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EVALUATION OF THE PATHWAYS PALLIATIVE CARE PROGRAM AT THE DENVER HOSPICE

Submitted by Adam Bergquist

December 6, 2008

A Master's Thesis Presented in Partial Fulfillment
Of the Requirements for the Degree
Master of Science, Health Service Administration

Regis University

December, 2008

FINAL APPROVAL OF MASTER'S PROJECT

HSA696 MASTER'S THESIS

I have **READ AND ACCEPTED**

the Master's Thesis by:

Adam Bergquist

Evaluation of the Pathways Palliative Care Program at the Denver Hospice

Submitted in partial fulfillment of

requirements for the

Master of Science in Health Services Administration

degree at

Regis University

Primary Research Advisor: Janet Houser PhD

Date: December, 2008

Abstract

As the patterns of morbidity and mortality in the United States shift toward chronic illness requiring the need for quality continuous care over extended periods of time, more research has been devoted to end-of-life care. The purpose of this study was to evaluate the *Pathways* palliative care program at the Denver Hospice as seen through the eyes of patient caregivers. Nine caregivers were interviewed in order to determine their perceptions of the *Pathways* program and a thematic analysis of their responses was performed. Results of the thematic analysis, as confirmed by a second reviewer, yielded very positive feelings towards the *Pathways* program (Cohen's Kappa = 0.862). Respondents continually stated a deep sense of having a burden lifted with the knowledge that help as a phone call away and that the help would come quickly, and this peace of mind prevented the majority of the caregivers from helplessly taking their loved one to the emergency room. Overall, all nine of the caregivers were very impressed with the *Pathways* program, and in particular, the *Pathways* staff.

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Chapter 1: Introduction

Research from the last decade has demonstrated major deficiencies in medical care for patients with advanced illness. By 2030, 20 percent of the United State's population will be over the age of 65, and most elderly adults will develop one or more chronic illnesses, including congestive heart failure (CHF), cancer, and chronic obstructive pulmonary disease (COPD) (Centers for Medicare and Medicaid Services, 2007 & NHPCO, 2007). These chronic illnesses are often accompanied by pain and psychological symptom distress, high use of burdensome technologies, progressive functional dependence and frailty, and high family support needs.

Due to the Unite States' patterns of morbidity and mortality shifting toward chronic illness, disease trajectories have become more unpredictable leading to a marked need for higher levels of continuous care over extended periods of time (Lynn & O'Mara, 2004). However, the current United States healthcare system provides relief only for terminally ill patients in the form of the Medicare Hospice Benefit, enacted in 1982 (Centers for Medicare and Medicaid Services, 2007). Under this Medicare benefit, patients can receive most hospice services, including nursing services, durable medical equipment, medical supplies, prescribed drugs, and short-term hospital care, but a doctor and hospice medical director must verify that the patient has a terminal illness and has less than six months to live. Patients must also sign a statement choosing hospice care and forgoing curative treatments (NHPCO, 2007).

Additionally, because of the increased difficulty in predicting non-cancer deaths, such as CHF or COPD, doctors may delay referrals to hospice care in favor of continued curative and restorative treatments. Thus, even though hospice programs are designed to provide care for patients in the last 6 months of life, the median length of stay in the program is 20.6 days, 35% of patients die within the first 7 days after hospice admission, and approximately 50% of adult

deaths occur in hospitals, despite the fact that the majority of adults prefer to die at home if faced with a chronic illness (NHPCO, 2007). Studies also report that only one quarter of dying Americans use hospice services because they don't want to forgo curative and life-sustaining treatments (Weitzen, Teno, Fennell, Morrison, 2003).

The increased costs of specialized care for the dying have brought further attention to the need for improved end-of-life services. Care for the terminally ill has been estimated to represent between 10% and 12% of the United States' total health care costs, while the last year of a terminally ill patient costs more than \$31,000 on average (Penrod, Deb, Luhrs, Dellenbaugh, Zhu, Hochman, 2006). Terminally ill patients will average almost 24 days in the hospital per year, with 68% of those days being in the intensive care unit at a cost of \$1287 per day (Penrod et al., 2006). Studies also demonstrate that many of the hospital and emergency room visits by patients suffering from chronic illness could be avoided with guided pain and symptom relief (Brumley et al., 2007, Brumley et al., 2003).

Therefore, it is the purpose of this research to perform strong, methodologically sound evaluations of the *Pathways* palliative care program at The Denver Hospice in order to determine whether this service supports broader development and implementation of community-based palliative care and whether it is a program that can recruit appropriate payer sources. Namely, can the *Pathways* palliative care program improve the quality of patient care, increase patient and family satisfaction, and reduce costs associated with end-of-life care for the chronically ill? Specific to this thesis, qualitative measurements of the *Pathways* patient caregivers will be made to assess perceptions of their overall satisfaction with this Denver Hospice palliative care program.

In order to determine the efficacy of the *Pathways* program to accomplish these two goals, data will be collected on quality of care offered to *Pathways* patients, patient and family satisfaction, and measures of patient utilization and per patient cost. Additionally, this research project will add another layer of descriptive data concerning people's satisfaction with the *Pathways* program by interviewing patient caregivers. It is proposed that *Pathways* patients will be given higher quality care, demonstrate improved patient and family satisfaction, and show reductions in care costs due to decreased hospitalizations and emergency room utilization as compared to control patients. It is also believed that patient caregivers will have favorable views of the *Pathways* program as it relates to the care of their loved ones and as it relates to their own personal satisfaction.

The growth in the number and needs of chronically ill patients who may not yet be terminally ill has led to the recent rapid growth of hospital based palliative care (Morrison, 2005). Surveys of patients and families have shown that relief of suffering, open communication with physicians and nurses, opportunities to relieve burdens on families and the choice to seek curative treatments while receiving palliative care are top priorities that the healthcare system needs to address (NHPCO, 2007). Out of these concerns, several longer-term palliative care services have been developed to care for the elderly.

Palliative care focuses on the relief of pain, symptoms and stress of serious illness and improving the quality of life for patients and their caregivers. It can be started at any time during an illness, and unlike hospice care, palliative care can be provided in conjunction with other curative treatments. Most comprehensive palliative care services are located in hospitals and include a team of providers from different disciplines such as, doctors, nurses, nutritionists, physical therapists, and chaplains who provide support for the physical, emotional, and spiritual

needs of the patients and their families (NHPCO, 2007). This blended model of curative and palliative care introduces pain relief, psychological services, and symptom control earlier in the disease progression than if the patients had waited for hospice care.

Several studies have demonstrated many positive outcomes associated with hospital-based palliative care programs. These include reduced pain and other unwanted symptoms, improved quality of life for patients and families, reduced hospital and emergency department visits, and improved patient satisfaction with their care (Morrison, 2005, Higginson et al., 2003, and Ringdal et al., 2002). Research also indicates reduced per-patient and per-visit costs associated with treatments for chronic illnesses due to fewer Emergency Department and Intensive Care Unit visits while these studies show no differences in mortality between patients receiving palliative care compared to those who don't (Penrod et al., 2006, and Jordhoy et al., 2000).

The development of the specialty of palliative medicine has been a critical step in addressing the unmet needs of patients with serious illness and their families. As a result, the growth of this field has been remarkable. From 2001-2003, the number of hospital based palliative care programs has grown by over 60% such that now one in four U.S. hospitals has a palliative care program and all U.S. medical schools must provide training in palliative medicine (Center to Advance Palliative Care, 2006). As of 2005, 30% of US hospitals and 70% of hospitals with more than 250 beds reported the presence of a palliative care program, which is an increase of 96% from 2000 (Morrison et al., 2008) However, unlike hospice services that are covered under Medicare, palliative care services in the US are paid by philanthropy, fee-for service mechanisms or from direct hospital support (Center to Advance Palliative Care, 2006).

In addition, although there is evidence of improved care for seriously ill patients, at reduced costs under palliative care programs, the validity and reliability of these studies' findings

is limited by important methodological weaknesses (Morrison, 2005). Some of the studies were conducted in healthcare systems different from the United States' healthcare system, thereby reducing the ability to generalize the results. Other studies lacked a control group to compare to the intervention group, observed small samples, which limited their power to detect differences, or did not use appropriate statistical tools to account for confounding variables and reduce bias. Finally, the palliative care model that was implemented in many studies was not well described and highly variable in terms of the services provided and the level of training and education of the caregivers (Morrison, 2005). Therefore, to date, substantive evidence for the efficacy of palliative care programs is limited and inadequate to guide the development of future palliative care programs in the United States.

A further limitation of the current state of palliative care offered to elderly, chronically ill patients is a lack of diverse palliative services that can meet the needs of patients across broad community settings, not just in the hospital. Recently, some city-based hospice organizations have offered "hospice bridging programs" that are designed to provide palliative care for chronically ill patients who have not yet met the Medicare standards for true hospice care (NPCRC, 2007). Unfortunately, these hospice-based bridging programs have not been well studied to determine their effectiveness on such variables as the quality of care provided, patient and family satisfaction, and the reductions in cost (Brumley et al., 2007). Furthermore, the lack of strong empirically based research evaluating the effectiveness of hospice bridging programs has restricted the ability and motivation of healthcare providers to replicate and adopt these models as standard practice and has prevented these programs from garnering consistent payer sources to cover the costs for these community palliative care services.

The focus of this research was to evaluate The Denver Hospice *Pathways* Palliative Care

Program, which is a community-based palliative care service established in 2003. The Denver Hospice opened its doors in 1978 as a hospice care service intended to provide patients facing advanced illness with comfort, compassion, and quality of care (The Denver Hospice, 2007). Currently, The Denver Hospice is the largest hospice in the state of Colorado and provides care for one out of every five hospice patients in Colorado as well as being a very visible end-of-life care presence in the Denver metro area (The Denver Hospice).

Due to the increasing number of chronically ill patients who required treatment for their physical and emotional distress but were not yet eligible for hospice care, The Denver Hospice created the *Pathways* Palliative Care Program to provide access for these patients to supportive care services. Before, these patients would be forced to seek treatment for pain and other symptoms from the emergency department or through hospitalization, incurring extremely high costs (The Denver Hospice). The *Pathways* program allows patients and their families to receive the same supportive services offered in hospice, but at a time when patients do not qualify for hospice, or are not ready for hospice.

Specifically, the *Pathways* Palliative Care program consists of palliative care-trained nurse practitioners, a care manager, a social worker, a chaplain, and a collaborating physician. *Pathways* provides pain and other symptom relief, psychosocial and spiritual support, helping to coordinate the completion of advance directives, and helping to support difficult decision-making at the end of life (The Denver Hospice). These services can be given at a patient's home or in an assisted living facility. Emphasizing the great need among patients with life-limiting illness, the *Pathways* Palliative Care program has seen steady growth since its inception in 2003 (The Denver Hospice).

Evaluating the *Pathways* Palliative Care program will add to the current body of research

evaluating the efficacy of community-based palliative services in improving chronically ill patient's care while reducing costs associated with this care. The results of this study will also provide health care administrators of other large metropolitan hospices that operate outside of an integrated health system with valuable data concerning benefits to implementing palliative care programs of their own while offering well-described interventions and services that can be easily replicated and implemented. Furthermore, data from the *Pathways* program will allow The Denver Hospice, other palliative care programs, and other healthcare administrators the information and methodological approaches needed to leverage support from local and national insurers for future bridging services or new program ventures.

Chapter 2: Literature Review

Quality health care for those individuals with advanced chronic illness is lacking (Morrison, 2008). Currently, Medicare provides health care services for patients who are dying, however, the Medicare Hospice Benefit stipulates that a patient must forgo curative treatments for their disease and have been diagnosed with less than six months to live (Centers for Medicare and Medicaid Services, 2007). Due to these limitations, terminally ill patients have a median length of stay in hospice care of less than 21 days, and 35% of patients die within the first 7 days after hospice admission. Furthermore, left with no other health care alternatives, terminally ill patients often visit the hospital or emergency department where 50% of them will die even though over 90% of adults prefer to die at home if faced with chronic illness (NHPCO, 2007).

Due to the substantial gap in care provided for individuals facing chronic illness before they are eligible for hospice care, many hospitals and other community based hospice programs have begun to establish palliative care services. These palliative care services are designed to provide pain and symptom relief, to improve quality of life, and to provide support services for family caregivers while still allowing patients to seek curative treatments (NHPCO, 2007). As of 2006, over 40% of hospitals provide palliative care consult services (70% in hospitals with more than 250 beds) and strong clinical palliative care programs are now firmly established in multiple settings and venues (Fromme, et al, 2007). However, although there have been many studies that have evaluated the efficacy of these palliative care programs in the past ten years, palliative care research, especially in community settings, remains relatively underdeveloped.

The purpose of this research study is to evaluate the *Pathways* palliative care program at the Denver Hospice to determine whether this service supports broader development and implementation of community-based palliative care and to provide supporting evidence of

adequate utilization and cost reduction so as to recruit outside payers and insurers. Can the *Pathways* palliative care program improve the quality of patient care, increase patient and family satisfaction, and reduce the costs associated with end-of-life care? To add an additional layer of descriptive information and to explore the perceptions of those participating in the *Pathways* program, qualitative measurements of the *Pathways* patient caregivers and nurses will be made to attempt to understand the good and the bad associated with *Pathways*.

The body of research is growing in the field of palliative care and this study would add to that literature by evaluating a community-based program operating in a large metropolitan area. In order to encourage outside payers and insurers to the merits of palliative care as a viable treatment option for those patients facing chronic illness, rigorous evaluations of the impact of palliative care programs on patients and families and the cost effectiveness of such programs are needed (Carlson, 2007). Furthermore, appropriate evaluation methodologies and standards of success must be carefully established so that the efficacy of palliative care programs can be objectively measured.

The Need for Improved End-of-Life Care

The United States' population is aging and it is estimated that by the year 2030, 20 percent of this country's inhabitants will be over the age of 65, and most elderly adults will develop one or more chronic illnesses (NHPCO, 2007). Despite advances in medical technology, hospital care for patients with advanced illness and their families still needs improvement as evidenced by several studies.

First, research done by Fried et al. (1999) demonstrated that the majority of terminally ill patients interviewed for this study preferred to die at home if given the choice. Thomas et al. (2004) took this a step further when they discovered that not only did 68 percent of terminally ill

patients prefer to die at home or under hospice care, but not one patient stated that their preference was to die at a hospital. Yet, data gathered from the 1993 National Mortality Followback Survey has shown that nearly 60 percent of deaths occurred in hospitals (Weitzen, 2003).

Weitzen (2003) also discovered that individuals enrolled in an HMO were more likely to die in a hospital compared to non-members, and that heart disease and COPD were some of the most prevalent chronic conditions leading to death in hospitals. Hospice care does allow for more home deaths, giving more than three quarters of patients the luxury of avoiding a hospital death, however, hospice still remains under utilized (NHPCO, 2007).

The underutilization of hospice care is very evident in those patients suffering from diseases that are unpredictable (Enguidanos, Chrin, & Brumley, 2005). In 2002, only 23 % of Medicare decedents received hospice care before death and nearly half of these patients died from cancer, which tends to follow a more predictable course. Diseases such as congestive heart failure, myocardial infarction, and lung cancer are much harder to predict in terms of life expectancy of the diagnosed patient, thus leading to late referral to hospice or no referral at all. In fact, patients diagnosed with diseases that follow an erratic trajectory usually die within two weeks of hospice admission, missing out on end-of-life care until just before death (Enguidanos et al., 2005).

Finally, due to several factors including the increasing costs of health care, and in particular the high costs of specialized care for the dying, end-of-life care is costing patients and taxpayers enormous amounts of money for less than quality services (Brumley, 2003). End-of-life care has been estimated to account for approximately 12% of the United States total health care costs, while simultaneously costing individual patients an average of \$31,000 for terminal

care in the last year of life (Emanuel, 1994) & (Penrod, 2006). Additionally, Medicare patients in the last year of life account for 25% of total Medicare costs even though this population represents less than 5% of Medicare recipients (Enguidanos et al., 2005). The costs of care for congestive heart failure, and chronic obstructive pulmonary disease are especially high, with hospitalization for congestive heart failure costing approximately \$17.8 billion in annual health care expenditures, and a study of expenditures in the last year of life showed that more than half of expenditures for those dying from congestive heart failure and chronic obstructive pulmonary disease were attributable to hospital care (Emanuel & Emanuel, 1994). Clearly there is a strong need for quality care for chronically ill patients prior to their enrollment in hospice.

The History of Palliative Care

In 1982, the United States government enacted the Medicare Hospice Benefit, which provides end-of-life care for patients who are diagnosed with less than six months left to live with the hope of allowing individuals to live out the time they have remaining to the fullest extent possible (Centers for Medicare and Medicaid Services, 2007). Under this Medicare benefit, patients are able to receive pain management, symptom management, nursing care, medical equipment, medical supplies, and drugs for pain relief of symptom control. Additionally, the hospice benefit provides psychosocial and spiritual support, and counseling for patients and their families (Centers for Medicare and Medicaid Services, 2007). As a result, there has been a steady increase in the utilization of hospice care over the years, with a 162% increase in the last 10 years alone (NHPCO, 2007).

However, due to several factors, the median length of stay for a patient in hospice has actually declined over the last 5 years to the current period of 20.6 days with 35% of patients dying within the first 7 days after hospice admission (NHPCO, 2007). Why are people waiting so

long before enrolling in a hospice program given Medicare allows for up to 6 months of care? Some people associate hospice with death and choose to put off this form of care as a last resort. Others are reluctant to give up curative treatment, which is a requirement for the Medicare Hospice Benefit, in the hopes that some treatment may still work to cure their disease. However, perhaps the biggest reason for patients forgoing hospice care is due to the fact that death is becoming unpredictable with the shift towards chronic illness (Morgan, 2003).

Research has shown a shift in the patterns of morbidity and mortality toward chronic illness that is marked by unpredictable disease trajectories, as opposed to sudden, more predictable deaths (Morgan, 2003). This change in illness patterns has made it difficult for physicians to discuss death with their patients and in predicting life span, thereby limiting referrals to hospice care until patients are too far along. At present, 75% of Medicare patients die of a disease other than terminal cancer, which is often characterized by sudden death, and the majority of these other diseases cause patients to deteriorate slowly, sometimes taking multiple years (Brumley, 2003). Non-cancer patients are not referred to hospice as readily as cancer patients due to the difficulty involved in predicting life expectancy for non-cancer diseases, such as congestive heart failure, and the unpredictable trajectories associated with these illnesses (Brumley, 2003).

Due to what many patients, doctors, and researchers alike feel is an irrational end-of-life care model that still allows patients with advanced life-limiting illnesses to suffer needlessly in the final stages of their lives, several continuous care models of palliative care have developed. The World Health Organization (2002) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and

impeccable assessment and treatment of pain and other problems, physical psychosocial and spiritual. Palliative care also offers a support system to help patients live as actively as possible until death while enhancing and prolonging their life, and can aid in family coping.”

Palliative care focuses on pain and symptom management as well as improving the overall quality of life for patients and their caregivers. It affirms life and regards dying as a normal process, and it offers a support system to help patients live as actively as possible until death. Palliative care also offers a support system or team to help family cope during the patient’s illness and in their own bereavement (World Health Organization, 2002). Psychosocial and spiritual support is provided as well as grief and death counseling. Palliative care also allows patients to continue with other treatments, including curative treatments, and can be started at any time during an illness (NHPCO, 2007).

Palliative care began initially in hospitals as a way to treat the chronically ill that would come to the emergency department. Over the past 10 years, palliative care has experienced substantial growth and development including strong advances in palliative care education and training, increasing penetration of palliative care content in medical school and residency curriculums, further training in palliative care as a part of nursing education programs, and a rigorous certifying board examination for physicians and nurses has been developed (Fromme et al., 2007). Currently, 40% of hospitals will have palliative care consult services where multidisciplinary teams provide care for chronically ill patients, and strong clinical palliative care programs are now becoming established in multiple settings and venues including outpatient clinics and as a part of community hospice programs (Fromme et al., 2007).

Additionally, in September, 2006, the American Board of Medical Specialties, under the broad sponsorship of 10 different primary medical boards, voted to recognize hospice and

palliative medicine as a subspecialty (Center to Advance Palliative Care, 2006). This designation allows for palliative care to be considered a distinct medical specialty, having a characteristic philosophy, specialized skill sets, and specific service delivery needs. Now, family physicians, internists and doctors in eight other specialties can be board certified in hospice and palliative medicine, giving credibility to the practice of palliative care in hospitals and in other settings (Center to Advance Palliative Care, 2006). Whereas we can point to these many successes in palliative care development over the past 10 years, palliative care research remains relatively underdeveloped. The evidence base for how palliative care is delivered in clinical practice remains sparse compared to more established medical specialties and important research questions in palliative care have yet to be adequately addressed or answered.

Palliative Care Research

Hospital-based studies.

To determine whether palliative care services are beneficial, many studies have been done in hospital-based programs. Variables of interest when researching palliative care include, pain reduction, non-pain symptom improvement, patient satisfaction, psychosocial and spiritual care, communication, and addressing grief and bereavement (Fromme et al., 2006). Cost reduction is another variable of interest in evaluating palliative care programs in order for hospital administrators to make informed decisions about the financial impact of adding palliative care to their end-of-life services.

Several studies have demonstrated a marked reduction in pain and other non-pain disease symptoms as a result of standard analgesic therapies provided by a hospital palliative care program (Penrod et al., 2006; Higginson et al., 2003; Ringdal et al. 2002; London et al., 2005). Ringdal et al. (2002) also provides evidence of improved patient satisfaction with their palliative

care and with the way they were treated, while a qualitative study of a palliative care day service by Low et al. (2005) showed that patients perceived an improvement in their quality of life as a result of being a part of the day service.

Research measuring psychosocial and spiritual well-being as a result of palliative care are harder to do and to analyze, but a study by Chochinov et al. (2005) asked patients a series of questions addressing issues that mattered most to them both before targeted spiritual and psychological counseling and afterwards. Examples of interview questions include, “What are your hopes and dreams for your loved ones?”, and “What have you learned about life that you would want to pass on to others?” The responses to preintervention versus postintervention measures showed a statistically significant improvement in “suffering” and “depressed mood” (Chochinov et al., 2005).

Although the majority of hospital-based palliative care research demonstrates improvements in pain and symptom relief of patients, there are some studies that have shown negative results or inconsistencies among hospitals. For example, a controlled trial done by Rabow et al. (2004) discovered that palliative care intervention patients had less anxiety and improved spiritual well-being, yet recorded no change in pain, depression, quality of life, or satisfaction with care when compared to controls. Similarly, Twaddle et al. (2007) found significant variability in palliative care performance across 35 academic hospitals in the United States on such variables as psychosocial support, communication with family/physician, pain reduction and overall satisfaction.

Integrated (home-based) studies.

Once removed from the hospitals, the amount of research devoted to other settings of palliative care is much less. The four studies referenced here were all conducted at large health

maintenance organizations (HMOs) that contracted with outside providers for home health and hospice care. The first study by Brumley et al., (2003) took place at Kaiser Permanente TriCentral Service Area located in Southern California. The research team compared individuals matched on equivalent diagnoses that were non-randomly enrolled in either the Palliative Care Program or the usual care home health program offered by Kaiser. The Palliative Care Program for this study was based on the Hospice Medicare benefit with modifications to provide care over longer periods of time. All participants were diagnosed with a life-threatening disease and given one to two years to live (Brumley et al., 2003). Results from this study demonstrated a significant improvement in patient satisfaction, a decreased use of the emergency department, fewer hospital days, skilled nursing days and physician office visits, and a reduction of medical costs of care by 45% for the palliative care program group (Brumley et al., 2003).

Four years later, Brumley et al. (2007) published a similar study, this time focusing on two HMOs, one in Colorado, and one in Hawaii. As in the first study, participants were given approximately one year or less to live and had one or more hospital or emergency department visits within the previous year. The palliative care intervention group also received palliative care based on the Hospice Medicare benefit that could be extended longer and patients could also undergo curative treatments, however, in the 2007 study, patients were randomized into the palliative care and the usual care groups. Results of the study were similar to the 2003 version with palliative care patients showing statistically significant improvements in satisfaction, fewer emergency department and hospital visits, and lower costs of care compared to the control subjects. Additionally, the more recent study found an increase in the number of patients that died at home as opposed to an acute care facility (Brumley et al., 2003).

Another Kaiser Permanente study conducted by Enguidanos et al. (2005) added to the results found in the first study conducted by Brumley et al. (2003), by focusing on disease type and how particular diagnoses would affect site of death and overall costs. The three disease types studied were cancer, congestive heart failure (CHF) and chronic obstructive pulmonary disease (COPD). Results indicated a significant difference in site of death for those patients receiving home-based palliative care as compared to the patients receiving normal care, with the palliative care patients more likely to die at home. This finding was true for all three disease types (Enguidanos et al., 2005). Similarly, enrollment in the palliative care program was significantly associated with declines in costs of care for each disease; however the cost reductions were greatest for CHF and COPD.

Finally, in a very recent study by Sweeney et al., (2007) conducted at a large HMO in California, subjects were non-randomly assigned to either a usual care management group that consisted of traditional end-of-life services, or to a patient-centered management group that was an independent, for-profit program with 13 years experience. The patient-centered management program consisted of palliative therapies given by trained nurses providing the day-to-day patient care, with a central physician and manager overseeing the entirety of the care. Similar to the previously mentioned Brumley studies, Sweeney et al., (2007) found reductions in emergency department visits, hospital days, inpatient admissions, and overall care costs comparing patient-centered management patients with control patients. Sweeney and colleagues also discovered that intervention patients increased the number of home care days they received, had a 62% increase in hospice days and demonstrated a reduction in inpatient diagnoses, such as nausea and dehydration, due to a more coordinated care model for the patient-centered management patients (Sweeney et al., 2007).

To date, there is a small sample of studies that have shown no improvements in pain and symptom relief, patient satisfaction, or a reduction in hospital and emergency department utilization for patients treated with a home-based palliative care program. However, a systematic review of palliative care literature by Thomas et al., (2006) demonstrated that most of these studies were conducted over 10 years ago when palliative care as a medical subspecialty had no rigorous system of standards or medical certification requirements, or were conducted on small samples of patients.

Community and hospice-based studies.

Even fewer studies exist on terminally ill patients who receive palliative care services from a community or hospice-based program. One such purely qualitative study was done in the United Kingdom looking at the impact of palliative care day services (PCDS) on patients and their caregivers (Low et al., 2005). PCDS are well established in the UK, and similar to palliative care in the United States, their purpose is to improve patients' quality of life by providing pain management in addition to other curative treatments. The study by Low et al. (2005) sought to discover the perceived impact PCDS have on patients and the individuals who care for them. The results show that patients perceive an improvement in their quality of life as a result of PCDS, yet their caregivers show no improvements in their own personal quality of life even though they fully support the program.

Another study on a health care system outside the United States' was conducted in Mataro, Spain by Serra-Prat et al. (2001), which researched the effectiveness of the *Programa d'Atencio Domiciliaria i Equips de Suport* (PADES) palliative care program. The PADES program developed out of a World Health Organization pilot program that sought to improve end-of-life care by providing health and social service support teams for patients in their homes.

There are now over 50 PADES programs in the Catalan region in Spain which provide palliative care services such as, pain management, grief counseling and help with daily activities. Serra-Prat et al. (2001) discovered that when compared to patients given standard treatment, PADES patients went to the hospital and emergency department less and for shorter lengths of stay, utilized palliative care units within nursing homes fewer times, and demonstrated an overall 71% decrease in cost per patient for the month period of study.

Studying patients in the U.S., Rabow et al., (2003) performed research on an urban, academic medical center that provided an outpatient palliative care center for patients that were referred by their PCP. Results from this qualitative, interview-based study state that 34% of patients in the palliative care service reported decreased primary care visits, 23% reported avoiding emergency department visits, and over 80% reported improved satisfaction with family caregivers and primary care physicians. However, the sample size was only 35 patients who completed the final interview.

One of the very few studies conducted on a palliative care program that was initiated by an existing hospice program was done in Kentucky at The Hospice of the Bluegrass (Passik et al., 2004). The main aim of the study was to determine if there were any cost benefits to the existing hospice program after adding the palliative care service, which will be examined further in the next section. It is worth noting that Passik et al. (2004) did not find a reduction in cost with the addition of the palliative care program to The Hospice of the Bluegrass, and in fact they saw a decrease in the hospice length of stay for patients that were initially enrolled in the palliative care program even though patients were overall satisfied with the new palliative services. Clearly, palliative care research is sparse in settings away from the hospital, and this is also true when assessing any potential cost benefits to a palliative care service.

Does Palliative Care Reduce Costs?

It has been previously well documented that initiating palliative care earlier in a patient's battle with a chronic illness can improve that patient's quality of life and can allow for fewer hospital and emergency department visits. However, establishing that palliative care is also cost efficient, in addition to the many other stated benefits, will go a long way towards securing funding for future palliative care programs around the country. This is especially true given that patients dying of chronic conditions, such as chronic obstructive pulmonary disease, congestive heart failure and cancer incur consistently high expenses (about \$58,000 in the last two years of life) and account for approximately 10-12% of all U.S. health care costs (Wennberg, 2005; Riley, 1989). Unfortunately, the research is quite mixed with several studies praising the cost benefits of palliative care and several others showing no change in cost or even higher costs associated with palliative care (Thomas et al., 2006).

Hospital-based palliative care programs have most often shown a large reduction in costs associated with palliative care as compared to normal end-of-life care. Specifically, studies by Smith et al., (2003) and Cowan (2004) demonstrate a per-patient cost reduction of between 66% and 71% for palliative care patients compared to normal care. More recently, a study of eight hospitals conducted by Morrison et al. (2008) compared patients who received palliative care to case-matched controls who received normal care and found a significant reduction of \$4908 in direct costs per admission and a reduction of \$374 in direct costs per day for the palliative care patients. This study also demonstrated a significant cost savings for the patients receiving palliative care in pharmacy, laboratory, and intensive care unit costs as compared with the usual care patients. In more dollar terms, Penrod et al. (2006) discovered that total direct costs for

palliative care patients were \$239 per day, per patient lower than for normal hospital care patients.

Home-based palliative care programs seem to add more variation in cost increases or decreases comparing palliative care to normal care. The three Kaiser Permanente home-based palliative care studies from 2003, 2005 and 2007 all reported between a 33% and 67% decrease in costs associated with palliative care compared to normal care while allowing patients to continue to receive all usual medical services and care, however, since these studies were conducted within a managed care organization, generalizability of the findings is limited to similar benefit structures, such as other managed care organizations and the Veterans Administration Health Plan (Brumley et al., 2003, Enguidanos et al., 2005, & Brumley et al., 2007). Similarly, a home-based palliative care model in Spain also resulted in a 71% decrease in the cost of care compared to normal care (Serra-Prat et al., 2001).

Conversely, Taylor et al. (2007) found that health care costs for home-based patients cared for by the Veterans Affairs palliative care team were 12.2% higher compared to those receiving conventional care from other providers even though the palliative care patients had fewer hospital admissions. Two recent studies reached similar conclusions. A study by Buntin & Huskamp (2002) showed no reduction in end-of-life costs for those patients receiving palliative care treatments at home, and another study published in 2002 found that although palliative care did reduce hospitalizations and intrusive interventions, total costs were not reduced for the last year of the patients life (Payne, Coyne, & Smith, 2002).

Perhaps the discrepancies found in the aforementioned studies dealing with medical costs for patients suffering with chronic illness are due in part to which “costs” are measured. An article in the *Clinics in Geriatric Medicine* journal in 2004 demonstrated that recent research

studying costs associated with palliative care had just scratched the surface of the potential costs and benefits (Boni-Saenz, Dranove, Emanuel, Lo Sasso, 2004). This article stated that a comprehensive analysis on palliative care cost-benefits should measure four key elements based on guidelines established by the United States Panel on Cost-Effectiveness. These are patient medical costs and benefits, patient non-medical costs and benefits, family medical costs and benefits, and family non-medical costs and benefits (Boni-Saenz et al., 2004).

Most research on potential cost savings associated with palliative care focus solely on the patient medical costs and benefits, leading to mixed results. Yet, because palliative care also includes a focus on family caregivers, there are significant cost benefits associated with family medical and non-medical expenses that are often overlooked (Boni-Saenz et al., 2004). For example, a study on caregiver burden in 2003 showed that those people caring for a terminally ill family member were more likely to have increased stress, depression, and increased risk of heart disease creating their own personal medical costs in addition to those accrued for the terminally ill patient (Lee, Colditz, Berkman, Kawachi, 2003). Palliative care can help to reduce the medical costs of the caregivers by offering services aimed at improving caregiver quality of life while also attenuating some of the stress associated with caring for a loved one. This was shown in a study by Christakis and Iwashyna (2003) where caregivers of patients participating in a hospice program had a significantly decreased rate of death compared to normal care.

Reductions in costs associated with palliative care must also factor in the non-medical patient and family costs. These include costs for transportation, homemaking, and personal care, as well as lost time at work (Boni-Saenz et al., 2004). Lost wages have a particularly large impact when quantifying the total costs associated with a terminal illness because this can affect both the patient, who must take off of work when experiencing pain or other symptoms, and the

caregiver, who may work fewer hours while caring for a terminally ill loved one (Boni-Saenz et al., 2004). Palliative care may improve pain and other symptoms enough to enable workers to remain on the job longer and could provide some base care for the ill patient allowing caregivers to return to work, both of which would reduce the total costs (Boni-Saenz et al., 2004).

The current literature, with the focus on patient medical costs alone, has indicated that the advantages of palliative care are small, if any are shown at all. The article by Boni-Saenz et al. (2004) has shown that the effects of palliative care on the family costs and other non-medical costs may be significant and must be studied in future cost-benefit analyses in order to determine the true savings involved. Adding complexity to the study of costs are palliative care programs that emerge out of existing hospice programs and will be the focus of the next section.

Costs associated with hospice-initiated Palliative care programs

Finally, studies on potential cost reductions for existing hospice programs that initiate palliative care programs are extremely rare and present multiple challenges (Passik et al., 2004). When studying hospital palliative care programs, cost savings can include shortened length of stay, reductions in emergency department admissions for patients who continue to return because of symptom management problems, and decreased stays in intensive care units by dying people (Penrod et al., 2006). Starting a palliative program in a hospital begins with anticipating future patients' needs, and attempting to plan a more economically viable way of delivering care, partly through avoiding costly overtreatments (Passik et al., 2004).

Hospice palliative care programs operate much differently. When a hospice facility initiates a palliative care program, it is hoping to influence the care provided to a patient at an earlier point on the patient's disease trajectory, attempting to integrate its services earlier. Unfortunately, the same cost savings from avoiding costly overtreatments as in hospitals are not

present in hospice care because hospice programs don't employ those treatments to begin with. Another difference lies in how hospitals and hospices are funded. Since hospices are funded primarily through the Medicare Hospice Benefit, more patient enrollees into hospice and longer lengths of stay actually generate more money for hospices (Passik et al., 2004). In both cases, palliative care centers rarely generate money, but they do yield rather significant cost savings for hospitals. Passik et al. (2004) demonstrated these trends when it was discovered that The Hospice of the Bluegrass actually lost money after initiating a palliative care program because patient length of stay in hospice went down, and drug and other ancillary costs increased due to a larger number of more complex patients.

As the Passik et al. (2004) study proves, cost savings realized by hospitals that initiate palliative care programs don't simply transfer into savings for hospice programs that do the same. However, is saving money for the hospice program really the only variable of interest? If it can be shown that total medical costs per chronically ill patient are, in fact, reduced with palliative care in general, would hospices be able to secure funding from other payers, like insurance companies, that would financially rather have their patients enrolled in a palliative care program as opposed to the traditional expensive end-of-life care? More research is needed in the area specific to hospice-initiated palliative care programs and in more viable and useful ways of interpreting the financial information generated.

Summary

Despite the substantial growth and development of palliative care over the past decade, palliative care research remains relatively underdeveloped, and important research questions in palliative care have yet to be adequately addressed or answered. In a review of palliative care by Dr. Morrison (2005), he discovers that much of the existing research focuses on hospital-based

palliative care programs that employ too small of sample sizes to detect significant changes in pain and symptom relief and that lack appropriate comparison groups. Additionally, research on home-based programs are generally from health care settings in other countries that are very different from the privately and publicly funded health care system in the U.S., thereby limiting the ability to generalize the findings to similar palliative programs in this country (Morrison, 2005).

Further analysis of palliative care research by Thomas et al. (2006) points out that many of the palliative care intervention teams that have been studied provided care before more recent standards of treatment were established and before advanced certifications in palliative care were needed. Thus, it is impossible to replicate the treatments that were provided in these studies for future comparisons. Similarly, the measures and surveys used by several studies to evaluate the quality of palliative programs, such as patient satisfaction, pain reduction, and caregiver satisfaction have been lacking in internal validity and reliability scores. Finally, due to the existence of many unmeasured confounding variables that make patients seeking palliative care different from patients who received usual care, there are no studies to date that have evaluated nor demonstrated that palliative care is cost-effective, an important piece of information if palliative care programs are going to develop further and to more settings (Thomas et al., 2006).

If the field of palliative care in the United States is to advance further, future studies must address three prominent areas of research design and methodology: using proven measurement instruments, applying appropriate research designs, and employing appropriate analytical techniques (Penrod and Morrison, 2004). The complete evaluation of the Denver Hospice *Pathways* program will include multiple quantitative analyses to establish whether patients received adequate care, whether quality of life improved, and whether there were significant total

cost reductions associated with the palliative care model. However, it will be the focus of this research to qualitatively measure the satisfaction of the *Pathways* patients' caregivers in order to understand the perceptions and concerns this group of people have with the *Pathways* program. The caregiver is defined as the person responsible for providing the large majority of care to the patient and whose opinions and perceptions have, for the most part, not been studied. Their voice is important in shaping the care and services provided to those struggling with chronic illness as.

Chapter 3: Methods

Methodological Approaches

Research designs

The evaluation of the *Pathways* palliative care program at the Denver Hospice was quasi-experimental in nature, utilizing both quantitative and qualitative data collection and analysis. Quantitative analysis was used to assess patient care, quality of life scores, patient satisfaction and costs associated with patient care. A listing of the variables measured throughout the entire evaluation study can be found in Appendix A. The focus of this research was on the qualitative measurements of the satisfaction of the caregivers who were involved with the *Pathways* program (bolded sections in Appendix A). Additionally, the qualitative analysis explored why caregivers feel the way they do about palliative care and what might improve the *Pathways* program in the future.

Although the randomized controlled trial (RCT) is the most powerful research design for demonstrating a cause and effect relationship between a certain treatment, such as palliative care, and an outcome, such as reduced costs, its usefulness in palliative care research is limited (Penrod and Morrison, 2004 & Ioannidis, et al., 2001). First, withholding palliative care from a comparison group, as in a randomized control study, is often deemed unethical if it is well established that the given treatment would benefit the patient. Second, the ability to generalize the results of a RCT study, whose population is rigorously controlled, to other populations is limited, and thus, it is hard to determine if the effects of the palliative care treatment in a RCT would be just as effective in another clinical practice or setting. Finally, RCT studies cannot answer questions related to death and prolonging life due to the lack of a viable control group (Penrod and Morrison, 2004; Twaddle et al., 2007).

Due to these limitations in RCT research, many palliative care studies employ observational, evaluation, or other quasi-experimental designs (Thomas et al., 2006). Evaluation studies are very effective in determining whether a particular program or intervention is effective in bringing about certain desired outcomes that are specified beforehand. For example, London et al. (2005) implemented an evaluation study to determine the effect of the Comprehensive, Adaptable, Life-Affirming, Longitudinal (CALL) palliative care intervention on a population with life-threatening illness. Participants reported improved pain and symptom management after the CALL intervention, and only 29% were hospitalized. Additionally, London et al. (2005) reported that 48% of participants in the CALL program enrolled in hospice and 38% died at home. A study of this nature is useful because it demonstrates that the CALL palliative care program was indeed effective and the results can be used as benchmarks for future studies in different settings and with different populations.

Evaluation studies also have the advantage of combining quantitative and qualitative analyses to the program of interest. Whereas most palliative care studies assessing improvements in quality of life, patient satisfaction, and cost reductions rely heavily on quantitative analysis, qualitative methods are increasingly being used in palliative care research (Henderson & Rheault, 2004). Qualitative research “seeks to understand a social or human problem through an inquiry process” (Henderson & Rheault, 2004). The aim in qualitative research is to answer the question of “why” while observing people in their natural environment. The information gathered is very rich and descriptive and can offer insight into the complex nature of people and their perceptions and feelings, adding another layer to the quantitative data.

Additionally, in conducting research into the efficacy and effectiveness of palliative care programs, qualitative research designs allow for a much more thorough understanding of what

people value and perceive. The responses to interview questions are not limited to discrete words or phrases on a survey as respondents are allowed to speak freely and express their opinions and feelings with open-ended questions. Thus, the descriptions garnered about the quality of palliative care programs reveal a very useful complexity with thick descriptions that can be analyzed for common themes. With its inductive and naturalistic approach, qualitative data have high content validity and can still be held to the rigors of quality research utilizing unbiased, second readers to objectively analyze the content of qualitative responses. Hence, qualitative methodology offers a suitable approach to evaluation of end-of-life programs, and increasingly, other studies have identified important benefits to patients using qualitative methods (Low et al., 2005).

Participant Selection

The *Pathways* nurse care manager contacted patient caregivers who were already enrolled in the *Pathways* palliative care program via telephone to explain the purpose of the study and to ask if they were agreeable to be interviewed. The goal was to interview between nine and twelve caregivers. Participants represented a purposeful sample aimed at encompassing the diversity within *Pathways* from the perspective of age, gender, chronic illness of the patient, days in the *Pathways* program, relationship to the patient and location within the Denver Metro Area.

To be included in the interview, patient caregivers had to have been enrolled with the *Pathways* program for at least one month and were identified by the patient as providing the most care outside of the *Pathways*' staff. Participants also had to agree to being interviewed and be willing to share their thoughts about the *Pathways* program. After identifying caregivers that

met the aforementioned criteria, ten individuals were called and ultimately nine caregivers agreed to be interviewed.

Measurement instruments.

In-depth interviews consisting of seven questions were used to assess the caregivers' perceptions of the *Pathways* palliative care program and were administered by a graduate student researcher with experience in conducting individual and group interviews. An example of the interview questions can be found in Appendix B. A caregiver is defined as the person identified by the *Pathways*' patient as providing the majority of their emotional and physical support.

Assessing what a person feels or perceives can be accomplished using direct observation, written documents or other artifacts, and through in-depth interviews (Neuendorf, 2002 & Rabow et al., 2003). The goal of the researcher is to encourage informants to elaborate their feelings and thoughts by asking open-ended questions and to report what people say. Thus, the researcher is the main instrument and the depth of response from the participants is due in part to the effectiveness of the questions being asked.

Pathways Palliative Care program

The *Pathways* Palliative Care program consists of palliative care-trained professionals including full-time Nurse Practitioners (2.75 FTE's), Care Manager (RN, 1 FTE), Social Worker (.25 FTE), Chaplain (.125 FTE), a collaborating physician and an administrative assistant (.5 FTE) that provide services to all of the Denver Metro area including the counties of Denver, Arapahoe, Boulder, Jefferson, Adams, Elbert, Broomfield, and Douglas (The Denver Hospice, 2008). The *Pathways* program is an interdisciplinary team that offers support to patients and their families by enhancing comfort, relieving pain and other distressing symptoms, providing

psychosocial and spiritual support, assisting the patient and family complete advance directives, and supporting difficult decision-making during the chaos and confusion at the end of life (The Denver Hospice, 2008).

In addition, patients are allowed to continue curative treatments while receiving palliative care, providing a blended model of care that is constantly monitored and evaluated by the *Pathways* team. Services are provided in varied settings including skilled nursing and assisted living facilities and in patient's homes. This patient-centered approach integrates patient and caregiver cultural, spiritual, and care preferences into the care plans, which encourages patients, family members and their nurses to exchange knowledge and facilitates communication on treatment preferences (The Denver Hospice, 2008).

Data Collection

Data was collected from nine caregiver interviews taking place in the spring and summer of 2008. The verbal content of the caregiver interviews was audio taped and transcribed verbatim for thematic content analysis.

Data Analysis

In order to assess the trustworthiness of the qualitative data gathered from the caregiver interviews, both the interview questions and the methods of analyzing the verbal responses to those questions were evaluated against the Rosalind Franklin Qualitative Research Appraisal Instrument (RF-QRA) (see Table 1) (Henderson & Rheault, 2004). The RF-QRA describes the four aspects of trustworthiness and their quantitative research equivalents as Credibility (Internal Validity), Transferability (External Validity), Dependability (Reliability), and Confirmability (Objectivity).

Table 1:

Rosalind Franklin-Qualitative Research Appraisal Instrument (RF-QRA)

<p style="text-align: center;">Credibility – can you believe the results?</p> <p>Example Strategies:</p> <ul style="list-style-type: none"> - Prolonged engagement - Field journal - Subjects judge results as credible - Triangulation: multiple data sources, methods, or investigators - Establish competence of researcher
<p style="text-align: center;">Transferability – can the results be transferred to other situations?</p> <p>Example Strategies:</p> <ul style="list-style-type: none"> - Detailed description of sample and context - Compare sample to larger group - Representative sample
<p style="text-align: center;">Dependability – Would the results be similar if the study was repeated?</p> <p>Example Strategies:</p> <ul style="list-style-type: none"> - Detailed description of methods - Two or more researchers independently judge the data - Triangulation: multiple data sources, methods, or investigators - Code-recode procedure - Peer examination/external audit
<p style="text-align: center;">Confirmability – Was there an attempt to enhance objectivity by reducing research bias?</p> <p>Example Strategies:</p> <ul style="list-style-type: none"> - Triangulation: multiple data sources, methods, or investigators - External audit - Field journal

As mentioned previously, the verbal content of the caregiver interviews was audio taped and transcribed verbatim. Participants were also asked to confirm the content of these transcriptions as a means to combat researcher bias. The transcriptions were then read through in their entirety by the graduate student researcher in order to identify themes and to develop a code sheet for themes related to each of the interview questions. To address the issues of credibility

and dependability, theme generation using the same code sheet was carried out independently by a Regis faculty member who acted as a second reviewer.

The percent agreement (PA) and the Cohen's Kappa (k) coefficient were then calculated to test the intercoder reliability between the two reviewers and account for researcher subjectivity in assessing themes. A calculation of the raw percent agreement between the two coders yielded a PA of **0.937** and the Cohen's Kappa calculation demonstrated a similar high level of agreement with a k score of **0.862**. Cohen's Kappa is used as a further evaluation of the level of agreement between two coders beyond a simple percent agreement calculation since some portion of coders' agreement can be attributed to chance alone. The Kappa coefficient allows researchers to account for this chance component in determining the reliability between the two coders and this coefficient is widely used as a research tool for qualitative research. Even though there is no universally accepted range for the Kappa coefficient, 0.61 – 0.80 is considered substantial agreement, and 0.81 – 1.00 is considered almost perfect agreement (Neuendorf, 2002). Finally, a third Regis faculty member previewed the interview questions to check for other signs of researcher bias.

Human subject approval

This study received approval for research involving human subjects from the Regis Institutional Review Board prior to any data collection.

Chapter 4: Results

Sample Characteristics

A total of nine patient caregivers agreed to participate in the interview process. The caregivers represented a purposive sample aimed at encompassing the diversity within the *Pathways* palliative care program and whose characteristics are displayed in Table 2 below.

Table 2:

	Gender	Relationship to Patient	Patient Age	Patient Diagnosis	Days in <i>Pathways</i> before interview	Admitted to Hospice?
Caregiver 1	Female	Daughter	95	Dementia	201	No
Caregiver 2	Female	Daughter	72	COPD	275	Yes
Caregiver 3	Male	Son	87	CHF and CAD	294	Yes
Caregiver 4	Female	Wife	63	Rectal Cancer	890	No
Caregiver 5	Female	Daughter-in-law	87	COPD	89	No
Caregiver 6	Female	Wife	65	ALS	137	Yes
Caregiver 7	Female	Daughter	87	Lung Disease, Dementia	570	No
Caregiver 8	Male	Son	53	Lung Cancer	73	No
Caregiver 9	Male	Son	87	CHF	63	No

As can be seen from table 2, the sample of nine caregivers consisted predominantly of females (6 females and 3 males) and included mainly children of the *Pathways* patients. All of

the caregivers interviewed had been a part of *Pathways* for at least two months with some participants having been enrolled for over a year. The age of the caregivers ranged from one man in his twenties up to several participants who were in their sixties.

There was also variation in the primary nurse who provided services to the patients and caregivers in this sample with three of the *Pathways* nurses included. Many chronic illnesses were also represented including three patients with diseases of the lung, two patients with cancer, two patients with congestive heart failure, and two patients with dementia. Finally, the nine families represented in this sample of nine caregivers utilized several of the services offered by *Pathways* including nursing care, chaplaincy services, other nurse practitioners, social workers, massage therapists, and respiratory therapists.

Main Findings

As mentioned previously, to combat the effect of researcher bias or subjectivity in assessing the themes that emerged from the caregiver interviews, a second reader from the Regis University faculty also read the interview transcriptions. Two coefficients were calculated to report the level of agreement between the two coders' assessments: Percent agreement (PA) and Cohen's Kappa (k). A calculation of the raw percent agreement between the two coders yielded a PA of **0.937** and the Cohen's Kappa calculation demonstrated a similar high level of agreement with a k score of **0.862**. Both of these coefficients demonstrate a high level of agreement between the two coders' assessment of the themes that emerged from the caregiver interviews.

In all, the caregivers were asked seven questions and upon review of the nine interviews, several themes emerged within the caregiver responses. The first question asked what is enjoyable about life right now and yielded multiple responses, yet 5 of the nine caregivers stated "time with family" as something that was enjoyable. Other similar responses were "rest",

“traveling” and “leisure time” demonstrating the desire of many caregivers to have time away from care giving duties in order to engage in other activities. Respondents also indicated that their times of joy and their times of sadness were very much dependent on how their loved one was feeling and could change quickly if their loved one’s condition worsened or improved.

The second question queried what would help the caregivers the most and this question also had a multitude of responses, but many answers were related. For instance, four of the nine responders answered, “support”, and another four responders cited “timely help”, while two people stated “more care” and two other caregivers said “lifted burden” would help them the most. This question seemed to elicit the desire of caregivers for more help and support to care for their loved one. Many responders also specified that the help was most effective if it was delivered quickly and this really helped lift a burden off the shoulders of the caregivers thinking they had to take care of everything on their own. One woman stated,

“The 24 hours a day coverage was incredible and it was wonderful to have somebody to call that could answer your questions. One time a nurse even came out and put a catheter in my husband at night so I wouldn’t have to take him to the emergency room...which was really above and beyond” (Caregiver 6, 2008).

The third question asked about emergency care and was split basically in half with 5 caregivers saying they had sought emergency care and 4 people saying they hadn’t. Most emergency room visits, if the caregiver had to take their loved one to the hospital, were for falls (3 patients), and for pain (2 patients). The interesting theme that kept emerging in this question was the number of caregivers who independently stated that being a part of Pathways prevented them from taking their loved one to the hospital. Six responders said that Pathways had “averted” an emergency room visit because they had received care at their house or they had spoken with a

nurse who guided them on how to handle their situation. As quoted above, one patient even recalled an event where a Pathways nurse came to her house at night to place a catheter so that her husband could receive the treatment he needed at his house rather than at the hospital. Another patient recalled not knowing whether to go to the emergency room or not.

“...but yeah, with them coming out and checking her vitals and all that stuff, that reassured me that I didn’t have to rush her to the emergency room. Otherwise, I wouldn’t have known the difference” (Caregiver 8, 2008).

There were two questions that resulted in unanimous responses with the first being whether *Pathways* offered a level of comfort and peace of mind and the second being what advice the caregiver would give to a friend. Nine responders said “yes” to the peace of mind question and nine also answered “would recommend Pathways” as to what advice they would give to a friend. Common themes that emerged from these questions were the fact that “someone was always there” and that the nurses were very knowledgeable and educated in the care they provided. Most responders cited that their peace of mind came from knowing that a nurse who “really knows her stuff” was only a phone call away and would come quickly. This enabled caregivers the comfort of knowing they weren’t the only ones caring for their loved ones and they had help for situations they did not know how to handle. One interviewee summed up the overall consensus of the caregivers as she remembered being introduced to *Pathways* for the first time.

“...but when our doctor introduced us to Pathways and to the nurses in particular, that was huge - I felt like a burden was lifted off of my shoulders in the event of - you know,

just understanding my husband's needs and helping him with his needs" (Caregiver 2, 2008).

Caregivers also stated they would tell their friends to be open to talking to the *Pathways* staff because the more they talked about their loved one and his or her needs, the more the staff could understand how to be a support and what services they could provide. Several caregivers raved about the educated nursing staff and the fact that the care comes to you so you never have to leave the house.

"I would highly recommend Pathways because it comes to you, it's very professionally run, and it eliminates us having to go anywhere" (Caregiver 9, 2008).

Finally, almost half (4) of the caregivers interviewed had no surprises or suggestions for improving *Pathways*. However, the other half stressed their shock in how available the nursing staff was to come to their house, and they expressed frustration at the lack of information about *Pathways*, and palliative care in general, they received ahead of time from their physician or anywhere else. The suggestions for improvement centered on more effectively getting the word out about *Pathways*, especially to physicians and insurance companies, and responders requested that a greater number of *Pathways* staff could be available for even more frequent visits (i.e. more than once a week). Caregivers were also surprised at the breadth of services available through *Pathways* including spiritual care, social workers, massage therapists, etc., but wished that the majority of insurance companies would reimburse for palliative care services.

Chapter 5: Discussion

It was the stated goal of this research to evaluate the Denver Hospice *Pathways* Palliative Care Program to determine whether this service supports broader development and implementation of community-based palliative care and whether the *Pathways* program can recruit appropriate payer sources. Answering these questions involved measuring the efficacy of *Pathways* on multiple different levels, yet the primary focus of this thesis pertained to understanding the feelings of the patient caregivers towards the care and services that were provided to them and their loved ones. While it was hypothesized that the *Pathways* palliative care program would reduce end-of-life costs and provide quality patient care, thus enticing insurers and other payers to support *Pathways*, assessing the value of the program also relied on qualitative measurements of human perceptions and feelings. The people who could benefit from *Pathways* included more than the patients and potential payers, but also the families and caregivers who deal with the reality and burden of caring for a terminally ill patient every day. Their reactions on a human level were and continue to be as important as any in informing the question of the value of *Pathways* and other community-based palliative care programs.

The findings from the evaluation of the caregiver interviews suggest that the *Pathways* palliative care program at the Denver Hospice was highly valued in the eyes of patient caregivers. This assessment was validated by the second reader who identified the same themes with a remarkable level of agreement ($PA = 0.937$, $k = 0.862$). Respondents continually stated their relief in having someone knowledgeable to talk to so that they could receive help with the care of their loved one, thus giving them the gift of time to spend with family, travel, or just take a needed break. There was a deep sense of having a burden lifted with the knowledge that help was a phone call away and that the help would come quickly, and this peace of mind prevented

the majority of the caregivers from helplessly taking their loved one to the emergency room. These patient caregivers found the most comfort in having a clinically knowledgeable person help them care for their loved ones, which allowed them to feel confident they were providing the correct care and the best care they could. Overall, the nine caregivers interviewed were impressed with the *Pathways* program, and in particular, the *Pathways* staff.

It was clear from the results of the interviews that care for the chronically ill is challenging and filled with many unknowns. In many ways the caregivers who participated in this study felt like they were on an island, on their own to care for their mother, or husband or wife. In addition to not knowing how best to physically care for a chronically ill individual, there were the unknowns associated with learning how to pay for care, who was the best provider to see, what insurance documents were needed at the end of life, and what legal documents were needed after that loved one passed away. All the respondents desired help and support, and ideally help and support that could be called upon quickly and that could be trusted to know how best to care for their loved one. In *Pathways* the nine individuals interviewed realized that desire and strongly believed others in similar positions to their own should jump at the chance to be a part of this community-based palliative care program. As previously mentioned in the literature, community-based palliative care programs allow patients to avoid visiting the hospital and stay in the comfort and familiarity of their own home and this is a strong desire of most individuals (Brumley et al., 2007).

Cost Savings?

In addition to an overall feeling of satisfaction about the *Pathways* program, a further interpretation of the caregiver interviews also revealed a qualitative perspective as to how

community-based palliative care could offer cost savings. A common burden caregivers identified was a feeling of not knowing what to do when their loved one experienced a decline in their health or began to experience pain. Many of those interviewed mentioned that during these times they would take their loved one to the doctor or the hospital because they did not know how else to care for them. Six of the nine respondents then stated that the ability to call a nurse or have a nurse come to the house had prevented them from taking a trip or many trips to the emergency department because the *Pathways* nurse could either provide the necessary care directly or inform the caregivers of what needed to be done. Given the extreme cost of hospital and emergency room stays, even one averted visit could yield significant cost savings as compared to the cost of being a part of the *Pathways* program.

A case for community-based palliative care

Evaluating whether future developments of community-based palliative care programs are beneficial to patients and their families includes an understanding of the needs of those who are providing the large majority of care to terminally ill patients. Patient caregivers offer a unique perspective as to what is important to care for the terminally ill and what services they will seek, and ultimately pay for. Current options to care for the rapidly growing population of elderly patients who are more frequently dealing with chronic illnesses are limited to Hospice care, or in some cases, palliative care services within hospitals. However, the large majority of adults prefer to be cared for and die at home if faced with chronic illness (NHPCO, 2006). As previously noted in the literature, one of the interviewees stated his objection to having to go to the hospital in this statement.

“...you know, and it gets so bad so fast that I have to take her to the emergency room. And then they dink around for six hours and then finally decide to get her into the hospital. Well, with Pathways I can tell when she's starting to get clobbered up in her lungs. I call the nurse, she comes and checks her out, talks to the doctors, they get a prescription and off we go” (Caregiver 7, 2008).

The richness of the responses to the interview questions came in getting a glimpse into what things are important to a caregiver or family when they are taking care of someone who is chronically ill. Words and phrases such as “time with family”, “rest”, “support”, “help”, “understanding what to do”, “knowing someone is there” all speak to the value of a community-based palliative care program that is separate from cost savings and other quantitative analyses. Many of those interviewed had been a part of other palliative care services offered during their hospital visits, and while appreciative of this service, the fact that care could be delivered to their home made all the difference in choosing to be a part of the *Pathways* program. The results of this study show the benefits of having a program available to help families care for chronically ill loved ones who are not yet ready for hospice care.

As mentioned previously, the growth in the number and needs of chronically ill patients has led to the recent rapid growth of hospital-based palliative care and several studies have demonstrated positive outcomes associated with hospital-based palliative care programs. However, due to methodological weaknesses and ambiguity related to the palliative care model implemented, studies involved with community-based palliative care programs have failed to yield substantive evidence that would drive the development of future programs of its kind. This study is the first to rigorously evaluate the merits and value of a community-based palliative care

program that operates within a large metropolitan area, thereby providing health service administrators a model to follow for future implementation and offering strong evidence to various payer sources as to the benefits of such programs for their customers. Additionally, results from the interviews can help health administrators identify and address the diverse palliative care services that are needed to meet the needs of patients across broad community settings and the people who care for these patients.

Study Limitations

There were some limitations to this study. First, the caregivers who participated in the interviews chose to be a part of the study, and therefore, could have been more satisfied with the *Pathways* program as compared to the general population of caregivers. The respondent's positive responses could also be due, in some part, to the Hawthorne Effect since they knew they were part of a research study measuring the efficacy of the *Pathways* program. All of the respondents were pleased with the *Pathways* program and the suggestions for improvement related more to getting the word out about palliative care rather than any major changes to the care or structure of *Pathways*. Assuming that not every caregiver involved with this program thinks highly of the services and care, this study did not receive input from those who had negative views. It should also be pointed out that this study only interviewed caregivers from one hospice facility, The Denver Hospice, which limits the generalizability of the findings. Finally, as with any qualitative research, there is a human element to interpreting the themes associated with the verbal interviews. Even though a second reader is utilized as a way to mitigate the potential for misinterpretation, there still exists a level of subjectivity in the final analysis.

Future Research

Further studies researching the efficacy of other community-based palliative care programs are needed as this study only evaluates one such program. This study also did not match *Pathways*' caregiver interviews with a case-controlled population of caregivers who were not part of a community-based palliative care program, which could have added more insight into the different perceptions of services needed for caring for the chronically ill. Based on the positive overall feelings of the caregivers interviewed, future studies drilling deeper into why the staff at *Pathways* was well received and what other services could have been provided should be done. Finally, the majority of respondents expressed their strong belief that being a part of *Pathways* had prevented them from going to the emergency room when they otherwise would have. This statement, while powerful, is an opinion and additional research possibly utilizing predictive modeling of emergency department use or case-control matching would lend more empirical evidence to this potentially significant cost savings.

The need for improved medical care and ubiquitous services for patients struggling with advanced illness is an issue that will continue to intensify in the United States. This country's population is aging and the patterns of morbidity and mortality continue to shift toward chronic illness and disease patterns that are more and more unpredictable, requiring high levels of care over extended periods of time (Lynn & O'Mara, 2004). Care at the end of life is very costly, accounting for 10% to 12% of the United States' total health care costs. The emotional burden on patients and their families is equally as important given the research showing most patients prefer to die at home, yet 50% of adult deaths occur in hospitals (NHPCO, 2006). The conclusions from this study provide insight into what an effective model of care for those with chronic illness looks like from the eyes of people who take care of these patients every day.

Caregivers need support, they need guidance, they need quality time to spend with their loved ones, and they would prefer if help could come to their homes instead of having to spend any more time in a hospital or waiting in a doctor's office. *Pathways* is a community-based palliative care program that fulfills the needs of patient caregivers and should be a model for future community-based services.

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Appendices

Appendix A

Measured Variables

Grant Objective	Data	Level	Type
Support development and utilization of community-based palliative care	Patient satisfaction Family satisfaction Provider satisfaction Demographic profiles Enrollment Ave. length of stay Number of visits Type of visits Cost of delivered service Education presentations Diagnoses/co-morbid condition Telephone volume support	Patient/case Patient/case Project Patient/case Project Project Project Project Project Project Patient/case Project	Both Qualitative Quantitative Quantitative Quantitative Quantitative Quantitative Quantitative Quantitative Quantitative Quantitative Quantitative
Provide comprehensive care	Symptom assessment (ESAS) Advance care planning Provision of psychosocial and spiritual support End-of-life decision support Decline in health condition Quality of life Palliative care score	Patient/visit Patient/case Patient/visit Patient/case Patient/visit Patient/visit Patient/visit	Quantitative Both Both Both Both Both Both
Data to encourage payer reimbursement	Emergency admissions/averted Inpatient admissions/averted Case management benefits Insurance company contacts Number of insurance companies with contracts	Patient/case Patient/case Patient/case Project Project	Quantitative Quantitative Qualitative Quantitative Quantitative
Data to standardize reimbursement	Cost/charge data Collaborative agreements	Patient/case Project	Quantitative Qualitative

Appendix B

Interview Questions for the caregivers

- 1) What is enjoyable about life right now?
- 2) What is the one thing that would help you the most?
- 3) Since starting the Pathways program, have you sought emergency care? If you have, for what reasons did you go to the hospital?
- 4) Do you feel Pathways offers a level of comfort and peace of mind? Explain.
- 5) What has been the most unexpected thing you have learned by being a part of Pathways?
- 6) What advice would you give a friend thinking about joining the Pathways program?
- 7) If you could suggest some improvements to the Pathways program, what would they be?