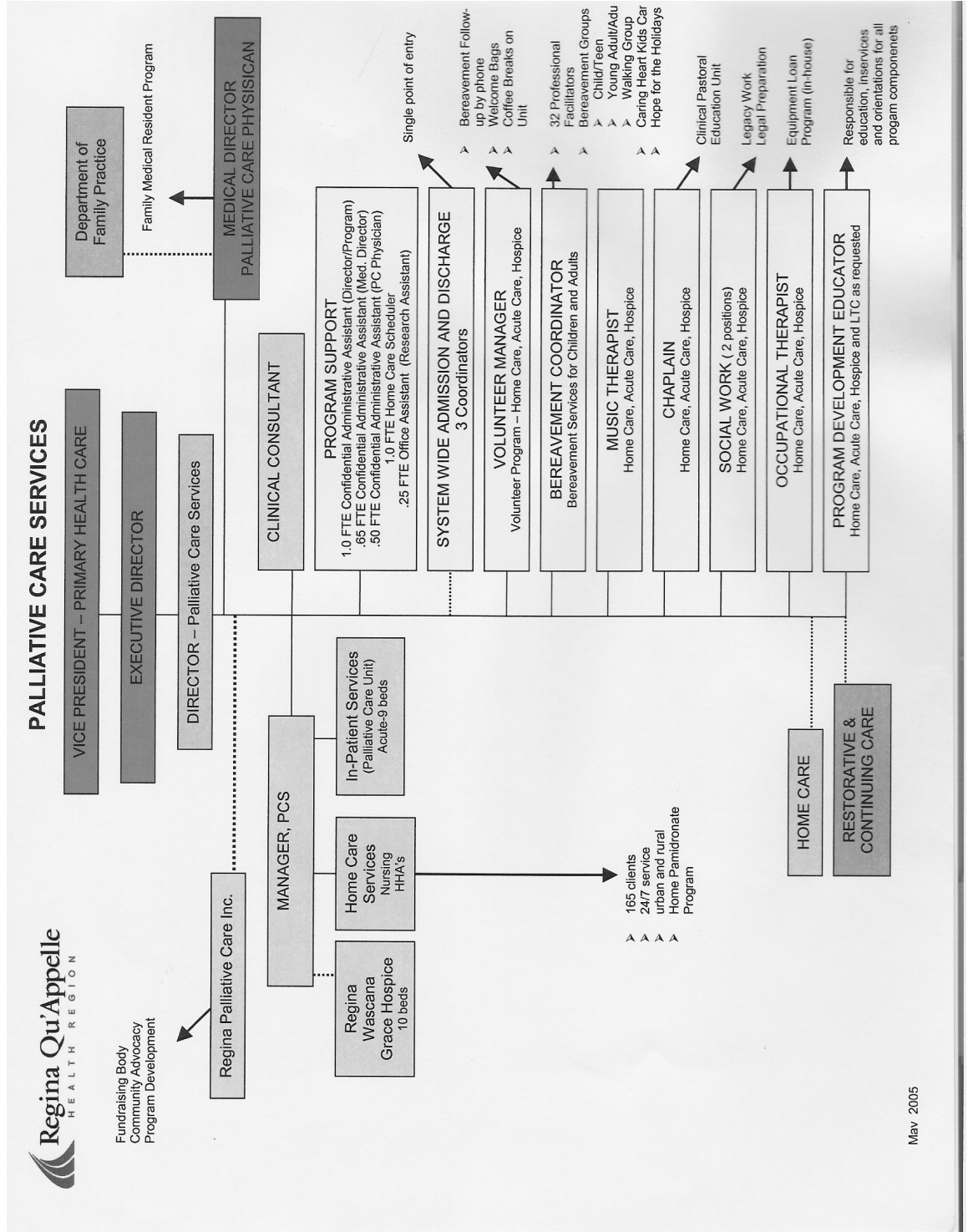
Appendix IV

Guiding Principles of the CHPCA

- *Patient/Family Focused* – treat patient and family as a unit, provide care remembering to be sensitive to the patient’s and family’s personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process.
- *High Quality* – ensure standards of practice are based on nationally-accepted principles and norms of practice, and implement policies and procedures which are evidence-based.
- *Safe and Effective* – provide collaborative care, ensure confidentiality, is without coercion, discrimination, harassment or prejudice, ensures continuity and is safe for all participants.
- *Accessible* – guarantee timely, equal access to care regardless of where clients reside.
- *Adequately Resourced* – ensure sufficient resources, both financial and human, to sustain organizational activities.
- *Collaborative* – hospice palliative care is a collaborative effort and recognizes the importance of partnering with community’s to assess and address needs.
- *Knowledge-Based* – ensure ongoing education of all patients, families, caregiver, staff and stakeholders.
- *Advocacy-Based* – regular interaction with legislators, regulators, policy makers, healthcare funders, palliative care providers, and associations to increase awareness about and develop hospice palliative care activities.
- *Research-Based* – develop, disseminate and integrate new knowledge in order to advance the quality of care provided.

Appendix V

Regina Qu'Appelle Palliative Care Services Graph



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