Comparing Heart Failure and Cancer Caregiver Satisfaction with Hospice Care

Meredith Ann MacKenzie

University of Pennsylvania, mere.mackenzie@gmail.com

Follow this and additional works at: http://repository.upenn.edu/edissertations

Part of the Family, Life Course, and Society Commons, and the Nursing Commons

Recommended Citation


http://repository.upenn.edu/edissertations/1355

This paper is posted at ScholarlyCommons. http://repository.upenn.edu/edissertations/1355

For more information, please contact libraryrepository@pobox.upenn.edu.
Comparing Heart Failure and Cancer Caregiver Satisfaction with Hospice Care

Abstract
In 2007, 38% of Medicare decedents with heart failure enrolled in hospice, along with an informal caregiver. Caregiver satisfaction with hospice care influences both patient and caregiver outcomes. Caregiver satisfaction with hospice has not been explored in the heart failure population and it is unknown whether caregiver satisfaction differs between the cancer and heart failure populations. This dissertation study had three major aims: 1) identify predictors of caregiver satisfaction separately in heart failure and cancer hospice caregivers; 2) test a model of the relationship between identified predictors and caregiver satisfaction; and 3) compare caregiver satisfaction between matched cohorts of heart failure and cancer hospice caregivers.

This was a retrospective cohort study of national data collected in 2011 by the National Hospice and Palliative Care Organization (NHPCO) using the Family Evaluation of Hospice Care (FEHC). FEHC responses of caregivers of adult cancer (n=70,782) and heart failure (n=19,818) patients were available for analysis, of which a stratified random sample of 1,000 each was selected for aims 1 and 2. Multiple linear regression and structural equation modeling were used to analyze the two cohorts separately, with burden measured by caregiver report of patient symptoms and satisfaction measured by the FEHC’s four satisfaction domains and a question on overall satisfaction with hospice care. Propensity scoring was then used to match 7,370 individuals from each diagnosis group prior to comparing satisfaction outcomes via t-tests.

Both cohorts of caregivers were predominantly White females. Cancer patients were more likely to be male (52%) spouses (50%), while heart failure patients were primarily female (55%) adult children (56%). Caregiver age, race, education and relationship to the patient predicted satisfaction, along with place of care, length of stay and reported patient symptoms (p<0.004). Structural equation modeling performed revealed that caregiving demand mediates the relationship between most caregiver and patient characteristics and caregiver satisfaction, but that race moderates the relationship between demand and satisfaction. After propensity-score matching, there was no difference in satisfaction between heart failure and cancer caregivers.

Hospices should assess the needs of vulnerable caregivers and plan for additional supports. Further research is needed on factors influencing caregiver satisfaction.

Degree Type
Dissertation

Degree Name
Doctor of Philosophy (PhD)

Graduate Group
Nursing

First Advisor
Barbara J. Riegel

This dissertation is available at ScholarlyCommons: http://repository.upenn.edu/edissertations/1355
COMPARING HEART FAILURE AND CANCER CAREGIVER SATISFACTION WITH HOSPICE CARE

Meredith A. MacKenzie

A DISSERTATION

in Nursing

Presented to the Faculties of the University of Pennsylvania

in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

2014

Supervisor of Dissertation

_________________________________
Barbara J. Riegel, Professor of Nursing

Graduate Group Chairperson

_________________________________
Barbara J. Riegel, Professor of Nursing

Dissertation Committee
Harleah G. Buck, Assistant Professor of Nursing
Salimah Meghani, Professor of Nursing
Dedication

In loving memory of Patricia Kaufmann MacKenzie. I never thought I’d have the courage or strength to complete this journey, but you always believed in me more than I could ever believe in myself. Although I still reach out for your hand only to find it gone, your boundless love, your zest for life and your encouragement of my curiosity and dreams continues to be my refuge and support. In some ways, this is all your doing.

And for Jonathan David Chaffee Stoltzfus.
Research Support
The following research was made possible by the support of:

1. T32, NR009356-04 *Individualized Care for At-risk Older Adults*
   (Principal Investigator: Mary Naylor)

2. The National Hospice and Palliative Care Organization
Acknowledgments

I’ve been told many times that producing a dissertation is like giving birth to a baby. This has been a far longer gestation than most human pregnancies and I would never have survived without the loving support of many individuals throughout the process. Many thanks are due to many people; first of all, to my fabulous advisor and chair, Dr. Barbara Riegel. Barbara, I’m probably responsible for most of the gray in your hair and I’m fairly certain that my dissertation gave you more stress than it ever gave me (which is saying a lot!). It took you two years to convince me to answer email within 24 hours and three years to get me to say the word “statistics” without sarcasm. I now get complimented on my email response speed and am going into a far more statistic-intensive career path than I ever thought was possible.

I could not have had a more wonderful dissertation committee. Dr. Harleah Buck has been an incredible resource on so many issues and has provided reassurance, motivation and moral support in addition to guidance on issues both clinical and research driven. Dr. Salimah Meghani assisted me to re-think the conceptual basis for this work and has provided keen statistical insight, in addition to dedicatedly reading my work despite travel to Pakistan and a myriad other demands on her time.

In addition to a great committee, my readers have been kind and supportive enough to stay with me since my proposal defense. Dr. Alexandra Hanlon mentored me throughout my research residency and was the one who finally lit the spark of interest in statistics in me. She has patiently answered my myriad of questions, both statistical and technical in nature. And Dr.
Matthew McHugh has lent his vast knowledge on the management of large databases and statistical analysis.

My undergraduate faculty were instrumental in starting me on this path from my very first year as a nursing student. My deepest thanks to Dr. Carolyn Kreamer, Marti Derr and Dr. Kay Huber especially.

This work would not have been possible without the support of the National Hospice and Palliative Care Organization and their permission to use their national dataset. I especially thank Matthew Haskins, who assisted me through the process of applying for use of the dataset and also pulled out and assembled the variables I needed.

I would not have been able to survive these last few years without the support and companionship of my colleagues in the doctoral program, especially Katharine Smith, Susan Kohl Malone and Youjeong Kang. I thank you for hearing and reading about my research so many times and for cheering me on every step of the way.

Maintaining work-life balance has been challenging throughout the doctoral program and I am deeply indebted to all of my friends and family who listened to me, loved me and had faith in me through my challenges, defeats and victories. There are too many to mention here, but special thanks to my “adopted aunt” Dr. Susan Renz, a constant cheerleader and inspiration; Amy, John and Cassie Norbury for lending me a home; and Maureen Greenle for supplying me with caffeine, sugar and neck massages through the last tense months of writing. But most of all, I express my deep gratitude to Lady Belle MacKenzie, who has tolerated her mother’s constantly changing schedule and
late work hours and has been my most constant course of love and companionship.
ABSTRACT

COMPARING HEART FAILURE AND CANCER CAREGIVER SATISFACTION WITH HOSPICE CARE

Meredith A. MacKenzie

Barbara J. Riegel

In 2007, 38% of Medicare decedents with heart failure enrolled in hospice, along with an informal caregiver. Caregiver satisfaction with hospice care influences both patient and caregiver outcomes. Caregiver satisfaction with hospice has not been explored in the heart failure population and it is unknown whether caregiver satisfaction differs between the cancer and heart failure populations. This dissertation study had three major aims: 1) identify predictors of caregiver satisfaction separately in heart failure and cancer hospice caregivers; 2) test a model of the relationship between identified predictors and caregiver satisfaction; and 3) compare caregiver satisfaction between matched cohorts of heart failure and cancer hospice caregivers.

This was a retrospective cohort study of national data collected in 2011 by the National Hospice and Palliative Care Organization (NHPCO) using the Family Evaluation of Hospice Care (FEHC). FEHC responses of caregivers of adult cancer (n=70,782) and heart failure (n=19,818) patients were available for analysis, of which a stratified random sample of 1,000 each was selected for aims 1 and 2. Multiple linear regression and structural equation modeling were used to analyze the two cohorts separately, with burden measured by caregiver report of patient symptoms and satisfaction measured by the
FEHC’s four satisfaction domains and a question on overall satisfaction with hospice care. Propensity scoring was then used to match 7,370 individuals from each diagnosis group prior to comparing satisfaction outcomes via t-tests.

Both cohorts of caregivers were predominantly White females. Cancer patients were more likely to be male (52%) spouses (50%), while heart failure patients were primarily female (55%) adult children (56%). Caregiver age, race, education and relationship to the patient predicted satisfaction, along with place of care, length of stay and reported patient symptoms (p<0.004). Structural equation modeling performed revealed that caregiving demand mediates the relationship between most caregiver and patient characteristics and caregiver satisfaction, but that race moderates the relationship between demand and satisfaction. After propensity-score matching, there was no difference in satisfaction between heart failure and cancer caregivers.

Hospices should assess the needs of vulnerable caregivers and plan for additional supports. Further research is needed on factors influencing caregiver satisfaction.
Table of Contents

Dedication.............................................................................................................................................. ii
Research Support ................................................................................................................................... iii
Acknowledgments.................................................................................................................................. iv
ABSTRACT.......................................................................................................................................... vii
LIST OF TABLES ................................................................................................................................ xii
LIST OF FIGURES ............................................................................................................................. xiv
CHAPTER 1: INTRODUCTION ........................................................................................................... 1
  Statement of the Problem .................................................................................................................... 3
  Purpose of the Study ........................................................................................................................... 4
  Aims & Hypotheses ........................................................................................................................ 5
  Significance ........................................................................................................................................ 6
  Definition of Terms ............................................................................................................................. 7
    Caregivers ....................................................................................................................................... 7
    Caregiver Demand .......................................................................................................................... 7
    Hospice ........................................................................................................................................... 9
  Conclusion .......................................................................................................................................... 9
  Organization of the Study ................................................................................................................... 9
CHAPTER 2: CONCEPTUAL BACKGROUND AND LITERATURE REVIEW ............................ 11
  Conceptual Model ............................................................................................................................. 11
    Assumptions of the Model. ........................................................................................................... 11
    Model Description. ....................................................................................................................... 11
  Overview of Hospice Care ................................................................................................................ 13
  Review of the Literature ................................................................................................................... 14
    Caregiving in the End of Life ....................................................................................................... 14
    Caregiver Satisfaction with Hospice Care .................................................................................... 17
  Factors Affecting Caregiver Satisfaction with Hospice Care ........................................................... 19
    Demand ......................................................................................................................................... 19
    Diagnosis ...................................................................................................................................... 20
    External Resources ....................................................................................................................... 25
    Internal Resources ......................................................................................................................... 28
  Conclusion ........................................................................................................................................ 31
CHAPTER 3: STUDY DESIGN AND METHODOLOGY ................................................................. 33
  Overview of the study design ........................................................................................................... 33
  Study Sample ..................................................................................................................................... 34
LIST OF TABLES

Table 2.1: New York Heart Association Classification ........................................ 21
Table 3.1: Variables, Definitions and Measurement .............................................. 42
Table 3.2: Predictors Correlational Matrix ......................................................... 48
Table 3.3: Outcomes Correlational Matrix ......................................................... 49
Table 4.1: Characteristics and outcomes by respondent status ......................... 59
Table 4.2: Caregiver demographics ................................................................. 61
Table 4.3: Patient demographics ................................................................. 62
Table 4.4: Patient clinical characteristics .................................................... 64
Table 4.5: Organizational characteristics ...................................................... 64
Table 4.6: Distribution of outcomes .............................................................. 65
Table 4.7: Predictors of overall satisfaction in Total sample ....................... 67
Table 4.8: Predictors of overall satisfaction in Cancer sub-sample ............. 67
Table 4.9: Predictors of overall satisfaction in Heart failure sub-sample .... 69
Table 4.10: Predictors of symptom management satisfaction in total sample ................................................................................................................. 69
Table 4.11: Predictors of symptom management satisfaction in Cancer sub-sample ........................................................................................................... 69
Table 4.12: Predictors of symptom management satisfaction in Heart failure sub-sample ........................................................................................................... 70
Table 4.13: Predictors of teaching satisfaction in total sample .................... 71
Table 4.14: Predictors of teaching satisfaction in Cancer sub-sample ......... 71
Table 4.15: Predictors of teaching satisfaction in Heart failure sub-sample .... 72
Table 4.16: Predictors of emotional satisfaction in total sample .................. 72
Table 4.17: Predictors of emotional satisfaction in Cancer sub-sample ...... 73
Table 4.18: Predictors of emotional satisfaction in Heart failure sub-sample .. 73
Table 4.19: Predictors of coordination satisfaction in total sample ............. 74
Table 4.20: Predictors of coordination satisfaction in Cancer sub-sample...74
Table 4.21: Summary of predictors......................................................74
Table 4.22: Pre- and post-match comparisons....................................84
Table 4.23: T-tests of satisfaction outcomes post-matching.................85
LIST OF FIGURES

Figure 2.1: Conceptual model.................................................................11
Figure 3.1: Conceptual model.................................................................52
Figure 4.1: Study sample selection...........................................................58
Figure 4.2: Basic SEM in Heart Failure Cohort.........................................76
Figure 4.3: Basic SEM in Cancer Cohort...................................................77
Figure 4.4: Testing Initial Theoretical Model in Heart Failure Cohort.........78
Figure 4.5: Testing Initial Theoretical Model in Cancer Cohort...............79
Figure 4.6: New Theoretical Model..........................................................80
Figure 4.7: Testing Adjusted Theoretical Model in Heart Failure Cohort.....81
Figure 4.8: Testing Adjusted Theoretical Model in Cancer Cohort.............82
CHAPTER 1: INTRODUCTION

Family caregivers are the overlooked “second patients” in end of life care (McGuire, Grant, & Park, 2012). Across the United States, there are nearly 66 million family caregivers, providing approximately 450 billion dollars worth of services (Alliance, 2012). Caregivers are integral to end of life care and enable patients to die at their preferred location, home (Bee, Barnes, & Luker, 2009). Caregiving is not without cost, though. Family caregivers of terminally ill patients experience significant physical, emotional, spiritual and financial distress (Andershed, 2006; Cora, Partinico, Munafo, & Palomba, 2012; L. Funk et al., 2010; McGuire et al., 2012; K. Stajduhar et al., 2010). Given the care demand that family caregivers experience, there is an ethical obligation to explore their satisfaction with end of life care and to seek to improve their experience (Guerriere, Zagorski, & Coyte, 2013). Pragmatically, caregiver dissatisfaction leads to an increased likelihood of patient hospitalization or nursing home admission, additional resource use and worse health outcomes for the caregiver (Cora et al., 2012; Lim & Zebrack, 2004; K. Stajduhar et al., 2010). Caregiver satisfaction with end of life care also predicts their own likelihood to complete advanced directives and plan for their own death (Carr, 2012).

Hospice care, a programmatic model under Medicare Part A to provide end of life care to eligible patients, is associated with higher caregiver satisfaction than inpatient acute care (Addington-Hall & O'Callaghan, 2009; Seamark, Williams, Hall, Lawrence, & Gilbert, 1998). Designed originally for the end-stage cancer population, hospice has been shown to reduce the risk
of hospitalization or emergency service use in this population and to reduce
caregiver health risks, including the risk of premature death (Christakis &
Iwashyna, 2003). Hospice care has been extensively studied in the cancer
population, but there is a dearth of evidence on its effect on caregivers of
patients with other life-limiting illnesses, such as heart failure (Andershed,
2006; McGuire et al., 2012).

Heart failure is the most rapidly growing cardiovascular disease in the
United States; its prevalence is predicted to rise by 25% during the next 20
years (Go et al., 2013). Currently, the lifetime risk of developing heart failure is
one in five for Americans (Go et al., 2013). The rise in heart failure is partially
due to the aging of the general population in the United States. As the
proportion of Americans who are over the age of 65 increase, so too will the
proportion of Americans dying with heart failure. Twenty percent of heart
failure patients will die within one year of diagnosis; 50% will die within five
years (Go et al., 2013; Roger et al., 2012).

Over the last two decades, heart failure has become an increasingly
common diagnosis in hospice; in 2011, it was the fourth most common reason
for hospice admission, accounting for 11.8% of patients on hospice (NHPCO,
2012a). Due the rise in heart failure, the Institute of Medicine, in its most
recent report on priorities for national health, included end of life care for
patients with end-stage heart failure as a particular priority (K. Adams &
Corrigan, 2003).
Statement of the Problem

Hospice care was originally designed for the cancer patient and caregiver (Clark, 1998). Much of the research on hospice quality outcomes, done in the cancer population, has been positive overall (Andershed, 2006). Hospice care has been shown to yield higher family satisfaction with care, along with reducing caregiver risk for premature death and major depressive disorder (Christakis & Iwashyna, 2003; Kris et al., 2006; Seamark et al., 1998). While the assumption has been that findings in the terminal cancer population can be applied to all hospice patients, recent studies have raised concerns about potential differences in quality outcomes between hospice patients with terminal cancer and those with end-stage chronic diseases, such as heart failure (Cheung et al., 2012; MacKenzie, 2013; Setoguchi et al., 2010; Teno et al., 2004; Zambroski, Moser, Roser, Heo, & Chung, 2005).

No study to date has directly compared the satisfaction of heart failure caregivers to cancer caregivers in hospice. Other studies have identified disparities between heart failure and cancer hospice patients in other outcomes, including symptom management, length of stay and cost of care (Blecker, Anderson, Herbert, Wang, & Brancati, 2011; Miller, Mor, & Teno, 2003; Miller, Weitzen, & Kinzbrunner, 2003; Unroe et al., 2011; Zambroski et al., 2005). Symptom management and length of stay are highly linked to caregiver satisfaction, suggesting that a disparity may exist in caregiver satisfaction between heart failure and cancer populations (Andershed, 2006; Bee et al., 2009; L. Funk et al., 2010; Schockett, Teno, Miller, & Stuart, 2005; Teno, Casarette, Spence, & Connor, 2012). Emergency service use, rehospitalization and acute care death are all positively associated with
caregiver dissatisfaction and demand and are higher in the heart failure population than the cancer population on hospice care (Cheung et al., 2012; MacKenzie, 2013; Unroe et al., 2011). These results raise the concern that hospice care does not provide the same quality outcomes for family caregivers of patients with heart failure as caregivers of patients with cancer.

Disparities in hospice outcomes may be due to poor knowledge about heart failure on the part of hospice agency staff. Only 14% of hospices in the United States have care plans specific to heart failure (S. J. Goodlin et al., 2005). Thirty-one percent (31%) of hospices provide some training for their staff on heart failure, but this is most often in the form of a single 2-hour training session (S. J. Goodlin et al., 2005). Another consideration is that there are other demographic and clinical differences between patients with heart failure and those with cancer (such as age and place of care) that might account for the reported differences in quality outcomes (Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005). While a small number of studies have investigated individual predictors of quality outcomes, such as length of stay and hospice use of volunteers, a broader exploration of the relationships between patient, family and hospice variables and quality outcomes is missing from the literature.

**Purpose of the Study**

This dissertation study compared caregiver satisfaction with hospice care between heart failure and cancer caregivers, through a retrospective cohort study of national hospice data collected by the National Hospice and Palliative Care Organization (NHPCO) using the Family Evaluation of Hospice Care (FEHC) survey for the year 2011. Bereaved family caregivers served by
caregiver hospices were contacted one to three months after the patient’s death and asked to participate in the survey; roughly 35% agreed to do so. Survey questions addressed family satisfaction with symptom management, the emotional support and education received and overall satisfaction with care (Connor, Teno, Spence, & Smith, 2005). Two cohorts were used for this study; the first consisted of caregivers of those individuals who died with a primary heart failure diagnosis, while the second cohort consisted of caregivers of those who died with a primary cancer diagnosis. Multiple linear regression and structural equation modeling were used to analyze the two cohorts separately; propensity scoring was then used to match individuals from the two cohorts prior to comparing the outcomes via t-tests.

Aims & Hypotheses
This study had three major aims and hypotheses. Note that the rationale for these hypotheses is provided in Chapter 2.

Specific Aim 1) Identify the predictors of family caregiver satisfaction separately for heart failure caregivers and cancer caregivers in hospice care

_H1: Significant predictors of caregiver satisfaction will include patient and family demographic variables (age, gender, family relationship, race/ethnicity, and educational attainment), patient clinical variables (length of stay, place of care, symptoms experienced) and hospice organizational variables (hospice agency size, ownership) in both cohorts._

Specific Aim 2) Test a model of the relationship between identified predictors and family caregiver satisfaction with care separately in the heart failure cohort and the cancer cohort.

_H2.1: Caregiver perception of demand (patient symptoms) will be associated with caregiver response (satisfaction). H2.2:_
**External and internal resources will moderate the relationship between demand and response.**

**Specific Aim 3)** Compare family caregiver satisfaction with care between matched cohorts of hospice patients with heart failure and those with cancer.  
*H3: Family caregivers from the cancer cohort will have higher satisfaction scores than those from the heart failure cohort.*

**Significance**

No previous studies have examined heart failure caregivers’ satisfaction with hospice care. Few studies have identified predictors of caregiver satisfaction in the general hospice population and none in the heart failure hospice population. The results of this study allow us to assess whether current hospice care is adequately supporting the needs of heart failure caregivers and to identify characteristics of more vulnerable caregivers who may require additional support. The results also illuminate the influence of caregiver demand and both caregiver and patient characteristics on the outcome of satisfaction. In doing so, they lay the foundation for the design of interventions to improve caregiver satisfaction.

The three aims of the study were purposefully designed to approach the issue of caregiver satisfaction in a triangulated fashion. The two diagnosis populations are very different in terms of age, patient gender, patient-caregiver relationship and nursing home use. In evaluating the predictors of satisfaction and examining the relationship between predictors and outcomes, we wanted to explore the degree to which diagnosis alone played a role in
determining satisfaction, beyond differences in population demographics and clinical characteristics.

To answer this question, we first evaluated the demographic and clinical characteristics that influence satisfaction outcomes in aim 1. We then modeled the relationship between these characteristics and caregiver satisfaction in aim 2. Finally, we explored whether diagnosis made a difference in satisfaction, when the population differences were removed from the picture in aim 3.

Definition of Terms

Caregivers

Stadjuhar and colleagues (2010) define caregivers as “individuals who provide any physical, emotional and instrumental support and assistance to individuals with life-limiting illness that they view as family members. These family caregivers are not acting in a professional or occupational capacity. They may or may not be co-residing with the care recipient and the care recipient may be in either a home or institutional setting” (p. 587).

Caregiver Demand

Caregivers take on tasks and responsibilities, both physical and emotional, and it is their perception of these responsibilities that constitutes ‘demand’ – the stressors that they perceive they must meet or overcome. The terminology of “demand” was first used in the literature in conceptualizations of job strain and has more recently been used in caregiver research to recognize the actual work that caregivers do (Molloy, Johnston, & Witham, 2005). Caregiver demand refers specifically to the perception of
responsibilities or work load and thus differs from caregiver burden, which is the caregiver's sense of the onerousness or challenge that the work load causes. Caregiver's perception of burden is influenced by the caregiver's sense of control and both internal and external resources that affect their ability to cope with caregiver demand (Molloy et al., 2005).

**End of Life**

Scholars have struggled to define what constitutes the end of life. Because of the challenge of prognostication, many have chosen to define end of life after the patient has died and view it as the period beginning with their last illness or their admission to hospice or palliative care (Teno et al., 2004). Others quantify it as the last year before the patient’s death (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). For the hospice benefit, end of life is defined as a life expectancy of six months or less (CMS, 2012). The National Institutes of Health (NIH) has created a broader definition that is not based on the timing of the patient’s death. According to the NIH, there are two components that define this phase of life: 1) the presence of a chronic disease that will lead to death; and 2) the need for a caregiver (NIH, 2004).

This broad definition is often further refined within disease processes. According to the American Heart Association, a heart failure patient with symptoms at rest despite optimal therapy (stage D) is considered to be end-stage, to have an estimated survival of less than one year and to be a qualified candidate for hospice care (S. J. Goodlin et al., 2005; Jessup et al., 2009). For cancer, a patient who is not responding to treatment, who has
extensive metastases or for whom there is no further treatment available is often considered end-stage or at the end of life (ACS, 2012).

**Hospice**

Hospice is a system of care for the dying, based on a philosophy of symptom management and respect for patient and family goals (Greer et al., 1986). In the United States, hospice is a form of managed care for the patient with less than six months life expectancy and is provided either in the patient’s home or inpatient settings. Covered by the Medicare hospice benefit, it replaces Medicare Parts A and B (CMS, 2012).

**Conclusion**

The number of heart failure patients enrolling in hospice has increased drastically over the past few decades and is likely to continue increasing with the aging of the population and the high rate of cardiovascular disease. Accompanying the majority of these hospice patients is an informal caregiver, whose needs and perceptions of hospice have rarely been investigated. This study sought to fill that gap by identifying predictors of heart failure caregiver satisfaction with hospice, testing a model of caregiver satisfaction with hospice and comparing heart failure caregivers’ satisfaction with hospice to that of their cancer caregiver peers.

**Organization of the Study**

This dissertation study is presented in five chapters. Chapter 1 includes the background of the study, statement of the problem, purpose of the study, specific aims, and the significance of the study. Chapter 2 presents the theoretical framework for the study and a review of the literature used as a
basis for hypothesis formation. Chapter 3 describes the methodology used for this research study, including a description of the dataset, instrumentation and data analysis procedures. It also includes strengths, limitations, delimitations, and assumptions of the study. Chapter 4 describes the results of the study, aim by aim. Chapter 5 concludes this study, with a discussion of the findings, comparison to previous literature and suggestions for future research.
For patients who want to die in the home setting, family caregivers are the backbone of end of life care (Bee et al., 2009). Caregiving is both a demanding and an enriching experience (Andershed, 2006). Hospice care aims to reduce the demand and improve the experience of end of life care for caregivers (Miceli & Mylod, 2003). How well it succeeds may differ by patient diagnosis (Cheung et al., 2012; MacKenzie, 2013). This study compared caregiver satisfaction with hospice care between heart failure and cancer caregivers. The purpose of this chapter is to present a conceptual model of caregiver satisfaction with end of life care, provide conceptual and working definitions of end of life, hospice and caregiver, and review the literature on end of life caregiving in the heart failure and cancer populations, focused on the variables included in the study.

**Conceptual Model**

**Assumptions of the Model.** Caregiver satisfaction is not an objective metric, but is a subjective perception on the part of the caregiver (Sofaer & Firminger, 2005). As a perception, caregiver satisfaction is not an isolated and direct response to actual care provided, but is influenced by both internal and external factors (Sitzia & Wood, 1997). However, caregiver satisfaction is a response to actual care received and differs from the opinion of the general public or caregivers in general (Pascoe, 1983).

**Model Description.** Caregiver satisfaction is posited to be related to their need for services and support, in other words, the demand that they face (see
Satisfaction reflects the degree to which hospice care has met their needs and alleviated the demand (Asadi-Lari, Tamburini, & Gray, 2004; Wen & Gustafson, 2004). Internal resources, such as age, sex and race, modify the relationship between demand and satisfaction (Meyers & Gray, 2001b; Rhodes, Teno, & Connor, 2007; Rhodes, Xuan, & Halm, 2012). This is partly through their influence on caregiver expectations of hospice and partly through their influence on caregiver’s perception of demand.

External resources, such as place of care or hospice ownership, modify the relationship between demand and satisfaction by changing the hospice’s available resources to meet caregiver demand (Carlson et al., 2011; Teno et al., 2004). Diagnosis also exerts a modifying influence on the relationship between demand and satisfaction. This is likely due to two issues: the first is the altered type of demand (i.e. that heart failure patients experience more shortness of breath and less pain than cancer patients) and second, that hospices are not as familiar with the needs of heart failure patients and thus their ability to meet the demand of heart failure caregivers is limited. This is suggested by the fact that heart failure patients utilize acute care services more frequently in hospice care than cancer patients and are more frequently discharged alive (Cheung et al., 2012; MacKenzie, 2013).
Overview of Hospice Care

David Greer defines hospice as “both a philosophy and a system of terminal care” (Greer et al., 1986). The basic meaning of hospice is related to the idea of hospitality, of providing a way station on a long and arduous journey (Doherty, 2009). Originally, hospices were places for travelers on pilgrimage to stop and rest overnight during the middle ages (Doherty, 2009). They were also places for sick or dying pilgrims to stay and receive care. In the 1800s, the Sisters of St. Joseph in Dublin, Ireland opened the first hospice that was specifically dedicated to the dying – not on pilgrimage to a geographical location per say, but rather reaching their last earthly destination on their life’s journey to another world. This hospice did not provide any health care, but served as an inspiration for Dr. Cecily Saunders who established St. Christopher’s Hospice in 1967, the first institution to provide medical and nursing care specifically for the dying (Clark, 1998). Although Dr. Saunders’ mission was to provide “care for the dying”, an inclusive term for patients dying of all diagnoses, she regularly interchanged the words “the dying” and “the cancer patient”, indicating that her thought process was really very focused on the patient dying of cancer (Clark, 1998).

After hearing Cecily Saunders speak, Lillian Wald established the first U.S. hospice care program in 1974 (Doherty, 2009). Unlike St. Christopher’s Hospice, however, Wald’s Connecticut hospice was a home-based system. Providing care for the dying in their homes has since become a hallmark of the U.S. hospice care system (Greer & Mor, 1986). Originally funded as a home health organization, federal recognition of hospice as a distinct system
of care came in 1982, when Medicare first made the hospice benefit available (Doherty, 2009).

The Medicare hospice benefit is limited by Medicare regulations to those who have been certified by two independent physicians (the patient’s own physician and the hospice medical director) to have a life expectancy of less than six months (Kinzbrunner & Policzer, 2011). The hospice benefit replaces all Medicare Part A benefits, including hospitalization and emergency department visits. For nursing home patients, the hospice agency assumes financial responsibility for their nursing home care and is reimbursed at an advanced rate by Medicare (CMS, 2012).

**Review of the Literature**

**Caregiving in the End of Life**

All caregivers face the challenge of caring for another in addition to caring for themselves and the associated stresses of managing another’s personal care and health care. The anticipation of limited time and the accompanying preparatory grief that caregivers face in the end of life often increases the amount of stress they feel and reduces the amount of self-care performed (Chentsova-Dutton et al., 2000). In addition, emotions around caregiving can be intensified – caregivers fear “bad dying more than death” and are terrified of failing in their caregiver role (Andershed, 2006, p.1162). Positive emotions are also strengthened – caregivers want to achieve closure, to spend the last amount of time with the patient and may derive enormous comfort from the task of caregiving (L. Funk et al., 2010). Their experience of end of life caring will shape their perception of end of life and death in such a
way that it has a profound impact on the grieving process after death and their
plans for their own death (Carr, 2012).

Caregivers report lower quality of life and poorer self-reported health
and are at higher risk for chronic pain, heart disease and pre-mature death
than their non-caregiver peers (Andershed, 2006; Cora et al., 2012). Sleep
disturbances are also prevalent among caregivers, particularly those of heart
failure patients (Rausch, Baker, & Boonmee, 2007). Sleep disturbances
contribute to the development of cardiovascular disease, but another
mechanism by which the stress of caregiving leads to cardiovascular disease
and mortality is through chronic activation of the hypothalamus-pituitary-
adrenal gland (HPA) axis and the sympathetic adrenomedullary axis
(Aschbacher et al., 2008; Cora et al., 2012; Lucini et al., 2008). Chronic stress
has been linked to higher sympathetic activation of the cardiovascular system,
as manifested by elevated higher systolic and diastolic blood pressure
readings, decreased variability in systolic blood pressure and blunted
baroreflex sensitivity (Lucini, Di Fede, Parati, & Pagani, 2005). Cancer
caregivers exhibit greater perceived stress, fatigue and sympathetic activation
than do sex and age matched non-caregivers (Cora et al., 2012; Lucini et al.,
2008). They also have higher levels of depression, state anxiety and sleep
dysfunction than matched non-caregiver controls (Cora et al., 2012).
Research in dementia caregivers indicates that the stress of caregiving leads
to heightened platelet activation due to the elevated levels of catecholamines
produced (Aschbacher et al., 2008), which may contribute to greater risk for
cardiovascular disease.
The negative effects of end of life caregiving do not completely resolve after the death of the patient. Anxiety, depression and sleep disturbances often persist and up to 86 percent of former caregivers report post-traumatic stress disorder symptoms (Parker Oliver et al., 2013; K. Stajduhar et al., 2010). In one study, depression and anxiety levels were highest during the caregiver period and the three months following the death of the patient and decreased gradually over the 13 months following (Chentsova-Dutton et al., 2002).

The effects of end of life caregiving are partially modifiable and interventions designed to reduce caregiver stress have been shown to modify health outcomes. The relationship between caregiver demand and platelet activation is mediated by depressive symptoms and platelet activation is reduced by the use of antidepressants (Aschbacher et al., 2008). Hospice care has been shown to reduce the risk of premature death in spousal caregivers (Christakis & Iwashyna, 2003). Providing coping skill training to caregivers in a hospice setting increases caregiver quality of life (Susan C. McMillan et al., 2006). In the Coping with Cancer study, caregiver perceptions of patient outcomes such as better quality of death and the completion of do-not-resuscitate orders predicted improved caregiver quality of life six months after patient death (Garrido & Prigerson, 2013). However, poor reported patient outcomes and a lack of support for caregivers has also been shown to predict complicated grief processes and increased depression after patient death (Ando, Ninosaka, Okamura, & Ishi, 2013).
Caregiver Satisfaction with Hospice Care

**Global satisfaction.** Overall satisfaction with hospice care historically runs fairly high – Press Ganey surveys of family members in 2003 indicated a mean satisfaction score of 93 percent for hospice care (Miceli & Mylod, 2003). Similarly, a 2005 study using the Family Evaluation of Hospice Care (FEHC) indicated a mean satisfaction score of 47 out of 50 items (96 percent) (Connor, Teno, et al., 2005).

Global satisfaction is strongly influenced by several aspects of care. Meeting the family’s need for information and emotional support has been shown to predict global satisfaction (Connor, Teno, et al., 2005; Rhodes, Mitchell, Miller, Connor, & Teno, 2008). Global satisfaction is also known to be influenced by several internal and external factors. African American caregivers are significantly less likely to be completely satisfied with hospice care (Rhodes et al., 2007; Rhodes et al., 2012). Length of stay and perceived timing of hospice admission are also highly predictive of global satisfaction. Shorter length of stay is linked to lower satisfaction scores (Kapo, Harrold, Carroll, Rickerson, & Casarett, 2005; Rickerson et al., 2005; Schockett et al., 2005), but even more significant is the caregiver’s perception of whether the patient was admitted to hospice ‘too late’ or at ‘the right time’; those who feel that the patient was referred ‘too late’ have lower satisfaction scores on average than those referred ‘at the right time’ (Miceli & Mylod, 2003; Schockett et al., 2005; Teno et al., 2007).

**Satisfaction with symptom management.** Exploration of caregiver satisfaction with symptom management is limited. In 2004, most hospice caregivers perceived symptom management favorably – only 6.3 percent of
caregivers indicated dissatisfaction with symptom management, making it the
most satisfactory area of hospice performance (Connor, Teno, et al., 2005).
Recent literature has raised concerns about symptom management in the
non-cancer hospice patient. A 2004 study in chronic disease decedents in
hospice revealed family perception of poor dyspnea control (Teno et al.,
2004), while a 2005 retrospective chart review of heart failure patients in one
hospice revealed no statistical difference in symptoms between admission
day and the day of death (Zambroski et al., 2005).

**Satisfaction with caregiver teaching.** Lack of information is the
number one dissatisfaction noted by hospice caregivers (Miceli & Mylod,
2003) and caregivers in general (Washington, Meadows, Elliott, & Koopman,
2011). Caregivers complain of lack of preparation when it comes to prognosis,
symptom management and the requirements of caring for a terminally ill
patient, including knowing when death has occurred (Washington et al.,
2011). Misconceptions about medications, particularly opioids are common.
Even when education on appropriate topics is provided, it may be provided in
inappropriate ways, with extensive medical jargon, or written at a level above
caregivers’ reading capacity (Eames, McKenna, Worrall, & Read, 2003;
Washington et al., 2011).

Caregivers’ satisfaction with teaching provided has an impact on other
satisfaction outcomes. Inadequate education around pain management can
result in unnecessary patient and caregiver suffering (Mazanec & Bartel,
2002). Misconceptions about opioids, including fear of addiction and fear of
respiratory depression, are a significant barrier to pain management
(Docherty et al., 2008; Kinzbrunner & Policzer, 2011). Improved caregiver
teaching leads to improved pain management outcomes, resulting in greater global satisfaction with hospice care (Mazanec & Bartel, 2002). Caregiver satisfaction with information is highly predictive of global satisfaction (Rhodes et al., 2008).

The length of stay in hospice can influence caregiver satisfaction with teaching. Hospice caregivers of patients with short lengths of stay must absorb vast amounts of information in a short period of time and thus are more likely to be dissatisfied with the education provided (Miceli & Mylod, 2003; Schockett et al., 2005). However, those with long lengths of stay have changing information needs over time and require ongoing education – if these needs are not met, dissatisfaction may occur (Washington et al., 2011).

**Satisfaction with emotional support.** Emotional support is a key component of hospice care, given the grief and loss involved and the high levels of depression and anxiety that caregivers experience (Andershed, 2006; Cora et al., 2012; L. Funk et al., 2010; K. Stajduhar et al., 2010). Hospice caregivers report more satisfaction with emotional support than non-hospice caregivers (Teno et al., 2012). Caregivers’ perception of the emotional support received is positively associated with global satisfaction (Rhodes et al., 2008). Caregiver satisfaction with emotional support differs by race/ethnicity, as minority caregivers report more unmet needs for emotional support than Whites (Rhodes et al., 2007).

**Factors Affecting Caregiver Satisfaction with Hospice Care**

**Demand**
Caregivers take on tasks and responsibilities, both physical and emotional, and it is their perception of these responsibilities that constitutes...
‘demand’ – the stressors that they perceive they must meet or overcome. Caregiver demand refers specifically to the perception of responsibilities or work load and thus differs from caregiver burden, which is the caregiver’s sense of the onerousness or challenge that the work load causes. A strong correlation exists between caregiver perception of patient symptoms and caregiver demand (Andrews, 2001). This may be because caregiver’s perception of the patient’s symptoms is usually the most important metric by which they judge their efficacy and worth as caregivers (Andershed, 2006; Bee et al., 2009). Pain management is particularly anxiety-provoking for caregivers (Andershed, 2006). Caregiver quality of life, anxiety and stress are directly proportional to the perceived level of pain experienced by the patient (Mazanec & Bartel, 2002). Uncontrolled symptoms disrupt sleep and decrease the amount of time and energy the caregiver has to devote to other aspects of life (K. Stajduhar et al., 2010). They also cause caregivers to feel angry, helpless and frustrated. Improved caregiver knowledge around symptom management decreases caregiver sense of demand by improving self-efficacy and decreasing anxiety (Bee et al., 2009).

**Diagnosis**

**Heart Failure.** Heart failure is a syndrome characterized by reduced cardiac output, the inability of the heart to keep up with the demands placed on it (Braunwald, 2005). The symptoms of heart failure are primarily related to neurohormonal imbalances, including activation of the Renin-Angiotensin–Aldosterone system, elevated levels of norepinephrine and pro-inflammatory cytokines (S. J. Goodlin, 2009; Lehmann, 2006). Symptoms of heart failure are significant, including dyspnea, orthopnea, edema, pain, sleep
disturbances, memory dysfunction, irritability, lack of energy and depression (Adler, Goldfinger, Kalman, Park, & Meier, 2009; Blinderman, Homel, Billings, Portenoy, & Tennstedt, 2008). These symptoms lead to significant impairments in psychological and physical functioning and poor quality of life (Blinderman et al., 2008).

Heart failure is classified by the New York Heart Association according to symptoms (See table 2.1). Symptoms are not well correlated to objective measures of heart function, such as ejection fraction or pulmonary capillary wedge pressure. Heart failure is thus more accurately known as a syndrome, rather than a disease (Lehmann, 2006).

<table>
<thead>
<tr>
<th>Class</th>
<th>Patient Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Class I (Mild)</td>
<td>No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, or dyspnea (shortness of breath).</td>
</tr>
<tr>
<td>Class II (Mild)</td>
<td>Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitation, or dyspnea.</td>
</tr>
<tr>
<td>Class III (Moderate)</td>
<td>Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitation, or dyspnea.</td>
</tr>
<tr>
<td>Class IV (Severe)</td>
<td>Unable to carry out any physical activity without discomfort. Symptoms of cardiac insufficiency at rest. If any physical activity is undertaken, discomfort is increased.</td>
</tr>
</tbody>
</table>

Patients with end-stage heart failure experience heavy symptom burden. Towards the end of life, they suffer a decline in functional status with impairment in Activities of Daily Living (ADLs) and become increasingly dependent (Levenson, 2000), although Harris and colleagues (2013) recently reported that the physical decline of heart failure hospice patients is much more gradual than cancer hospice patients (P. Harris et al., 2013). The top three symptoms in the end of life for heart failure patients are dry mouth, lack
of energy and shortness of breath (Wilson & McMillan, 2013). Shortness of breath, or dyspnea, is the hallmark of heart failure and continues to be so through the end of life (Levenson, 2000). Although pain is not typically thought to be characteristic of heart failure, there is increasing evidence that heart failure patients do indeed experience significant pain in the end of life (Sarah J. Goodlin et al., 2012; Levenson, 2000). To complicate the situation, heart failure patients generally are also suffering from multiple comorbidities (Bain, Maxwell, Strassels, & Whellan, 2009; Hauptman et al., 2007).

Heart failure caregivers provide a significant amount of both personal and emotional care (Hwang, Luttik, Dracup, & Jaarsma, 2010). Providing regular physical care is related to a greater sense of caregiver burden, along with managing the multiple comorbidities and administering multiple medications (Hooley, Butler, & Howlett, 2005). A greater sense of burden is associated with an increased risk of depression in heart failure caregivers and decreased quality of life (Hooley et al., 2005).

While the symptom burden of end-stage heart failure patients and the heavy caregiver burden of their informal caregivers make them good candidates for hospice care, hospice agencies may struggle to provide these patient-caregiver dyads with the resources they need. One significant challenge is identifying and referring patients with end-stage heart failure to hospice early enough for positive impact to occur. Heart failure patients are at higher risk for a short hospice stay (<10 days) than cancer patients (Miller, Weitzen, et al., 2003). Currently, the median hospice length of stay for heart failure patients is 10 days and around 20% are admitted to hospice in the last three days of life (Cheung et al., 2012; Zambroski et al., 2005).
The reason for delayed admission to hospice may partially be due to the difficulty of prognostication in heart failure. The trajectory of end-stage cancer does not fit the trajectory of end-stage heart failure (Murray, Kendall, Boyd, & Sheikh, 2005), in that end-stage heart failure contains multiple periods of interchanged instability and stability, making the terminus point difficult to predict. Heart failure patients admitted to hospice are likely to be older with multiple comorbidities, complicating the picture further (Bain et al., 2009; Hauptman et al., 2007). Hospice admission requires a 6-month life expectancy, which few providers feel confident predicting for the heart failure patient (Hauptman, Swindle, Hussain, Biener, & Burroughs, 2008). Although some tools have been developed to assist healthcare providers in predicting which heart failure patients are candidates for hospice care, these tools are not yet widely known or used (Huynh, Rovner, & Rich, 2008). Overall, poor physician knowledge of and comfort level with managing end-stage heart failure is a significant barrier to effective end of life care, including timely referral of the patient with heart failure to hospice (Hauptman et al., 2008; Schockett et al., 2005).

Even when admitted to hospice, patients with end-stage heart failure continue to face the barrier of poor clinician knowledge and experience. In 2005, only 14% of hospices nationwide had care plans specific to heart failure (S. J. Goodlin et al., 2005). Thirty-one percent (31%) of hospices do provide some training to their staff on heart failure but this is most often in the form of a 2-hour training session (S. J. Goodlin et al., 2005). While hospices are well-intentioned, the knowledge deficit can have severe repercussions on the symptom management of patients with end-stage heart failure. For instance,
almost all (94%) accept patients with implantable cardioverter defibrillators (ICDs), but only 27% have policies and procedures in place to deactivate them (S. J. Goodlin et al., 2005). Furthermore, the majority of hospices do not recognize the palliative nature of many mainstay medications for heart failure and they are erratically prescribed or discontinued completely (Zambroski et al., 2005). This lack of knowledge may be responsible for why one study found no difference in dyspnea symptoms between hospice and acute care settings and another found no difference in symptoms between day of admission and day of death in a sample of heart failure patients on hospice (Teno et al., 2004; Zambroski et al., 2005).

**Cancer.** Cancer describes a “group of diseases characterized by uncontrolled and unregulated growth of cells” (Cady & Jackowski, 2011) (p. 261). Cancer can be classified as solid tumor or liquid (hematological); the most common cancer causes of death are lung, breast, prostate and colon/rectum cancers (ACS, 2013). Metastasis to other organs is commonly found in terminal cancer, particularly to the brain, bone, liver and kidneys. Common symptoms of terminal cancer include pain, breathlessness, fatigue and anxiety (Walsh, Rybicki, Nelson, & Donnelly, 2002). Although disease course varies, the average cancer hospice patient has a more rapid and consistent functional decline than their counterpart with heart failure (P. Harris et al., 2013).

Much of palliative care in terminal cancer involves the administration of opioids and oxygen (Kinzbrunner & Policzer, 2011). Curative options, such as chemotherapy, radiation and surgical resection, are only used if the original tumor or metastases cause symptoms by encroaching on vital health tissue
(i.e. spinal cord compression or vena cava syndrome) and are then used only for decompression or debulking (Kinzbrunner & Policzer, 2011).

Cancer patients are younger on average than heart failure patients and are more likely to have a spouse as a caregiver (MacKenzie, 2013). However, adult child caregivers of cancer hospice patients report more depression and burden than do spousal caregivers (Given et al., 2004). In one study, terminal cancer caregivers reported less psychological, physical and social strain than other diagnosis caregivers (Townsend, Ishler, Shapiro, Pitorak, & Matthews, 2010), but in another study reported depression as frequently and rated their physical health similarly to other diagnosis caregivers (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001). Caregivers of cancer patients in hospice also report poorer quality of life and physical health than caregivers of cancer patients undergoing curative therapy (Weitzner, McMillan, & Jacobsen, 1999).

**External Resources**

**Hospice Size.** Hospice size has not been extensively studied as a factor in caregiver satisfaction. However, Carlson and colleagues (2009) found that end-stage cancer patients who were served by smaller hospices were more likely to disenroll than those served by larger hospices (Carlson et al., 2009). Their study focused on patients who died of cancer, rather than those who experienced remission and left hospice due to improvement of their condition. Although Carlson admits that the reasons for disenrollment are complex, a likely reason is that smaller hospices do not have the same resources as larger hospices and thus may not be as able to meet patient and caregiver needs (Carlson et al., 2009). Larger hospices more commonly offer
bereavement services to family and offer more comprehensive and labor-intensive family services than are smaller hospices (Barry et al., 2012).

**Hospice Ownership.** Hospice ownership also has not been extensively studied as a factor in caregiver satisfaction. In the same study on bereavement services cited above, for-profit hospices were less likely to offer bereavement services than were non-profits and were more likely to offer a limited range of services (Barry et al., 2012). For-profits over a narrower scope of services in general and also assign a higher case-load of patients to healthcare providers than do non-profits (Canavan, Aldridge Carlson, Sipsma, & Bradley, 2013; Carlson, Gallo, & Bradley, 2004). While these factors have been linked to poorer patient outcomes in general (Aiken, Clarke, & Sloane, 2002; Aiken, Clarke, Sloane, & International Hospital Outcomes Research, 2002; Aiken, Clarke, Sloane, Sochalski, & Silber, 2002), no study has yet confirmed that hospice ownership is linked to hospice caregiver satisfaction.

**Care Setting.** Hospice care may be provided in a private home, a nursing home or an inpatient setting. In the United States, the private home setting is by far the most common site for hospice (NHPCO, 2012b). Miceli and Mylod (2003) found no difference in caregiver satisfaction across care settings, using Press Ganey survey data. However, Teno and colleagues (2004) found that caregivers of patients receiving hospice care in a nursing home were less satisfied than those of patients who received care in a private home (Teno et al., 2004).

Caregiving for a nursing home patient is a different experience than caregiving at home – less hands-on care and symptom management are required, as these roles are assumed by nursing home and hospice staff.
While this may alleviate some caregiver demand, the setting may decrease the caregiver's interaction with hospice staff and diminish the emotional support and information received. When Munn and colleagues (2006) investigated caregiver satisfaction with end of life care in a nursing home, they found no difference in satisfaction between hospice and non-hospice caregivers (Munn, Hanson, Zimmerman, Sloane, & Mitchell, 2006), suggesting that hospice may not be perceived to be as useful to caregivers of patients in nursing homes.

**Length of stay.** The average length of stay in hospice has been decreasing over time and is currently approximately 10 days (NHPCO, 2012b). While experts have suggested a minimum hospice stay of 90 days is the most beneficial, no evidence exists as to what length of stay yields the best outcomes for patients. Taylor and colleagues found that a length of stay of 50-108 days maximizes cost savings for non-cancer hospice patients (Taylor, Ostermann, Van Houtven, Tulsky, & Steinhauser, 2007).

Length of stay is inversely related to caregiver satisfaction, with shorter lengths of stay being associated with higher rates of dissatisfaction (Kapo et al., 2005; Rickerson et al., 2005; Schockett et al., 2005). The actual length of stay may not be as predictive of family satisfaction as the caregiver’s perception that the patient entered hospice ‘too late’ versus at ‘the right time’ (C. E. Adams, Bader, & Horn, 2009; Kapo et al., 2005; Miceli & Mylod, 2003; Schockett et al., 2005; Teno et al., 2007). Caregivers who thought the patient entered hospice ‘too late’ experienced a shorter hospice length of stay on average than those who thought the patient entered hospice at ‘the right time’ (Schockett et al., 2005; Kapo et al., 2005; Miceli & Mylod, 2003).
Certain subgroups of hospice patients are more likely to experience a short length of stay than others, including those over 85 years of age, those admitted from a nursing home, males and Whites (Miller, Weitzen, et al., 2003; Park et al., 2012). Park and colleagues also found that minorities, especially Hispanic caregivers, have longer stays than Whites (2012), despite the fact that Hispanic caregivers are more likely to think that the patient was referred ‘too late’ (C. E. Adams et al., 2009). This may be due to poor quality of care Hispanics experienced before hospice admission and/or the sense that the patient might have had better care overall if admitted earlier.

There have been mixed results when it comes to diagnosis and length of stay. Miller and colleagues found that heart failure, stroke, and renal failure patients were at higher risk for short lengths of stay (2003) while Park (2012) found that cancer patients were at higher risk. This may be due to the way length of stay and short length of stay were measured – length of stay in the heart failure population is curvilinear, rather than linear, with 33 percent of patients dying within the first 10 days of hospice care, but 17 percent surviving past 180 days (MacKenzie, 2013).

**Internal Resources**

**Age.** Younger caregivers have been reported in the literature to experience more caregiver strain than older caregivers (Bainbridge, Krueger, Lohfeld, & Brazil, 2009; Lin, Fee, & Wu, 2012). This is hypothesized to be related to either a lower tolerance for the demands of caregiving or to the other responsibilities (e.g. job, young children) that younger adults are more likely to have (Bainbridge et al., 2009; L. Funk et al., 2010). However, it must be noted that most “younger” caregivers in the literature are in their 40’s-50’s
and we know little about even younger (20’s-30’s) caregivers and their response to the demands of caregiving. A relationship may exist between age and race/ethnicity, as minority caregivers are younger on average than White caregivers; the studies on age previously cited were completed in largely White samples (Hebert & Schulz, 2006). Furthermore, the age of the patient matters as well as the age of the caregiver – caring for a younger patient is more distressing than caring for an older one (K. Stajduhar et al., 2010).

**Race/Ethnicity.** The majority of caregivers in the United States are currently White, due to the younger mean age of racial minorities. However, the proportion of racial minorities over 65 years of age is set to increase exponentially and will outpace the growth rate of White older adults by 2050 (Hebert & Schulz, 2006). There is still a dearth of literature on caregiving in the end of life in minority populations. It has been shown that Black caregivers are more likely to report unmet needs, particularly in the areas of emotional support and information received (Rhodes et al., 2007). While they report lower levels of stress, they experience greater physical and financial consequences of caregiving (Phipps, Braitman, True, Harris, & Tester, 2003). Caregiver satisfaction with hospice care is lower among Black caregivers than White caregivers (Rhodes et al., 2007). This is possibly related to their higher level of unmet needs or may be related to cultural factors. Black patients and families express desire for intensive care at the end of life at higher rates than do White patients and families (A. E. Barnato, Chang, Saynina, & Garber, 2007; A. E. Barnato, Herndon, et al., 2007; Phipps, True, et al., 2003).

Black caregivers may have a cultural protective factor, in that faith plays a greater role on average in their coping strategies than it does for
Caucasian caregivers. Caucasian caregivers report more spiritual strain during the end of life period than their Black counterparts (Townsend et al., 2010).

Similarly to Blacks, Hispanics are less likely to utilize hospice care services than their White counterparts and are more likely to want intensive care services at the end of life (A. E. Barnato, Herndon, et al., 2007; Givens, Tjia, Zhou, Emanuel, & Ash, 2010). Despite lower frequency of hospice use, Adams and colleagues (2009) found that among hospice enrollees, Hispanics were more likely than non-Hispanics to state that they would have benefited from starting hospice care earlier (C. E. Adams et al., 2009).

**Gender.** The majority of caregivers are female, as women are more likely to serve as caregivers than men, regardless of the relationship to the patient (Lin et al., 2012). However, there is a growing segment of male caregivers (Hebert & Schulz, 2006). Even though men and women may both be designation as a ‘caregiver’, the way they experience caregiving is likely to be different. Women work longer hours as caregivers and engage in more hands-on care than men (M. Pinquart & Sorensen, 2006). Men are more task-oriented and less likely to provide nurturing or emotional support (Calasanti & King, 2007). Outside support for the caregiver tends to differ by gender as well – men receive more praise and acknowledgement for caregiving than women do (P. B. Harris, 2002). Perhaps due to these differences, female caregivers generally report greater strain than male caregivers (Andershed, 2006; Bee et al., 2009; Townsend et al., 2010).

**Caregiver-Patient Relationship**
Gender is influenced by relationship to the patient, as daughters who serve as caregiver for a parent report more stress than wives caregiving for husbands; similarly, sons who serve as caregiver for a parent report more stress than husbands caregiving for wives (Lin et al., 2012). This may be a function of age and other responsibilities, rather than actual relationship (Bainbridge et al., 2009), particularly as middle-aged adult children report the highest levels of depression during the caregiving period (Given et al., 2004).

**Education.** Caregiver educational level affects caregiver sense of demand, with less educated caregivers reporting more demand and stress (K. Stajduhar et al., 2010). This may be due to poorer health literacy and increased difficulty navigating healthcare directions (Bee et al., 2009). It may also be partially due to gender role expectations, as those with more education are less likely to hold onto traditional gender roles and may more equally distribute the demand of caregiving (Lin et al., 2012).

**Conclusion**

Caregiving in the end of life can be deeply stressful to caregivers, decrease their self-care and place them at risk for depression, heart disease and pre-mature death (Andershed, 2006; Chentsova-Dutton et al., 2000; Cora et al., 2012). There is evidence that caregiver experience of, and satisfaction with, end of life care may shape their physical and emotional response to caregiving (Carr, 2012; S. C. McMillan et al., 2006). Hospice care is a system of care that aims to provide holistic care to both patient and caregiver. It may alleviate caregiver demand and improve their satisfaction with end of life care (Christakis & Iwashyna, 2003).
Caregiver satisfaction with hospice care is a complex concept that is influenced by caregiver experience of demand and internal and external resources that shape their perception (Asadi-Lari et al., 2004; Sitzia & Wood, 1997; Sofaer & Firminger, 2005; Wen & Gustafson, 2004). Internal resources, such as identification as Black, may alter the likelihood of caregiver satisfaction (Rhodes et al., 2012). Similarly, external resources, such as place of care, may alter both expectations and perception of hospice care (Teno et al., 2004). The role of diagnosis in caregiver satisfaction is largely unexplored and we are uncertain whether there is a difference in caregiver satisfaction between heart failure caregivers and cancer caregivers. Furthermore, few studies have evaluated the internal and external resources in concert with each other as part of a model of caregiver satisfaction. We aimed to fill this gap with the current study. The following chapter, Chapter 3, outlines the study methods.
CHAPTER 3: STUDY DESIGN AND METHODOLOGY

This dissertation study compared caregiver satisfaction with hospice care between heart failure and cancer caregivers. The study had three major aims: 1) identify the predictors of family caregiver satisfaction separately for heart failure caregivers and cancer caregivers in hospice care; 2) test a model of the relationship between identified predictors and family caregiver satisfaction with care separately in the heart failure cohort and the cancer cohort; and 3) compare family caregiver satisfaction with care between matched cohorts of hospice patients with heart failure and those with cancer. This chapter presents the methodology used to achieve these aims and is organized into six sections: a) overview of the study design, b) study sample, c) human subjects protection, d) instrumentation, e) data management and f) analytical plan.

Overview of the Study Design

A retrospective cohort design was used to achieve the aims of this study. We analyzed data from a large national hospice dataset, the National Hospice and Palliative Care Organization (NHPCO)’s National Data Set. Part of this dataset is the Family Evaluation of Hospice Care (FEHC) survey responses. The FEHC evaluates multiple domains of family caregiver satisfaction with hospice care. We used data from the 2011 FEHC survey results. Additionally, organizational data (ownership, organization size) from reporting hospices was included in the analysis. Multiple statistical methods, including multiple regression, structural equation modeling, propensity score matching and t-tests were used to analyze the data.
Study Sample

The targeted population was all heart failure and cancer hospice caregivers in 2011, the latest year for which data were available. According to the National Hospice and Palliative Care Organization (NHPCO), an estimated 1,059,000 patients died in hospice care in 2011. Of these, 11.4 percent (120,726 patients) had a primary diagnosis of heart failure while 37.7 percent (399,243 patients) had a primary diagnosis of cancer (NHPCO, 2012b).

The study sample was drawn from heart failure and cancer caregivers who were served by NHPCO member hospices in 2011 and who completed the Family Evaluation of Hospice Care (FEHC) survey after the death of their family member. NHPCO represents around 2600 hospices, about 75% of all Medicare-certified hospices nationwide (S. J. Goodlin et al., 2005; Hanson et al., 2010; NHPCO, 2013). Beginning in 2000, NHPCO began collecting yearly data on program, patient, staffing and financial statistics and also on patient and family outcomes from member hospices (Connor, Horn, Smout, & Gassaway, 2005). In 2004, they introduced a standardized survey to measure family perceptions of hospice care that is entitled Family Evaluation of Hospice Care (FEHC) (Connor, Teno, et al., 2005). Although this voluntary survey is sent only to NHPCO member care recipients, the demographics of past FEHC respondents are representative of the total hospice recipient population when compared to the Medicare Payment Advisory Commission (MedPAC) report released yearly (Mitchell et al., 2007).
NHPCO supplied a total of 90,548 FEHC responses, of which 70,765 (78.2%) were from cancer caregivers and 19,783 (21.8%) were from heart failure caregivers.

**Inclusion and Exclusion Criteria**

Caregivers of adult (21+ years of age) hospice patients with heart failure or cancer listed as the primary diagnosis for hospice admission who answered the FEHC in English were included in the study. Caregivers of pediatric patients, caregivers of hospice patients with another primary diagnosis and caregivers who responded to the FEHC in a non-English language were excluded. Caregivers of pediatric patients were excluded as different protocols are used in the pediatric hospice population and pediatric patients rarely die of heart failure (Organization, 2009).

**Stratified Random Sampling**

After selecting out those who met the inclusion/exclusion criteria, we stratified the database into heart failure caregivers and cancer caregivers. We then used a computer-generated algorithm to draw a random sample of 1000 caregivers from each stratum.

**Power Analysis**

Power estimation was performed to support the first aim of the study. PASS (Power Analysis and Statistical Significance) software was used to calculate the appropriate sample size for the first aim, in which multiple regression was used. The sample size of 1000 per strata achieves 90% power to detect an R2 change of 0.02 attributed to 15 independent variables.
using an F-Test with a significance level (alpha) of 0.05 (Cohen, 1988).

Please see the fifteen variables to be tested in the discussion of first aim below. It was difficult to establish R2 change based on the literature, so preliminary analyses were run to establish a baseline R2 change.

For the second aim, structural equation modeling was used. Using Jackson’s (2003) N:q rule, which states that the ratio of cases (N) to number of model parameters (q) should be ideally at least 20:1, our sample size of 1000 was more than sufficient for the number of paths analyzed (Jackson, 2003).

The third aim utilized propensity score matching. Using propensity score matching ensures that the baseline characteristics of the matched heart failure and cancer pairs will be similarly distributed (Austin, 2009). Once propensity score matching was complete, basic bivariate analyses (t-tests) were used. Because we wanted to ensure that we were able to select the best possible matches for optimal bias reduction, we opted to select matches from all respondents who met inclusion criteria and had no missing data. We ended up with 7370 matches, which was more than enough to fully power our bivariate analyses.

Propensity score matching

The end-stage cancer and end-stage heart failure populations are very different populations, in terms of demographic and clinical characteristics (Bain et al., 2009; Cheung et al.; Hauptman et al., 2007; Setoguchi et al., 2010). Our sample reflected those differences: heart failure hospice patients were on average, older, female, single and more likely to reside in a nursing home, while cancer hospice patients were, on average, younger, male,
married and living at home. Their caregivers were different as well – the heart failure caregivers were more likely to be older, female and the child of the patient than the cancer caregivers, who were more likely to be male and the spouse of the patient. Given how different the populations represented are, we wanted to explore whether diagnosis alone makes a difference in terms of caregiver satisfaction or if these population differences make a difference. We explored whether the population differences make a difference in Aim 1, in which we explored predictors of caregiver satisfaction. For Aim 3, we chose to utilize propensity score matching to determine if diagnosis made a difference in caregiver satisfaction, when the population differences were removed.

The propensity score represents the conditional probability that a randomly selected individual will belong to the cancer or heart failure cohort, given the observed covariates chosen (Rosenbaum, 2010). Using the propensity score, we matched heart failure caregivers to the cancer caregivers who most closely resembled them. The matched groups of heart failure and cancer caregivers had very similar demographic and clinical characteristics. This allowed us to examine if caregiver satisfaction varies based on diagnosis alone.

Propensity scoring does not, unfortunately, balance the two cohorts in terms of unobserved covariates. While there is no way to know how unobserved covariates influence the outcome, it is possible to assess how great an influence an unobserved covariate would have to exert in order to significantly change the results. This was assessed via a sensitivity analysis, which was performed after the analysis was completed.
There are multiple methods of propensity scoring, including one-to-one, one-to-one with replacement, one-to-one with calipers, optimal matching and full propensity scoring. All of these methods aim to reduce the distance between observations from the two cohorts and each may be the best method given defined circumstances. We estimated each method of propensity scoring and compared the bias reduction achieved. The method that achieved the greatest bias reduction was the method used to match the two cohorts for comparison. The list of observed covariates chosen for propensity scoring and the rationale behind their selection is found under the Aim 3 analysis section below.

After propensity score matching was completed, caregiver satisfaction was compared between the two groups using t-tests. A sensitivity analysis was then performed to assess the rigor of the findings. After the entire analysis was completed, another simple random sample was drawn from each cohort and the steps of the analysis were re-run for confirmation.

Protection of Human Subjects

The data were originally collected for quality improvement and tracking purposes by NHPCO member hospices. Using the FEHC and submitting data to the NHPCO national dataset allows them to identify areas of potential improvement in practice and to compare their own results against national benchmarks and averages. There are ethical concerns to be considered when using data originally collected for quality improvement projects rather than research. While it is well known that data derived from quality improvement projects can be utilized to study research questions and build generalizable knowledge, quality improvement faces less scrutiny and is
subject to less oversight than research (Nerenz, 2009). The process of FEHC administration and collection was not subject to institutional review board review, nor were the caregivers who responded to the FEHC formally consented. This is largely because although the use of the data for research was considered possible with the creation of NHPCO’s national dataset, there were no specific research questions identified.

In designing this research study, we were mindful of the need to protect the caregivers involved. All identifying data (such as name or address) were removed by NHPCO prior to supplying the data. Furthermore, all individual hospices were identified only by a code in the dataset, rather than name. This removed the risk of an individual caregiver’s identity being revealed. The data we received from the NHPCO was not considered to meet the standards for “human subjects” according to the US Department of Health and Human Services rule 45CFR46.102(f) which defines a human subject as “a living individual about whom an investigator conducting research obtains (1) data through intervention or interaction with the individual; or (2) identifiable private information” (DHHS, 2009). The study was only conducted after undergoing expedited review and obtaining approval from the Institutional Review Board of the University of Pennsylvania.

All study data were stored in a secured file on the University of Pennsylvania School of Nursing’s server. The server was protected by a firewall and registered as a University “Critical Host” Participant. Nightly Backups and weekly backups were stored at a secure off site location. The server was monitored via the Enterprise System Monitoring Solution and has antivirus protection. All data analysis was done on a desk-top computer at the
School of Nursing with a password-secured user account.

**Instrumentation**

The FEHC is a 61-item questionnaire that asks family members of hospice decedents to assess the end of life care provided (Connor, Teno, et al., 2005). The FEHC is a shortened version of the After-Death Bereaved Family Member Interview, which has been tested and used in prior research (Connor, Teno, et al., 2005) and has been endorsed by the National Quality Forum as an end of life quality care measure (Forum, 2012). Hospices contact caregivers one to three months after the patient’s death and ask them to complete the survey. Most surveys are mailed to the caregiver and completed with paper and pencil, but telephone administration with an established script is used by some hospices (Connor, Teno, et al., 2005). Equivalency of paper and telephone administration has been verified and documented (L. Welch, Teno, Casey, & Moorhead, 2004).

The FEHC has four domains, which examine 1) caregiver satisfaction with symptom management, 2) caregiver satisfaction with emotional support provided, 3) caregiver satisfaction with the caregiver teaching provided, and 4) coordination of care. The FEHC asks one additional question about overall family satisfaction with the hospice care provided. Appendix B contains the breakdown of which items are assigned to each domain.

Each question on the FEHC has multiple answer choices, one of which is selected to be the “desirable” answer; all others are considered “negative” answers. Scoring is done in two ways: first a problem score (the number of negative responses within a domain) is calculated and then a domain score
(the percentage of negative responses) is calculated. For example, domain 1 (caregiver satisfaction with symptom management) contains four items. If one negative response is given, the problem score is one, the domain score is 0.25 (25%). For both of these scores, higher numbers indicate a lower quality outcome of care. A domain score of greater than 0.20 is considered an opportunity to improve care (Teno, Clarridge, Casey, Edgman-Levitan, & Fowler, 2001).

The FEHC also includes a question evaluating overall family satisfaction with care. Overall satisfaction with care is measured via a five point Likert scale ranging from excellent to poor. We chose to utilize the domain scores and this one scaled question as outcomes for the analysis of aims 1-3. Utilizing domain scores allows the different domains to be more easily compared. For example, a problem score of one in the domain of symptom management, which contains eight items, is not readily comparable to a problem score of one in the domain of coordination of care, which only has three items. However, the domains scores of these two domains can be compared, as they both indicate the percentage of problems noted in that domain.

Psychometric testing of the FEHC included testing of the instrument as a whole and the individual domains. Test-retest reliability was examined via Kappa statistics for dichotomous response questions and intra-class correlations for multi-level response questions in the original validation study (Teno et al., 2001). Kappa statistics and intra-class correlations were above 0.4 for all items, which is considered a fair to good measure of reliability (Fleiss, 1981; Teno et al., 2001). The Cronbach’s alpha was utilized as a test
of internal reliability for each domain and ranged from 0.58-0.87 in the initial study (Teno et al., 2001). The one domain with a Cronbach’s alpha less than 0.70, caregiver satisfaction with emotional support, was modified; subsequent testing of the current FEHC translated into Spanish yielded a Cronbach’s alpha of 0.71 (Portenoy & Teno, 2007). Teno and colleagues (2001) noted that the domains with the fewest number of items had the lowest Cronbach’s alphas, as Cronbach’s alpha is influenced by item number (Cortina, 1993).

Pearson’s or Spearmen’s correlation coefficients were used to examine inter-item and item-to-total correlations, depending on the distribution. The mean inter-item correlations for each domain ranged from 0.30-0.42 in the initial study and from 0.45-0.56 in the later study on the Spanish language version (Portenoy & Teno, 2007; Teno et al., 2001). The mean item-to-total correlations for each domain were all above 0.3 and most were roughly 0.50 in the initial study, while the mean domain item-to-total correlations ranged from 0.53-0.57 in the Spanish language version (Portenoy & Teno, 2007; Teno et al., 2001). Criterion validity (how well each problem score measures satisfaction in comparison to another measure) was measured by examining the correlation between each problem score and the 5-point scaled item on overall satisfaction. The correlation between problem scores and overall satisfaction ranged from 0.45-0.52 in the initial study (Teno et al., 2001).

The variables to be used in the analysis, with their conceptual definitions and measurement strategies are found below in Table 3.1.

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>Conceptual Definition</th>
<th>Variable type &amp; Measurement strategy</th>
<th>Sample Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major Outcomes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom Management</td>
<td>Family caregiver’s perception of the patient’s symptom severity and symptom management on the part of the hospice</td>
<td>Ratio: Domain score from the hospice provision of physical comfort and emotional support to the decedent domain on the FEHC</td>
<td>B6: How much help in dealing with his/her breathing did the patient receive while under the care of the hospice? A) less than was wanted, b) the right amount, c) more than was wanted</td>
</tr>
<tr>
<td>---------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Emotional &amp; Spiritual Support</td>
<td>Family caregiver’s perceptions of the emotional and spiritual support offered by the hospice, in relationship to their needs.</td>
<td>Ratio: Domain score from the hospice support of family emotional needs domain on the FEHC</td>
<td>How much emotional support did the hospice team provide to you prior to the patient’s death? A) less than was wanted, b) right amount, c) more than was wanted</td>
</tr>
<tr>
<td>Caregiver teaching</td>
<td>Caregiver’s perception of the teaching provided by the hospice on care for the patient and what to expect</td>
<td>Ratio: Domain score from the FEHC domain on caregiver teaching</td>
<td>How confident were you that you knew what to expect when the patient was dying? A) Very confident, B) Somewhat confident, C) Not confident</td>
</tr>
<tr>
<td>Coordination of Care</td>
<td>Caregiver’s perception of the hospice’s coordination of care for the patient</td>
<td>Ratio: Domain scores for the FEHC domain of coordination of care</td>
<td>While under the care of the hospice, was there always one nurse who was identified as being in charge of the patient’s overall care? Yes/no</td>
</tr>
<tr>
<td>Overall Satisfaction</td>
<td>Family caregiver’s perception of their overall satisfaction with the hospice care provided.</td>
<td>Ordinal: FEHC question G1, a scale rating of satisfaction from Poor to Excellent</td>
<td>Overall, how would you rate the care the patient received while under the care of the hospice?</td>
</tr>
</tbody>
</table>

**Patient and Family Demographic Variables**

<table>
<thead>
<tr>
<th>Age</th>
<th>Chronological age in years</th>
<th>Interval: FEHC H1 (patient age) and I2 (family member’s age), which provides 19 options covering 5-year implements from “younger than 17” to “100 years old or older”</th>
<th>How old was the patient when he/she died? _____ years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Family perception of patient’s gender identification and family member’s own</td>
<td>Nominal: FEHC H2 (patient’s gender) and I3 (family member’s gender): Male or Female</td>
<td>Was the patient male or female?</td>
</tr>
<tr>
<td><strong>Family relationship</strong></td>
<td>Self-identified biological or social relationship to the patient.</td>
<td>Nominal: FEHC question I1, categorical options: spouse, partner, child, parent, sibling, other relative, friend or other</td>
<td>What is your relationship to the patient?</td>
</tr>
<tr>
<td>-------------------------</td>
<td>---------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td>The ethnicity to which one most closely identifies oneself</td>
<td>Nominal: FEHC H5/ 6 (patient) and I5/6 (family member): five categorical race options and a Hispanic/non-Hispanic ethnicity option</td>
<td>Are you of Hispanic or Spanish family background?</td>
</tr>
<tr>
<td><strong>Educational attainment</strong></td>
<td>Degree status in the Western educational system</td>
<td>Interval: FEHC H4 (patient) and I4 (family member): 6 categorical options from less than 8th grade to more than 4-year college degree</td>
<td>What is the highest grade or level of school that you have completed?</td>
</tr>
<tr>
<td><strong>Patient Clinical Variables</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of stay</td>
<td>Days spent in hospice care, from admission to death</td>
<td>Ratio: The number of days from day of admission to day of death</td>
<td>For about how many days or months did the patient receive hospice services?</td>
</tr>
<tr>
<td>Place of care</td>
<td>Report of whether the patient received care in a nursing home</td>
<td>Nominal dischotomous: nursing home or not</td>
<td>While under the care of the hospice, was the patient in a nursing home?</td>
</tr>
<tr>
<td>Symptoms experienced</td>
<td>Family reports of physiological symptoms experienced by the patient</td>
<td>Nominal: Pain, dyspnea or depression</td>
<td>While under the care of the hospice, did the patient have pain or take medicine for pain?</td>
</tr>
<tr>
<td><strong>Hospice Organizational Variables</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospice agency size</td>
<td>The average number of patients served by the hospice annually</td>
<td>Ratio: The number of patients each hospice agency reported serving in the year in which service to decedent was provided</td>
<td>Not a question on the FEHC, but provided by the NHPCO separately</td>
</tr>
<tr>
<td>Ownership</td>
<td>The nature of the hospice agency’s ownership, in terms of private ownership versus ownership by another healthcare agency</td>
<td>Nominal: Private/free-standing or owned by another agency</td>
<td>Not a question on the FEHC, but provided by the NHPCO separately</td>
</tr>
</tbody>
</table>

**Data Management**
StataMPv.12 (College Station, Texas) was used for most statistical analysis, although R was used for the propensity score matching. Descriptive statistics were computed, including frequencies and percentages for binary/categorical variables and means and standard deviations for continuous variables. The distribution of each continuous variable was checked with a histogram, stem and leaf plot or box plot. After examining the distribution of variables, patient and caregiver age and education variables were re-coded into fewer categories to ensure that each category had a large enough number of respondents. Furthermore, the ethnicity and race variables needed to be re-coded to ensure that the base category would be the one with the greatest number of respondents (Paul David Allison, 1999).

The data were examined for missing data. For most variables, less than 10 percent of the data were missing. The patient variable of education and the caregiver variables of age, race, education and gender were more problematic - approximately 15 percent of data were missing for these variables. Caregiver age was highly problematic, with almost 52% of respondents failing to answer that question. In managing missing data, most methods are based on the assumption that the data are either missing completely at random (MCAR) or missing at random (MAR). For data to be MCAR, the value of “missing” for any given variable must not be dependent on any other variable included in study or on the missing values of that variable itself. To meet the definition of MAR, the value of “missing” for any given variable must not be dependent on the missing values of that variable itself (P. D. Allison, 2003). Although there is no specific test for MAR (because there is no way to know the true value of the “missing” responses),
we had reason to suspect that the data were not MAR for the caregiver variables, particularly caregiver age. Caregivers may not have responded to this question out of an unwillingness to disclose such information, particularly older or younger caregivers who might have worried that such information could bias the assessment of their response.

Because the data were likely not MAR, using such approaches as imputation through maximum likelihood would likely not be valid. According to Allison (2003), listwise deletion can be a valid approach in this type of case; “as long as missingness on predictors does not depend on dependent variables, listwise deletion will yield approximately unbiased estimates of regression coefficients” (p. 75). To assess this issue, we ran a regression analysis, testing whether missing data predicted any of the specified outcomes (the domain scores of the FEHC or the question on overall satisfaction). For each caregiver variable, we created a dummy variable indicating data presence of missingness. None of these dummy variables were statistically significant predictors of our outcomes. Respondents with missing data on key variables of interest were thus excluded from the study sample. In eliminating missing data, there was a slightly greater loss of younger caregivers and caregivers of Hispanic origin than other caregivers. There was no significant difference in respondents lost between diagnosis groups.

A correlational analysis was performed to check for multicollinearity. The correlation matrix is presented on the next page in table 3.2. As seen, the only variables with a correlation above 0.7, suggesting multicollinearity, were the patient and caregiver race and ethnicity variables. Upon further
assessment of the data, there were more non-White caregivers than non-White patients and more Hispanic caregivers than Hispanic patients. As caregiver race and ethnicity was judged to be more likely to affect responses than patient race and ethnicity, the decision was made to include caregiver race and ethnicity and drop patient race and ethnicity from the analyses of aims 1 and 2 to avoid the issue of multicollinearity. When running the analysis of aim 1, variance inflation factors (VIFs) were also assessed to confirm that multicollinearity was avoided.
### Table 3.2: Correlational Matrix

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
<th>16</th>
<th>17</th>
<th>18</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Patient Age</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2) Patient Sex</td>
<td>-0.14</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3) Patient Ethnicity</td>
<td>-0.01</td>
<td>0.00</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4) Patient Race</td>
<td>0.10</td>
<td>-0.00</td>
<td>-0.33</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5) Patient Education</td>
<td>-0.01</td>
<td>-0.12</td>
<td>-0.02</td>
<td>0.04</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6) Caregiver Age</td>
<td>0.04</td>
<td>0.20</td>
<td>0.01</td>
<td>0.06</td>
<td>-0.05</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7) Caregiver Sex</td>
<td>-0.06</td>
<td>-0.22</td>
<td>0.00</td>
<td>-0.01</td>
<td>-0.02</td>
<td>-0.03</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8) Caregiver Ethnicity</td>
<td>-0.04</td>
<td>-0.01</td>
<td>0.90</td>
<td>-0.29</td>
<td>0.01</td>
<td>0.02</td>
<td>0.01</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9) Caregiver Race</td>
<td>0.10</td>
<td>0.00</td>
<td>-0.32</td>
<td>0.83</td>
<td>0.01</td>
<td>0.06</td>
<td>-0.00</td>
<td>-0.33</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10) Caregiver Education</td>
<td>-0.19</td>
<td>0.12</td>
<td>-0.01</td>
<td>0.05</td>
<td>0.37</td>
<td>0.20</td>
<td>-0.09</td>
<td>-0.00</td>
<td>0.03</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11) Relationship</td>
<td>-0.21</td>
<td>0.33</td>
<td>0.03</td>
<td>0.06</td>
<td>-0.08</td>
<td>0.47</td>
<td>-0.03</td>
<td>0.05</td>
<td>0.06</td>
<td>0.27</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12) Place of care</td>
<td>0.10</td>
<td>-0.14</td>
<td>-0.02</td>
<td>0.08</td>
<td>0.01</td>
<td>-0.08</td>
<td>0.04</td>
<td>0.00</td>
<td>0.07</td>
<td>-0.08</td>
<td>-0.20</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13) Length of stay</td>
<td>-0.09</td>
<td>-0.02</td>
<td>0.05</td>
<td>-0.07</td>
<td>-0.04</td>
<td>-0.01</td>
<td>0.04</td>
<td>0.03</td>
<td>-0.05</td>
<td>0.02</td>
<td>-0.00</td>
<td>-0.08</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14) Pain</td>
<td>-0.03</td>
<td>-0.06</td>
<td>-0.02</td>
<td>0.06</td>
<td>0.06</td>
<td>-0.07</td>
<td>-0.01</td>
<td>-0.01</td>
<td>0.05</td>
<td>0.02</td>
<td>-0.02</td>
<td>0.06</td>
<td>-0.04</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15) Dyspnea</td>
<td>-0.04</td>
<td>0.01</td>
<td>-0.02</td>
<td>0.04</td>
<td>-0.01</td>
<td>-0.08</td>
<td>-0.04</td>
<td>0.00</td>
<td>0.02</td>
<td>-0.04</td>
<td>0.01</td>
<td>-0.02</td>
<td>-0.13</td>
<td>0.10</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16) Anxiety</td>
<td>-0.04</td>
<td>0.04</td>
<td>-0.04</td>
<td>0.04</td>
<td>0.02</td>
<td>-0.08</td>
<td>-0.06</td>
<td>-0.03</td>
<td>0.04</td>
<td>-0.08</td>
<td>0.02</td>
<td>-0.03</td>
<td>-0.35</td>
<td>0.16</td>
<td>0.26</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17) Hospice ownership</td>
<td>0.06</td>
<td>-0.01</td>
<td>-0.01</td>
<td>0.03</td>
<td>-0.00</td>
<td>-0.04</td>
<td>-0.02</td>
<td>-0.01</td>
<td>0.05</td>
<td>-0.07</td>
<td>-0.01</td>
<td>0.07</td>
<td>-0.07</td>
<td>-0.01</td>
<td>-0.04</td>
<td>0.02</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>18) Agency size</td>
<td>0.00</td>
<td>0.00</td>
<td>-0.03</td>
<td>0.00</td>
<td>0.02</td>
<td>0.07</td>
<td>-0.03</td>
<td>-0.03</td>
<td>0.01</td>
<td>0.04</td>
<td>0.05</td>
<td>-0.04</td>
<td>-0.01</td>
<td>0.02</td>
<td>-0.00</td>
<td>0.01</td>
<td>-0.23</td>
<td>1.00</td>
</tr>
</tbody>
</table>
We assumed that the outcomes would have some degree of correlation, but we assessed this as well.

Table 3.3: Outcomes Correlation Matrix

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Overall Satisfaction</th>
<th>Symptom management</th>
<th>Caregiver teaching</th>
<th>Emotional Support</th>
<th>Coordination of Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Satisfaction</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom management</td>
<td>0.338</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver teaching</td>
<td>0.387</td>
<td>0.402</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional support</td>
<td>0.307</td>
<td>0.327</td>
<td>0.306</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Coordination of care</td>
<td>0.346</td>
<td>0.333</td>
<td>0.337</td>
<td>0.260</td>
<td>1.00</td>
</tr>
</tbody>
</table>

Data Analysis

Aim 1) Identify the predictors of family caregiver satisfaction separately for heart failure caregivers and cancer caregivers in hospice care. A series of multiple linear regression analyses were performed to explore the relationship between the caregiver satisfaction indicators and the demographic, clinical, and organizational variables listed in Table 3.1. Analyses were run in each cohort separately, in order to compare the predictors and the strength of those predictors between the two cohorts. Each outcome (domain scores of symptom management, caregiver teaching, emotional support and coordination, along with overall satisfaction) served as the dependent variable in separate regression equations. Manual backwards deletion was used to remove the predictor (independent) variables that are not significant. Using backwards deletion, rather than forward deletion, allows for the possibility that some predictor variables will only be significant in pairs
(when both are included in the model). To perform backwards deletion, we started with all hypothetical predictor variables (the demographic, clinical and organizational variables in Table 3.1) in a regression model. Then we systematically dropped variables, one at a time, whose p-values fell above a set significance established based on the Bonferroni criterion. This criterion suggests that the p-value significance level cut-off point should be 0.05/m where m is the number of independent variables (Paul David Allison, 1999). With the omission of patient ethnicity and race, there were 16 variables initially included in the regression models. This suggests that the p-value significance level cut-off point should be 0.003. However, with the adjustments made in dropping variables from the model, the p-value significance cut-off was often revised to a higher cut-off point (the cut-off point for each model will be discussed in Chapter 4). With each change in predictor set, the model fit (as measured by adjusted R2) was re-evaluated. Multicollinearity was assessed by evaluating the variance inflation factors (Rosenbaum, 2010). Standardized coefficients were used when comparing predictors between the models for each cohort.
Aim 2) Test a model of the relationship between identified predictors and family caregiver satisfaction with care separately in the heart failure cohort and the cancer cohort. The hypothesized model (figure 3.1) was tested with structural equation modeling (SEM). SEM was selected because it can simultaneously estimate the relationships between the predictor variables specified and caregiver satisfaction indicators (Bentler, 1987). It also permits the simultaneous analysis of multiple mediating pathways. The specified model was built a priori, based on the literature, as described above. Because we did not expect the model to be identical in both the cancer cohort and the heart failure cohort, we tested the model in each cohort, separately (Lee & Tsui, 1982). This approach allowed for different sets of parameters and different covariance structures for each cohort (Lee & Tsui, 1982).

The model analyzed included the direct relationship between demand (perception of symptoms) and response (caregiver satisfaction indicators). It simultaneously evaluated the moderating effect of diagnosis, external and internal resources. The maximum likelihood (ML) method will be used to generate path coefficients (Bentler, 1987). Using ML estimates allows for
formal statistical tests of model fit even for over-identified models. Furthermore, ML estimates are scale invariant and scale free, so transformed data may be used without altering fit values (Schermelleh-Engel, Moosbrugger, & Müller, 2003).

Goodness of model fit was assessed by multiple fit indices, including chi square, standardized Root Mean Square Residual (SRMR), comparative fit index (CFI), and Root Mean Square Error of Approximation (RMSEA). Using multiple fit indices is suggested for a fuller understanding of goodness of fit and to evaluate for the possibility of erroneous results (Bentler, 1987; Hu, 1998; Rex B Kline, 2011). Chi square is the most basic test and tests the null hypothesis that there is no significant difference between sample covariances and those predicted by the model (Rex B Kline, 2011). Ideally, then, the chi square has an associated p-value that is greater than 0.05. However, the chi square is highly dependent on sample size and in large samples the p-value is often less than 0.05 when the difference between the sample and the model are actually insignificant. To help solve this problem, it is recommended to examine the ratio of the chi square to the degrees of freedom ($\chi^2/df$), which ideally should be less than 3 (Jöreskog, 1993; Schermelleh-Engel et al., 2003). However, this does not wholly solve the problem and thus other fit indices are recommended in conjunction with the chi-square and chi-square ratio (Jöreskog, 1993; Schermelleh-Engel et al., 2003). SRMR measures the correlation residual and is the most sensitive fit index to mis-specified factor covariances (Hu, 1998; R.B. Kline, 1998). SRMR should be less than 0.8 (R.B. Kline, 1998). The CFI compares the fit of the model to that of the independence model (one in which no correlations are assumed) and
measures the improvement of fit from the independence model to the specified one. Ideally, the CFI is 0.95 or greater, but values of 0.90 or greater are acceptable (Schermelleh-Engel et al., 2003). The RMSEA tests the discrepancy between the model’s covariance matrix and that of the population (Schermelleh-Engel et al., 2003). RMSEA may be particularly useful, as it is relatively unaffected by sample size and is preferential towards parsimonious models (Schermelleh-Engel et al., 2003). The RMSEA should ideally be less than 0.5, although values between 0.5 and 0.8 are acceptable (Schermelleh-Engel et al., 2003).

**Aim 3)** Compare family caregiver satisfaction with care between matched cohorts of hospice patients with heart failure and those with **cancer**. As described above, the propensity score method with the greatest bias reduction was used to match the two cohorts. After trials, the method selected was propensity score matching with calipers, set at 0.20. The calipers define the maximum difference by which the propensity scores of any given matched pair may differ (Austin, 2011). The cohort members were matched on age, gender, race and educational status of both the patient and the caregiver; the caregiver-patient relationship, the reported patient symptoms of pain, shortness of breath and anxiety, the length of hospice stay, the place of care delivery and the ownership status and size of the hospice.

**Choice of matching variables:** Age was included as heart failure patients on hospice are, on average, older than the general hospice population (Setoguchi et al., 2010). Gender was included as the majority of heart failure patients on hospice are female; while a larger portion of cancer patients on hospice are male (Bain et al., 2009). Ethnicity of the decedent and family
member was included; heart failure affects fewer Hispanics than cancer, in large part due to a younger overall age of the Hispanic population on the United States (Colon & Lyke, 2003; Givens et al., 2010). Educational attainment is predictive of enrollment in hospice and also of preference for intensity of care (Amber E. Barnato et al., 2005) and thus was included. Educational attainment has often served as a predictor of socioeconomic status (SES) in healthcare research, although cautionary notes have been sounded about this approach (Braveman, Cubbin, Marchi, Egerter, & Chavez, 2001; Grzywacz, Almeida, Neupert, & Ettner, 2004). Caregivers of heart failure patients are more likely to be adult children, while cancer patients more often have spousal caregivers (MacKenzie, 2013). It has been reported that shortness of breath is more prevalent among heart failure patients, while pain is more significant among cancer patients (Levenson, 2000; Wilson & McMillan, 2013). Length of hospice stay is known to be shorter on average among heart failure patients and thus will be used as a matching variable (Kapo et al., 2005; Rickerson et al., 2005; Zambroski et al., 2005). Place of care was used, as heart failure patients are much more likely to receive hospice care in a nursing home (Cheung et al., 2012). While it is unknown whether heart failure or cancer patients utilize hospices of different sizes or ownership statuses, it is important to control for these factors, to ensure that diagnosis alone is tested.

The mean domain score of each domain was compiled within each cohort. T-tests were then used to compare the mean domain scores between the heart failure and cancer cohorts. T-tests were used to test the null hypothesis that there is no difference between the mean domain scores of
the heart failure and cancer cohorts. A t-test was also used to compare global satisfaction with care between the cohorts. The null hypothesis was that there is no difference in mean global satisfaction with care between the heart failure and cancer cohorts. After the analyses were completed, a sensitivity analysis was done to examine the magnitude of unobserved covariates that would be required to significantly change the results (Rosenbaum, 2010).

Limitations and Methodological Considerations

This was an analysis of an existing dataset; hence, we were limited to the data collected. Furthermore, the data were not collected for research purposes, although it has been used for research in the past. We had no control over how the data were collected or the completeness of the information. Because the sample contains participants who voluntarily responded to a survey, it may not be representative of all hospice caregivers.

The FEHC is a voluntary survey for families of hospice members and the response rate is annually about 35%. The survey response rate of 35%, while lower than generally found in primary research studies, is very similar to the averages of most surveys collected by organizations (Baruch & Holtom, 2008). In order to assess its representativeness, we compared the patient characteristics of our sample to the National Hospice and Home Care Survey 2007 (NHHCS 2007) data on heart failure and cancer hospice patients. The NHHCS 2007 was a nationally representative study and we found no major differences between the characteristics of heart failure and cancer hospice patients in their sample and ours. The only caregiver data available in NHHCS 2007 was their relationship to the patient, which we compared to our data and
found to be similar. This is no guarantee that our sample is representative of all hospice caregivers, but provides some reassurance that the patient population is representative.

Unfortunately, the significant amount of missing data we encountered caused us to lose a greater number of young and Hispanic respondents. While our numbers still looked comparable to the NHHCS 2007, we would likely have been even more representative of the true hospice caregiver population had we not lost those respondents.

**Conclusion**

In order to examine family caregiver satisfaction with hospice care, we analyzed data obtained from the National Hospice and Palliative Care Organization. The data analyzed included the Family Evaluation of Hospice Care survey responses obtained from hospice caregivers of heart failure and cancer patients who died in hospice care in 2011. In order to achieve our aims of identifying predictors of satisfaction, testing a model of caregiver satisfaction and comparing the satisfaction of heart failure and cancer caregivers we utilized a variety of statistical techniques including multiple regression, structural equation modeling and propensity score matching followed by t-tests. In the next chapter, Chapter Four, we present the results of our analysis.
CHAPTER 4: RESULTS

This chapter presents the results of this retrospective cohort study of caregiver satisfaction with hospice care. The demographic, clinical and organizational characteristics of the sample are described first. The results of the three aims of the study are then presented in sequence.

STUDY SAMPLE SELECTION

As discussed in the previous chapter, the dataset had missing data which likely did not meet the requirements for MAR. We eliminated responses with missing data on the variables of interest. We then performed stratified random sampling from each diagnosis group (see figure 4.1).

Because of the large amount of missing data and the likelihood that the missing data were not MAR, we estimated differences between those excluded due to missing data (“non-respondents”) and those included with intact data (“respondents”) in terms of both demographics and outcomes (see table 4.1). All differences are significant at the p<0.01 level, but the actual difference is minute in most cases. However, the respondents are more likely
to be White, female, non-Hispanic and hold a college degree or higher. They are also more likely to be served by a free-standing hospice agency, rather than a provider-based agency.

### Table 4.1: Characteristics and outcomes by respondent status

<table>
<thead>
<tr>
<th>Variable</th>
<th>Respondents (n=32,732) %</th>
<th>Non-Respondents (n=57,868) %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart Failure</td>
<td>23.71</td>
<td>20.84</td>
</tr>
<tr>
<td>Cancer</td>
<td>76.29</td>
<td>79.16</td>
</tr>
<tr>
<td><strong>Patient sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>49.23</td>
<td>43.80</td>
</tr>
<tr>
<td>Female</td>
<td>50.77</td>
<td>42.23</td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td>13.96</td>
</tr>
<tr>
<td><strong>Patient education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;High school diploma</td>
<td>19.93</td>
<td>13.90</td>
</tr>
<tr>
<td>High school diploma</td>
<td>40.89</td>
<td>29.46</td>
</tr>
<tr>
<td>Some college</td>
<td>19.45</td>
<td>14.03</td>
</tr>
<tr>
<td>Bachelor's</td>
<td>10.17</td>
<td>7.01</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>9.56</td>
<td>8.48</td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td>27.13</td>
</tr>
<tr>
<td><strong>Patient ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>98.14</td>
<td>85.44</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.86</td>
<td>2.96</td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td>11.60</td>
</tr>
<tr>
<td><strong>Patient race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>94.00</td>
<td>85.32</td>
</tr>
<tr>
<td>Black</td>
<td>3.06</td>
<td>4.67</td>
</tr>
<tr>
<td>Other</td>
<td>2.94</td>
<td>3.12</td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td>6.89</td>
</tr>
<tr>
<td><strong>Patient-caregiver relationship</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>44.62</td>
<td>44.63</td>
</tr>
<tr>
<td>Child</td>
<td>39.82</td>
<td>33.72</td>
</tr>
<tr>
<td>Other</td>
<td>15.56</td>
<td>15.07</td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td>6.58</td>
</tr>
<tr>
<td><strong>Caregiver age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;80</td>
<td>10.05</td>
<td>2.40</td>
</tr>
<tr>
<td>70-79</td>
<td>18.79</td>
<td>3.97</td>
</tr>
<tr>
<td>60-69</td>
<td>30.11</td>
<td>5.25</td>
</tr>
<tr>
<td>50-59</td>
<td>26.57</td>
<td>4.39</td>
</tr>
<tr>
<td>&lt;50</td>
<td>14.48</td>
<td>2.45</td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td>81.55</td>
</tr>
<tr>
<td><strong>Caregiver sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>28.23</td>
<td>21.14</td>
</tr>
<tr>
<td>Female</td>
<td>71.77</td>
<td>54.20</td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td>24.66</td>
</tr>
<tr>
<td><strong>Caregiver education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;High school diploma</td>
<td>5.31</td>
<td>4.24</td>
</tr>
<tr>
<td>High school diploma</td>
<td>32.34</td>
<td>22.92</td>
</tr>
<tr>
<td>Study Sample Characteristics</td>
<td>Mean (Standard Deviation)</td>
<td></td>
</tr>
<tr>
<td>------------------------------</td>
<td>---------------------------</td>
<td></td>
</tr>
<tr>
<td>Agency size (average daily census)</td>
<td>3.26 (1.27)</td>
<td>3.81 (1.30)</td>
</tr>
<tr>
<td>Overall satisfaction (Likert)</td>
<td>1.36 (0.82)</td>
<td>1.48 (1.0)</td>
</tr>
<tr>
<td>Symptom management Domain score</td>
<td>0.04 (0.11)</td>
<td>0.04 (0.12)</td>
</tr>
<tr>
<td>Caregiver teaching Domain score mean (SD)</td>
<td>0.20 (0.23)</td>
<td>0.22 (0.24)</td>
</tr>
<tr>
<td>Emotional Support Domain score mean (SD)</td>
<td>0.09 (0.17)</td>
<td>0.10 (0.18)</td>
</tr>
<tr>
<td>Coordination of care Domain score mean (SD)</td>
<td>0.08 (0.17)</td>
<td>0.08 (0.19)</td>
</tr>
</tbody>
</table>
After selecting out our stratified sample of 1000 heart failure and 1000 cancer caregivers, we analyzed the demographic, clinical and agency characteristics of both stratum.

**Demographics**

As seen in table 4.2, there were significant differences between the demographic composition of the heart failure and cancer caregivers. Both groups of caregivers were predominantly non-Hispanic White (94%) and female (74%). Of the non-White respondents, the majority were Black (3.45%), with a higher percentage of Blacks in the cancer group (5.00%). Heart failure caregivers were older than cancer caregivers (50-70 years) in general. Heart failure and cancer caregivers differed significantly in their relationship to the patient, with heart failure caregivers more likely to be a child of the patient (56%), while the majority of cancer caregivers were the patient's spouse/partner (50%).

**Table 4.2: Caregiver Demographics (N= 2000)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total Sample (%)</th>
<th>Cancer (%)</th>
<th>Heart (%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationship to Patient</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>39.45</td>
<td>50.40</td>
<td>28.50</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Child</td>
<td>45.20</td>
<td>34.00</td>
<td>56.40</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>15.35</td>
<td>15.60</td>
<td>15.10</td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;80</td>
<td>18.45</td>
<td>19.10</td>
<td>17.80</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>70-79</td>
<td>12.15</td>
<td>9.70</td>
<td>14.60</td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>31.25</td>
<td>28.90</td>
<td>33.60</td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>25.85</td>
<td>25.00</td>
<td>26.70</td>
<td></td>
</tr>
<tr>
<td>&lt;50</td>
<td>12.30</td>
<td>17.30</td>
<td>7.30</td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>26.50</td>
<td>28.20</td>
<td>24.80</td>
<td>0.085</td>
</tr>
<tr>
<td>Female</td>
<td>73.50</td>
<td>71.80</td>
<td>75.20</td>
<td></td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; High School Diploma</td>
<td>5.90</td>
<td>6.60</td>
<td>5.20</td>
<td>0.511</td>
</tr>
<tr>
<td>High School Diploma</td>
<td>33.40</td>
<td>34.10</td>
<td>32.70</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>28.95</td>
<td>28.80</td>
<td>29.10</td>
<td></td>
</tr>
<tr>
<td>Bachelor’s</td>
<td>14.30</td>
<td>14.10</td>
<td>14.50</td>
<td></td>
</tr>
<tr>
<td>Graduate</td>
<td>17.45</td>
<td>16.40</td>
<td>18.50</td>
<td></td>
</tr>
</tbody>
</table>
The patients for whom the caregivers cared also differed significantly between the diagnosis groups (table 4.3). Both groups were more likely to be non-Hispanic White although cancer patients were more likely to be identified as Black or other than were heart failure patients. Heart failure patients were more likely to be female (55%), while the majority of cancer patients were male (52%). Heart failure patients were older, on average, than cancer patients – the vast majority of heart failure patients were 80 years of age or older, while most cancer patients were between the ages of 50 and 70. Patients were less educated overall than their caregivers, with the majority possessing a 12th grade education or less. However, heart failure patients were overall less educated than cancer patients.

Table 4.3: Patient Demographics (N=2000)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total (%)</th>
<th>Cancer (%)</th>
<th>Heart (%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;90</td>
<td>21.65</td>
<td>7.60</td>
<td>35.70</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>80-89</td>
<td>36.35</td>
<td>28.60</td>
<td>44.10</td>
<td></td>
</tr>
<tr>
<td>70-79</td>
<td>22.45</td>
<td>29.80</td>
<td>15.10</td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>12.50</td>
<td>21.30</td>
<td>3.70</td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>5.05</td>
<td>9.00</td>
<td>1.10</td>
<td></td>
</tr>
<tr>
<td>&lt;50</td>
<td>2.00</td>
<td>3.70</td>
<td>0.30</td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>48.55</td>
<td>51.70</td>
<td>45.40</td>
<td>0.005</td>
</tr>
<tr>
<td>Female</td>
<td>51.45</td>
<td>48.30</td>
<td>54.50</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;High School Diploma</td>
<td>24.60</td>
<td>20.70</td>
<td>28.50</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>High School Diploma</td>
<td>39.10</td>
<td>39.30</td>
<td>38.90</td>
<td></td>
</tr>
<tr>
<td>Some College</td>
<td>19.35</td>
<td>22.00</td>
<td>16.70</td>
<td></td>
</tr>
<tr>
<td>Bachelor’s</td>
<td>8.95</td>
<td>8.60</td>
<td>9.30</td>
<td></td>
</tr>
</tbody>
</table>
Graduate Ethnicity
Hispanic 1.80 2.10 1.50 0.313
Non-Hispanic 98.20 97.90 98.50
Race
White 94.05 91.40 96.70 <0.0001
Black 3.35 4.80 1.90
Other 2.60 3.80 1.40

Clinical Characteristics
Heart failure patients were more than twice as likely to receive hospice care in a nursing home as cancer patients (29% vs. 13%). As the FEHC only asks whether the patient received care in a nursing home or not, we were unable to ascertain the location of care beyond nursing home or other. Cancer patients had a relatively normal distribution of length of stay, with the largest group staying 1-3 months. Heart failure patients had a distribution that was heavily weighted on both ends; 35.5% stayed less than one week, while another 18.8% stayed longer than four months. Pain was the most frequently reported symptom in both cancer and heart failure groups (90% vs. 81%, respectively). Dyspnea was more frequently reported in the heart failure group (64.20% vs. 48.10). Anxiety was reported by roughly half of patients in both groups (see table 4.4).

Table 4.4: Patient Clinical Characteristics (n=2000)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total (%)</th>
<th>Cancer (%)</th>
<th>Heart (%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place of Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing home</td>
<td>20.80</td>
<td>12.50</td>
<td>29.10</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Other</td>
<td>79.20</td>
<td>87.50</td>
<td>70.90</td>
<td></td>
</tr>
<tr>
<td>Length of Stay</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;2 days</td>
<td>10.25</td>
<td>9.70</td>
<td>10.80</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>3-7 days</td>
<td>23.20</td>
<td>21.70</td>
<td>24.70</td>
<td></td>
</tr>
<tr>
<td>8-14 days</td>
<td>14.00</td>
<td>15.20</td>
<td>12.80</td>
<td></td>
</tr>
<tr>
<td>15-29 days</td>
<td>9.50</td>
<td>10.70</td>
<td>8.30</td>
<td></td>
</tr>
<tr>
<td>1-3 months</td>
<td>28.10</td>
<td>31.60</td>
<td>24.60</td>
<td></td>
</tr>
<tr>
<td>4-6 months</td>
<td>6.95</td>
<td>5.80</td>
<td>8.10</td>
<td></td>
</tr>
<tr>
<td>&gt;6 months</td>
<td>8.00</td>
<td>5.30</td>
<td>10.70</td>
<td></td>
</tr>
</tbody>
</table>
Perceived Pain

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Pain</td>
<td>85.65</td>
<td>14.35</td>
<td></td>
</tr>
<tr>
<td></td>
<td>90.00</td>
<td>10.00</td>
<td>81.30</td>
</tr>
<tr>
<td></td>
<td>81.30</td>
<td>18.70</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&lt;0.0001</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Perceived Dyspnea

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Dyspnea</td>
<td>56.15</td>
<td>43.85</td>
<td></td>
</tr>
<tr>
<td></td>
<td>48.10</td>
<td>51.90</td>
<td>64.20</td>
</tr>
<tr>
<td></td>
<td>64.20</td>
<td>35.80</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&lt;0.0001</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Perceived Anxiety

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Anxiety</td>
<td>51.70</td>
<td>48.30</td>
<td></td>
</tr>
<tr>
<td></td>
<td>54.80</td>
<td>45.20</td>
<td>48.60</td>
</tr>
<tr>
<td></td>
<td>48.60</td>
<td>51.40</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0.021</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Organizational Characteristics

There was no real difference between the hospice organizations that served the caregiver groups. Both groups on average were served by a free-standing hospice that admitted slightly more than three patients per day.

Table 4.5: Organizational Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total (%)</th>
<th>Cancer (%)</th>
<th>Heart failure (%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agency size (adc*)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.24</td>
<td>3.18</td>
<td>3.31</td>
<td>0.030</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>1.25</td>
<td>1.25</td>
<td>1.25</td>
<td></td>
</tr>
<tr>
<td>Ownership</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Free-standing</td>
<td>52.45</td>
<td>50.63</td>
<td>54.29</td>
<td>0.109</td>
</tr>
<tr>
<td>Provider-based</td>
<td>47.55</td>
<td>49.37</td>
<td>45.71</td>
<td></td>
</tr>
</tbody>
</table>

*adc=average daily census

Distribution of Outcomes

The outcomes were all skewed to the right, indicating that overall satisfaction was high and few problems were reported on average. The only domain with a mean domain score equal to or greater than 0.20 (the threshold for requiring improvement) was the domain of caregiver teaching.

Table 4.6: Distribution of Outcomes

<table>
<thead>
<tr>
<th>Domain</th>
<th>Total Sample</th>
<th>Cancer</th>
<th>Heart Failure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### ANALYSIS OF AIMS

**Aim 1: Identify the predictors of family caregiver satisfaction separately for heart failure and cancer caregivers in hospice care.**

Problem and domain scores were calculated for the domains of symptom management, education, emotional support and coordination as described in chapter 3. The problem score is the number of “undesirable answers” in that domain (i.e. number of unmet needs). The domain score is the percentage of undesirable answers (the number of undesirable answers over the total number of items in that domain). Overall satisfaction, measured by caregivers’ response to a question which asks them to rate hospice care received on a 5-point scale from Excellent to Poor, was also used as a measure of overall satisfaction. For all outcomes, higher scores indicate increasing dissatisfaction or a higher number of perceived problems with care.

Linear regression with manual backwards deletion was used to identify determinants of each outcome, as described in Chapter 3. Predictors were first evaluated in the total sample and then in the cancer and heart failure cohorts separately. As noted in the previous chapter, patient race and

<table>
<thead>
<tr>
<th></th>
<th>Mean (standard deviation)</th>
<th>Mean (standard deviation)</th>
<th>Mean (standard deviation)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Satisfaction</td>
<td>1.35 (0.79)</td>
<td>1.36 (0.78)</td>
<td>1.35 (0.79)</td>
</tr>
<tr>
<td>Symptom management</td>
<td>0.04 (0.10)</td>
<td>0.04 (0.11)</td>
<td>0.04 (0.11)</td>
</tr>
<tr>
<td>Caregiver teaching</td>
<td>0.20 (0.23)</td>
<td>0.21 (0.24)</td>
<td>0.19 (0.22)</td>
</tr>
<tr>
<td>Emotional support</td>
<td>0.10 (0.17)</td>
<td>0.10 (0.17)</td>
<td>0.10 (0.17)</td>
</tr>
<tr>
<td>Coordination of care</td>
<td>0.08 (0.17)</td>
<td>0.08 (0.17)</td>
<td>0.08 (0.17)</td>
</tr>
</tbody>
</table>
ethnicity variables were excluded as predictors due to multicollinearity with caregiver race and ethnicity. Multicollinearity was assessed by variance inflation factors (VIFs) after regression models were run and the included variables all had VIFs between 1 and 1.5, indicating that multicollinearity was not present. A summary of predictors is shown in table 4.20.

**Overall Satisfaction**

Overall satisfaction was measured by a five-point scale which asked caregivers to rate their overall satisfaction with hospice care from excellent (1) to poor (5). In assessing the statistical significance of the predictors, we used Bonferroni’s criteria stating that the p-value should be $\leq 0.5/n$ where $n$ is the number of predictors. We adjusted the p-value requirement as we deleted predictors. Our final model has four predictors, all of which are significant at a p-value $\leq 0.01$. The adjusted R2, a measure of the amount of variance explained by the model, was 0.02. Caregiver education, place of care, length of stay and reported patient pain were all predictors of overall satisfaction in the total sample. Greater caregiver education, care provided in a nursing home setting and shorter lengths of stay were associated with lower caregiver satisfaction compared to lower caregiver educational attainment, care provided in a nursing home and longer lengths of stay. Because the comparison value for pain was “yes”, indicating the presence or treatment of pain, we found that caregivers who indicated that the patient experienced or was treated for pain were more likely to be satisfied with hospice care than those who did not report the presence or treatment of pain.
Table 4.7: Predictors of Overall Satisfaction in total sample (n=2000)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver education</td>
<td>0.0590</td>
<td>0.009</td>
</tr>
<tr>
<td>Place of care (v. nursing home)</td>
<td>-0.0611</td>
<td>0.007</td>
</tr>
<tr>
<td>Length of stay</td>
<td>-0.0839</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Pain</td>
<td>0.0762</td>
<td>0.001</td>
</tr>
</tbody>
</table>

Our final model in the cancer cohort has two predictors, with a p-values ≤ 0.025. The adjusted R2 was 0.02. In the cancer cohort, length of stay and reported dyspnea were associated with overall satisfaction. Caregivers who experienced longer lengths of stay were more likely to be satisfied with hospice care than those who experienced shorter lengths of stay. Because the comparison value for dyspnea is “yes”, indicating the presence or treatment of dyspnea, we found that caregivers who reported that the patient experienced or was treated for dyspnea were less likely to be satisfied with hospice care than those who did not report patient dyspnea.

Table 4.8: Predictors of Overall Satisfaction in Cancer cohort (n=1000)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length of stay</td>
<td>-0.1018</td>
<td>0.001</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>-0.0816</td>
<td>0.010</td>
</tr>
</tbody>
</table>

Our final model in the heart failure cohort has four predictors, with p-values ≤ 0.01. The adjusted R2 was 0.02. In the heart failure cohort, caregiver-patient relationship, caregiver education, the place of care and reported patient pain were all associated with caregiver satisfaction. Spousal caregivers, more educated caregivers and those caring for patients receiving care in a nursing home were less likely to be satisfied with hospice care than
caregivers who were adult children or other relatives, less educated
caregivers and those who cared for patients outside the nursing home setting.
Caregivers who reported that the patient experienced pain were more likely to
be satisfied with hospice care than those who reported that the patient did not
experience pain.

Table 4.9: Predictors of Overall satisfaction in Heart Failure cohort (n=1000)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship (v. spouse)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>-0.1068</td>
<td>0.005</td>
</tr>
<tr>
<td>Other</td>
<td>-0.0868</td>
<td>0.020</td>
</tr>
<tr>
<td>Caregiver Education</td>
<td>0.0855</td>
<td>0.009</td>
</tr>
<tr>
<td>Place of care</td>
<td>-0.0813</td>
<td>0.011</td>
</tr>
<tr>
<td>Pain</td>
<td>0.1046</td>
<td>0.001</td>
</tr>
</tbody>
</table>

Satisfaction with Symptom Management

The domain of symptom management measures caregiver satisfaction
with hospice management of the patient’s pain, shortness of breath and
anxiety. Our final model has six predictors with p-values ≤0.008 and an
adjusted R2 of 0.04. Caregiver age, caregiver race, caregiver-patient
relationship, the place of care, reported pain, and reported dyspnea were
significant predictors of caregiver satisfaction with symptom management in
the total sample. Black and spousal caregivers were less likely to be satisfied
with hospice care compared to White and otherwise related caregivers.
Caregiver age is measured in descending years, so domain scores increase
as age decreases. This indicates that younger caregivers perceive more
problems or are less satisfied with symptom management than older
caregivers. Because the comparison values for pain and dyspnea are “yes”,

67
indicating the presence or treatment of these symptoms, we found that caregivers who reported these symptoms were less likely to be satisfied than caregivers who did not report the presence or treatment of these symptoms.

Table 4.10: Predictors of Symptom management satisfaction in total sample (n=2000)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver age</td>
<td>0.1012</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Relationship (v.spouse)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult child</td>
<td>-0.1139</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Other</td>
<td>-0.0782</td>
<td>0.0002</td>
</tr>
<tr>
<td>Caregiver race (v.White)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>0.0725</td>
<td>0.001</td>
</tr>
<tr>
<td>Other</td>
<td>0.0290</td>
<td>0.218</td>
</tr>
<tr>
<td>Place of care</td>
<td>0.0613</td>
<td>0.001</td>
</tr>
<tr>
<td>Pain</td>
<td>-0.0740</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>-0.1443</td>
<td>&lt;0.000</td>
</tr>
</tbody>
</table>

In the cancer cohort, our final model has four predictors, with p-values ≤0.01 and an adjusted R2 of 0.06. Patient age, caregiver race, caregiver-patient relationship and reported dyspnea were significantly associated with caregiver satisfaction with symptom management. Black and spousal caregivers were less likely to be satisfied with symptom management than White or adult child caregivers. Patient age is measured in descending fashion, so younger patient age was associated with a lower likelihood of satisfaction than older patient age. Caregivers who reported patient dyspnea were less likely to be satisfied than those who did not report dyspnea.

Table 4.11: Predictors of Symptom management satisfaction in Cancer cohort (n=1000)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient age</td>
<td>0.0863</td>
<td>0.008</td>
</tr>
<tr>
<td>Caregiver Race</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Our final model in the heart failure cohort has three predictors with p-values <0.02 and an adjusted R2 of 0.02. Caregiver age, place of care and reported dyspnea were significant predictors of satisfaction with symptom management. Younger caregiver age, the nursing home setting and reported dyspnea were associated with lower caregiver satisfaction.

Table 4.12: Predictors of Symptom management satisfaction in Heart Failure cohort (n=1000)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver age</td>
<td>0.0885</td>
<td>0.005</td>
</tr>
<tr>
<td>Place of care</td>
<td>-0.080</td>
<td>0.011</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>-0.1059</td>
<td>0.001</td>
</tr>
</tbody>
</table>

**Satisfaction with Caregiver Teaching**

The domain of caregiver teaching measured caregiver satisfaction with the information provided by the hospice on patient care, what to expect in the last few days and what to expect when the patient died. In the total sample, our final model had three predictors with p-values <0.01 and an adjusted R2 of 0.03. Caregiver education, relationship to the patient and reported dyspnea were significant predictors of satisfaction with the teaching provided by the hospice. More educated, spousal caregivers and those who reported patient dyspnea were less likely to be satisfied with the teaching provided by the hospice.
hospice agency than were less educated, otherwise related caregivers or caregivers who did not report patient dyspnea.

Table 4.13: Predictors of Teaching Satisfaction in total sample (n=2000)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver education</td>
<td>0.1291</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Relationship (v. spouse)</td>
<td>-0.1264</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Child:</td>
<td>-0.1344</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Other:</td>
<td>-0.0565</td>
<td>0.011</td>
</tr>
</tbody>
</table>

In the cancer cohort, our final model had four predictors with p-values < 0.01 and an adjusted R2 of 0.06. Patient age, patient-caregiver relationship, caregiver education and reported dyspnea were all significantly associated with caregiver satisfaction with hospice teaching. More educated and spousal caregivers, along with caregivers of younger adults were less likely to be satisfied with hospice care in comparison to less educated, otherwise related caregivers and caregivers of older adults. Caregivers who reported patient dyspnea were less likely to be satisfied with hospice teaching than caregivers who did not report patient dyspnea.

Table 4.14: Predictors of teaching satisfaction in Cancer cohort (n=1000)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient age</td>
<td>0.0999</td>
<td>0.002</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>-0.0984</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Caregiver education</td>
<td>-0.1305</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Relationship (v. spouse)</td>
<td>-0.1471</td>
<td>&lt;0.0001</td>
</tr>
</tbody>
</table>

In the heart failure cohort, our final model had two predictors with p-values <0.03 and an adjusted R2 of 0.02. Caregiver education and
relationship to the patient were significant predictors of caregiver satisfaction with hospice teaching. More educated caregivers and spousal caregivers were less likely to be satisfied with the teaching provided by the hospice agency than were less educated and otherwise related caregivers.

Table 4.15: Predictors of teaching satisfaction in Heart Failure cohort (n=1000)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver education</td>
<td>0.1321</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Relationship (v. spouse)</td>
<td>-0.0729, -0.1081</td>
<td>0.051, 0.003</td>
</tr>
</tbody>
</table>

Satisfaction with Emotional Care

The domain of emotional care measured caregiver's satisfaction with the emotional and spiritual support provided by the hospice team. In the total sample, our final model contained one predictor with a p-value <0.05 and an adjusted R2 of 0.01. The only identified significant predictor of caregiver satisfaction with emotional support received was the level of caregiver education. The more educated the caregiver, the less likely they were to be satisfied.

Table 4.16: Predictors of Emotional satisfaction in total sample (n=2000)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver education</td>
<td>0.0800</td>
<td>&lt;0.0001</td>
</tr>
</tbody>
</table>

In the cancer cohort, our final model contained two predictors with p-values ≤0.03 and an adjusted R2 of 0.01. Place of care and hospice agency size were significantly associated with caregiver satisfaction with emotional
support. The nursing home setting and larger agency size were associated with lower caregiver satisfaction with emotional support.

Table 4.17: Predictors of Emotional satisfaction in Cancer cohort (n=1000)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver education</td>
<td>0.0836</td>
<td>0.008</td>
</tr>
<tr>
<td>Agency size</td>
<td>0.0777</td>
<td>0.015</td>
</tr>
</tbody>
</table>

In the heart failure cohort, our final model contained one predictor with a p-value ≤0.05 and an adjusted R2 of 0.01. Caregiver education was the only significant predictor of caregiver satisfaction with emotional support. More educated caregivers were less likely to be satisfied with hospice emotional support than were less educated caregivers.

Table 4.18: Predictors of Emotional satisfaction in Heart Failure cohort (n=1000)

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place of care</td>
<td>-0.0846</td>
<td>0.007</td>
</tr>
</tbody>
</table>

Satisfaction with Care Coordination

The domain of care coordination measured caregivers’ satisfaction with care coordination by the hospice team, including a consistent team and consistent information. In the total sample, our final model contained two predictors with p-values ≤0.03 and an adjusted R2 of 0.01. Caregiver age and patient experience of shortness of breath were significant predictors of caregiver satisfaction with the coordination of care during the hospice episode. Younger caregivers and caregivers who reported patient dyspnea
were less likely to be satisfied with coordination of care in comparison with older caregivers and those who did not report patient dyspnea.

**Table 4.19: Predictors of Coordination satisfaction in total sample (n=2000)**

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver age</td>
<td>0.0670</td>
<td>0.003</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>-0.0733</td>
<td>0.001</td>
</tr>
</tbody>
</table>

In the cancer cohort, our final model contained the same two predictors with p-values <0.03 and an adjusted R2 of 0.01. Again, younger caregivers and caregivers who reported patient dyspnea were less likely to be satisfied with coordination of care in comparison with older caregivers and those who did not report patient dyspnea.

**Table 4.20: Predictors of Coordination satisfaction in Cancer cohort (n=1000)**

<table>
<thead>
<tr>
<th>Predictors</th>
<th>Standardized coefficient</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver age</td>
<td>0.0861</td>
<td>0.006</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>-0.0901</td>
<td>0.004</td>
</tr>
</tbody>
</table>

No significant predictors of caregiver satisfaction with coordination of care could be identified in the heart failure cohort.

**Table 4.21: Summary of predictors**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Predictors in Total sample</th>
<th>Predictors in Cancer sub-sample</th>
<th>Predictors in Heart Failure sub-sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Satisfaction</td>
<td>Patient-caregiver relationship</td>
<td>Patient age</td>
<td>Patient-caregiver relationship</td>
</tr>
<tr>
<td></td>
<td>Caregiver education</td>
<td>Length of stay</td>
<td>Caregiver education</td>
</tr>
<tr>
<td></td>
<td>Place of Care</td>
<td>Perceived pain</td>
<td>Place of care</td>
</tr>
<tr>
<td></td>
<td>Length of stay</td>
<td>Perceived dyspnea</td>
<td>Perceived pain</td>
</tr>
<tr>
<td>Symptom Management</td>
<td>Patient-caregiver relationship</td>
<td>Patient-caregiver relationship</td>
<td>Patient-caregiver relationship</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Aim 2: Test a model of the relationship between identified predictors and family caregiver satisfaction with care separately in the heart failure cohort and the cancer cohort.

Based on review of the literature, a theoretical model was developed that posits that there is a relationship between demand (measured by patient symptoms) and satisfaction (measured by the five satisfaction measures of the FEHC). The model further posited that the relationship between demand and satisfaction is modified by internal and external resources (measured by patient and caregiver characteristics, clinical characteristics and agency characteristics). The model is further described with a figure presented in Chapter 2.

Several Structural Equation Modeling (SEM) models were constructed and tested to explore the associations between demand, satisfaction and caregiver resources. First, a basic model representing the relationship...
between demand and satisfaction was tested in both the cancer and the heart failure samples (see Figures 4.2 and 4.3).

Figure 4.2: Basic SEM in Heart Failure Cohort

Figure 4.3: Basic SEM in Cancer Cohort
All of the factor loadings for the measured variables on the latent factors were significant in both the cancer and heart failure samples at the p<0.001 level. Model fit indices were run and indicated that the model fit well in the heart failure (LR chi2 63.75, df 19; RMSEA 0.049; CFI 0.951; SRMR 0.033) and the cancer (LR chi2 57.61, df 19, p<0.0001; SRMR 0.035, RMSEA 0.045, CFI 0.959) cohorts. The relationship between demand and satisfaction was not significant in the heart failure cohort (p = 0.26), but was significant in the cancer cohort (p =0.02). In interpreting the coefficients, it is important to remember that positive coefficients mean more dissatisfaction and thus less satisfaction.

Next, the full model, including patient and caregiver characteristics as moderators, was tested in each cohort (see figures 4.4 and 4.5 below). Agency characteristics did not prove to be predictors during aim 1 analyses, nor were they shown to be significant in initial modeling. For the purposes of parsimony, we excluded them from the final models (no appreciable differences in fit indices were found).

Model fit was evaluated and although most of the indices indicated a good fit, the CFI was found to be problematic in the heart failure cohort (LR chi2=326.51, df 89; RMSEA=0.052; CFI=0.788; SRMR=0.039) and in the cancer cohort (LR chi2 332.76, df 89, p<0.0001; SRMR 0.040, RMSEA 0.052, CFI 0.793).
Only some of the relationships between the patient and caregiver characteristics and satisfaction were significant in the heart failure cohort; the patient-
caregiver relationship ($p=0.008$), caregiver education ($p=0.003$) and place of care ($p=0.005$) were the only three variables that significantly modified the relationship between satisfaction and demand. Furthermore, the relationship between demand and satisfaction was not significant in the heart failure cohort ($p=0.33$).

In the cancer cohort, patient age ($p=0.005$), caregiver race ($p=0.037$), caregiver education ($p=0.009$), the patient-caregiver relationship ($p=0.004$) and length of stay ($p=0.001$) were significant moderators of the relationship between demand and satisfaction. The relationship between demand and satisfaction was significant in the cancer cohort ($p=0.010$).

Given the low CFI, which indicated that some factor loadings might be mis-specified, modification indices were examined. It appeared that patient and caregiver variables influenced demand, as well as satisfaction. Since patient and caregiver variables may influence caregivers’ perception of demand, this was deemed theoretically justifiable.

It also appeared that overall satisfaction influenced demand. Given that caregivers’ overall sense of the hospice experience may influence their recall of demand, this was also considered theoretically justifiable. The following theoretical model was then tested (see figure 4.6), with overall satisfaction allowed to predict demand, as well as measured satisfaction.

**Figure 4.6: New Theoretical Model**

![Diagram of new theoretical model]

Demand $\rightarrow$ Satisfaction

Internal and External Resources

Demand $\leftarrow$ Satisfaction
This revised model was tested in the heart failure and cancer cohorts (Figures 4.7 and 4.8). Model fit statistics indicated that the model fit well in both the heart failure (LR chi2 158.03, df 79; SRMR 0.025; RMSEA 0.032; CFI 0.93) and the cancer cohorts (LR chi2 189.08, df 78, p<0.0001; SRMR 0.030, RMSEA 0.038, CFI 0.906).

In the heart failure cohort, demand was a significant predictor of satisfaction (p=0.043). Caregiver race (p=0.048), caregiver education (p=0.019), the patient-caregiver relationship (p=0.022) and the place of care (p=0.003) significantly predicted satisfaction (p<0.05), while patient age (p=0.014), caregiver age (p=0.007), caregiver education (p=0.005) and length of stay (p<0.0001) were significant predictors of perceived demand (p<0.05). Overall satisfaction with hospice care was also a significant predictor of perceived demand (p=0.042).

**Figure 4.7: Testing Adjusted Theoretical Model in Heart Failure Cohort**

In the cancer cohort, demand was a significant predictor of satisfaction (p=0.005). Patient age (p=0.026), caregiver race (p=0.029), caregiver education (p=0.006),
patient-caregiver relationship ($p=0.010$) and length of stay ($p=0.006$) were significant predictors of satisfaction, while patient age ($p=0.022$), caregiver age ($p=0.034$), caregiver sex ($p=0.054$) and length of stay ($p=0.001$) were significant predictors of demand. Overall satisfaction was also a significant predictor of demand ($p=0.043$).

**Figure 4.8: Testing Adjusted Theoretical Model in Cancer Cohort**

Aim 3: Compare family caregiver satisfaction with care between matched cohorts of hospice patients with heart failure and those with cancer.

In this aim, we are testing the hypothesis that differences in caregiver satisfaction are functions of demographic and clinical characteristics rather than diagnosis. In the data received from the NHPCO and the two cohorts drawn for Aims 1 and 2, there were clear differences in the demographic and
clinical characteristics between the two cohorts. In order to test our hypothesis that a portion of the difference in satisfaction scores is due to diagnosis, rather than demographic and clinical differences, we took steps to match the cohorts via propensity scoring. As explained in Chapter 3, the variables selected for propensity scoring were selected based on literature review, as they have been shown to influence outcomes in other studies. The variables included were patient age, sex, race, ethnicity and education level, caregiver age, sex, race, ethnicity, education level and relationship to the patient, length of stay, place of care, the reported symptoms of pain, dyspnea and anxiety, and the organizational variables of facility size and ownership.

In order to select the method with the greatest bias reduction, multiple methods for propensity scoring including nearest neighbor (with and without replacement and with and without calipers), optimal matching and full matching were trialed and the bias reduction of each was considered. The method with the greatest bias reduction proved to be 1:1 with calipers. Using calipers in propensity score matching limits the degree to which a heart failure and cancer caregiver could differ in propensity score and still be considered a match. Calipers were set at 0.20, which reduced the bias to 0.20 or less on each variable.

After propensity score matching was completed, 7370 caregivers from each cohort were matched for a total sample of 17,740. We were able to match 95% of the total heart failure caregivers available for matching, but only 30% of the total cancer caregivers available. We examined the differences in
cohort characteristics. Table 4.6 demonstrates that although there are still some differences in demographic, clinical and agency variables between the two cohorts, differences are greatly reduced from the pre-matched sample. However, it also demonstrates that the average characteristics of the heart failure sample post-matching did not differ much from their pre-matching values. The characteristics of the cancer post-matching sample differ significantly from their pre-matching values and the post-matching sample now strongly resembles the heart failure sample.

Table 4.22: Pre-and Post-match Comparisons of Sample Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pre-match Cancer (%)</th>
<th>Pre-match Heart failure (%)</th>
<th>Post-match Cancer (%)</th>
<th>Post-match Heart failure (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;90</td>
<td>8.06</td>
<td>35.65</td>
<td>25.10</td>
<td>31.23</td>
</tr>
<tr>
<td>80-89</td>
<td>28.45</td>
<td>44.53</td>
<td>47.39</td>
<td>47.37</td>
</tr>
<tr>
<td>70-79</td>
<td>28.45</td>
<td>14.50</td>
<td>18.18</td>
<td>15.64</td>
</tr>
<tr>
<td>60-69</td>
<td>20.37</td>
<td>4.01</td>
<td>5.05</td>
<td>4.31</td>
</tr>
<tr>
<td>50-59</td>
<td>10.85</td>
<td>0.95</td>
<td>1.83</td>
<td>1.04</td>
</tr>
<tr>
<td>&lt;50</td>
<td>3.82</td>
<td>0.37</td>
<td>2.44</td>
<td>0.39</td>
</tr>
<tr>
<td><strong>Patient sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>51.03</td>
<td>45.04</td>
<td>46.91</td>
<td>46.17</td>
</tr>
<tr>
<td>Female</td>
<td>48.97</td>
<td>54.96</td>
<td>53.09</td>
<td>53.83</td>
</tr>
<tr>
<td><strong>Patient education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;High School Diploma</td>
<td>18.02</td>
<td>26.84</td>
<td>24.50</td>
<td>25.97</td>
</tr>
<tr>
<td>High School Diploma</td>
<td>40.94</td>
<td>41.05</td>
<td>40.56</td>
<td>40.94</td>
</tr>
<tr>
<td>1-3 years of college</td>
<td>20.14</td>
<td>16.71</td>
<td>17.01</td>
<td>17.16</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>10.69</td>
<td>8.05</td>
<td>9.46</td>
<td>8.21</td>
</tr>
<tr>
<td>Graduate Degree</td>
<td>10.21</td>
<td>7.35</td>
<td>8.47</td>
<td>7.72</td>
</tr>
<tr>
<td><strong>Patient ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.93</td>
<td>1.61</td>
<td>1.75</td>
<td>1.52</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>98.07</td>
<td>98.39</td>
<td>98.25</td>
<td>98.48</td>
</tr>
<tr>
<td><strong>Patient race</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>93.47</td>
<td>95.46</td>
<td>94.11</td>
<td>95.29</td>
</tr>
<tr>
<td>Black</td>
<td>3.38</td>
<td>2.30</td>
<td>3.09</td>
<td>2.37</td>
</tr>
<tr>
<td>Other</td>
<td>3.14</td>
<td>2.24</td>
<td>2.80</td>
<td>2.33</td>
</tr>
<tr>
<td><strong>Patient-caregiver Relationship</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>50.17</td>
<td>28.53</td>
<td>34.49</td>
<td>30.22</td>
</tr>
<tr>
<td>Child</td>
<td>33.99</td>
<td>56.26</td>
<td>49.16</td>
<td>55.07</td>
</tr>
<tr>
<td>Other</td>
<td>15.84</td>
<td>15.22</td>
<td>16.35</td>
<td>14.71</td>
</tr>
<tr>
<td><strong>Caregiver age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;80</td>
<td>19.64</td>
<td>17.58</td>
<td>18.70</td>
<td>17.30</td>
</tr>
<tr>
<td>70-79</td>
<td>9.38</td>
<td>13.75</td>
<td>13.89</td>
<td>14.15</td>
</tr>
<tr>
<td>60-69</td>
<td>28.46</td>
<td>34.62</td>
<td>28.39</td>
<td>33.19</td>
</tr>
<tr>
<td></td>
<td>50-59</td>
<td>&lt;50</td>
<td>&lt;50</td>
<td>50-59</td>
</tr>
<tr>
<td>----------------</td>
<td>-------</td>
<td>------</td>
<td>------</td>
<td>-------</td>
</tr>
<tr>
<td>Caregiver sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>29.22</td>
<td>24.32</td>
<td>26.51</td>
<td>24.78</td>
</tr>
<tr>
<td>Female</td>
<td>70.78</td>
<td>75.68</td>
<td>73.49</td>
<td>75.22</td>
</tr>
<tr>
<td>Caregiver education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;High School Diploma</td>
<td>5.58</td>
<td>5.46</td>
<td>5.52</td>
<td>5.59</td>
</tr>
<tr>
<td>High School Diploma</td>
<td>33.11</td>
<td>31.50</td>
<td>31.07</td>
<td>31.74</td>
</tr>
<tr>
<td>1-3 years college</td>
<td>29.50</td>
<td>28.56</td>
<td>29.06</td>
<td>28.59</td>
</tr>
<tr>
<td>Bachelor’s</td>
<td>15.25</td>
<td>15.22</td>
<td>16.20</td>
<td>15.02</td>
</tr>
<tr>
<td>Graduate</td>
<td>16.55</td>
<td>19.27</td>
<td>18.14</td>
<td>19.06</td>
</tr>
<tr>
<td>Caregiver ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.97</td>
<td>1.83</td>
<td>1.89</td>
<td>1.76</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>98.03</td>
<td>98.17</td>
<td>98.11</td>
<td>98.24</td>
</tr>
<tr>
<td>Caregiver race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>93.45</td>
<td>95.40</td>
<td>94.25</td>
<td>95.24</td>
</tr>
<tr>
<td>Black</td>
<td>3.22</td>
<td>2.31</td>
<td>3.03</td>
<td>2.35</td>
</tr>
<tr>
<td>Other</td>
<td>3.23</td>
<td>2.29</td>
<td>2.73</td>
<td>2.42</td>
</tr>
<tr>
<td>Place of care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing home</td>
<td>12.87</td>
<td>30.25</td>
<td>24.98</td>
<td>26.55</td>
</tr>
<tr>
<td>Private Residence/other</td>
<td>87.13</td>
<td>69.75</td>
<td>75.02</td>
<td>73.45</td>
</tr>
<tr>
<td>Length of stay</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;2 days</td>
<td>7.94</td>
<td>11.94</td>
<td>7.99</td>
<td>12.01</td>
</tr>
<tr>
<td>3-7 days</td>
<td>20.77</td>
<td>23.25</td>
<td>20.92</td>
<td>23.57</td>
</tr>
<tr>
<td>8-14 days</td>
<td>14.87</td>
<td>12.33</td>
<td>14.37</td>
<td>12.25</td>
</tr>
<tr>
<td>15-29 days</td>
<td>11.16</td>
<td>7.77</td>
<td>11.10</td>
<td>7.82</td>
</tr>
<tr>
<td>1-3 months</td>
<td>29.14</td>
<td>22.37</td>
<td>27.30</td>
<td>22.09</td>
</tr>
<tr>
<td>4-6 months</td>
<td>6.98</td>
<td>7.73</td>
<td>7.50</td>
<td>7.71</td>
</tr>
<tr>
<td>&gt;6 months</td>
<td>9.12</td>
<td>14.60</td>
<td>10.81</td>
<td>14.56</td>
</tr>
<tr>
<td>Perceived Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>91.24</td>
<td>81.42</td>
<td>85.07</td>
<td>83.16</td>
</tr>
<tr>
<td>No</td>
<td>8.76</td>
<td>18.58</td>
<td>14.93</td>
<td>16.84</td>
</tr>
<tr>
<td>Perceived Dyspnea</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>49.74</td>
<td>63.83</td>
<td>56.34</td>
<td>61.76</td>
</tr>
<tr>
<td>No</td>
<td>50.28</td>
<td>36.17</td>
<td>43.66</td>
<td>38.24</td>
</tr>
<tr>
<td>Perceived Anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>56.05</td>
<td>49.16</td>
<td>50.07</td>
<td>49.61</td>
</tr>
<tr>
<td>No</td>
<td>43.95</td>
<td>50.84</td>
<td>49.93</td>
<td>50.39</td>
</tr>
<tr>
<td>Ownership</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Free-standing</td>
<td>50.35</td>
<td>53.45</td>
<td>59.26</td>
<td>57.41</td>
</tr>
<tr>
<td>Provider-based</td>
<td>49.65</td>
<td>46.55</td>
<td>40.74</td>
<td>42.59</td>
</tr>
<tr>
<td>Agency size (adc)*</td>
<td>3.24 (1.28)</td>
<td>3.31(1.25)</td>
<td>3.29(1.31)</td>
<td>3.30(1.25)</td>
</tr>
</tbody>
</table>

*adc=average daily census

We examined the mean domain scores of the cancer and heart failure caregivers both pre-matching (n=24,972 cancer and 7,760 heart failure) and post-matching (n=7,370 cancer and 7,370 heart failure) via t-tests. While the
pre-matched cohorts differed significantly on the domain scores of caregiver teaching (p<0.0001) and emotional support (p=0.005), these differences disappear post-matching.

Table 4.23: t-tests of satisfaction outcomes pre- and post-matching

<table>
<thead>
<tr>
<th>Satisfaction Measure</th>
<th>Pre-match Cancer mean (standard deviation)</th>
<th>Pre-match Heart Failure mean (standard deviation)</th>
<th>p-value</th>
<th>Post-match Cancer mean (standard deviation)</th>
<th>Post-match Heart Failure mean (standard deviation)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Satisfaction</td>
<td>1.37 (0.830)</td>
<td>1.39 (0.864)</td>
<td>0.0345</td>
<td>1.37 (0.82)</td>
<td>1.35 (0.80)</td>
<td>0.155</td>
</tr>
<tr>
<td>Symptom management domain score</td>
<td>0.05 (0.109)</td>
<td>0.05 (0.109)</td>
<td>0.9124</td>
<td>0.04 (0.11)</td>
<td>0.04 (0.11)</td>
<td>0.736</td>
</tr>
<tr>
<td>Caregiver teaching domain score</td>
<td>0.21 (0.232)</td>
<td>0.20 (0.224)</td>
<td>&lt;0.0001</td>
<td>0.20 (0.23)</td>
<td>0.21 (0.23)</td>
<td>0.078</td>
</tr>
<tr>
<td>Emotional support domain score</td>
<td>0.09 (0.167)</td>
<td>0.10 (0.173)</td>
<td>0.0050</td>
<td>0.09 (0.16)</td>
<td>0.10 (0.17)</td>
<td>0.093</td>
</tr>
<tr>
<td>Coordination of care domain score</td>
<td>0.08 (0.174)</td>
<td>0.07 (0.169)</td>
<td>0.0547</td>
<td>0.08 (0.17)</td>
<td>0.08 (0.17)</td>
<td>0.417</td>
</tr>
</tbody>
</table>

CONCLUSION

In this chapter, the three aims of the study were re-introduced and the results of the statistical analyses presented. Heart failure caregivers were generally older, White females caring for an older adult parent, while cancer caregivers were most often middle-aged White females caring for a spouse. Overall, caregiver characteristics such as age, race, education and relationship to the patient predicted satisfaction. Clinical characteristics such as place of care, length of stay and reported patient symptoms were also
predictive of satisfaction. Structural equation modeling demonstrated that the hypothesized model of caregiver satisfaction fit the data satisfactorily, although some adjustments improved model fit. After matching, there are no significant differences in satisfaction outcomes between the two cohorts.

The next chapter will discuss these findings in detail and compare them to the literature.
CHAPTER 5: DISCUSSION

Family caregivers serve as the uncompensated and largely untrained backbone of end of life care in the United States (Alliance, 2012; Bee et al., 2009; McGuire et al., 2012; Kl Stajduhar et al., 2010). As more patients and their family caregivers enroll in hospice care with a variety of diagnoses and background characteristics, it is important that hospice care providers understand how these characteristics may influence caregivers’ experience of end of life care, in order to optimally support patient/caregiver dyads (Meyers & Gray, 2001a). In this dissertation study, we sought to understand the relationship between the characteristics of heart failure and cancer hospice caregivers and the outcome of caregiver satisfaction with hospice care. In order to do this, we purposefully triangulated three aims to give us three viewpoints on the relationship. We first identified the characteristics associated with satisfaction in the heart failure and cancer cohorts separately. We then modeled the relationship between these characteristics and caregiver satisfaction in each cohort. Finally, we examined whether there existed a relationship between diagnosis and caregiver satisfaction or whether the true relationship lay between the population characteristics and caregiver satisfaction.

In this chapter, we present the major findings of this study in order of significance and discuss these results in the context of the previous literature. Major findings include 1) caregivers of heart failure patients are just as likely to be satisfied with hospice care as are caregivers of cancer patients; 2) Black, spousal and younger caregivers are less likely to be satisfied with hospice, as are those caring for an younger patient, caregivers of nursing
home residents and those experiencing a short length of stay; 3) caregiving
demand mediates the relationship between most caregiver and patient
characteristics and caregiver satisfaction; 4) race moderates the relationship
between demand and satisfaction; 5) caregivers’ overall perception of hospice
care influences their perception of past demand; and 6) nationally, it is still
challenging to refer heart failure patients early enough to realize the full
benefits of hospice, but not so early that they end up being discharged alive
and possibly later dying in the hospital. After reviewing these findings, we then
discuss the limitations and strengths of this study and suggest future research
directions. Finally, the major implications of this study are presented.

A major finding of this study was that heart failure caregivers are just
as likely to be satisfied with hospice care as are cancer caregivers. Diagnosis,
in and of itself, does not appear to make a difference in caregiver satisfaction.
Rather, differences between heart failure and cancer caregiver satisfaction
are associated with the characteristics of each population. This was
unexpected, as our previous research had indicated that the diagnosis of
heart failure alters other hospice outcomes, such as emergency service use,
despite adjustment for population covariates (MacKenzie, 2013). However,
this result concurs with the findings of Mitchell and colleagues (2007) who
investigated whether there were differences in satisfaction between hospice
caregivers of dementia patients and caregivers of cancer and other chronic
disease patients, using the FEHC. They found no significant differences in
satisfaction between hospice caregivers of patients with dementia, cancer or
another chronic disease (Mitchell et al., 2007).
In the context of our other results, which support our conclusion that it is the population’s demographic and clinical characteristics that affect satisfaction, we believe that these results are likely to be applicable to other chronic disease populations. The characteristics of dementia, chronic obstructive pulmonary disease and chronic renal failure patients on hospice are very similar to the characteristics of heart failure hospice patients and our results can likely be extrapolated to these populations (Mitchell et al., 2007).

This study is one of the first to evaluate caregiver characteristics as potential predictors of satisfaction with hospice care. We found that younger age, identifying as Black, caregiving for an younger adult, and experiencing shorter lengths of hospice care decreased the likelihood of satisfaction. This suggests that more vulnerable caregivers may not receive adequate support from hospice agencies. Place of care, patient relationship to the caregiver and caregiver education were also associated with satisfaction.

These characteristics, which we label “vulnerability factors”, are not intrinsically problematic. They represent either a risk for a high number of needs or a risk for needs going unmet by the healthcare system. A higher number of needs or unmet needs increase caregiver demand and stress, thereby decreasing caregiver satisfaction. For example, younger caregivers often have multiple competing roles and responsibilities (such as career and child care) that increase the burden and demand they face (Bainbridge et al., 2009; L Funk et al., 2010; Lin et al., 2012). Caring for a younger patient is often more emotionally challenging than caring for an older patient due to cultural expectations around “normal” time for death and the multiple roles which a younger patient may leave unfilled upon death (K. Stajduhar et al.,
Both of these scenarios indicate that there are likely to be a higher number of patient/caregiver needs, which increases the risk for needs going unmet by hospice care if these needs are not identified.

Caregivers who identify as Black may be at risk for a higher number of needs than those who identify as White. Pinquart and Sorensen (2005) found that Black, Hispanic and Asian-American family caregivers have a lower socioeconomic status on average than White caregivers. They are also younger and tend to have more competing demands than their White counterparts (Martin Pinquart & Sörensen, 2005). However, the real risk to Black caregivers is thought to be racial inequalities and cultural insensitivity within the healthcare system (Levkoff, Levy, & Weitzman, 1999). Welch and colleagues (2005) found that Black hospice caregivers report multiple issues with physician communication and lack of family support, while Levkoff and colleagues (1999) found that the cultural values of Blacks are not recognized or accommodated by health care providers (Levkoff et al., 1999; L. C. Welch, Teno, & Mor, 2005). Thus, Black caregivers may be at higher risk for having needs unmet by the healthcare system.

Short lengths of stay and receiving hospice care in a nursing home also raise the risk for unmet needs. As discussed further below, the short lengths of time between entry into hospice care and death leave little time to address and manage patient and caregiver needs. Receiving care in a nursing home raises the risk that caregivers, who are not always present, will not receive support from the hospice team and that patient care will suffer without the constant presence of a caregiver advocate.
Previous literature on the relationship between patient and caregiver characteristics and satisfaction is scarce. The one previous study to examine caregiver characteristics in relationship to satisfaction with hospice was done by Meyers and Gray (2001), who examined a sample of 44 hospice caregivers in northern Idaho and Eastern Washington; they also found that length of stay and patient-caregiver relationship predicted satisfaction. However, they did not find that age, sex or educational level predicted satisfaction. Furthermore, they found that being a wife or a daughter increased the likelihood of satisfaction, contrary to our finding that spousal caregivers are less likely to be satisfied with hospice care. Differences in findings may be due to their use of a different measure of satisfaction to examine a small sample of caregivers who cared for patients with a wider variety of diagnoses (Meyers & Gray, 2001b). Our finding that a spousal relationship was associated with lower satisfaction may be explained as a vulnerability factor; spouses are vulnerable because of increased emotional needs. Pinquart and Sorensen (2011) found that spouses report more depression and lower levels of psychological well-being than adult children or children-in-law (M. Pinquart & Sorensen, 2011). However, a spousal relationship may also alter the perception of hospice care. For instance, a spouse may perceive symptom control differently than an adult child – the better the caregiver knows the patient, the more likely they may be to pick up on subtle cues of distress. And the closer they feel emotionally to the patient, the less likely they may be to be satisfied with care, feeling that nothing is good enough for their loved one.
One characteristic that has been well studied in the literature is length of stay; this study confirmed previous findings that shorter lengths of stay are associated with poorer caregiver satisfaction (Kapo et al., 2005; Meyers & Gray, 2001b; Rickerson et al., 2005; Schockett et al., 2005). These results differ from those of Teno and colleagues who found that length of stay made no difference to satisfaction, but the caregivers’ perception of the appropriateness of the length of stay did affect satisfaction (Teno et al., 2012). The difference in results is likely due to the fact that Teno and colleagues performed their study in a sample of caregivers who had all experienced a length of hospice stay of seven days or less, while our study and others examined patients across a wider spectrum of stay lengths.

Interestingly, in this study, length of stay only influenced caregiver’s overall sense of satisfaction and not their satisfaction in the domains of symptom management, hospice teaching, emotional support or coordination or care. This result may be explained by findings from Rickerson and colleagues (2005) who demonstrated that although family caregivers generally give hospice care good ratings, their sense of the usefulness of hospice care is greater with longer lengths of stay. Although caregivers may not report unmet needs or dissatisfaction with specific areas of hospice care, their sense of how helpful hospice care was in the larger scheme of providing care for their loved one may be influenced by the length of time they actually received hospice care.

Caregivers of patients who received hospice care in a nursing home were less likely to be satisfied with hospice care than were those who received hospice care elsewhere. Overall satisfaction was lower, as was
satisfaction with symptom management and emotional support. Teno and colleagues (2004) also found that hospice care provided in settings other than the private residence was less likely to be satisfactory to caregivers. However, Miceli and Mylod (2003) found no difference in satisfaction across care settings. The difference in findings may be due to different instruments used – Miceli and Mylod used Press Ganey scores, while Teno and colleagues used the ‘Toolkit of Instruments to Measure End of Life Care (TIME)’, an instrument that has many similarities to the FEHC, used in this study (Miceli & Mylod, 2003; Teno et al., 2004). Previous literature suggests that nursing home residents who receive hospice care are more likely to get adequate pain medication and less likely to be hospitalized than those who do not receive hospice care (Miller, Gozalo, & Mor, 2001; Miller, Mor, Wu, Gozalo, & Lapane, 2002). However, it seems that nursing home patients are still not receiving care that is as good as they might receive outside the nursing home setting. Caregiver dissatisfaction both overall and with symptom management may be partially due to dissatisfaction with the nursing home staff who serve as proxy caregivers during the hospice care episode. Nursing home staff, responsible for multiple patients, may not be as attentive to patient signals of distress or as diligent in the role of patient advocates, as family caregivers with an attachment to the patient.

One concerning finding was that Black caregivers were less likely to be satisfied with hospice symptom management than White caregivers. While Reese and colleagues (2013) found that Black caregivers of patients who received hospice care were more satisfied with end of life care than caregivers of those who did not, they were still not as satisfied with the
hospice care experience as their White counterparts. Rhodes and colleagues also found that Black caregivers were less likely to be satisfied with symptom management than were White caregivers; in addition, Black caregivers were less likely to be satisfied with emotional support and coordination of care and less likely to have an overall positive view of hospice care (Rhodes et al., 2007). In a later study, they found these differences to persist even in hospices with a higher proportion of Black care recipients (Rhodes et al., 2012). Although Rhodes and colleagues adjusted their analysis for some patient characteristics (age, gender and diagnosis), they did not adjust for caregiver characteristics (Rhodes et al., 2012). Caregiver characteristics may explain why they found differences in satisfaction in the emotional support and coordination of care domains and overall satisfaction, while we did not. However, in examining caregiver characteristics, we had to delete a large number of respondents because of missing data. We lost 1121 Black caregivers whose responses might have altered our findings; although when comparing the percentage of Black caregivers in the total original data to the percentage of Black caregivers in the final sample without missing data, there is only a 0.02% difference (Black caregivers composed 3.6% of the original data and 3.4% of sample without missing data).

In relation to symptom management, it is well documented that racial disparities exist in pain management in the United States outside of the end of life setting (Meghani, Byun, & Gallagher, 2012). Blacks are less likely to have their pain documented, be treated for pain and to be prescribed opioids (Cintron et al, 2006). But in the hospice care setting, authors of a recent review concluded that the limited number of studies show no evidence of
disparity in pain assessment, level of pain or prescribing practices between White and Black patients (Wilkie & Ezenwa, 2012). Black patients and family caregivers do express a preference for more aggressive treatment towards the end of life (A. E. Barnato, Chang, et al., 2007; A. E. Barnato, Herndon, et al., 2007; Phipps, True, et al., 2003) and they may perceive pain levels differently than do Whites. While further research is needed to clarify these issues, one consideration is that identification as Black may not be a good indicator of risk for increased number of needs or greater risk for unmet needs. Measures of socioeconomic status or measures of cultural care may be more appropriate.

Although multiple studies have mentioned that heart failure hospice patients are older, on average, than cancer patients, no study appears to have evaluated patient age as a predictor of caregiver satisfaction (Bain et al., 2009; Cheung et al., 2012; Setoguchi et al., 2010; Zambroski et al., 2005). Dumont and colleagues found that caring for a younger patient is more stressful for cancer hospice caregivers than caring for an older patient (Dumont et al., 2006). The added stress in caring for a younger patient may have been due to the sense of unforeseen loss and potentially the loss of the main financial contributor in the patient-caregiver relationship. Our findings seem to confirm that this additional stress is related to lower caregiver satisfaction with hospice care among cancer caregivers. However, another explanation is that older patients may not experience or report symptoms to the same degree that younger patients do (Gibson & Helme, 2001; Morgan, Pendleton, Clague, & Horan, 1997). Furthermore, caregivers may perceive that symptoms are normal among older adults in a way that they may not
perceive them in younger adults. Interestingly, we only found patient age to be a factor predicting satisfaction in the cancer cohort. This cohort discrepancy may be due to the number of patients younger than 60 years of age; the number was very low in the heart failure cohort, suggesting there may be a ceiling effect when it comes to the relationship between patient age and caregiver satisfaction.

We found that younger caregivers were less likely to be satisfied with hospice coordination of care. This result conflicts with Meyers and Gray’s (2001) finding that caregiver age has no relationship to their satisfaction with hospice care. In a systematic review of caregiving in the end of life, Stadjuhar and colleagues (2010) report that younger caregivers are more likely to experience more emotional disturbance and a higher sense of burden than are older caregivers. Similarly, Bainbridge and colleagues (2009) found that younger caregivers reported more caregiver strain than older caregivers. Younger caregivers are likely to have multiple roles and responsibilities, including the demands of career and child-care activities. Competing demands on caregivers increase stress and burden (L Funk et al., 2010). Older caregivers are more likely to be retired and have completed their child-care responsibilities, leaving more time to devote to caregiving for the patient. They may also be more familiar with the tasks of caregiving, having had more caregiving experience in their life.

The above discussion of characteristics that influence caregiver satisfaction is given greater nuance by exploring the model of caregiver satisfaction that we found to fit well in the heart failure and cancer samples.
In estimating our model of caregiver satisfaction with hospice care, we found that demand predicted satisfaction. We also found that the relationship between demand and satisfaction was stronger in the cancer cohort than in the heart failure cohort. Despite evidence that managing patient symptoms is the greatest concern of caregivers at the end of life and that this can be a significant psychological strain, few studies have evaluated patient symptoms as a measure of caregiver demand and the relationship between patient symptoms and caregiver outcomes (Andershed, 2006; Bee et al., 2009). Haley and colleagues (1996) found that measures of patient pain or other physical symptoms did not predict caregiver depression or life satisfaction in hospice caregivers of patients with dementia or cancer (Haley, LaMonde, Han, Burton, & Schonwetter, 2003). However, caregiver perception of patient symptoms was found to impact caregiver quality of life in another study (Moody & McMillan, 2003). While there are other components to caregiver demand, patient symptoms are likely the one component of demand that hospice is most expected to alleviate. This hypothesis is supported by our findings that caregivers who perceived that the patient experienced pain or shortness of breath were less likely to be satisfied with hospice care across several domains. Given that symptom control is a major component of how caregivers measure their success at caregiving and that the lack of symptom control is a predictor of caregiver depression and suicidal ideation, caregiver perception of hospice care is likely to be strongly tied to their perception of patient symptoms (Abbott, Prigerson, & Maciejewski, 2013; Ando et al., 2013; Dumont et al., 2006). Thus, it is not surprising that we found a relationship
between caregiver demand, as measured by patient symptoms, and caregivers’ satisfaction with hospice care.

It is not clear why the relationship between demand and satisfaction is stronger in the cancer cohort, but this may be because heart failure patients are older and likely to have more comorbidities than cancer patients (MacKenzie, 2013). Thus, the actual symptom profiles of the heart failure patients may be more variable and may include important symptoms that are not recorded in the FEHC. In addition, we did not have data about patients’ functional status or cognitive impairment, which might be more relevant measures of demand in the older heart failure sample.

In contrast to our initial model of caregiver satisfaction, we found that demand mediated the relationship between most patient and caregiver characteristics and satisfaction. While our conceptual model of caregiver satisfaction has not been previously tested, it shares some commonalities with the stress-process model (SPM) in that both posit that caregiver characteristics moderate the relationship between demand and outcomes (Pearlin, Mullan, Semple, & Skaff, 1990). The SPM also posits that the relationship between caregiver characteristics and outcomes is mediated by demand variables, as caregiver characteristics contribute to their perception of demand (Pearlin et al., 1990), which our modified model also posited. In a sample of Alzheimer’s caregivers, the caregiver characteristics of age and education were found to predict caregiver physical and emotional health and this relationship also was found to be mediated by demand (Hilgeman et al., 2009). There is little other literature evaluating the relationship between caregiver characteristics, demand and outcomes; however, several studies
have confirmed the relationship between caregiver characteristics and perception of demand (Bainbridge et al., 2009; Townsend et al., 2010).

Race moderated the relationship between demand and satisfaction in both cancer and heart failure samples. When Hilgeman and colleagues (2009) tested the SPM in Alzheimer’s caregivers, race was found to moderate the relationship between caregiver characteristics and outcomes (Hilgeman et al., 2009). As mentioned earlier, the impact of race may be partially due to socioeconomic status and thus an increased number of needs, but may also be due to cultural differences and the lack of cultural competency on the part of hospice care providers. The authors of a qualitative examination of racial differences in perceptions of end of life care found that Blacks often feel that their cultural preferences are not respected by healthcare providers (Levkoff et al., 1999). Specifically, they noted that their faith beliefs, preferences in terms of being addressed and their views on family involvement were rarely taken into consideration or honored (Levkoff et al., 1999). While cultural competency is not measured by the FEHC or other tools utilized in the literature, the overall perception of the lack of cultural competency is likely to leave a negative impression that colors the caregiver’s responses to the FEHC and other measures.

Similarly to Blacks, Hispanics are less likely to enroll in hospice and tend to prefer intervention-intensive end of life care (Givens et al., 2010). Like Blacks, spirituality is a strong cultural component and extended family involvement is common (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004). We were unable to explore the relationship between ethnicity and caregiver satisfaction because we had a very small percentage of Hispanic respondents.
and were unable to demonstrate any significant relationships. It is unlikely that no true differences exist – rather, we began with a small number of Hispanic respondents and lost more with missing data. The FEHC does have a Spanish language version which is used by some hospices and using the Spanish version may capture a higher percentage of Hispanic respondents (Portenoy & Teno, 2007).

An interesting finding that emerged from this study is that while caregiver demand predicted satisfaction, caregivers’ overall sense of satisfaction with hospice predicted their sense of demand. This relationship between demand and satisfaction illustrates an issue with both post-service surveys and with the measurement of satisfaction in general; that responses are historically skewed towards the positive and that users’ overall sense of the experience influences their responses to specific questions (Williams, Coyle, & Healy, 1998). Memory is influenced by emotion and thus overall positive emotions sway the memory of specific needs (Williams et al., 1998). Furthermore, there is a strong correlation between respondents’ view of their specific health care providers (e.g. nurses) and their view of a healthcare organization as a whole; thus, respondents with an overall positive view of their care providers tend to provide overall positive responses of the service in general (Williams et al., 1998; Zifko-Baliga & Krampf, 1997). Respondents may consciously or unconsciously downplay the amount of demand they experienced in order to provide more positive feedback for the care providers.

In interpreting the results of this survey, it is important to remember that we are focused on the outcome of caregiver satisfaction. Caregiver satisfaction is an emotional response, not an objective measurement. While
the FEHC has previously been used as surrogate reporting on the actual performance of the hospice (Connor, Teno, et al., 2005), our modeling suggests that the FEHC is not effective as an objective measure of performance. Caregivers’ recall of hospice performance is linked to their overall impression of hospice care. We would argue that the FEHC should be looked at as a measure of hospice quality care for the caregiver, rather than surrogate reporting on the patient experience. As a measure of hospice quality care for the caregiver, the FEHC captures the emotional response of hospice caregivers to the care received. This emotional response is what is linked to the caregiver outcomes of cardiovascular disease, depression, suicidal ideation, resource use and future planning (Abbott et al., 2013; Carr, 2012; Chentsova-Dutton et al., 2000; Garrido & Prigerson, 2013). Because of the linkage between these outcomes and caregiver satisfaction, the FEHC is a key measure of hospice quality care for the caregiver, although further research is needed to specifically link FEHC responses to objective caregiver outcomes.

Our finding that heart failure patients are clustered at either end of the length of stay continuum indicates that health care providers currently struggle with anticipating heart failure patients’ need for hospice and enrolling them in a timely manner. Many arrive to hospice likely too late, with only a few days stay, while others spend well over six months on hospice. This finding confirms our findings from a previous study, in which we found that almost a third of patients died within one week of admission to hospice, while another 17% stayed beyond 180 days (MacKenzie, 2013). It also explains the apparent contradiction between literature that shows that heart failure patients
are at higher risk for short lengths of stay compared to cancer patients (Miller, Weitzen, et al., 2003; Zambroski et al., 2005), yet are also more likely to stay longer than six months (Bain et al., 2009). We have already demonstrated that short lengths of stay decrease the likelihood of caregiver satisfaction. But more fundamentally, short lengths of stay in hospice are problematic due to decreased time available for symptom management, caregiver education and support, and preparation for the death of the patient (Kapo et al., 2005; Miceli & Mylod, 2003; Rickerson et al., 2005; Schockett et al., 2005; Teno et al., 2012). The failure to adequately complete these tasks threatens caregiver outcomes; short lengths of stay have been associated with increased risk of subsequent major depression in family caregivers (Kris et al., 2006). Yet longer lengths of stay may increase the risk of discharge from hospice and subsequent death in an inpatient setting (Bain et al., 2009). Provider discomfort with prognosis and end of life discussions in the heart failure population are well documented (Allen et al., 2012; Hauptman et al., 2008; Schockett et al., 2005). After a decade of rising enrollment, the number of heart disease patients who enrolled in hospice in 2011 dropped for the first time, even as heart failure mortality rates held steady (Go et al., 2013; NHPCO, 2012a, 2012b).

Implications for Research, Practice and Policy

To quickly summarize our findings again, we found that heart failure caregivers are just as likely to be satisfied with hospice care as cancer caregivers, once demographic and clinical characteristics are taken into account. Race, age, caregiver-patient relationship, place of care, length of stay and the reported symptoms of pain and dyspnea all affect caregiver
satisfaction. The symptoms of pain and dyspnea affect satisfaction directly, while age, caregiver-patient relationship, place of care and length of stay affect satisfaction through the mediating variables of caregiver demand, as measured by symptoms. Race moderates the relationship between other characteristics and satisfaction. Heart failure patients have a bimodal pattern of hospice enrollment; over a third enroll within three days of death, while almost a fifth stay longer than six months.

We found that the demographic and clinical characteristics of hospice caregivers and patients are more important than diagnosis in determining caregiver satisfaction. Several characteristics that we found to be associated with lower caregiver satisfaction (such as care received in a nursing home and shorter length of stay) are more common to hospice patients with a chronic disease diagnosis (Mitchell et al., 2007). As these chronic disease patients are increasingly enrolling in hospice care, we suggest that hospice agencies and care providers be mindful of the patient and caregiver characteristics of enrollees. Further research examining the relationship between these characteristics and measurable outcomes such as caregiver depression and resource use are needed. Further research is also needed to determine what interventions are most effective for vulnerable caregivers. Ultimately, the development of a screening tool to alert hospice agencies to vulnerable caregivers and suggest interventions is desirable.

Characteristics for hospice agencies to examine closely include caregiver-patient relationship, place of care and race. Spousal caregivers exhibit less satisfaction across the domains of care than adult child caregivers. These results suggest that hospice care providers may want to consider tailoring
emotional support to spousal caregivers and also include them in assessment of patient comfort. As hospice enrollment of nursing home patients increases, hospice agencies may want to consider whether the traditional model of hospice care needs to be re-worked in the nursing home setting. It is concerning that caregivers of nursing home patients perceive more unmet needs when it comes to emotional support than do caregivers of patients in the home setting. It does require more time and effort for hospice agencies to reach out to caregivers of nursing home patients, as they may not always be present at the bedside, but emotional support is still critical for these caregivers.

We found that Black caregivers are less likely to be satisfied with hospice care than White caregivers and that race significantly modifies the relationship between most other characteristics and caregiver satisfaction. This finding concurs with previous findings on racial disparities in hospice satisfaction (Rhodes et al., 2007; Rhodes et al., 2012). In order to better understand the etiology of racial dissatisfaction, the NHPCO may want to consider adding questions on cultural sensitivity to the FEHC. These questions may help us to understand the roles of socioeconomic status and provider insensitivity in racial dissatisfaction. Given our findings on race, we also strongly suggest future research examining the relationship between ethnicity and caregiver satisfaction.

Shorter lengths of stay were associated with lower satisfaction than longer lengths of stay. Length of stay is particularly concerning in the heart failure population, in which over a third of patients are enrolled in hospice for three days or less. While health care providers for heart failure patients need to
become more aware of end of life issues and more willing to address these
needs, we recommend that policy adaptations also be considered. The
qualifications for hospice enrollment should be reviewed and it is time to
consider whether the six month prognosis rule really works for end-stage
patients with chronic disease.

**Limitations and Strengths**

We analyzed data from the FEHC, a voluntary survey that informal
caregivers take following hospice care. Because it is voluntary, it is difficult to
know whether it is truly representative of the national population of informal
caregivers. Furthermore, significant missing data on caregiver variables
meant that some caregiver responses were lost, with a higher volume of
younger and Hispanic caregivers lost than others. When the patient
characteristics are compared to national data from MedCAPS and from the
2007 National Hospice and Home Care Survey, the FEHC appears to be
relatively representative, but there are no national data on caregivers of
cancer and heart failure hospice patients to which to compare our caregiver
characteristics. The FEHC data is also cross-sectional and thus we were
unable to examine true predictors of caregiver satisfaction.

Although we were successful in identifying characteristics associated
with caregiver satisfaction with hospice care, the amount of variance
explained by our models was quite small. Despite caregivers’ own resources
and needs, the actual hospice care received is likely to make the largest
contribution to caregiver satisfaction. Aspects of hospice care, such as
volunteer use, have been demonstrated to contribute to caregiver satisfaction.
However, we suggest that the characteristics we examined were proxy
measures for caregiver and patient needs or risk for unmet needs. We recommend future research to examine actual needs and whether or not those needs were met, as well as research to examine the correlation of those needs with patient/caregiver characteristics.

Previous studies have raised concerns about caregivers’ ability to recall details of the care they received, given both that the survey is sent one to three months distant from the care received and the potentially emotionally volatile state of the caregivers. If we were using this survey as an objective measure of care, these would be serious concerns and limitations. But because we were looking specifically at caregivers’ satisfaction – an emotional response to care – it is unlikely that time significantly altered that emotional reaction. It is the longer-term and long-standing emotional evaluation of hospice care that drives the consequences of caregiver satisfaction, such as resource use, disenrollment rates, caregiver emotional health and mortality and future hospice use (Abbott et al., 2013; Carr, 2012; Chentsova-Dutton et al., 2000; Garrido & Prigerson, 2013).

Despite these limitations, this study is one of the first to use a large, national dataset to examine predictors of caregiver satisfaction with hospice care in the heart failure and cancer populations. It provides a critical examination of the caregiver and patient characteristics that influence caregivers’ perceptions of hospice care and further, is one of the first to test a model of caregiver satisfaction with hospice care. The propensity score analysis used to compare heart failure and cancer caregivers helps to ensure that issues with sampling did not unduly influence the outcome. And despite the voluntary nature of the FEHC, using the same tool as multiple previous
studies allows for comparisons with the literature and the evolution of knowledge surrounding caregivers’ perceptions of hospice care.

**Conclusions**

This study brings to light both the strengths and the weaknesses of hospice care in the United States at this point in time. Overall, hospice care is perceived in a highly positive light by informal caregivers and dissatisfaction rates are relatively low. Furthermore, that satisfaction does not appear to be affected by diagnosis group and thus hospice agencies can feel comfortable continuing outreach to heart failure patients and their caregivers. Yet hospice care providers need to focus on improving the care provided to the most vulnerable of caregivers, including older adults, Blacks, and those caring for a younger adult and patients in nursing homes. Furthermore, the progressive diminishment in median length of hospice stay over the past several decades is cause for concern on the part of healthcare providers and policy makers as it demonstrably decreases caregiver satisfaction and increases the number of unmet needs.

With the rise of chronic illness and the changing demographics of the population, hospice care providers are likely to see an increasing number of older adults with multiple comorbidities enrolling into hospice care and a higher number of minority patients and caregivers. In addition, increasing numbers of patients are enrolling in hospice care in the nursing home setting, which places their informal caregiver in a different role. At the moment, these caregivers are facing unmet needs in the areas of symptom management, emotional support, hospice teaching and coordination of care. More research
is needed to fully understand the needs and vulnerabilities of these caregivers and to test the interventions that would best meet these needs.

Hospice agencies and healthcare providers need to focus on cultural competency and cross-cultural outreach in the end of life. Well over a decade has passed since Levkoff and colleagues (1999) documented that Blacks perceive that hospice care providers do not understand or adapt to their cultural preferences and yet we still note significant differences in satisfaction with hospice care between Black and White caregivers. When we examine hospice enrollment over the past decade by race, it is clear that although Black enrollment into hospice has increased, it has not kept pace with the increase in White enrollment (MedPAC, 2012). In order to provide the highest quality of hospice care and the support that Black patients and their caregivers need, hospice care providers need to be aware and respectful of their cultural preferences and views. It is likely that Black hospice enrollment will continue to lag behind their White counterparts until cultural competency becomes the norm. Further research is needed to more fully understand Black preferences around end of life care in the hospice setting and to identify interventions to assist in the development of healthcare providers’ cultural competency.

Policy makers and healthcare organizations need to carefully examine their definitions around “end of life” and hospice eligibility. Too many patients are enrolling in hospice with lengths of stay too short to make a significant difference in their lives or the lives of their informal caregivers. Interventions to both encourage and promote healthcare providers earlier referral of patients to hospice care programs need to be developed. Hospice eligibility criteria
may need to be revised to promote earlier identification of patients and caregivers who would benefit from these services.
Appendix A: Family Evaluation of Hospice Care

❖ Section A ❖

A1) In what month and year did the patient die?
   Month ________ year __________

A2) For about how many days or months did the patient receive hospice services?
   ______  □ days  □ months

A3) As far as you know, did any member of the hospice team speak to the patient or to a family member about the patient’s wishes for medical treatment as he/she was dying?
   □ Yes
   □ No

A4) At any time while the patient was under the care of hospice, did the doctor or another hospice team member do anything with respect to end-of-life care that was inconsistent with the patient’s previously stated wishes?
   □ Yes
   □ No

❖ Section B ❖

B1) While under the care of hospice, did the patient have pain or take medicine for pain?
   □ Yes
   □ No → If No, Go to Question B5

B2) How much medicine did the patient receive for his/her pain?
   □ Less than was wanted
   □ Just the right amount
   □ More than patient wanted
B3) Did you or your family receive any information from the hospice team about the medicines that were used to manage the patient’s pain?

- Yes
- No
- Don’t Know

B4) Did you want more information than you got about the medicines used to manage the patient’s pain?

- Yes
- No

B5) While under the care of hospice, did the patient have trouble breathing?

- Yes
- No → If No, Go to Question B9

B6) How much help in dealing with his/her breathing did the patient receive while under the care of hospice?

- Less than was wanted
- Just the right amount
- More than patient wanted

B7) Did you or your family receive any information from the hospice team about what was being done to manage the patient’s trouble with breathing?

- Yes
- No
- Don’t Know
- No treatments used for breathing → Go to Question B9

B8) Did you want more information than you got about what was being done for the patient’s trouble with breathing?

- Yes
- No

B9) While the patient was under the care of hospice, did he/she have any feelings of anxiety or sadness?

- Yes
- No → If No, Go to Question C1

B10) How much help in dealing with these feelings did the patient receive?

- Less than was wanted
- Right amount
- More help or attention to these feelings than patient wanted
Section C

C1) How often were the patient’s personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been by the hospice team?

- Always
- Usually
- Sometimes
- Never
- Hospice team was not needed or wanted for personal care

C2) How often did the hospice team treat the patient with respect?

- Always
- Usually
- Sometimes
- Never

Section D

D1) While the patient was under the care of hospice, did you participate in taking care of him/her?

- Yes
- No  → If No, Go to Question D5

D2) Did you have enough instruction to do what was needed?

- Yes
- No

D3) How confident did you feel about doing what you needed to do in taking care of the patient?

- Very confident
- Fairly confident
- Not confident
D4) How confident were you that you knew as much as you needed to about the medicines being used to manage the patient’s pain, shortness of breath, or other symptoms?
- Very confident
- Fairly confident
- Not confident

D5) How often did the hospice team keep you or other family members informed about the patient’s condition?
- Always
- Usually
- Sometimes
- Never

D6) Did you or your family receive any information from the hospice team about what to expect while the patient was dying?
- Yes
- No

D7) Would you have wanted more information about what to expect while the patient was dying?
- Yes
- No

D8) How confident were you that you knew what to expect while the patient was dying?
- Very confident
- Fairly confident
- Not confident

D9) How confident were you that you knew what to do at the time of death?
- Very confident
- Fairly confident
- Not confident

❖ Section E ❖

E1) Did any member of the hospice team talk with you about your religious or spiritual beliefs?
- Yes
- No

E2) Did you have as much contact of that kind as you wanted?
☐ Yes
☐ No

E3) How much emotional support did the hospice team provide to you prior to the patient’s death?
☐ Less than was wanted
☐ Right amount
☐ More attention than was wanted

E4) How much emotional support did the hospice team provide to you after the patient’s death?
☐ Less than was wanted
☐ Right amount
☐ More attention than was wanted

E5) How much help did the patient and/or you receive from volunteers while under the care of hospice?
☐ Less than wanted
☐ Just the right amount
☐ More than wanted
☐ Did not receive volunteer services

❖ Section F ❖

F1) How often did someone from the hospice team give confusing or contradictory information about the patient’s medical treatment?
☐ Always
☐ Usually
☐ Sometimes
☐ Never

F2) While under the care of hospice, was there always one nurse who was identified as being in charge of the patient’s overall care?
☐ Yes
☐ No
F3) Was there any problem with hospice doctors or nurses not knowing enough about the patient’s medical history to provide the best possible care?

☐ Yes
☐ No

✧ SECTION G ✧

G1) Overall, how would you rate the care the patient received while under the care of hospice?
   ☐ Excellent
   ☐ Very good
   ☐ Good
   ☐ Fair
   ☐ Poor

G2) How would you rate the way the hospice team responded to your needs in the evenings and weekends?
   ☐ Excellent
   ☐ Very good
   ☐ Good
   ☐ Fair
   ☐ Poor
   ☐ Never contacted evening or weekend services

G2a) Did the hospice team explain the plan of care to you in a way that you could understand?
   ☐ Yes
   ☐ No
☐ Hospice team did not explain plan of care to me

G2b) How often did you agree with changes in the plan of care?
☐ Always
☐ Usually
☐ Sometimes
☐ Never
☐ No changes were made to plan of care

G3) Based on the care the patient received, would you recommend this hospice to others?
☐ Definitely No
☐ Probably No
☐ Probably Yes
☐ Definitely Yes

G4) In your opinion, was the patient referred to hospice too early, at the right time, or too late during the course of his/her final illness?
☐ Too early → Go to Question G5
☐ At the right time → Go to Question G5
☐ Too late → Please explain

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

G5) While under the care of hospice, was the patient in a nursing home?
□ Yes
□ No → Go to Question H1

G5a) After hospice became involved, would you say the quality of end-of-life care the patient received:
□ Improved
□ Stayed the same
□ Decreased

❖ Section H ❖

H1) How old was the patient when he/she died?   ______ years

H2) Was the patient male or female?
□ Male   □ Female

H3) Please choose the one disease group that best describes the primary illness that caused the patient to be referred to hospice. Please choose only one.
□ Cancers - all types
□ Heart & circulatory diseases
□ Lung & breathing diseases
□ Kidney diseases
□ Liver diseases
□ Stroke
□ Dementia or Alzheimer's disease
□ AIDS & other infectious diseases
□ Frailty and decline due to old age
□ Another disease (Please write in) ____________________________

H4) What is the highest grade or level of school that the patient completed?
□ 8th grade or less
□ Some high school but did not graduate
□ High school graduate or GED
□ 1-3 years of college
□ 4-year college graduate
□ More than a 4-year college degree

H5) Was the patient of Hispanic or Spanish family background?
□ Yes
□ No

H6) Which of the following best describes the patient’s race?
□ American Indian or Alaskan Native  □ Asian or Pacific Islander
□ Black or African-American
□ White
□ Another race or multiracial (Please write in)
______________________

❖ Section I ❖

I1) What is your relationship to the patient?
□ Spouse  □ Partner  □ Child
□ Parent  □ Sibling  □ Other Relative
□ Friend  □ Other (Please write in) __________________________

I2) How old were you on your last birthday? _______ years

I3) Are you male or female?
□ Male  □ Female

I4) What is the highest grade or level of school that you have completed?
□ 8th grade or less
□ Some high school but did not graduate
□ High school graduate or GED
☐ 1-3 years of college
☐ 4-year college graduate
☐ More than a 4-year college degree

I5) Are you of Hispanic or Spanish family background?
☐ Yes
☐ No

I6) Which of the following best describes your race?
☐ American Indian or Alaskan Native
☐ Asian or Pacific Islander
☐ Black or African-American
☐ White

☐ Another race or multiracial (Please write in) ______________________

❖ Section J ❖

J1) Is there anything else that you would like to tell us about the care provided by the hospice team?
☐ No
☐ Yes Please explain

___________________________________________________________
___________________________________________________________
___________________________________________________________
___________________________________________________________
___________________________________________________________
___________________________________________________________
___________________________________________________________

118
## Appendix B: Domains of Care on the FEHC Used in Analyses

<table>
<thead>
<tr>
<th>Domain of Care</th>
<th>Questions on FEHC</th>
<th>Sample question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attending to family needs for support (Emotional Support)</td>
<td>E1-E5</td>
<td>E1: did any member of the hospice team talk with you about your religious or spiritual beliefs?</td>
</tr>
<tr>
<td>Attending for family needs for information (Caregiver Teaching)</td>
<td>D1-D9</td>
<td>D3: How confident did you feel about doing what you needed to do in taking care of the patient?</td>
</tr>
<tr>
<td>Symptom management</td>
<td>B1-B10</td>
<td>B1: While under the care of the hospice, did the patient have pain or take medicine for pain?</td>
</tr>
<tr>
<td>Coordination of Care</td>
<td>F1-F3</td>
<td>F2: While under the care of hospice, was there always one nurse who was identified as being in charge of the patient’s overall care?</td>
</tr>
<tr>
<td>Family satisfaction</td>
<td>G1</td>
<td>G1: Overall, how would you rate the care the patient received while under the care of hospice?</td>
</tr>
</tbody>
</table>


References


Austin, P. C. (2009). Balance diagnostics for comparing the distribution of baseline covariates between treatment groups in propensity-score matched samples. Statistics in Medicine, 28, 3083-3107.


Carr, D. (2012). "I don't want to die like that ...": the impact of significant others' death quality on advance care planning. *Gerontologist, 52*(6), 770-781. doi: 10.1093/geront/gns051


Miller, S. C., Gozalo, P., & Mor, V. (2001). Hospice enrollment and hospitalization of dying nursing home patients. *American Journal of Medicine, 111*(1), 38-44. doi: http://dx.doi.org/10.1016/S0002-9343(01)00747-1


Setoguchi, S., Glynn, R. J., Stedman, M., Flavell, C. M., Levin, R., & Stevenson, L. W. (2010). Hospice, opiates, and acute care service use among the elderly before death from heart failure or cancer. *Am Heart J*, 160(1), 139-144. doi: 10.1016/j.ahj.2010.03.038


Teno, J. M., Casarett, D., Spence, C., & Connor, S. (2012). It is "too late" or is it? Bereaved family member perceptions of hospice referral when their family member was on hospice for seven days or less. *J Pain Symptom Manage, 43*(4), 732-738. doi: 10.1016/j.jpainsymman.2011.05.012


