

EXPLORING THE ROLE OF PALLIATIVE CARE IN HEART FAILURE:
REFERRAL BARRIERS, CARE GAPS, AND QUALITY OF CARE

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ABSTRACT

DIO KAVALIERATOS: Exploring the Role of Palliative Care in Heart Failure:
Referral Barriers, Care Gaps, and Quality of Care
(Under the direction of Morris Weinberger, Ph.D.)

Heart failure is a chronic, incurable disease that presents significant burdens to patients, caregivers, and the healthcare system. With approximately 5 million Americans currently diagnosed with heart failure, the effective management of heart failure patients is of prime interest to clinicians, policymakers, and payers. Palliative care, which has been shown to improve patient outcomes in cancer, may hold similar promise for heart failure patients. However, despite similar disease experiences and prognosis, heart failure patients are less likely to receive palliative care than cancer patients. This dissertation investigates the current and potential role of specialist palliative care in heart failure.

Through the use of mixed qualitative and quantitative methodologies, the three papers in this dissertation provide contributions to the medical literature related to: (1) palliative care referral barriers in heart failure; (2) the unresolved symptoms and treatment gaps of heart failure patients prior to palliative care consultation; and, (3) the link between palliative processes and patient outcomes in a cohort of heart failure patients receiving community-based palliative care.

Our findings suggest that the term “palliative care” is ambiguous to providers and itself may stand as a barrier to referral. Nevertheless, we documented agreement

among primary care, cardiology, and palliative care providers regarding the likely potential benefit of palliative services in advanced heart failure. Next, we found that among a group of heart failure and cancer patients receiving palliative care, both groups possessed significant palliative needs. Furthermore, the profiles of burden were not strikingly different between disease groups, thereby suggesting that the need for palliative care is similar for patients living with either illness. Lastly, we present data regarding the impact of palliative care in a cohort of heart failure patients. Of five quality indicators, the completion of a comprehensive assessment was found to be associated with improved patient health.

In sum, this dissertation provides a glimpse into the needs of HF patients and how they might be addressed by specialist palliative care. Our work suggests that in heart failure, palliative care is underutilized, that patients have unmet needs, and that specific palliative interventions such as comprehensive assessment should be prioritized.

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PREFACE

This dissertation is structured to follow the 3-paper format. As such, Chapters 1 and 2 offer an introduction to the overall dissertation study, as well as provide the requisite review of the literature. Chapter 3 broadly describes the analytic methods used in each of the three dissertation studies. Next, Chapters 4-6 each contain standalone manuscripts that have been prepared for submission to biomedical journals. As such, repetition and redundancy may be evident across Chapters. Lastly, Chapter 7 synthesizes the findings of the dissertation studies, places this synthesis within the context of current and future trends in medicine, and offers implications for future policy, practice, and research.

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LIST OF ABBREVIATIONS

ACC	American College of Cardiology
AHA	American Heart Association
ACO	Accountable Care Organization
CMS	Centers for Medicare & Medicaid Services
COPD	Chronic obstructive pulmonary disease
DCCRP	Duke Cancer Care Research Program
DO	Doctor of Osteopathy
GLM	Generalized linear model
HF	Heart failure
ICD-9-CM	International Classification of Diseases, Ninth Revision, Clinical Modification
ICU	Intensive care unit
MD	Doctor of Medicine
MOST	Medical Orders for Scope of Treatment
NC	North Carolina
NP	Nurse Practitioner
NYHA	New York Heart Association

OR	Odds ratio
PA	Physician Assistant
PC-PHS	Palliative Care-Patient Health Status
PCRR	Palliative Care Research Registry
PEACE	“Prepare, Embrace, Attend, Communicate, Empower”
PPACA	Patient Protection and Affordable Care Act
PPS	Palliative Performance Scale
QAPI	Quality Assessment and Performance Improvement
QDACT	Quality Data Collection Tool
QOL	Quality of life
RQ	Research question
RR	Risk ratio
SE	Standard error
UK	United Kingdom
US	United States

CHAPTER 1: INTRODUCTION AND SPECIFIC AIMS

Heart failure (HF) is a prevalent, irreversible, and progressive disease that leads to morbidity, hospitalizations, health care costs, and death. Furthermore, research suggests that HF patients experience physical and emotional distress throughout their course of illness and increasingly so toward the end of life;¹ such distress may be addressed by palliative care. However, due to lack of research in this area, the specific mechanisms by which palliative care might confer benefit to HF patients and their caregivers remains unknown. Palliative care seeks to improve quality of life for those individuals suffering from life-limiting illnesses and their families. Through multidisciplinary intervention, palliative care provides symptom management, psychological and spiritual support, and logistical assistance with care coordination and planning.² Research suggests that palliative care improves satisfaction with care;³ decreases the risk of patient depression³ and complicated bereavement for family caregivers;^{4,5} reduces patients' symptom intensity;⁶ lowers rates of intensive care unit (ICU) admissions;⁷ and, reduces hospital expenditures.⁸

The long-term goal of this line of research is to enhance the quality of care for and to improve the outcomes of patients with advanced HF. As such, this dissertation comprises three specific aims described below:

Aim 1 To identify potential provider-related barriers to referring patients with HF for palliative care

Sub-aim 1.1 To explore physician and non-physician provider (cardiologist, primary care, and palliative medicine) knowledge, attitudes, experiences, and potential barriers regarding palliative care, in general, as well as specifically related to HF

Sub-aim 1.2 To elicit provider perceptions of the components that comprise high-quality advanced HF care

Sub-aim 1.3 To explore provider attitudes regarding palliative care quality metrics and their relevance to advanced HF care

Aim 2 To assess and compare unresolved symptoms and treatment gaps between HF and cancer patients referred for community-based palliative care

Sub-aim 2.1 To identify unaddressed symptoms and treatment gaps experienced by HF and cancer patients at first palliative care consultation

Sub-aim 2.2 To determine whether differences in unresolved symptom and treatment gap prevalence can be explained by primary disease (i.e., HF or cancer)

Aim 3 To describe patient-centered outcomes for patients with HF and cancer referred for community-based palliative care and the association between outcomes and quality indicators

Sub-aim 3.1 To describe patient-centered outcomes in HF and cancer patients receiving community-based palliative care, and investigate any differences between the two cohorts

Sub-aim 3.2 To assess the association between palliative care quality indicators and patient-centered outcomes

Findings from this study can be used to: (1) inform future research to develop a model of palliative care that is appropriate for HF; (2) examine potential disparities in palliative care access and uptake in HF; and (3) demonstrate the clinician-perceived relevance of palliative care quality indicators and their association to meaningful patient-centered outcomes. By assessing the barriers and outcomes related to the palliation of HF, *this work may encourage discussion of the applicability of the current cancer-focused palliative care model to other non-neoplastic diseases* (e.g., chronic obstructive pulmonary disease, renal disease, AIDS). In sum, this dissertation investigates issues of quality and access to palliative care within HF, a disease population whose needs are believed to be under-recognized relative to cancer, using a mixed methods approach.

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CHAPTER 2: BACKGROUND AND SIGNIFICANCE

Heart failure is a prevalent and chronic disease, representing a significant portion of U.S. healthcare utilization and expenditures

HF is an increasingly prevalent disease that affects approximately 5.8 million Americans, with more than 550,000 new cases diagnosed yearly.¹ The current lifetime risk of developing HF is 1 in 5 for those individuals older than age 40.² The one-year mortality from HF rivals the risk for most cancers, ranging from 50-70%.³ Especially in its advanced stages, HF is a particularly costly disease. The estimated direct and indirect cost of HF in the United States (U.S.) during 2010 is \$39.2 billion.⁴ HF is responsible for 12-15 million outpatient visits per year.⁵ Hospital discharges related to HF increased from 877,000 to 1,106,000 between 1996 and 2006.¹ HF is the leading cause of hospitalization among Medicare beneficiaries,⁶ and nearly half of these stays exceed diagnosis-related groups reimbursement averages, making it the costliest disease in the Medicare population.^{7,8} Additionally, HF patients are likely to spend twice as many days in intensive care units than all other patients.⁸ Given the disproportionate prevalence of HF in the Medicare-eligible population,¹ the issues of cost, quality, and access to care are of prime relevance to policymakers.

What is palliative care and how can it improve the HF illness experience?

Palliative care seeks to improve quality of life for those individuals suffering from serious or life-limiting illness, and to support families throughout the disease experience. Through multidisciplinary intervention, palliative care achieves its aims by: expert assessment and treatment of pain and other symptoms; psychological and spiritual support; care coordination; support for complex and difficult medical decisions; assistance in communicating and setting goals related to care; and, bereavement support for families.⁹ Figure 2.1 provides a graphical depiction of how palliative care might be leveraged to improve HF patient outcomes.

Non-hospice palliative care is critically distinct from “hospice” care. Whereas being a part of palliative care, “hospice” care specifically targets patients entering the terminal phase of their lives. Eligibility under the Medicare Hospice Benefit requires physician certification of expected prognosis less than 6 months, as well as patient agreement to forego insurance coverage for curative or life-prolonging therapies. Conversely, non-hospice palliative care (hereinafter, “palliative care”) may be initiated at any point post-diagnosis, and may be provided concurrently with curative or life-prolonging therapies. In contrast, palliative care focuses on the optimization of patient and family quality of life (QOL), regardless of disease stage or prognosis. As defined by the National Consensus Project for Quality Palliative Care, “Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth... Palliative care aims to guide and assist the patient and family in making decisions that enable them to work toward their goals during whatever time they have remaining.” In sum, all hospice care is palliative; however, palliative care is not necessarily hospice care. The current research focuses

on palliative care in its entirety, which by definition will include patients receiving hospice services.

Research has shown that palliative care improves satisfaction with care,¹⁰ decreases the risk of patient depression¹⁰ and complicated bereavement for family caregivers;^{11,12} and increases the likelihood of an at-home death.¹³ Furthermore, evidence suggests that palliative care consultations decrease healthcare utilization and expenditures at the end of life. A recent multi-site study demonstrated an adjusted net savings of \$4,908 in direct costs per admission and \$374 in direct costs per day for recipients of palliative care compared to propensity score-matched control subjects.¹⁴ Such savings may result from a decrease in the number of procedures performed,¹⁵ length of hospitalizations,¹⁶ and length of intensive care unit stays¹⁵ near the end of life.

Research suggests that HF patients experience significant physical and emotional distress that may be addressed by palliative care. Regrettably, symptoms experienced by HF patients may go unrecognized and unaddressed.¹⁷ Whereas dyspnea and fatigue are considered to be characteristic of HF,¹⁸ numerous studies suggest that patients may suffer from symptoms including pain, depression, anxiety, edema, and constipation.¹⁸⁻²⁰ For example, in a study of U.S. veterans with HF, 55.2% reported pain; of those individuals, more than half noted their pain as moderate to severe.²¹ As such, current guidelines from the American College of Cardiology and the American Heart Association recommend palliative care and/or hospice referral for HF patients, especially in advanced stages of disease.⁵

HF poses an excellent disease model in which to study the potential effects of palliative care for several reasons. First, given that HF patients commonly experience multi-morbidity and frequently receive care from numerous providers, the role of

palliative care as a care coordination entity may be pivotal. Second, palliative care's focus on clear communication regarding prognosis and the setting of care goals may serve to reduce potentially unnecessary emergency department, hospital inpatient, and intensive care unit utilization. Indeed, a source of anxiety for HF patients is the unclear guidance regarding how to manage such events.²²

HF and cancer are remarkably similar in advanced stages, yet disparities exist regarding receipt of supportive services

Hospice enrollment statistics demonstrate that despite higher prevalence and similar late-stage prognosis, fewer HF patients access such supportive services than do cancer patients; non-hospice palliative care statistics are currently unavailable.²³ In 2008, cancer was the leading diagnosis among hospice enrollees (38.3%), whereas HF ranked 3rd (11.7%).²⁴ Given that the physical, psychological, and spiritual needs of advanced HF patients are similar to those needs of cancer patients,^{19,25} we must question whether systems- or provider-level barriers can explain why they appear to underuse palliative care. A recent systematic review regarding symptom burden in five advanced diseases suggests that the heart disease illness burden may not be entirely unique from cancer illness burden, for example.²⁵ As noted by the authors, pain, dyspnea, and fatigue were present in more than 50% of patients from all five diseases, lending credence to the notion of “common final pathways” at the end-of-life.

Interestingly, a recent analysis of 513 cancer patients receiving palliative care in North Carolina documented a striking number of care gaps experienced by such patients.²⁶ For example, of 10 symptoms assessed 95% of these patients reported the

presence of one symptom, and 67% reported three or more symptoms. Additionally, it was frequently the case that patients were not receiving interventions for distressing symptoms (e.g., only 25% of patients reporting moderate or severe constipation were receiving related treatment). It is critical to note that these symptoms were assessed at patients' first palliative care visit and were only counted if reported at a level of at least "moderately problematic." The presence of such distressing and uncontrolled symptoms at the time of palliative care initiation may suggest inadequate focus on symptom management prior to palliative care referral. Though not confirmable at present, it is plausible that such gaps in care are experienced more frequently by HF patients for two reasons: 1) cancer patients may be more likely to be comprehensively screened for symptoms, as seen by previous references to under-recognition of distressing HF symptoms; and, 2) cancer patients are more likely to receive hospice services than are HF patients, proportionally speaking.

Barriers related to uptake of palliative care in HF populations

Several factors appear to be related to the low rates of palliative care enrollment by HF patients, including: the unpredictable disease trajectory of HF;²⁷⁻²⁹ the view of HF as a chronic, manageable disease;^{27,28} and patient and caregiver confusion regarding prognosis.³⁰ Several qualitative studies exploring physician-related palliative care referral barriers for patients with HF in the U.K. suggest organizational, professional, and cognitive factors potentially at play.^{29,31} However, given differences in healthcare delivery systems, reimbursement policy, and culture, it is important to explore barriers to referral in the U.S. By examining provider perceptions regarding palliative care for HF, we may discover barriers explaining the relatively low rate of palliative care uptake by HF patients. I believe the physician aspect to be critically relevant due to the fact that palliative care is most often a consult service, many times requiring physician referral.

Quality assessment in palliative care

Historically, rigorous quality monitoring and research efforts have not been priorities of the hospice and palliative medicine disciplines.³² Issues motivating this paucity of research include: the relative infancy of hospice and palliative medicine in the U.S., a lack of standardized research and quality improvement practices across the field, and logistical concerns related to conducting interventional research with terminal patients.³³ Recently, there has been an increased focus on the quality of care received by individuals in advanced or terminal stages of illness. Perhaps most impressively, the Patient Protection and Affordable Care Act (PPACA) includes a mandate requiring the Centers for Medicare and Medicaid Services (CMS) to publish hospice quality measures by October 1, 2012. Hospices that fail to report quality data will receive a 2 percentage-point reduction in payments beginning in fiscal year 2014.³⁴ It is expected that this 2-percentage-point margin will be converted into bonuses and penalties related to quality performance at some point thereafter.³⁴ Additionally, PPACA mandates that CMS begin to test value-based purchasing in hospice no later than January 1, 2016. Though the focus of such efforts has been hospice care, any hospice-focused quality efforts naturally affect the non-hospice palliative care community given the high degree of interconnectedness between the two entities.

In 2006, CMS contracted the Carolinas Center for Medical Excellence to address quality assessment and improvement in hospice and palliative care.³⁵ The purpose of this initiative was to provide guidance for hospice programs to begin systematically collecting and monitoring quality of care, in preparation for Quality Assessment and Performance Improvement (QAPI) program participation. As such, this project sought to:

a) compile a set of quality metrics for hospice and palliative medicine; b) provide resources such as validated instruments and scales; and, c) suggest strategies for quality monitoring and improvement. Guiding their work, Schenck and colleagues followed a framework previously used by the National Consensus Project for Palliative Care Quality.³⁶ This framework defines eight domains of palliative care, as well as 38 related preferred practices; this work was subsequently endorsed by the National Quality Forum in 2006. The authors first conducted a focused literature search of the scientific and gray literature, including metrics used by governmental entities and national hospice/palliative care organizations. To be included, metrics had to explicitly define their numerators and denominators, and could not have been developed solely for research purposes. Furthermore, the authors chose metrics that aligned with a care process or outcome identified by the National Consensus Project, and those metrics that could be applied across the various care settings of hospice and palliative medicine. After filtering for appropriateness, the authors convened a 14-member expert panel to rate each of the 86 identified metrics on four criteria: importance, scientific soundness, usability, and feasibility. Average scores were calculated for each metric, and those ranking above the 75th percentile were ultimately selected. Additional metrics were added based on “high” importance scores, despite being below the 75th percentile, yielding a total of 34 metrics. The result of this project, known as the PEACE (Prepare, Embrace, Attend, Communicate, Empower) metric set, was used in this dissertation.

A recent white paper by Kamal and colleagues summarizes the results of a literature review related to quality indicators in palliative and end-of-life care.³⁷ The authors describe 12 sets of quality measures, which comprise 281 individual metrics; one of these sets was the PEACE set. After comparing all available metric sets, I ultimately chose the PEACE set due to its general focus (versus disease- or setting-

specific focus), as well as its close connection to policy, being that it is the product of a CMS mandate.

Summary

Uncontrolled symptom distress and unaddressed psychosocial needs within HF pose a target for the multidisciplinary expert management from palliative medicine. Regrettably, prior research has shown that for a variety of potential reasons, HF patients access palliative care at a rate disproportionate to cancer patients, despite striking similarities between the two illnesses. The high costs and healthcare utilization associated with the typical advanced HF trajectory represent areas of prime interest for clinicians, payers, and policymakers, especially in the contemporary climate related to healthcare reform. Additional work is necessary to unravel U.S.-specific factors related to low palliative care utilization in HF, as well as to establish a knowledge base regarding the effectiveness of palliative interventions in this population. This dissertation intends to contribute to this very effort.

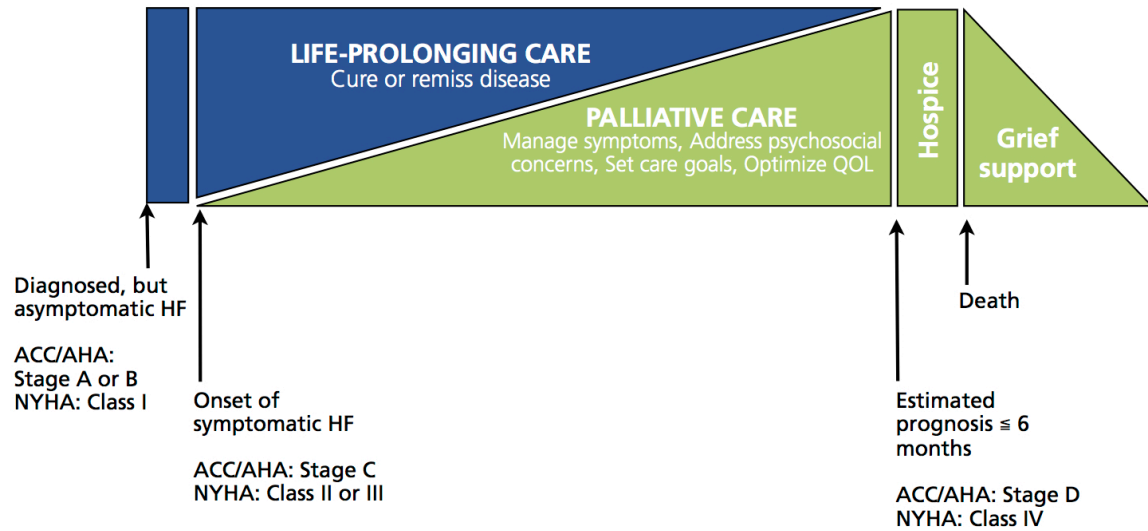
In this dissertation, I explored the role of palliative care in HF, focusing on three overarching questions:

- What provider-level factors might serve as barriers to palliative care referral among HF patients? (Study 1)
- When HF patients do receive palliative care consultations, with what unaddressed symptoms do they present, and are these care needs different than the needs of cancer patients? (Study 2)

- Is there an association between specialist palliative care intervention and patient outcomes? (Study 3)

FIGURES AND TABLES

Figure 2.1: Optimal integration of non-hospice and hospice palliative care with standard heart failure treatment across the typical disease trajectory



Abbreviations: HF, heart failure; ACC/AHA, American College of Cardiology/American Heart Association; NYHA, New York Heart Association

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CHAPTER 3: OVERVIEW OF METHODS

In this dissertation, I sequentially employed qualitative and quantitative methods to execute the Specific Aims previously described. Table 3.1 offers a description of the methods used in this dissertation.

Aim 1: Palliative care referral barriers in heart failure

Data for Aim 1 came from two sources, in the following sequence: 1) an internet-based survey to collect demographic information, as well as providers' perceptions regarding palliative care quality metrics; and, 2) 60-minute semi-structured interviews related to various aspects of palliative care and heart failure.

Internet-based survey to evaluate quality indicators

Subjects

I chose to include both physician and non-physician providers (i.e., nurse practitioners, physician assistants) in this study. Non-physician providers were included because: a) they are frequently involved in both cardiac and palliative service provision and b) their perspectives will complement views of physicians, resulting in a more thorough assessment of this research question. Interview participants were sampled

through purposive, referral sampling, with the help of Committee members to identify potential interviewees. I recruited participants via email solicitation. To be eligible for this study, participants must have been in current practice (i.e., greater than 60% clinical time), and must have cared for at least three HF patients in the past six months. To increase sample heterogeneity, I enrolled a mix of providers based on: clinical discipline; type of provider (i.e., physician versus non-physician); and academic practice affiliation, in the following fashion (Table 3.2). Participants were compensated with \$50 for completing all study-related tasks (i.e., pre-interview questionnaire, and interview).

Measures

Upon study enrollment, participants were sent a list of 14 PEACE quality indicators via email. Participants were asked to reflect on a typical HF patient for whom they care, as well as their own practice style. Next, participants were asked to enter a Qualtrics® survey website customized for this study, where they chose and rank-ordered the top three indicators which they believe: “are likely to be valid indicators of overall high-quality HF care, so much so that it would be appropriate on which to base Centers for Medicare and Medicaid (CMS) reimbursement decisions (bonuses or penalties).” The latter condition is important due to the prospective penalties to be potentially imposed by CMS regarding quality performance in palliative care. Indicators were not referred to as “palliative care metrics,” rather as “indicators of quality care for patients with life-limiting illness, such as heart failure” so as to avoid non-palliative care clinicians from disregarding them as irrelevant to their practice. Some indicators were reworded to make sense in a non-hospice palliative care context (e.g., increased time intervals between visits). Results from the indicator ranking exercise were used to inform Aim 3 of

this dissertation. The five highest-ranked indicators were used in regression models to assess their association with various patient-centered outcomes.

The following criteria were used to select the specific PEACE indicators to be used in this dissertation: a) the indicator must be assessable with the data available in PCRR (Palliative Care Research Registry), the data source for this dissertation; and, b) the indicator must be measured at the patient level (i.e., no organizational policy metrics).

Other variables collected in the survey included: general demographics (age, race, gender); degree type; additional certifications/training; years in practice; estimated current and past year HF patient caseload; and, the most common types of referrals made for HF patients.

Semi-structured interviews

Subjects

Individuals who completed the pre-interview internet survey described above also served as respondents for the semi-structured interviews.

Measures

Upon completion of the Qualtrics® survey, providers participated in a 60-minute interview. Interviews were conducted in a semi-structured format, following the interview guide displayed in Figure 3.1. The guide was informed by a review of the previous

literature on care transitions in HF, as well as through discussions with three key informants: the Medical Director of a HF clinic; a rural, community-based practicing cardiologist; and the Director of a HF disease management program.

The overall objective of the interviews was to ascertain provider knowledge, attitudes, and perceptions regarding the use of palliative care services for HF patients. Given that palliative care is a supportive service, it is possible that simply asking participants whether they endorse palliative care may have yielded socially-desirable and biased responses. As such, I indirectly gauged physician endorsement of palliative care by constructing interviews around four major themes: (1) hypothetical treatment strategy for a New York Heart Association (NYHA) Class III HF patient with significant palliative care needs; (2) the balance between survival improvement and symptom management in HF; (3) knowledge, attitudes, and experiences with palliative care; and (4) barriers to palliative care referral and uptake. To guide discussion related to the first theme, I constructed a case of a hypothetical NYHA Class III HF patient with significant comorbidities and symptom management needs (Table 4.2). This case was carefully constructed to simultaneously present a patient clearly eligible and appropriate for palliative care, although not ill enough to prompt automatic referral to hospice (thereby bypassing non-hospice palliative care).

Analysis

Interview data were collected and analyzed following template analysis, a qualitative approach that combines the strengths of content analysis and grounded theory.¹ Whereas purist grounded theory demands an entirely inductive approach to data analysis without a priori assumptions, template analysis affords the investigator flexibility

to integrate external perspectives (e.g., conceptual framework), for a hybrid inductive/deductive theory generation process. Interview transcripts were coded using the process of open, axial, and selective coding, performed line-by-line.² Consistent with the qualitative concept of “constant comparison,” text units were compared with previously-coded data to challenge the stability and relevance of emergent themes. A master codebook was informed by an extensive literature review. Coding was performed using NVivo 9, a qualitative data analysis program.³

Data were analyzed using an assortment of common qualitative techniques, including coding dendrograms and matrix queries.⁴ Quality and rigor of the interviews in Aim 1 were addressed following the guidelines of Charmaz, who suggests that attention be paid to: credibility, originality, resonance, and usefulness.⁵ Additionally, confirmability of qualitative findings was addressed by having a random 50% (n = 9) sample of interview transcripts independently coded by a second analyst, an experienced qualitative nursing researcher.⁶ Consensus meetings were held to resolve coding discrepancies, as well as to assist in refining the study's master codebook. All changes made to the codebook were retroactively applied to previously-coded transcripts.

Aim 2: Unaddressed symptoms and treatment gaps at the time of first palliative care consult

Data source

Data for Aims 2 and 3 were accessed from the Palliative Care Research Registry (PCRR), the database of the Carolinas Palliative Care Consortium (hereinafter, the Consortium). The PCRR accumulates clinician, patient, and proxy reported data, detailing individual patients' demographics, disease characteristics, symptoms and

related interventions. Patient outcomes including QOL, survival, and transition to hospice are captured at each visit. Data are collected via paper, tablet computers, or digital pens at the point of care. To date, these data have been used for quality monitoring purposes; however, the Duke Cancer Care Research Program (DCCRP) (later folded into the newly formed Duke Center for Learning Health Care) successfully received approval from the Duke University Institutional Review Board so that research analyses may be performed with these data. The PCRR is the first, and currently the only, multi-site initiative to collect quality performance and outcomes data in community-based palliative care. As a proof-of-concept, the PCRR was developed with the explicit intent of continuous improvement and refinement, yet required relative simplicity to ensure initial buy-in from non-academic clinicians. This proposal represents the first HF-focused analysis of PCRR.

Description of the Carolinas Palliative Care Consortium

The Carolinas Palliative Care Consortium is a collaborative partnership between the DCCRP and three palliative organizations: Four Seasons Hospice and Palliative Care, Horizons Palliative Care, and Forsyth Medical Center. The DCCRP serves as the administrative and research hub of all Consortium activity, and is headed by Amy Abernethy, MD. Born from a recognized paucity of rigorous quality improvement initiatives within the hospice and palliative care community,⁷ the Consortium presents a unique vehicle through which research may be conducted. The three clinical partner sites are briefly described here; however, a more thorough description of the Consortium may be found in a 2010 article by Bull and colleagues.⁸ The first clinical partner site, Four Seasons Hospice and Palliative Care, is a community-based hospice and palliative

care organization, based in Hendersonville, NC. Four Seasons has earned an international reputation, having been a pioneer in the field of community-based palliative care. They provide care across a variety of settings, including patient homes, 21 nursing homes, 30 assisted living facilities, and their own 19-bed inpatient facility. Second, Horizons Palliative Care of Raleigh, NC, another community-based palliative care organization, similarly serves patients in a various settings across five counties. The last contributor is the inpatient palliative care unit of Forsyth Medical Center of Winston-Salem, NC. As it is a hospital-based unit, patients from Forsyth may or may not be different from other patients in the PCRR.

Subjects

As of January 01, 2012, the PCRR contained data for 6,019 patients spanning a total of 19,668 visits. Of these records, 4,981 patients were listed to have a primary diagnosis other than HF or cancer, and as such, were excluded from this study. Further, I excluded data from the two HF patient and five cancer patients seen at the Horizons Palliative Care site. A cluster so small posed methodological challenges in terms of controlling for institution-level effects.

The study cohort for Aim 2 comprised HF and cancer patients contained in the PCRR. Heart failure patients were identified using the following *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) diagnostic codes: 428.xx (heart failure); 429.3 (cardiomegaly); 402.01 (malignant hypertensive heart disease with heart failure); 402.11 (benign hypertensive heart disease with heart failure); 402.91 (unspecified hypertensive heart disease with heart failure); and, 425.xx (cardiomyopathy).⁹ For the sake of clarity, this cohort hereinafter will be referred to as

the “heart failure” (HF) cohort, despite its multifactorial composition. The “cancer” cohort was defined as all patients carrying an ICD-9-CM primary diagnosis code within the range 140-239.9. As previously mentioned, patients from Horizons Palliative Care were excluded.

Measures

The key dependent variables in Aim 2 were: (1) number of unresolved symptoms; (2) number of treatment care gaps; (3) performance status; and (4) palliative care patient health status (PC-PHS), a composite indicator of adequate symptom control and QOL. I defined an “unresolved symptom” as a patient (or proxy) reported severity rating of “moderate” or “severe” for each of the 11 symptoms captured in the PCRR; counts could range from 0-11. My use of the term “unresolved” signifies that symptoms persist at the time of first palliative care consultation – likely a reflection of the care received prior to palliative care referral. A “treatment gap” was defined as the lack of a documented intervention for a symptom rated as “moderate” or “severe.” As interventions were documented for only four symptoms (pain, dyspnea, constipation, depression) treatment gap counts could range from 0-4. All dependent variables were measured at the patient level.

Performance status was assessed using the Palliative Performance Scale (PPS), version 2.0¹⁰, a modification of the Karnofsky Performance Scale that has been well-validated in palliative care patients.¹¹ The PPS uses an 11-category ordinal scale from 0-100% in 10-percentage point increments, with higher scores indicating better functioning. As others have previously done,^{12,13} I transformed PPS into a 3-category

ordinal variable (low performance status: 0-30%; medium performance status: 40-60%; high performance status: 70-100%) for clinical relevance and interpretability.

Finally, I created PC-PHS, a composite indicator of symptom control and quality of life that summarized symptom management and quality of life outcomes. Originally, this variable was conceptualized as a scaled composite of three factors that are relevant to patients with advanced illness: fair/good QOL, adequate pain control, and adequate dyspnea control. For symptom management, I focused on pain control and dyspnea, which are relevant to patients with advanced HF and cancer^{14,15} and are often targets of palliative care interventions. Providers asked patients about both their current and maximal tolerable level of each symptom. If current symptoms were less than the maximum tolerable level, or if the patient reported no current symptom, I considered that patient to have adequate control. QOL was assessed by providers using a single item measured on a 3-category ordinal scale (i.e., “poor,” “fair,” “good”); this was derived from the McGill QOL Questionnaire Single Item Scale: “Considering all parts of my life-physical, emotional, social, spiritual, and financial – my quality of life in the past two days was...”¹⁶ The original McGill item is scored on a 7-point scale, ranging from “very bad” to “excellent.” However, it is highly unlikely that in practice, this question is asked of Consortium patients exactly as phrased in the McGill validation studies. As such, QOL in this dissertation was analyzed and interpreted with caution, given that we cannot be confident regarding its psychometric properties. Given the small proportion of patients who reported “good” QOL (5%), we created a binary measure (i.e., “poor” vs. “fair/good” QOL). The resulting PC-PHS variable is a binary indicator that takes the value of 1 if all three conditions were met (i.e., controlled pain, controlled dyspnea, and fair/good QOL), and 0 otherwise. Presence of the PC-PHS outcome suggests better overall health, as it indicates adequate pain and dyspnea control, and fair/good QOL. We performed

sensitivity analyses using various permutations of the composite PC-PHS variable (i.e., 1-2 vs. 3 outcomes). A graphical description of the PC-PHS variable used for Aim 2 is offered in Figure 3.2.

Recognizing concerns that a dichotomous indicator of QOL might be limited in its sensitivity, I explored the possibility of combining QOL and performance status to provide a more comprehensive and clinically meaningful measure. However, since I found final-visit QOL and PPS to be weakly correlated (Spearman's $\rho = 0.26$, $p \leq 0.001$), it was inappropriate to proceed with this transformation. Instead, I chose to analyze QOL and PPS separately.

Analysis

Aim 2 sought to answer three broad questions: 1) Is the prevalence of unresolved symptoms and treatment gaps similar between HF and cancer patients; 2) Do HF patients report similar QOL and exhibit similar PPS at the time of admission to palliative care; and 3) Are HF patients as likely as cancer patients to experience better health status at the time of palliative care admission?

After calculating unresolved symptoms and treatment gaps as previously described, I used descriptive statistics to compare their prevalence within both the HF and cancer cohorts. To address hypothesis 2b1, which states that HF patients will present with more unresolved symptoms and treatment gaps than cancer patients, I first used Student's t-tests between cohorts. Next, Poisson regression was used to model the effect of primary diagnosis on the count of care gaps, while adjusting for relevant covariates.¹⁷ I chose Poisson regression given the count nature of the unresolved

symptom and treatment gap index variables. Therefore, hypothesis 2b1 entailed two separate Poisson regressions for each of the indices (Eq. H2b1).

$$\text{Count(unresolved symptoms or treatment gaps)} = f(\beta_0 + \beta_1 \text{HF} + \beta_2 \text{Age} + \beta_3 \text{Male} + \beta_4 \text{Non-white} + \beta_5 \text{PPS} + \beta_6 \text{ProxyRespondent} + \beta_7 \text{CareSetting} + \epsilon)$$

Eq. H2b1

To test hypothesis 2c1 regarding the effect of HF on PC-PHS, I constructed the following modified Poisson regression, with PC-PHS operationalized as a dichotomous variable (Eq. H2c1). Due to the binary nature of these outcomes, modified Poisson regressions with robust sandwich errors was used to estimate risk ratios.¹⁸ Robust standard errors were calculated to avoid bias from incorrectly specified variance.¹⁹ I chose risk ratios over odds ratios for two reasons. First, although odds ratios derived from logistic regression are commonly reported in the health services literature, odds ratios are known to overestimate relative risk when outcomes are non-rare (>10%).²⁰ Second, confusion over the appropriate interpretation of odds ratios is common, whereas risk ratios may be more intuitive to a wider audience.

$$\text{Pr(PC-PHS)} = f(\beta_0 + \beta_1 \text{HF} + \beta_2 \text{Age} + \beta_3 \text{Male} + \beta_4 \text{Non-white} + \beta_5 \text{ProxyRespondent} + \beta_6 \text{CareSetting} + \epsilon)$$

Eq. H2c1

Performance status was modeled as 3-category ordinal variable regression (low, medium, high) using a generalized ordered logistic regression (Eq. H2d1).²¹ This modification is in line with prior analyses of the PPS operationalized in this fashion.¹²

$$\text{PPS} = f(\beta_0 + \beta_1 \text{HF} + \beta_2 \text{Age} + \beta_3 \text{Male} + \beta_4 \text{Non-white} + \beta_5 \text{ProxyRespondent} + \beta_6 \text{CareSetting} + \varepsilon)$$

Eq. H2d1

Aim 3: Assessment the process-outcome link in HF patients receiving community-based palliative care

Subjects

Aim 3 assessed the association between quality indicator adherence at first palliative care consultation and outcomes assessed at final palliative care consultation. As such, the analytic sample of Aim 3 required that all patients were deceased at the time of analysis, and were a subset of the dataset in Aim 2 , described previously. Given the patient population, it is reasonable to speculate that more patients were indeed deceased, and that dates of death had not been not been recorded in the database. As such, I manually reviewed all HF patient records in the PCRR, and confirmed vital status using the Social Security Death Index, accessed via www.ancestry.com.²²

An additional inclusion criterion for Aim 3 was that patients have at least two palliative care consultations documented in the PCRR. Patients seen only once may differ from other palliative care patients on a variety of dimensions, including baseline

illness severity, poor prognosis, and access to care issues. As I was limited in my ability to control for such potential sources of selection bias, I chose to exclude such patients from this analysis. Imposing these restrictions, I was left with an analytic sample of 85 HF patients.

Measures

The overarching goal of Aim 3 was to identify quality indicators that are independently associated with patient-centered outcomes at patients' final palliative care consultations. As in Aim 2, I used the PC-PHS variable as the outcome of choice; however, in Aim 3, PC-PHS equaled 1 if at least two of the three component outcomes (i.e., fair/good QOL, adequately controlled pain, adequately controlled dyspnea) were true, whereas in Aim 2, all three outcomes had to be present for PC-PHS to equal 1. These justifications were based on the distribution of outcomes within each analytic sample. A graphical description of the PC-PHS variable used in Aim 3 is offered in Figure 3.3.

The key independent variables of Aim 3 were dichotomous indicators of quality indicator satisfaction. As described previously, a central component of Aim 1 was the quality indicator ranking exercise, which resulted in five indicators that were ranked as clinically important by provider interviewees. These variables were constructed by reviewing clinical details contained in PCRR, and captured processes of care related to patients' first palliative care consultations. Given the mixed-methods approach of this dissertation, Aim 3 analyses depended on Aim 1, and followed in sequence.

Given the limited and fixed sample size, I constructed a patient-level adjustment score to reduce the dimensionality of regression models; this technique has been previously applied to similar studies of healthcare quality assessment.^{23,24} Variables in the adjustment score were: (1) age at time of first palliative care consultation; (2) gender; (3) race; (4) patient versus proxy report; (5) care setting (i.e., hospital inpatient versus patient's home); and, (6) total number of palliative care consultations recorded in the PCRR. I attempted to include performance status (as a proxy for disease status and prognosis) in the adjustment model; however, it was excluded due to multicollinearity with number of palliative care consultations.

Analysis

Described here is the regression modeling used to assess the palliative care process-outcome link in a cohort of HF patients receiving community-based palliative care services. In a recent study of stroke care quality that is conceptually similar to the Aim 3, Bravata and colleagues used a 3-step process to conduct their analyses.²³ First, they calculated descriptive statistics to describe the prevalence of quality indicator adherence in their population. Next, they modeled each process indicator in separate regressions to yield unadjusted measures of association. Finally, they created a model that adjusted for all of their quality indicators of interest, as well as other covariates. Aim 3 of this dissertation followed a similar analytic process.

As with several Aim 2 regressions, due to the binary nature of PC-PHS, modified Poisson regression with robust standard errors was used.¹⁸ Robust standard errors were calculated to avoid bias from incorrectly specified variance.¹⁹ Risk ratios were chosen for

the same reasons as in Aim 2. Additionally, risk ratios are the proper measure of association given that Aim 3 was a cohort study.

FIGURES AND TABLES

Table 3.1. Summary of analyses in Kavalieratos dissertation

Research Questions (RQ) & Hypotheses	Analytic Methods
AIM 1: TO IDENTIFY POTENTIAL PHYSICIAN BARRIERS TO REFERRING PATIENTS WITH HF FOR PALLIATIVE CARE	
RQ 1a: What are the knowledge, attitudes, and experiences that cardiology, primary care, and palliative care physician and non-physician providers have regarding heart failure-specific palliative care?	Semi-structured interviews; template analysis
RQ 1b: What barriers potentially impede greater referral of HF patients for palliative care?	
RQ 1c: What are the attitudes of cardiology, primary care, and palliative care physician and non-physician providers regarding the relevance and utility of proposed palliative care quality metrics to advanced HF care?	
AIM 2: TO ASSESS & COMPARE UNRESOLVED SYMPTOMS AND TREATMENT GAPS, AND PATIENT-CENTERED OUTCOMES BETWEEN HF AND CANCER PATIENTS RECEIVING PALLIATIVE CARE	
RQ 2a: What are the unresolved symptom and treatment gaps experienced by HF patients at their first palliative care consultation?	Descriptive statistics
RQ 2b: Is a primary diagnosis of HF associated with a greater prevalence of unresolved symptoms and treatment gaps at first palliative care consultation, relative to cancer?	Poisson regression
H2b1 <i>HF patients will present with a greater number of unresolved symptoms and treatment gaps at their first palliative care consultation, than will cancer patients</i>	
RQ 2c: Does palliative care patient health status differ between cancer and HF patients at the time of first palliative care consultation?	Modified Poisson regression
H2c1 <i>There will be no statistically significant difference in the proportion of HF and cancer patients with fair/good QOL, adequate pain control, and adequate dyspnea control at the time of their first palliative care consultation.</i>	
RQ 2d: Does performance status differ between cancer and HF patients at the time of first palliative care consultation?	Generalized ordered logistic regression
H2d1 <i>Primary disease (HF vs. cancer) will not be significantly associated with performance status at the time of first palliative care consultation</i>	
AIM 3: TO ASSESS THE ASSOCIATION BETWEEN PALLIATIVE CARE QUALITY INDICATORS AND PATIENT-CENTERED OUTCOMES	
RQ 3a: What is the profile of outcomes experienced by HF and cancer patients at their final palliative care consultation?	Descriptive statistics
RQ 3b: What is the association between the satisfaction of palliative care quality indicators at first palliative care consult, to palliative care patient health status (PC-PHS) assessed at final palliative care consult?	Modified Poisson regression
H3b1 <i>Adherence to palliative care quality indicators at first palliative care consultation will be positively associated PC-PHS at final palliative care visit</i>	

Table 3.2. Recruitment matrix for Study 1 interviews

	Cardiology	Primary Care	Palliative Care
Academic Affiliation	2 MD/DO; 1 NP/PA	2 MD/DO; 1 NP/PA	2 MD/DO; 1 NP/PA
Non-Academic Affiliation	2 MD/DO; 1 NP/PA	2 MD/DO; 1 NP/PA	2 MD/DO; 1 NP/PA

Abbreviations: MD, Doctor of Medicine; DO, Doctor of Osteopathy; NP, Nurse Practitioner; PA, Physician Assistant.

Figure 3.1. Interview guide used in Aim 1

#	Question and associated probes
0	[All] What drew you into [cardiology/primary care/palliative care] as a specialty?
1	[All] Using the patient case before you, could you please walk me through your main concerns regarding how to best manage his care? <ul style="list-style-type: none"> What is your approximation of this patient's life expectancy?
2	[All] What needs do HF patients possess, and how do you try to address them? <ul style="list-style-type: none"> How successful do you think you are in managing these needs? Are there any specific needs/concerns that you feel you might not be addressing well? [Cardiology/primary care] Who is typically involved in the care of HF patients?
3	[Cardiology/primary care] How do you approach discussions with patients about prognosis? What about the balance between a focus on symptom management and quality of life improvement vs. increasing survival?
4	[Cardiology/primary care] What is your familiarity with palliative care? How do you define it? [Palliative care] How prepared do you feel to care for HF patients, relative to cancer patients? Is there anything that you think needs to change to improve your ability to care for HF patients? <ul style="list-style-type: none"> [Cardiology/primary care] Please describe to me your familiarity with HF-specific palliative care?
5	[All] What, in your opinion, makes a HF patient <u>eligible</u> for palliative care? <ul style="list-style-type: none"> What, in your opinion, would need to happen to make this patient eligible for palliative care?
6	[All] What opportunities exist for other clinical specialties to assist in the management of HF patients? <ul style="list-style-type: none"> Should palliative care could be incorporated into HF care? If yes, how so? Can palliative care be helpful to the management of HF patients, and if so, how? [Cardiology/primary care] What are your thoughts regarding collaborating with a palliative care service in managing HF patients?
7	[Cardiology/primary care] Do you know whether palliative care services exist in your area? If so, have you ever referred a HF patient for palliative care? [Palliative care] Have you ever cared for a patient with HF who needed symptom relief and palliation? <ul style="list-style-type: none"> [All] If yes, can you please describe the experience? [Cardiology/primary care] If not, can you please describe your reasons for not doing so? [Palliative care] If not, why do you think that you haven't yet been referred a HF patient?
8	[All] What are some of the barriers that you believe might impede the uptake of HF-specific palliative care? Physician-level barriers? System- or policy-level barriers? Patient- or family-level barriers? <ul style="list-style-type: none"> How might these barriers be overcome?
9	[All] If you suspect that a HF patient can benefit from palliative or hospice care, who do you believe is responsible for discussing this with the patient: Primary care, cardiology, or a palliative care specialist? A physician or a nurse?
10	[All] Are there any points regarding symptom management for HF patients that you think we haven't covered?

Table 3.3. Distribution of HF and cancer patients within the Carolinas Palliative Care Consortium

Provider	Care Setting	Heart Failure	Cancer	Total
Forsyth Medical Center	Hospital inpatient only	84	367	451
Four Seasons	Mixed	250	330	580
Horizons Palliative Care ^a	Mixed	2	5	7
Total		336	702	1038

Note: ^a: excluded from dissertation analyses.

Figure 3.2. Composition of the Palliative Care – Patient Health Status (PC-PHS) variable used in Aim 2 analyses

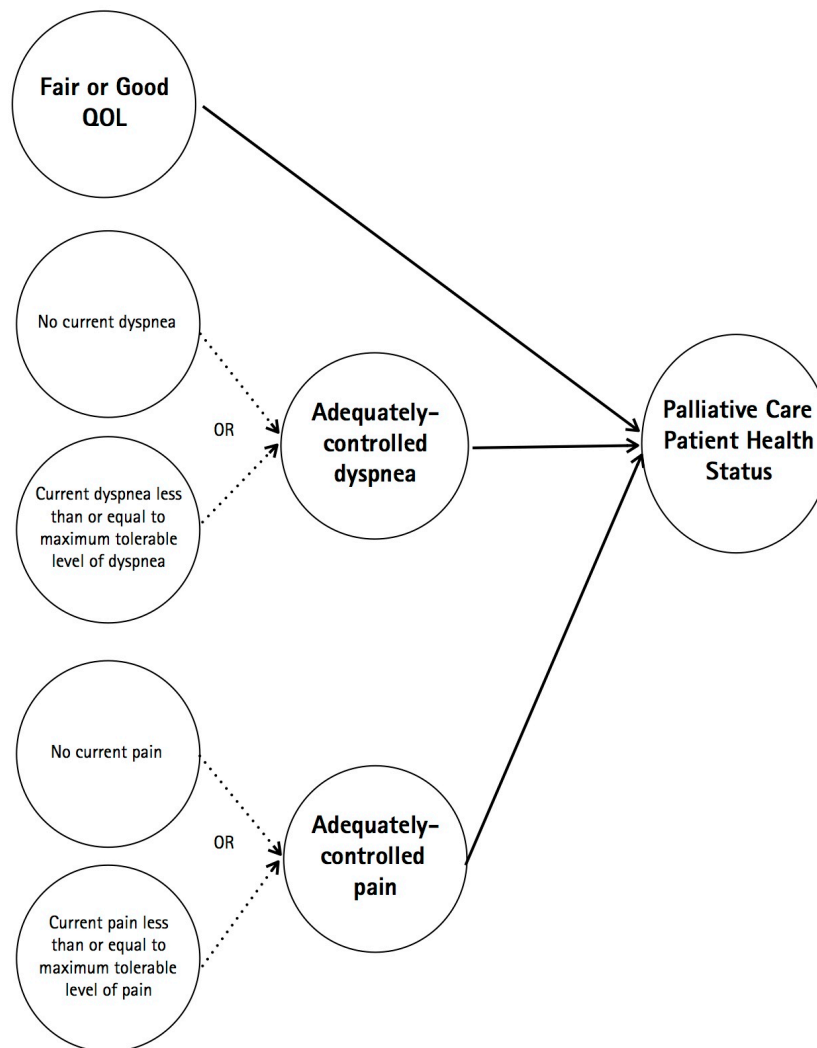
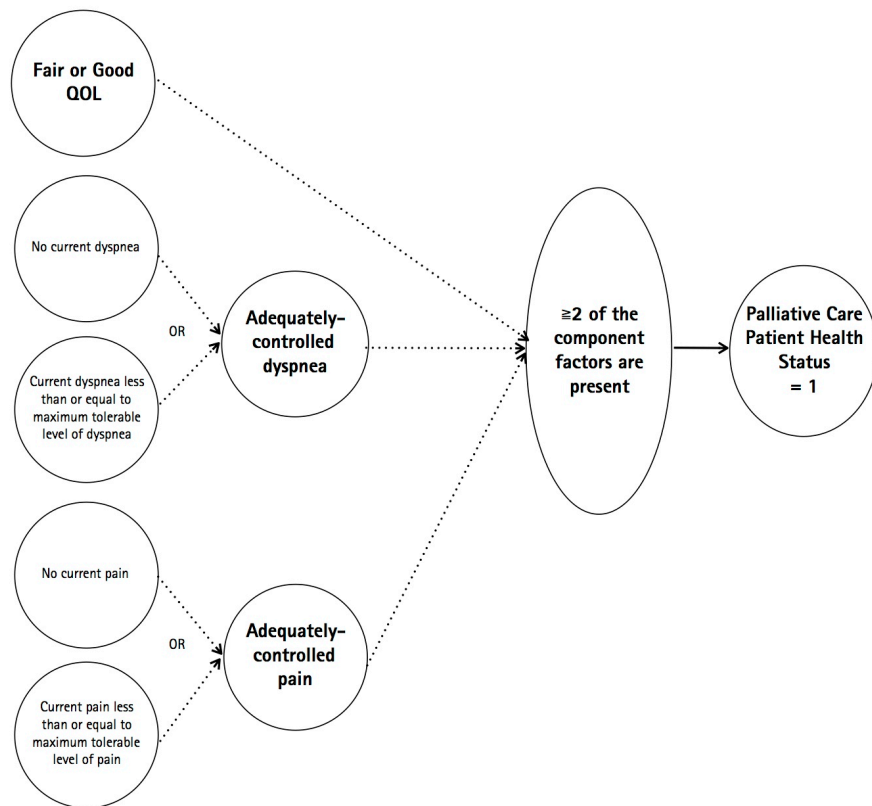


Figure 3.3. Composition of the Palliative Care – Patient Health Status (PC-PHS) variable used in Aim 3 analyses



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CHAPTER 4: PROVIDER-RELATED BARRIERS IMPEDING HEART FAILURE PALLIATIVE CARE REFERRAL

INTRODUCTION

Heart failure (HF) is a highly prevalent chronic disease characterized by high physical and psychosocial burdens that dramatically impair patients' quality of life and performance status.¹⁻³ Approximately 80% of Medicare beneficiaries with HF are hospitalized within the last 6 months of life, a trend that has increased over time.⁴ Current therapies for HF relieve symptoms and prolong survival, but are not curative.⁵

Palliative care is a multidisciplinary intervention that focuses on optimizing quality of life for patients and families affected by serious illness, independent of prognosis.⁶ Important components of palliative care intervention include: expert identification and management of pain and other symptoms; psychological, spiritual, and logistical support; assistance with treatment decision-making and setting care goals; and, complex care coordination.⁷ Palliative care utilization has been suggested to improve survival,⁸ quality of life,^{8,9} symptom burden,¹⁰ healthcare expenditures,⁷ hospice transitions,⁷ and caregiver outcomes.¹¹ Notably, palliative care is distinct from hospice care, which is intended for patients with a maximum expected life expectancy of six months. Non-hospice palliative care may be initiated at any point in the disease trajectory and may be administered in conjunction with curative or life-prolonging treatments. (Figure 4.1)

The American College of Cardiology and the American Heart Association recommend that palliative and/or hospice care be considered with advanced HF

patients¹² while mounting attention elsewhere calls for palliative care integration across the HF trajectory.^{5,13-18} However, despite striking similarities regarding symptom burden^{3,19-21} and prognosis with advanced cancer patients, HF patients use supportive services at lower rates. In 2008, cancer was the leading diagnosis among hospice enrollees (38.3%), whereas HF ranked 3rd (11.7%).²² Recent U.S. incidence statistics estimate 1.6 million patients to be diagnosed with cancer in 2012,²³ and more than 550,000 HF diagnoses in 2008.²⁴ Importantly, recent research suggests that implementation of the aforementioned guidelines may be suboptimal. In one study, more than half of cardiologists surveyed would not discuss palliative care with elderly patients with advanced HF.²⁵ Coupled with extremely low public knowledge of palliative care,²⁶ this barrier may contribute to its underutilization among patients with HF. Past research on palliative care referral barriers in HF have been conducted in the U.K. and Australia.²⁷⁻³⁰ Recognizing differences in healthcare delivery systems, reimbursement policies, and culture, we conducted a qualitative study with diverse American providers to understand barriers to referring patients with advanced HF to palliative care. Among primary care, cardiology, and palliative medicine providers, what are the barriers related to palliative care referral for patients with HF?

METHODS

Design

We conducted semi-structured interviews both to allow flexibility in exploring topics and for subjects' convenience. The University of North Carolina at Chapel Hill Institutional Review Board approved this study. Participants provided informed consent electronically.

Sample and recruitment

We used purposeful, stratified sampling to recruit primary care, cardiology, and palliative care physicians and non-physician providers from diverse practice settings (i.e., academic/non-academic, urban/rural).³¹ We chose these providers because of their prominent role in decision-making regarding palliative care for patients with advanced systolic HF. We used the following eligibility criteria: a) physician, nurse practitioner, or physician assistant; b) currently in practice in North Carolina; and, c) cared for ≥ 3 HF patients in the preceding six months. We offered a \$50 honorarium and a summary of our findings.

Data collection

One author (DK) conducted all interviews, either in person or by telephone, between December 2011 and May 2012. Based upon a literature review regarding care transitions in HF and discussions with three experts, we developed an interview guide (Table 4.1) containing ten questions in four domains: (1) needs of HF patients; (2)

knowledge and perceptions of palliative care; (3) indications for, and optimal timing of, palliative care referral in HF; and, (4) barriers to palliative care referral in HF. We designed probes for “iterative questioning” to explore participants’ responses to questions to increase validity.³²

Prior to the interview, we asked participants to review a vignette of a hypothetical patient with advanced HF, typical comorbidities, and unaddressed palliative needs (Table 4.2). Such elicitation methods are helpful when exploring values and perceptions.³³ Interviews were audiotaped and transcribed verbatim. Demographic information was collected in a pre-interview internet survey.

Data analysis

We analyzed data using template analysis, a qualitative approach that combines content analysis and grounded theory.³⁴ Template analysis allows flexibility to integrate a priori assumptions and hypotheses for a hybrid inductive/deductive analytic process. Data analysis was performed in an iterative fashion, with the initial codebook informed by an extensive literature review. Two authors (DK, EMM) independently read and coded a random 50% sample of transcripts in three iterative stages. After each round of coding, consensus meetings were held to discuss and arbitrate discrepancies. DK coded all remaining transcripts, which were reviewed and verified by EMM. Using the constant comparative technique, text units were compared with previously-coded data to ensure the stability and relevance of emergent themes.³⁵ We used NVivo9³⁶ to code and query transcripts. Matrix and compound queries were performed to further explore our data. We applied eight techniques (Table 4.3) to improve the trustworthiness of our findings across four domains: 1) credibility; 2) transferability; 3) dependability; and, 4)

confirmability.³⁷ Themes and illustrative quotes identified were agreed upon by all authors.

RESULTS

We conducted 18 interviews, generating 188 pages of data. The median interview lasted 37 minutes (range: 25-51 minutes). Within each of our three specialty areas of interest, we recruited four physicians and two non-physician providers (Table 4.4). Generally, non-physician providers' comments resembled the comments of physicians within their respective specialties; thus, we present findings by specialty, and not by provider type. We inductively discovered a natural structure to our themes in a "what, when, why, who, where, and how" framework (Figure 4.2).

"What": Lack of functional knowledge regarding palliative care

Although all participants reported that they could define palliative care, further probing revealed that their conception varied among the providers and also varied from the standard definition of palliative care from the literature. Specifically, nearly all primary care and cardiology respondents lacked clarity that palliative care is not prognosis-dependent and may be administered concurrently with aggressive or life-sustaining therapy. As opposed to hospice, participants in our sample failed to recognize palliative care as a tangible clinical service. For example, one primary care physician said:

"Palliative care is a philosophy. Hospice is a treatment approach complete with billables, and payers, and all that crap, within that treatment philosophy." When we asked participants to describe eligibility and appropriateness criteria for palliative care (for

which there are none, aside from patient need), cardiology and primary care participants generally used the terms interchangeably until explicitly prompted for clarification.

Interviewer: So in your opinion, what makes a HF patient eligible for palliative care?

Cardiologist: Eligible? Well, eligibility is not my decision. I mean, that's a legislative decision....

Interviewer: And, so in your mind, is there a distinction between palliative care and hospice care?

Cardiologist: Between palliative and hospice care? No. There's not. Not in my mind. Is there?

Incorrectly believing that palliative care mandates the suspension of aggressive or life-prolonging therapies, participants claimed that patient goals determine eligibility:

...If the patient wants to focus on symptoms and is willing to accept the sort of basics, and that's significantly and far away the primary goal of care for the patient, then the patient's eligible for palliative care. (Primary care physician)

A few cardiology and primary care providers recognized differences between palliative care and hospice. For example, as one primary care physician stated:

... I think I'm reasonably familiar [with palliative care], but I also think that to me, it's become somewhat of a confusing term. I view palliative care as trying to understand the patient's symptoms and values and wishes, and really trying to help them maximize their quality of life and reduction of symptoms. And I see it as something distinct from, say, hospice care. I worry that sometimes we confuse palliative care, meaning it has to equal end of life care, and I prefer to view palliative care as clear management of symptoms and emphasis of the patient's quality of life in decision-making.

We asked participants whether they had ever collaborated with a palliative care service. Most non-palliative care participants had no experience with a formal palliative care provider/team. Participants frequently acknowledged not knowing how to access palliative care support within their own institutions, such as this primary care physician from a large academic medical center:

I don't even know where they are or where they exist, or even really what they do....I wouldn't even know where to start to try and get in touch with someone.

“When”: Appropriate timing for palliative care referral

Most participants conceptualized referral in terms of “triggers,” including physiological findings (e.g., symptom presence), disease status (e.g., functional decline), or events (e.g., ventricular assist device implantation). Among primary and palliative care providers, repeated hospitalization over a short interval (e.g., 3 in 6 months) was perceived to indicate that palliative care might be appropriate. However, cardiology participants frequently discussed the “point at which you are unable to do more” as another trigger:

... I think that the trigger to get [the palliative care service] involved was knowing that my patient was dying and that I didn't have other medical options for them. Meaning that they weren't candidates for advanced therapies and that there was nothing else I could do to alter the natural history of the disease and that there was a clear need for someone skilled in palliative care to help with that patient and not only help with that patient but help with that patient's family... (Cardiologist)

However, some participants reflected on the difficulty of recognizing and acting upon triggers.

...I think the main challenge is both for the cardiologist and for the patient, recognizing those prognostic signs that say this is an individual who is moving into the last phase of their disease. There's so much experience with successful management of exacerbations, of systolic congestive HF, that it's hard for both the patient and the doctor to say, 'Wait a minute. The pattern is changing. There's (sic) more exacerbations. They are more often. They're more severe. It's more difficult to get this person back from the edge.' So just recognizing that I think is difficult. (Palliative care physician)

Participants commonly mentioned the insistence on life-prolonging treatments, such as inotrope therapy, as a barrier to palliative care referral. One palliative care physician stated:

I think that [cardiologists] are not only procedure driven but intervention driven in that . . . I think they have a hard time seeing an endpoint with it, in the same way that oncologists have a difficult time really seeing when their treatments just aren't working anymore.

The unpredictable trajectory of HF was a frequently-cited barrier to palliative care, especially when participants believed that palliative care eligibility or reimbursement were prognosis-dependent (as with hospice).

...I think what we do, at least what I do, from a palliative care standpoint is I think, 'Oh, patient has likely less than six months of life, and an official team involved would be really helpful.' As opposed to someone who has longer than that, a palliative care team might be helpful, but it might not yet be appropriate because we're not exactly sure how long they have... (Cardiologist)

Unprompted, our palliative care participants lamented that late referrals limit the potential benefit to patients:

In general, I feel like I'm consulted much later than I would prefer to be....Usually it's someone that's in pretty severe distress from symptoms is when I'm consulted. And I feel like when I've had a more close working relationship with a group of hospitalists, then that makes them much more comfortable sort of consulting me early with a symptom-management focus, and so I've sort of seen my practice change since I've been in this setting for over a year now. I feel like initially, ...I was called for hospice evaluation for appropriateness... Now, I feel like I'm getting consulted much more early with just a symptom sort of focus. And I sort of begin that education process with them. You know, unfortunately or fortunately, however you see it, as a patient is readmitted over time, myself or my colleagues now have multiple times and we're able to sort of increase the education and improve on their symptom burden and kind of relieve that a little bit over time. (Palliative care physician)

“Why”: Perceptions of palliative care in HF

All participants endorsed palliative care in HF, to varying degrees. They believed that palliative care providers are experts regarding: symptom management; care coordination; and advance care planning (e.g., facilitating difficult discussions regarding prognosis). Many appreciated its focus on quality of life:

...I think a more formal collaboration with the palliative care service team would be ideal so that we're not using them haphazardly “oh yeah when we think about it,” but I think that we have that in our thought process. We're trained as physicians and want to make everyone live forever, and we advocate very strongly for our individual patients during these meetings, but to have a voice from the palliative care service team where we don't forget to focus on quality of life as much as survival would be I think ideal for the patient population that we see.... [W]e're so focused on altering the natural history of their heart disease rather than necessarily looking at the whole patient. (Cardiologist)

Participants also discussed how sociocultural attitudes regarding mortality influence provider behavior. Again, we noted a tendency for participants to allude to hospice when discussing the role of palliative care in HF.

It's almost a cultural-level barrier. You know, if there's more than a trivial possibility you might live three or four years, then why not go for it? I think it's the way that many of us were raised, both as patients and physicians.... [C]ardiologists often go into cardiology 'cause they want to save lives with their stents and the like, and so that may be a barrier.... [There is a] cultural bias against adopting palliative care unless you 'know you're going to die.' (Primary care physician)

Participants commonly drew contrasts between HF and cancer. Unlike the cure-oriented goal of oncology, participants believed that the reality of HF as a progressive, incurable disease poses challenges to conceptualizing how palliative care differs from standard HF management: "...[A]ll medical therapy for HF is really to relieve their symptoms. And so, in a sense, to me, it all feels like palliative care." (Primary care physician)

A cardiologist participant did not feel as strongly, but did maintain the notion that a sizable portion of his work in treating HF is palliative in nature:

Cardiologist: Well, unfortunately I think a lot of what we do as HF doctors involves the idea of palliative care...

Interviewer: When you say that most of what you do in HF care is of a palliative nature, can you describe how you come to that determination?

Cardiologist: I guess I shouldn't say most of what I do. I guess I should say a fair portion of what I do.... I think that it's important to be candid...that for Class III or IV patients, medical therapy over the course of the past twenty years really hasn't changed their life expectancy at all. And so there are no magic pills that we can pull out that will help this patient to live longer. And so I think given that, I think it's important to focus your discussion on how they want to live the life that they have remaining.

“Who”: Inter-provider relationships and responsibilities

To gain or increase acceptance in contexts of limited palliative care familiarity, participants thought that palliative care must demonstrate and market its benefit to patients and providers. Trust and rapport were identified as key facilitators to palliative care referral, particularly when knowledge of palliative care is limited. Palliative care participants discussed how networking and peer education have resulted in greater and earlier referrals, by “winning over” previously skeptical colleagues:

...I think a lot of people really don't know what we do. I did a consult not too long ago. I showed up. The doctor looked up from the desk and he said 'My patient doesn't need a morphine drip' and I said, 'I'm not here to start one.' I said, 'I do a whole lot more than start morphine drips, thank God.' So I actually in a good-natured way, really try to do a little education with folks, and I think they really appreciate it. That same cardiologist has sent me several more consults since then...I think once he realized that we're not the grim reaper service and that we're really about what does the patient want, they sort of lay down their baggage.
(Palliative care physician)

“Where”: Origin of referral

All participants, except one cardiology nurse practitioner, felt that primary care or cardiology providers should initiate conversations about palliative care because of their preexisting, ongoing relationships with patients. However, palliative care participants feared that such conversations might not occur due to providers' discomfort with discussing palliative options or due to time constraints. One palliative care physician discussed what she perceived as her flexible, but overall supportive role within a care team:

I think any of those physicians can introduce the concept. Any of them. And I'm perfectly comfortable handling the relationship any way that the other physicians involved want to. They need to acknowledge that we're coming. They need to say, 'Yeah, we're going to involve palliative care. We endorse the palliative care team being involved in your care.' But I think it's perfectly fine for the primary treating cardiologist to begin that conversation . . . to say, 'We need to start talking about your HF being in its latest stages. We need to think about what our options are for how to give you the best quality of life under these circumstances.' But it's also perfectly fine for them to duck that conversation and say, 'I want to pass the baton. I want the palliative care team to really help with that more difficult communication.' It's really just whatever works for the group of people involved.

"How": Provider-level strategies to increase palliative care referral

Overwhelmingly, participants felt that the primary barrier to palliative care referral was lack of knowledge within the medical community. Though some participants commented on the value of educating patients about palliative care options, most viewed healthcare providers as the most logical target for intervention. Cardiology and primary care participants recognized the need to increase exposure to palliative care during graduate or postgraduate education:

...[E]ducating HF physicians on the value and availability and the utilization of palliative care services is key. I don't think we get a good job of learning about that during our medical school or residency or fellowship training and if you don't train us at that point, you can't expect us to understand or know how to use them at this point.... I think many of us physicians struggle with even bringing up the palliative care concept with patients because we're just not skilled necessarily at doing it.
(Cardiologist)

Participants from all specialties perceived the need to develop "palliative care basics" (e.g., symptom identification/management in serious illness, communication

skills regarding goals of care). Motivations for this varied across specialties. For example, whereas some of our cardiology participants desired to gain confidence in difficult communication, palliative care providers often spoke of workforce constraints:

...There are still only 3,000 board-certified palliative medicine physicians in the US. Most of them are hospital-based or their practices are predominantly hospital-based. So from a practical standpoint, I think that has a couple of implications. One is the dominant model in the next several years would be to promote early inpatient consultation or inpatient assistance with management, maybe through identifying mutually agreed upon triggers for referrals with a cardiology service. And then I think the second element is to ramp up the level of palliative care expertise that cardiologists, particularly those that focus on HF, have to exercise in their own practice so that it's not purely dependent on consultative services...
(Palliative care physician)

Lastly, participants discussed various practical strategies by which to encourage palliative care referral. One primary care nurse practitioner noted her desire for better integration of palliative care in existing clinical decision support systems:

...[Palliative care referral] relies on me asking for it when it probably should be more automated. It's like if someone has a big tumor on a CT scan, it's pretty quick how they get into an oncologist or get in for a biopsy but if it's got a really clear indicator for worsening trajectory, they don't automatically get these services. So I think that's where the system is kind of impeding people getting into palliative care."

DISCUSSION

To our knowledge, this study is the first to explore provider-related barriers to palliative care referral for advanced HF patients among U.S. providers, particularly clinical specialties frequently caring for these patients. We found limited knowledge related to: what palliative care is (especially how it differs from hospice); what it offers patients, families, and providers; when it is indicated; and, how to access it.

One barrier is confusion about the term “palliative care” itself. Through iterative probing, all providers claimed to be familiar with non-hospice palliative care; however, we often heard phrases such as “comfort care” or “just the basics,” hinting that they equated non-hospice and hospice palliative care. Notably, providers often reported criteria for hospice (i.e., less than six months expected survival and desire to suspend life-sustaining treatments) as those criteria for non-hospice palliative care. Though alarming, this finding has been documented elsewhere.^{30,38,39} However, because providers almost unanimously reported using trigger events (e.g., symptom intractability or patients becoming too complex to be managed by primary care or cardiology) to initiate palliative care, this misconception may encourage late (if any) palliative care referrals.³⁸ Our findings echo previous work suggesting that providers choose to delay conversations regarding prognosis or end-of-life decision-making.⁴⁰ These provider misperceptions, along with a 2011 public opinion poll in which 70% of adult respondents claimed to be “not at all knowledgeable” regarding palliative care,²⁶ may partially explain its underutilization in HF. In addition, we interviewed providers across North Carolina, including in regions without palliative care services, which may inherently limit knowledge of and familiarity with specialist palliative care services; however, the majority of providers interviewed were within close proximity of palliative care services (both inpatient and outpatient).

Participants frequently reported the unpredictable nature of HF as a barrier to palliative care referral.^{27,29,30} Clearly reflecting a hospice-oriented mindset, this finding highlights the risks of using rigid, standardized heuristics when caring for seriously ill persons,²⁹ thus adding to the longstanding discussion regarding the appropriateness of the Medicare hospice benefit model,⁴¹ particularly for diseases with unpredictable trajectories.⁴² Crisp demarcations between curative and palliative treatment modalities reflect a false dichotomy that defers a focus on quality of life improvement until disease futility has been established.¹⁷

Prior qualitative research with physicians²⁷⁻²⁹ and nurses³⁰, performed in the U.K. and Australia, suggests a mixture of professional, organizational, and cognitive factors impeding palliative care referral for HF patients, including concerns that patients might be “stolen” by palliative care providers.²⁷ In contrast, all non-palliative providers we interviewed explicitly expressed interest in exploring how to collaborate with palliative care providers. The frailty of patients with chronic, debilitating illnesses such as HF warrants exploration of methods to increase access to palliative services, such as outpatient and community-based palliative care programs.⁴³⁻⁴⁵

As suggested by others,^{28,46} our findings support that the role of specialist palliative care has yet to be defined in cardiology, as it has in oncology. Indeed, though our inherent assumption is that specialist palliative care improves HF patient outcomes (as has been shown in lung cancer⁸), data do not currently exist to support this claim. Furthermore, no research exists to delineate the role of specialist palliative care providers versus cardiologists versus primary care providers in providing palliative services to HF patients. Nevertheless, our participants saw inherent value in the expertise of palliative care providers. Although some expressed difficulty understanding how formal palliative care services would differ from the ultimately palliative treatments

of standard HF management, others viewed palliative care as particularly attractive for HF care, owing to the complex treatment decisions such patients face. Palliative care may be especially beneficial during the early stages of disease, as a way to elicit patient preferences and discuss understanding of likely prognosis.⁶ Moreover, because HF patients commonly experience multi-morbidity and receive care from numerous providers palliative care services can help reduce care fragmentation and suboptimal inter-provider communication patterns.^{27,47} Such coordination is especially important as American healthcare delivery moves towards patient-centered medical homes.

Participants expressed interest in educational interventions regarding palliative care, which is consistent with previous work.^{17,48} Participants reported that efforts must originate from the field of palliative care, a view echoed by one palliative care physician: “We must reach out and give [cardiology and primary care providers] the language [of palliative care].” Medical school curricula should both educate medical providers about palliative care and hospice services, as well as train providers to feel confident in: navigating difficult or uncomfortable conversations regarding prognosis and life-prolonging treatments (e.g., device deactivation); identifying and managing symptoms of advanced HF; and, recognizing when and how to maximize the utility of specialist palliative care services to improve HF patients’ quality of life. Currently, palliative care providers will need to correct misconceptions regarding their discipline, services, and role in managing seriously ill patients.

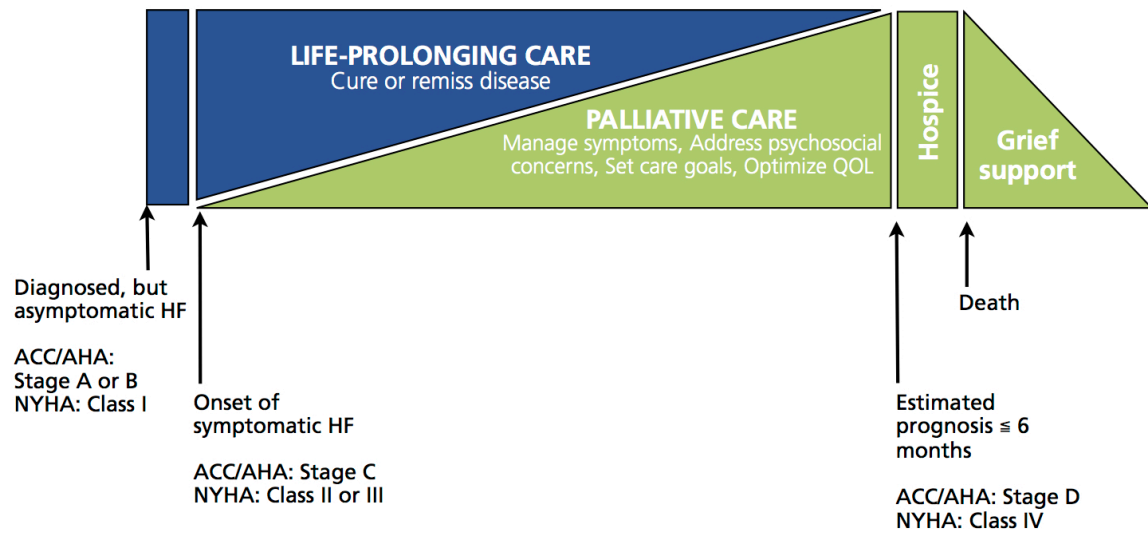
This study has several limitations. First, the generalizability of our conclusions may be limited because: (1) our respondents practice in North Carolina, which may vary from other regions regarding palliative practice patterns and culture; and (2) although we achieved relative balance between urban and rural settings (data not shown), a greater proportion of our sample practice in large, academic medical centers, the site of most

palliative care programs.⁴⁹ As such, it is defensible that our work reflects a positive bias regarding palliative care knowledge. In other words, our participants were likely more familiar with palliative care than most providers. Second, although we used sound methodological techniques to maximize rigor and trustworthiness of our data, it is possible that others may have identified different themes. Third, participants' responses may have been influenced by social desirability and interviewer bias. Finally, our study did not explicitly assess patient or family perspectives, which may influence the healthcare experiences of patients with serious illness.⁵⁰

We provide empirical data to initiate the discussion regarding provider-related palliative care barriers for patients with HF in the U.S. This issue is relevant to a generalist audience due to the prevalence of HF, and the frequency with which primary care providers orchestrate the care of such patients. Our findings suggest that deficits in both knowledge about palliative care and providers' comfort in discussing end-of-life care for a clinical condition with a difficult-to-predict course present major barriers to referring patients with advanced HF to palliative care. Our findings highlight the need for efforts to increase awareness of palliative care among the medical and lay communities. While establishing and promoting its role, palliative care must correct misconceptions that it is only appropriate for the terminally ill. Future research should seek to develop provider- and patient-centered interventions to reduce actionable barriers to palliative care uptake in HF. Additionally, efforts are needed to understand patient and family-level barriers to palliative care utilization amongst HF patients.

FIGURES AND TABLES

Figure 4.1. Illustration of the relationship between non-hospice and hospice palliative care



Abbreviations: HF, heart failure; ACC/AHA: American College of Cardiology/American Heart Association; NYHA: New York Heart Association

Table 4.1. Interview guide: domains of interest and sample questions

Domain	Sample Question
Needs of heart failure patients	On the whole, what needs do your heart failure patients possess?
	How effective do you believe that you are in managing your heart failure patients' needs?
Knowledge and perceptions of palliative care	What is your familiarity with palliative care? How do you define it?
	Throughout our conversation, I've been using the term "palliative care," and I've been hearing you use the term "hospice." Are those interchangeable for you, or do you see a distinction between them?
	Can palliative care be helpful in the management of heart failure patients? If so, how? If not, why not?
Indications for, and optimal timing of, palliative care referral in heart failure	In your opinion, what makes a heart failure patient eligible for palliative care?
	In your opinion what makes a heart failure patient appropriate for palliative care?
Barriers to palliative care referral in heart failure	What are some of the barriers that you believe might be impeding the uptake of palliative care in heart failure?
	If you suspect that a heart failure patient can benefit from palliative care, who do you believe is responsible for having this discussion [with the patient]?

Table 4.2. Hypothetical heart failure patient vignette used to frame interviews

Characteristic	
Demographics	67-year-old, Caucasian male; married, 2 non-local children
History	<ul style="list-style-type: none"> • 3 hospitalizations within the past year for acute HF decompensation events • History of ST elevation myocardial infarct 5 years ago followed by coronary artery bypass grafting • On recent cardiac catheterization, has multi-vessel coronary artery disease with all grafts patent • No ischemia on stress testing and no angina symptoms
BMI	34.5 kg/m ²
Ejection fraction	18%
Transplantation	Carefully reviewed by transplantation team and deemed ineligible for cardiac transplantation or other cardiac surgery due to age, kidney disease, and insulin-dependent diabetes
Dyspnea	9/10 on exertion; 3/10 at rest
Orthopnea	4-pillow orthopnea
Edema	Reports worsening bilateral lower extremity edema over the last 2 weeks
Pain	5/10 over the past 2 weeks, in both legs and limiting walking
Depression	Moderate over the past 2 weeks
Physical exam	Vitals: SBP 88, HR 80 Neck: JVP elevated 10 cm Irregular rate, 3/6 systolic murmur consistent with mitral regurgitation Lungs with bilateral rales at both bases Abdomen normal Extremities: bilaterally edema, 2/4, pitting
NT-ProBNP	2100 pg/mL
Devices	Implantable biventricular pacemaker - cardioverter-defibrillator; ventricular resynchronization x 3 years (not recent)
Comorbidities	<ul style="list-style-type: none"> • Atrial fibrillation • Major depression • Chronic kidney disease, stage 3, creatinine 2.5 mg/dl and has increased from 2.0 in the past 2 months • Hypertension; recently with hypotension due to heart failure and has not tolerated higher doses of antihypertensive medications • Type II diabetes mellitus
Current medications	<ul style="list-style-type: none"> • lisinopril 5 mg QD • furosemide 80 mg BID • carvedilol 3.125 mg BID • spironolactone 12.5 mg QD • insulin lispro • humulin n • bupropion xl 300 mg QD • warfarin

Abbreviations: HF, heart failure; NT-ProBNP, N-terminal prohormone of brain natriuretic protein; BMI, body mass index; QD, daily; BID, twice daily; SBP, systolic blood pressure; HR, heart rate; JVP, jugular venous pressure.

Table 4.3. Techniques used to ensure qualitative rigor and trustworthiness of findings

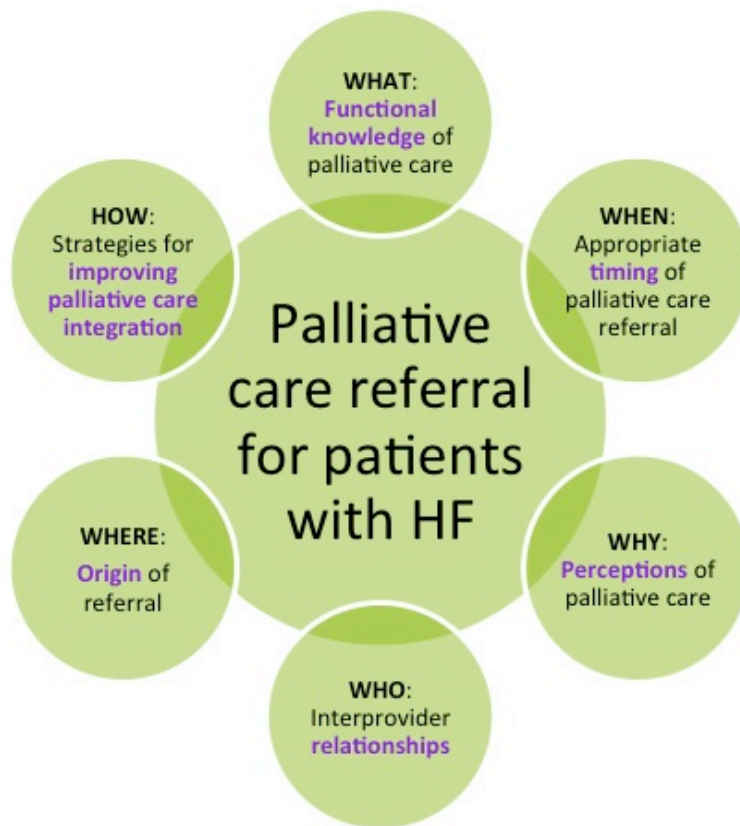
Aspect	Technique	Description
Credibility <i>How reflective are the research findings of reality?</i>	Field observation	DK observed patient encounters in heart failure clinics and palliative care home visits during study design.
	Iterative questioning ³²	We employed deliberate, explicit probes in order to understand participants' responses with greater precision.
	Expert review of protocol	Disciplinary experts assisted in the development of the interview guide and patient vignette.
	Frequent debriefing	Weekly meetings were held between the lead and senior authors to discuss findings and concerns.
Transferability <i>How applicable are the research findings to other contexts or situations?</i>	Contextual review	We performed a detailed literature review to understand the context within which our work falls.
Dependability <i>How reproducible are the research findings?</i>	Audit trail	We maintained an extensive audit trail throughout the analytic process, detailing decision rules and justifications.
Confirmability <i>How objective was the analysis?</i>	Bracketing ⁵¹	Recognition of investigators' preconceptions and assumptions regarding the phenomena of interest.
	Triangulation	Investigator triangulation (i.e., multiple researchers analyzed data) and disciplinary triangulation (i.e., researchers represented a variety of related expertise)

Table 4.4. Characteristics of study participants

Characteristic	Full Sample n (%)	Cardiology n (%)	Primary Care n (%)	Palliative Care n (%)
N	18	6	6	6
Age, median [range], years	42.5 [27-57]	39.5 [33-56]	46 [35-55]	52.5 [27-57]
Female	11 (61)	3 (50)	3 (50)	5 (83)
Race				
White	16 (89)	4 (67)	6 (100)	6 (100)
African-American	1 (5)	1 (17)	--	--
Asian	1 (5)	1 (17)	--	--
Years in practice, median [range]	12 [2-38]	9.5 [2-23]	16.5 [7-32]	23 [3-38]
Practice setting				
Academic	12 (67)	4 (67)	6 (100)	2 (33)
Non-academic	5 (28)	1 (17)	--	4 (67)
Both	1 (6)	1 (17)	--	--
Current HF caseload, patients				
0	1 (6)	--	--	1 (20)
1-10	5 (28)	--	2 (33)	3 (50)
11-25	3 (18)	--	2 (33)	2 (40)
26-50	3 (18)	2 (33)	1 (17)	--
51-100	2 (12)	1 (17)	1 (17)	--
>100	3 (18)	3 (50)	--	--
HF caseload in past year, patients				
1-10	3 (18)	--	3 (50)	--
11-25	2 (12)	--	1 (17)	1 (20)
26-50	5 (29)	1 (17)	2 (33)	2 (40)
51-100	2 (12)	--	--	2 (40)
>100	5 (29)	5 (83)	--	--

Legend: HF, heart failure. Columns may not total 100% due to rounding and missing data.

Figure 4.2. Qualitative themes identified in Aim 1 interviews



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CHAPTER 5: COMPARING THE UNMET NEEDS OF COMMUNITY-BASED PALLIATIVE CARE PATIENTS WITH HEART FAILURE AND CANCER

INTRODUCTION

Palliative care seeks to optimize quality of life for patients and their families affected by serious illness, regardless of prognosis.¹ One form of palliative care, hospice, is restricted to patients with an expected prognosis of six months or less. However, non-hospice palliative care may be initiated at any point in the disease trajectory and may be administered in conjunction with curative or life-prolonging treatments. Palliative care includes: expert identification and management of pain and other symptoms; psychological, spiritual, and logistical support; assistance with treatment decision-making and setting of care goals; and, complex care coordination.² Palliative care has been shown to improve survival,³ quality of life,^{3,4} symptom burden,⁵ healthcare expenditures,² and caregiver outcomes.⁶ Although palliative care may be thought of as a guiding approach to care,⁷ here the term indicates provision of care by a specialist palliative care provider or service.

By its very nature, the predominant model of palliative care in the U.S., inpatient palliative care, is reactionary. Such consultations may focus more on symptom management related to the event precipitating the hospitalization, while paying less attention to proactive or holistic care, such as medication management, care goals discussion, complex care alignment across multiple providers, and transition coordination (e.g., hospital to skilled nursing or home).⁸ Accordingly, recent years have

seen the emergence of community-based palliative care services, also known as “bridging programs.”⁹ Such services allow for longitudinal and prospective patient interaction, and are flexible enough to address patient needs across a variety of care settings, meeting patients and caregivers wherever they may find themselves (i.e., inpatient, outpatient, at patients’ place of residence), at any point in the illness trajectory. Indeed, outpatient palliative care programs have been labeled the “next frontier” in palliative care service delivery.¹⁰

Historically, palliative care in the U.S. has largely served patients with cancer; however, this phenomenon seems to be changing.¹¹ Nevertheless, patients with other serious illnesses may similarly benefit from palliative care. One such condition is heart failure (HF), a progressive and incurable condition that is associated with extensive health services utilization, particularly at the end of life (Figure 5.1).¹²⁻¹⁶ More than 5 million American adults currently suffer from HF, and it is estimated that 550,000 incident cases are diagnosed yearly.¹⁷ Given the high prevalence of HF and improved survival owing to life-prolonging therapies, the burden of chronic HF is greater than ever before, and is expected to grow.¹⁸ Patients with advanced HF suffer from physical symptoms,^{13,14,19} as well as psychosocial and emotional distress;^{14,15} unresolved symptoms have a profound effect on patients with HF and their caregivers.²⁰ The burdens typically experienced by patients with HF may not be markedly divergent from those of patients with cancer or chronic obstructive pulmonary disease (COPD); differences in symptom experience and distress may be a function of disease stage, as opposed to the diagnosis itself.²¹

Despite the American College of Cardiology and the American Heart Association (ACC/AHA) recommending palliative and/or hospice care for patients with end-stage HF,²² HF patients tend to access such services far less often than cancer patients,²³

despite a similar illness experience and prognosis. Because lack of provider knowledge regarding palliative care may be a barrier to referring HF patients,⁷ HF patients who receive palliative care may ultimately present with more advanced symptoms than do patients with cancer. Moreover, little research has been conducted among patients with HF receiving palliative care, and most of this work has focused on inpatient or academic medical settings. Although community-based palliative care is a growing option in the U.S.,^{9,10} patients with HF are poorly represented, overall, in palliative care-related research.

This study has three goals: (1) to describe a sample of HF and cancer patients referred for community-based palliative care services; (2) to determine the differential impact of having HF vs. cancer on unresolved symptoms and treatment gaps; and (3) to assess associations between primary diagnosis (i.e., HF vs. cancer) and outcomes such as performance status, adequate symptom control, and quality of life. All analyses were cross-sectional, at the patient level, and assessed at the time of first palliative care visit.

METHODS

Data Source

The Carolinas Palliative Care Consortium is a quality improvement partnership between Duke University and three North Carolina community-based palliative care organizations.²⁴ In June 2008, the Consortium established the Palliative Care Database, the first American initiative to systematically collect patient-, caregiver-, and provider-reported data for quality monitoring purposes.^{24,25} At every visit, trained palliative care providers collected data using the Quality Data Collection Tool (QDACT).^{25,26} The

QDACT is a palliative care-specific assessment tool that can be completed on paper or by direct computerized entry, depending on user needs and preferences. Data are both stored locally at each site, and securely transferred to Duke University at regular intervals for analysis. In 2012, these retrospective quality improvement data were transitioned into what is known as the Palliative Care Research Registry (PCRR). The Duke University Institutional Review Board approved this study and the creation of the PCRR. The Institutional Review Board at the University of North Carolina at Chapel Hill additionally approved the study protocol.

Procedures

We extracted data from patients' initial palliative care visits between June 1, 2008 and January 1, 2012. We excluded data from one of the three palliative care institutions due to low patient counts. At each palliative care visit, Consortium providers used the QDACT to collect patient- or proxy-reported data. Patients were asked to rate the severity, duration, and tolerability of 11 symptoms: agitation, anorexia, anxiety, constipation, depression, diarrhea, dyspnea, fatigue, insomnia, nausea, and pain using the McCorkle Symptom Distress Scale,²⁷ a commonly used instrument in palliative populations. Proxy (i.e., provider or caregiver) ratings were substituted for patients when patients were unable to communicate independently (e.g., dementia, delirium, extreme frailty). Providers documented whether the patient was receiving interventions (pharmacologic or non-pharmacologic) for pain, dyspnea, depression, and constipation. In addition, providers assessed patients' quality of life (QOL), which is described in Measures.

Measures

Dependent Variables: Our four dependent variables were: (1) number of unresolved symptoms; (2) number of treatment care gaps; (3) performance status; and, (4) palliative care patient health status (PC-PHS), a composite indicator of adequate symptom control and QOL. We defined an “unresolved symptom” as a patient (or proxy) reported severity rating of “moderate” or “severe” for each of the 11 symptoms captured in the QDACT; counts could range from 0-11. Our use of the term “unresolved” signifies that symptoms persist at the time of first palliative care consultation – likely a reflection of the care received prior to palliative care referral. A “treatment gap” was defined as the lack of a documented intervention for a symptom rated as “moderate” or “severe.” As interventions were documented for only four symptoms (listed previously), treatment gap counts could range from 0-4. All dependent variables were measured at the patient level.

Performance status was assessed using the Palliative Performance Scale (PPS), version 2.0²⁸, a modification of the Karnofsky Performance Scale that has been well-validated in palliative care patients.²⁹ The PPS uses an 11-category ordinal scale from 0%-100% in ten-percentage point increments, with higher scores indicating better functioning. As others have previously done,^{8,30} we transformed PPS into a three-category ordinal variable (low performance status: 0%-30%; medium performance status: 40%-60%; high performance status: 70%-100%) for clinical relevance and interpretability.

Finally, we created PC-PHS, a composite indicator of symptom control and quality of life that summarized symptom management and quality of life outcomes. For symptom management, we focused on pain control and dyspnea, which are relevant to patients with advanced HF and cancer^{19,31} and are often targets of palliative care

interventions. Providers asked patients about both their current and maximal tolerable level of each symptom. If current symptoms were less than the maximum tolerable level, or if the patient reported no current symptom, we considered that patient to have adequate control. QOL was assessed by providers using a single item measured on a 3-category ordinal scale (i.e., “poor,” “fair,” “good”); this scale was derived from the McGill QOL Questionnaire Single Item Scale.³² Given the small proportion of patients who reported “good” QOL (5%), we created a binary measure (i.e., “poor” vs. “fair/good” QOL). The resulting PC-PHS variable is a binary indicator which takes the value of 1 if all 3 conditions were met (i.e., controlled pain, controlled dyspnea, and fair/good QOL), and 0 if otherwise. Presence of the PC-PHS outcome suggests better overall health, as it indicates adequate pain and dyspnea control, and fair/good QOL. We performed sensitivity analyses using various permutations of the composite PC-PHS variable (i.e., 1-2 vs. 3 outcomes).

Independent Variable: Our independent variable was primary diagnosis, that is, HF or cancer. Heart failure patients were identified by the following *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) diagnostic codes: 428.xx (HF); 429.3 (cardiomegaly); 402.01 (malignant hypertensive heart disease with HF); 402.11 (benign hypertensive heart disease with HF); 402.91 (unspecified hypertensive heart disease with HF); and, 425.xx (cardiomyopathy).³³ Cancer patients were defined by ICD-9-CM diagnostic codes in the range of 140-239.9. Four patients’ records listed both HF and cancer diagnoses; these patients were excluded from analysis.

Control Variables: Recognizing that patients who receive palliative care consultations while hospitalized likely differ regarding acuity, we included a binary indicator to control for location of consultation. Additional control variables included:

patient age, gender, race, and a binary indicator reflecting whether symptom assessment data were patient- vs. proxy-reported.

Statistical analysis

After describing the sample, we used Pearson's chi-square tests, unpaired Student's t-tests and Wilcoxon-Mann-Whitney tests to examine bivariate differences between disease cohorts. Next, we conducted several multivariate analyses to estimate the impact of primary diagnosis on unresolved symptom, treatment gap, and PC-PHS outcomes between HF and cancer patients at the time of first palliative care consultation. First, we used Poisson regression to estimate models of predicted counts of unresolved symptoms and treatment gaps.³⁴ We chose the Poisson estimator due to absence of overdispersion and superior model performance, as compared to negative binomial regression.³⁴ Second, we estimated risk ratios (RRs) to assess the effect of primary diagnosis on the probability of the PC-PHS outcome. We chose RRs given the frequency of our study outcome, as odds ratios may overstate relative risk in situations of non-rare outcomes.³⁵ We calculated RRs using modified Poisson regression with robust/sandwich standard errors.³⁶ This method has been shown to estimate RRs consistently and efficiently in samples as small as 100.³⁵ We compared RR point estimates calculated from this Poisson method and manually from 2x2 contingency tables and found them to be exact within two decimal places. Third, we employed generalized ordered logistic regression to model the effects of primary disease on performance status (i.e., PPS).^{37,38} We chose a partial proportional odds model, as a Brant test revealed that our data violated the proportional odds assumption necessary for unbiased estimation of a standard ordered logistic model. We used Stata "gologit2"

with the “autofit” option to estimate this model.³⁸ Average marginal effects are provided for the generalized ordered logistic regression for ease of interpretability. Average marginal effects express the average change in the probability of an outcome occurring attributable to a specific variable, keeping all else in the model constant.

The sample size had a sufficient number of cases to conduct all multivariable analyses using the 10:1 event-to-variable ratio.^{39,40} We assessed model fit by plotting fitted data vs. both actual data points and deviance residuals. Various sensitivity analyses were conducted to assist in model specification decisions and diagnostics (e.g., variable recoding, additional control variables). We also conducted formal tests of normality, heteroscedasticity, and multicollinearity to ensure proper modeling. Statistical tests were two-tailed with a critical α -level of 0.05. Analyses were conducted using Stata/IC, version 12.⁴¹

RESULTS

Cohort characteristics

Of 1,031 patients meeting study criteria, 334 (32%) had a primary diagnosis of HF and 697 (68%) had cancer (Table 5.1). Overall, our patients were predominantly White, and 45% were male. Nearly 70% of encounters were in an inpatient hospital setting. The majority of patients from both disease groups had initiated advance care planning, most often a “do not resuscitate” order. At baseline, the median PPS score for all patients was 40%, indicating a predominantly bedfast patient with extensive evidence of disease, requiring assistance for self-care tasks. Approximately half of each disease group reported fair/good QOL. Compared to cancer patients, those patients with HF

were significantly older, (84 years vs. 71 years, $P<0.001$), had at least one prior hospitalization in the preceding six months (81% vs. 63%, $P<0.001$), and more likely to reside in a nursing home (18% vs. 4%, $P<0.001$).

Effect of primary diagnosis on symptom and treatment gap prevalence

HF patients presented with fewer unresolved symptoms than did cancer patients, both at moderate/severe levels (1.77 vs. 2.24, $P=0.0001$, Table 5.2), and overall (3.36 vs. 3.87, $P=0.0002$, data not shown). HF patients, relative to cancer patients, less frequently rated the following symptoms as moderate/severe: anorexia (29% vs. 46%, respectively, $P<0.001$), pain (19% vs. 32%, $P<0.001$), insomnia (14% vs. 20%, $P=0.02$), anxiety (12% vs. 20%, $P=0.002$), constipation (8% vs. 15%, $P=0.004$), and nausea (4% vs. 13%, $P<0.001$). Only dyspnea was more commonly reported by HF than cancer patients as moderate/severe (25% vs. 18%, respectively, $P=0.02$) (Figure 5.2). HF patients more commonly experienced dyspnea treatment gaps (17% vs. 8%, $P<0.001$, Figure 5.3), whereas cancer patients more frequently had constipation-related treatment gaps (11% vs. 6%, $P=0.008$).

Compared to cancer patients, an HF diagnosis was significantly associated with a 13.8%-reduction in the predicted number of unresolved symptoms per patient, after accounting for the control variables (Table 5.3). However, we did not detect a statistically significant association between primary diagnosis and predicted number of treatment gaps (Table 5.3).

Effect of primary diagnosis on palliative care patient health status at first consultation

In bivariate analysis, having HF as a primary diagnosis was not significantly associated with the probability of experiencing differential overall patient health status as defined by the PC-PHS composite outcome (unadjusted RR: 1.20, 95% confidence interval [CI]: 0.96, 1.50, Table 5.4). However, after adjusting for clinical and demographic factors, HF was associated with a decreased probability of positive health status (as captured by PC-PHS), compared to cancer patients (adjusted RR: 0.70, 95% CI: 0.55, 0.90).

Effect of primary diagnosis on performance status at first consultation

A primary diagnosis of HF was significantly associated with a greater probability of medium performance status (i.e., PPS = 40%-60%) at first visit (average marginal effect: 0.11, 95% CI: 0.033, 0.187), but a lower probability of high performance status (i.e., PPS = 70%-100%) (average marginal effect: -0.065, 95% CI: -0.118, -0.011), compared to cancer patients. To assess model performance, we compared predicted probabilities of each PPS outcome category to observed sample frequencies, and found them to be similar within two decimal points.

DISCUSSION

We investigated differences regarding unresolved symptom burden, treatment gaps, and outcomes between HF and cancer patients referred for community-based palliative care. This work extends the literature beyond previous efforts in two important ways. First, our sample is larger, allowing us to conduct more sophisticated analyses while controlling for important covariates. Second, our study is the first to examine these questions among community-based palliative care, a growing venue for palliative care in the U.S.⁹

Findings support the notion that HF patients possess care needs that are clearly within the purview of palliative care, even if not at the same level of severity or frequency experienced by the classic palliative care population – patients with advanced cancer. Two studies explicitly comparing HF and cancer patients' physical and psychosocial needs found the groups to be indistinguishable vis-à-vis symptom burden, but that differences existed regarding specific symptom prevalence.^{15,21,42} Our findings are generally concordant with their results. Cancer patients in our study reported greater symptom burden, as reflected by the number of unresolved symptoms at moderate or severe levels; whether the observed difference in the number of unresolved symptoms between cancer and HF patients (i.e., 2.24 vs. 1.77 moderate/severe symptoms) is sufficient to affect clinical decision-making is unknown, but our general clinical experience suggests that symptom prioritization becomes paramount when people are suffering from multiple problems simultaneously. Nevertheless, the question remains whether it is overall cumulative symptom burden or the severity of a specific symptom that prompts provider intervention. Echoing previous work,^{42,43} we found dyspnea to be more prevalent in HF patients than in cancer patients; shortness of breath, like pain, is a high priority symptom that must be addressed or quality of life degrades and caregiver

burden escalates.⁴³⁻⁴⁷ Lastly, a diagnosis of HF was associated with poorer health status (as measured by our composite PC-PHS outcome); this finding persisted even after we controlled for the advanced age of our HF patients. As with most advanced illnesses, particularly those illnesses involving the elderly, our findings suggest that patients with advanced HF and cancer are appropriate for palliative care; however, the pattern of disease burden appears to differ between the two illnesses and therefore the portfolio of palliative interventions must be appropriately tailored.

Our findings are not intended to obviate disease-specific policies and palliative care referral for HF and cancer patients. Indeed, we strongly caution against such conclusions. Despite overarching similarities regarding disease-related burden, we contend that the natural histories of HF and cancer patients require different approaches to optimize palliative care. Particularly for diseases with notoriously unpredictable trajectories, such as HF,⁴⁸ the timing of palliative care referral must be customized to patients' needs and preferences if the goal is a more patient-centric experience. Because palliative care can be administered at different points in the illness trajectory, its introduction and intensity might best be tailored to patients' specific incident and fluctuating needs (e.g., HF-related comorbidities, use of morphine for dyspnea, advance care planning). By introducing palliative care before symptoms become intractable or hospice enrollment is the only option, one can offer patients and caregivers an array of supportive services that are consistent with their needs and goals for care.^{49,50} Another noteworthy finding in our study is the advanced age of our patients (median: 85 years), which combined with a HF diagnosis, may point to a short life expectancy. This may perhaps point to a possible selection issue in that HF patients are being referred for palliative care at a point in their illness experience when hospice care may be more appropriate. Previous work has documented confusion amongst medical providers

regarding non-hospice palliative care and hospice care,⁷ which also may suggest that HF patients are currently being referred for palliative care later in their illness than is ideal for optimal integration of palliative and standard cardiac treatments.

Whereas numerous studies have demonstrated the benefits of palliative care to patients with cancer,^{3,4,51} the role of palliative care for cardiac conditions, including HF, has yet to be clearly defined.^{7,52,53} As such, ACC/AHA recommendation of palliative care for patients with advanced HF is largely based upon consensus, rather than empirical evidence. Although it is encouraging that palliative care is included in treatment guidelines put forth by the ACC/AHA,²² it is important to note that these recommendations are discussed in the context of end-of-life care. Such guidelines are likely to further exacerbate the misconception that non-hospice palliative care and hospice care are synonymous amongst healthcare providers. Educational efforts to correct such misconceptions and to clearly emphasize what palliative care can offer patients and referring providers, as well as how it can be accessed locally may be worthwhile; preliminary research suggests that cardiology and primary care providers may be receptive to such interventions.⁷

Regrettably, symptoms experienced by HF patients may go unrecognized and unaddressed.⁵⁴ Dyspnea and fatigue are characteristic of HF,⁵⁵ yet the literature and our data support that HF patients may suffer from various other symptoms including pain, depression, insomnia, anorexia, anxiety, edema, and constipation.^{14,55-57} Thus, although most unaddressed symptoms were more common in our cancer cohort, we must not diminish the need for thorough clinical assessment and management among HF patients.

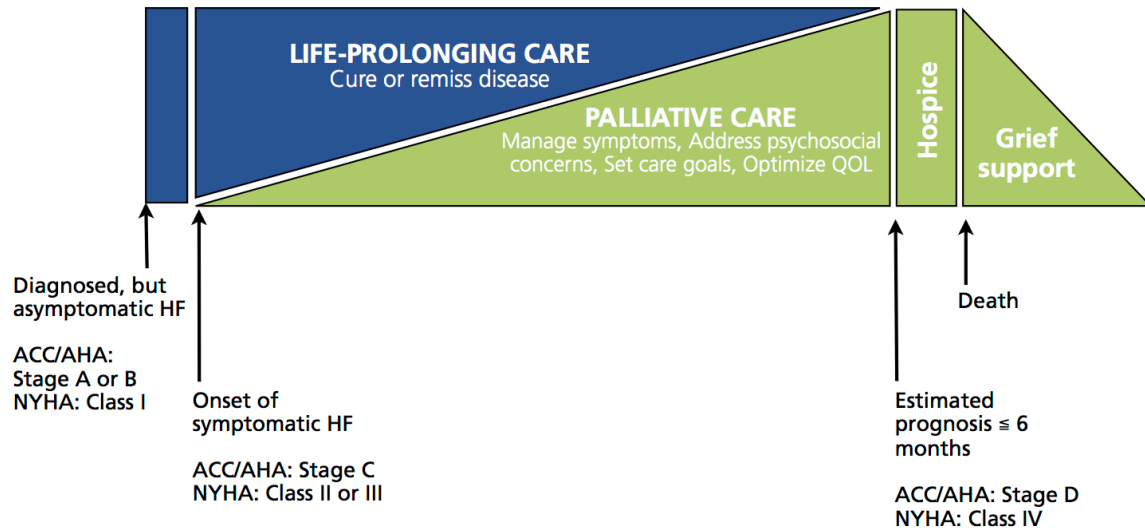
This study has several limitations. First, we combined all cancer patients, which precludes our ability to identify differences related to tumor type. Second, PC-PHS is a composite measure. Although it has face validity and was based on clinical and intuitive logic, the PC-PHS has not been validated and may represent another source of measurement bias. Perhaps future multi-site studies with larger sample sizes should employ disease-specific measures to complement generic measures of QOL and functioning. Third, we were limited in our ability to control for potential confounders by the data available in PCRR. Notably, patients with HF were substantially older than were those patients with cancer. Thus, we cannot separate the effect of age from disease. Moreover, data from a quality-monitoring database may be less accurate and consistent than research databases, although more reflective of care as actually delivered in usual practice. Fourth, given the cross-sectional nature of this study, the types of conclusions that can be drawn are limited. Finally, our data come from two community-based palliative care organizations in North Carolina, which may limit generalizability to other care settings and regions. The patients in this study all had been referred for palliative care consultation, and may therefore differ from HF and cancer patients who were not referred to palliative care.

Our study is the first HF-focused analysis of a database profiling community-based palliative care practice in the U.S. As such, we hope that it will serve as a first step to describe a model of care through which we may expect a growing number of HF patients to receive supportive services.^{10,16} Additionally, given the increasing prevalence of HF, we hope that this work will spark discussion regarding palliative care workforce planning especially as it relates to ensuring that palliative care teams have the skills and resources necessary to take care of people with HF. Lastly, we hope that this work will draw providers' attention to sources of distress in HF patients that may currently be

going unnoticed and undertreated. Providers may lack clarity regarding how to best leverage specialist palliative care services to support their efforts to optimize HF patient experiences.^{7,52,58,59} Methodologically rigorous, clinically relevant, and patient-centered clinical and health services research is needed to elucidate the potential role of palliative care in HF, given the anticipated growth of this population over the coming decades.

FIGURES AND TABLES

Figure 5.1. Illustration of a proposed model of palliative care and hospice integration across the heart failure trajectory



Abbreviations: HF, heart failure; ACC/AHA: American College of Cardiology/American Heart Association; NYHA: New York Heart Association

Table 5.1. Demographic and disease characteristics of study cohort

Characteristic	Heart Failure Patients N (%)	Cancer Patients N (%)	P-value
N	334	697	
Age in years, median [range]	84 [33-102]	71 [12-101]	<0.001
Male gender	138 (41)	327 (47)	0.09
Race			0.001
White	302 (90)	602 (86)	
Black	16 (5)	78 (11)	
Other or unknown	16 (5)	17 (2)	
Advance care planning activities completed prior to or during initial palliative care visit			
“Do not resuscitate” status declaration	217 (65)	472 (68)	0.64
Living will completed	136 (41)	249 (36)	0.003
MOST form completed	16 (5)	24 (3)	0.30
Designation of healthcare surrogate	191 (57)	472 (68)	<0.001
Number of hospitalizations within 6 months before first palliative care visit			<0.001
0	64 (19)	256 (37)	
1	90 (27)	183 (26)	
2	53 (16)	97 (14)	
3	28 (8)	38 (5)	
>3	17 (5)	15 (2)	
Unknown	82 (25)	108 (15)	
Care setting at time of first palliative care visit			<0.001
Hospital inpatient	230 (69)	544 (78)	
Nursing home or assisted living facility	61 (18)	30 (4)	
Patient home	25 (8)	83 (12)	
Outpatient clinic	1 (0.3)	6 (0.7)	
Respondent			0.03
Patient	222 (66)	507 (73)	
Caregiver or provider	110 (33)	183 (26)	
Palliative Performance Scale, median [range]	40 [10-80]	40 [10-90]	0.27
Low (10%-30%)	92 (28)	236 (34)	
Medium (40%-60%)	154 (46)	296 (42)	
High (70%-100%)	13 (4)	74 (11)	
General quality of life rating			0.99
Poor	134 (40)	301 (43)	
Fair/Good	153 (46)	344 (49)	

Note: Values may not sum to 100 due to rounding and/or missing data. MOST = Medical Orders for Scope of Treatment. The Palliative Performance Scale rates functional status across five domains from 0%-100% in 10-percentage point increments, with greater scores indicating higher performance. Chi-square tests of independence were calculated for categorical variables, Student's t-tests were used for normally distributed continuous variables, and Wilcoxon-Mann-Whitney tests calculated for interval or non-normally distributed continuous outcomes.

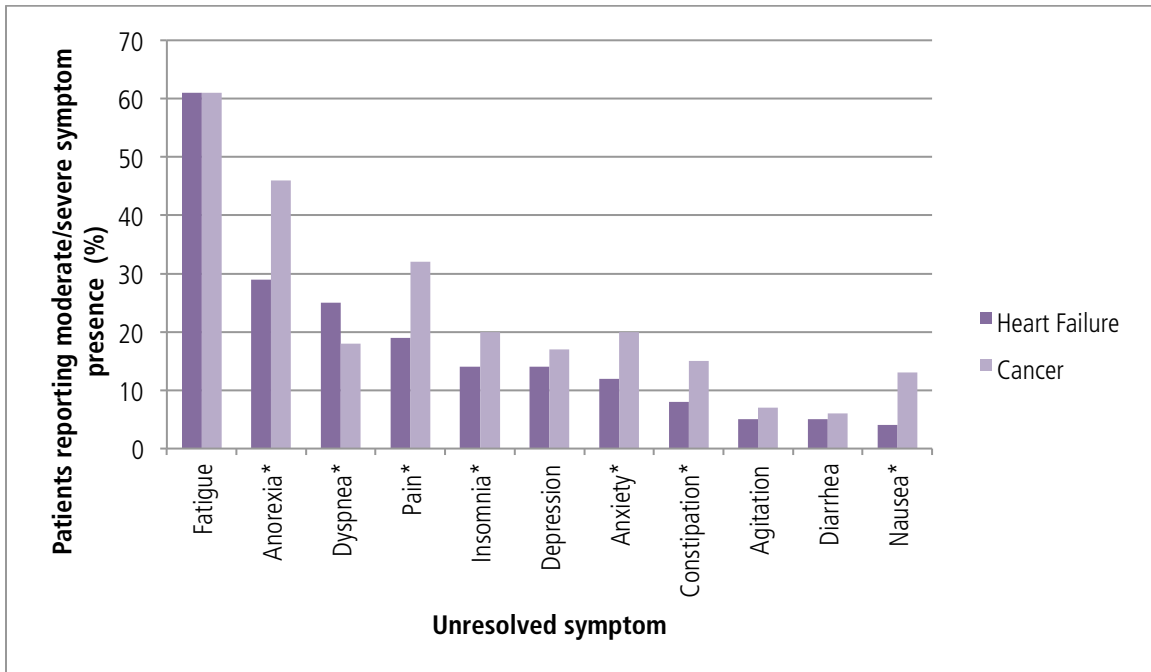
Table 5.2. Comparison of unresolved symptoms and treatment gaps between heart failure and cancer patients referred for palliative care

Variable	HF patients (N=334)	Cancer patients (N=697)	P- value
Symptoms reported at any moderate or severe levels, mean \pm SD [range]	1.77 \pm 1.60 [0-9]	2.24 \pm 1.82 [0-10]	0.0001
Treatment gaps per patient, mean \pm SD [range]	0.40 \pm 0.037 [0-4]	0.40 \pm 0.025 [0-4]	0.98

Note: Abbreviations: HF, heart failure; SD, standard deviation.

The number of symptoms reported at any level is provided only for contextual purposes, but was not used as an outcome in our analyses.

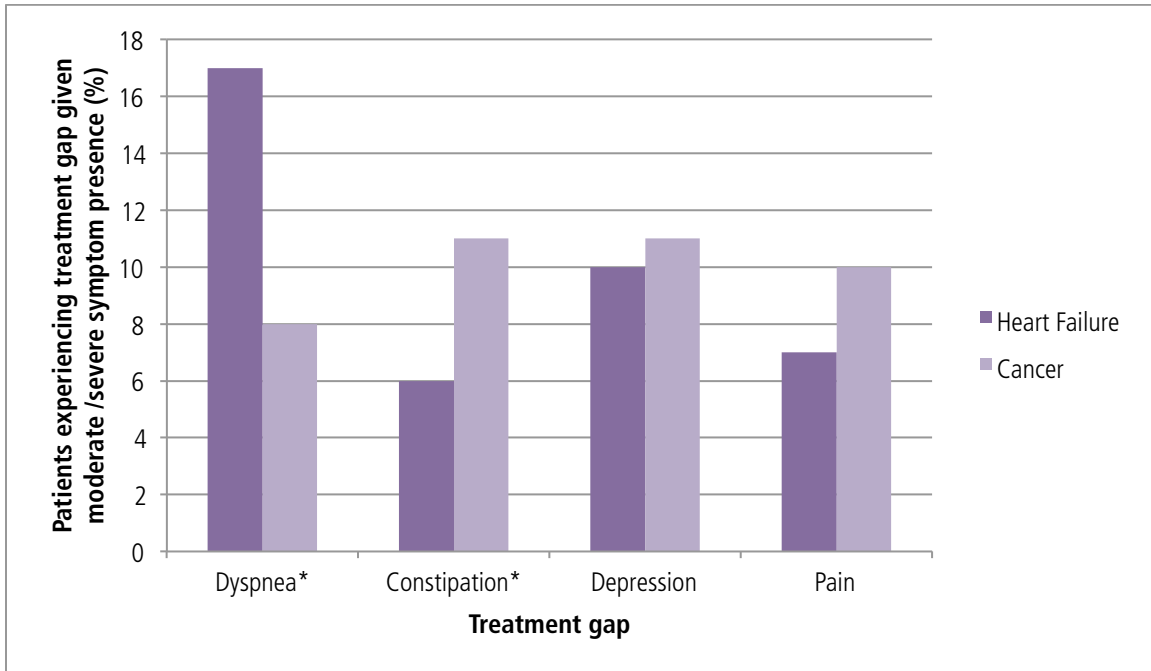
Figure 5.2. Prevalence of unresolved symptoms at first palliative care consultation



Note: A symptom was defined as “unresolved” when its current severity was rated as either “moderate” or “severe.”

* Pearson’s chi-square test indicates significant difference in unresolved symptom prevalence between heart failure and cancer patients at the $\alpha=0.05$ level.

Figure 5.3. Prevalence of treatment gaps at first palliative care consultation



Note: We defined a “treatment gap” as the lack of a documented intervention for a symptom rated as “moderate” or “severe.”

*: Pearson’s chi-square test indicates significant difference in treatment gap prevalence between heart failure and cancer patients at the $\alpha=0.05$ level.

Table 5.3. Results of Poisson models estimating the effect of primary diagnosis on unresolved symptom and treatment gap prevalence at the time of first palliative care consultation

Variable	β (SE)	95% CI	Percent change
<i>Outcome: Expected number of unresolved symptoms</i>			
Heart failure (vs. cancer)	-0.148 (0.069)*	-0.285, -0.012	-13.8
Age, years	-0.0055 (0.0021)**	-0.0096, - 0.0014	-0.5
Male gender	-0.099 (0.057)	-0.212, 0.012	-9.5
Non-White race	-0.008 (0.087)	-0.178, 0.161	-0.8
Palliative Performance Scale	-0.0020 (0.0017)	-0.0054, 0.0014	-0.2
Proxy-reported symptom assessment	-0.046 (0.073)	-0.189, 0.096	-4.5
Outpatient	-0.063 (0.080)	-0.220, 0.094	-6.2
<i>Outcome: Expected number of treatment gaps</i>			
Heart failure (vs. cancer)	0.23 (0.13)	-0.03, 0.48	25.3
Age, years	-0.0076 (0.0037)*	-0.0149, - 0.0002	-0.8
Male gender	0.12 (0.11)	-0.11, 0.34	12.6
Non-White race	-0.10 (0.20)	-0.49, 0.28	-9.7
Palliative Performance Scale	0.0016 (0.0036)	-0.0054, 0.0086	0.2
Proxy-reported symptom assessment	-0.03 (0.14)	-0.31, 0.25	-3.1
Outpatient	-0.46 (0.17)**	-0.79, -0.13	-36.8

Note: β , Regression coefficient; SE, Standard error; CI, confidence interval.

Sandwich-robust standard errors provided.

The percent change in the expected count of an outcome for a δ -unit change in variable k , holding all else constant, is calculated as: $100 * \{\exp(\beta_k * \delta) - 1\}$.³⁴

*: Significant at the 5% level. **: Significant at the 1% level.

Table 5.4. Associations between various demographic and clinical variables and palliative care patient health status at first palliative care consultation

Variable	RR (95% CI)			
	Unadjusted	P-value	Adjusted	P-value
Heart failure (vs. cancer)	1.20 (0.96-1.50)	0.11	0.70 (0.55-0.90)**	0.01
Age, in years	1.01 (1.00-1.02)**	0.01	1.02 (1.01-1.03)**	<0.001
Male gender	0.75 (0.62-0.92)**	0.01	1.34 (1.10-1.62)**	0.003
Non-White race	1.24 (0.88-1.73)	0.22	0.86 (0.62-1.20)	0.37
Proxy-reported symptom assessment (vs. patient-reported)	1.69 (1.30-2.20)**	<0.001	0.58 (0.45-0.76)**	<0.001
Outpatient (i.e., not hospitalized) at time of visit	0.75 (0.61-0.93)**	0.01	1.27 (1.04-1.57)*	0.02

Note: Abbreviations: RR, risk ratio; CI, confidence interval.

*: Significant at the 5% level. **: Significant at the 1% level.

The outcome variable (PC-PHS, palliative care patient health status) was a binary indicator defined as positive if a patient reported all three of the following criteria: fair/good quality of life; adequately controlled pain; and, adequately controlled dyspnea. Akaike's Information Criterion (AIC) of adjusted model: 1.24

Table 5.5. Average marginal effects after generalized ordered logistic regression of Palliative Performance Scale score at first visit

Variable	Average marginal effect (SE)	P-value	95% CI
Probability of low PPS (0%-30%) at first visit			
Heart failure	-0.045 (0.032)	0.16	-0.11, 0.018
Age, years	-0.00045 (0.00099)	0.65	-0.0023, 0.0015
Male gender	-0.015 (0.024)	0.53	-0.062, 0.032
Non-White race	-0.016 (0.036)	0.66	-0.087, 0.055
Proxy-reported symptom assessment	0.406 (0.018)**	<0.001	0.370, 0.440
Outpatient	-0.354 (0.049)**	<0.001	-0.451, -0.257
Probability of medium PPS (40%-60%) at first visit			
Heart failure	0.110 (0.039)*	0.01	0.033, 0.187
Age, years	0.0019 (0.0010)	0.06	-0.00009, 0.0039
Male gender	0.007 (0.12)	0.53	-0.016, 0.031
Non-White race	0.008 (0.018)	0.66	-0.027, 0.043
Proxy-reported symptom assessment	-0.199 (0.020)**	<0.001	-0.24, -0.16
Outpatient	0.265 (0.051)**	<0.001	0.016, 0.366
Probability of high PPS (70%-100%) at first visit			
Heart failure	-0.065 (0.027)*	0.02	-0.118, -0.011
Age, years	-0.0015 (0.00063)*	0.02	-0.003, -0.0002
Male gender	0.008 (0.012)	0.53	-0.016, 0.032
Non-White race	0.008 (0.019)	0.66	-0.028, 0.044
Proxy-reported symptom assessment	-0.207 (0.024)**	<0.001	-0.253, -0.160
Outpatient	0.089 (0.020)**	<0.001	0.049, 0.130

Note:

Abbreviations: SE, Standard error; CI, confidence interval; PPS, Palliative Performance Scale. The PPS rates functional status across five domains from 0%-100% in 10-percentage point increments, with greater scores indicating higher performance.

*: Significant at the 5% level. **: Significant at the 1% level.

Average marginal effects indicate the average difference in the probability of a patient experiencing one of the three PPS outcome categories, controlling for all other factors in the model. Average marginal effects computed using “margins” command of Stata version 12.

Pseudo-R²: 0.21.

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CHAPTER 6: ASSESSING THE QUALITY OF PALLIATIVE CARE RECEIVED BY PATIENTS WITH HEART FAILURE LIVING IN THE COMMUNITY

INTRODUCTION

Heart failure (HF) is a prevalent, chronic, and ultimately incurable condition that is associated with extensive health services utilization, particularly at the end of life.¹⁻⁵ Given the increasing incidence of HF and improved survival owing to life-prolonging therapies, the burden of chronic HF both in terms of morbidity and mortality, as well as healthcare costs, is greater than ever before, and is expected to grow.⁶ Historically, our understanding regarding HF healthcare quality has centered on the relationship between provider/facility processes of care (e.g., appropriate use of cardiac drugs, devices, and procedures) and outcomes such as post-hospitalization readmission and mortality.⁷⁻¹¹ Recently, a growing effort has begun to examine end-of-life experiences of HF patients to reflect the quality of care that such individuals receive. To date, such research has predominantly assessed hospice utilization trends in Medicare claims¹² or large clinical registries.¹³

Traditionally, palliative care services in the U.S. have been administered in the inpatient setting; however, emerging models of care, such as community-based and outpatient palliative care hold promise for creatively addressing the increasing demand of patients needing support living with chronic diseases, such as HF.^{14,15} Community-based palliative care is an attractive approach for people with advanced HF given its flexibility to provide care for patients despite volatile disease trajectories with multiple

transitions across care settings (e.g., home, hospital, skilled nursing) and treatment modalities. The ability for palliative care to extend beyond acute care hospitalizations is especially critical for frail patients, who, for example, may experience added burdens or barriers as a result of traveling to accessible palliative care services.

The role of palliative care has yet to be clearly defined in cardiology.¹⁶⁻¹⁸ To deliver high quality palliative care to patients with HF, it is imperative to prospectively study processes of care and outcomes, as people with HF transition between care settings in a natural, “real world” context. The goal of this study was to examine the relationship between quality metrics for palliative processes and patient outcomes in community-based palliative care in a cohort of HF patients.

METHODS

Data Source

The Carolinas Palliative Care Consortium is a quality improvement partnership between Duke University and three North Carolina community-based palliative care organizations.¹⁹ In June 2008, the Consortium established the Palliative Care Database, the first American initiative of its kind to systematically collect patient-, caregiver-, and provider-reported data for quality monitoring purposes.^{19,20} At every consultation, trained palliative care providers collected data using the Quality Data Collection Tool (QDACT).^{20,21} Data are both stored locally at each site, and securely transferred to Duke University at regular intervals for mining and analysis. In 2012, these retrospective quality improvement data were transitioned into what is known as the Palliative Care Research Registry (PCRR). The Duke University Institutional Review Board approved

this study and the creation of the PCRR. The Institutional Review Board at the University of North Carolina at Chapel Hill additionally approved the study protocol.

Procedures

We extracted consultation data entered from June 1, 2008 until January 1, 2012. HF patients were identified by the following *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM) diagnostic codes: 428.xx (HF); 429.3 (cardiomegaly); 402.01 (malignant hypertensive heart disease with HF); 402.11 (benign hypertensive heart disease with HF); 402.91 (unspecified hypertensive heart disease with HF); and, 425.xx (cardiomyopathy).²² We included only patients with at least two consultations to allow for process performance and a subsequent effect on patient outcomes, if any. To assess the association between palliative care processes and end-of-life outcomes, we restricted our cohort to patients for whom we could confirm death by January 2012 via the Social Security Administration Death Master File and obituary notices accessed using www.ancestry.com. Such sources have a high degree of sensitivity in identifying mortality.²³

Measures

Quality of palliative care was assessed based upon the “Prepare, Embrace, Attend, Communicate, and Empower” (PEACE) indicator set developed for the Centers for Medicare and Medicaid Services (CMS).²⁴ Quality measures identified from a literature review were pilot-tested, and subsequently evaluated by a 14-member expert panel. Of the 34 adopted indicators, 14 could be assessed within the PCRR. We chose

to focus our analysis on the subset of indicators believed by providers to be the most likely to positively influence patient outcomes. To reduce the number of quality indicators used in this study, we electronically surveyed a convenience sample of 14 North Carolina providers in cardiology, primary care, or palliative care.¹⁸ With a median of 12 years (range: 2-38) in practice, the provider raters were clinically knowledgeable to comment on the quality indicators. Providers were asked to select the top three indicators which they believed were “likely to be valid indicators of overall high-quality HF care, so much so that it would be appropriate on which to base CMS reimbursement decisions (bonuses or penalties).” We chose the five indicators most frequently selected in the survey (Figure 6.1). The quality indicator for symptom assessment was met if all eleven symptoms assessable in the QDACT were evaluated at the first palliative care consultation. Similarly, the dyspnea indicator measured whether a clinical assessment of dyspnea was performed at the first consultation. If patients screened positive for dyspnea, a subsequent quality indicator reflected initiating pharmacologic or non-pharmacologic treatment by the end of the following consultation. The comprehensive assessment indicator was scaled as a binary variable (scored 0 and 1) with a score of 1 requiring all of the following: (1) the clinical screening of at least one symptom, (2) a quality of life (QOL) assessment, and (3) the assessment of any advance care planning activities. Finally, the indicator for preferences for life-sustaining treatments required completion of a living will, a Medical Orders for Scope of Treatment (MOST) form, or having declared “full code” or “do not resuscitate” status prior to or during the first palliative care consultation. Each indicator was dichotomized (i.e., present = 1 or absent = 0).

During palliative care consultations, Consortium providers assessed three patient-reported outcomes that are both meaningful to patients at the end of life²⁵ and

key targets of palliative intervention: QOL, adequately controlled pain, and adequately controlled dyspnea. For QOL, we used a single item, scored on a three-category ordinal scale (i.e., “poor,” “fair,” “good”) derived from the McGill QOL Questionnaire Single Item Scale;²⁶ given the small proportion of patients who reported “good” QOL at both initial and terminal consultations (5% and 7%, respectively), we created a binary measure (i.e., “poor” versus “fair/good” QOL). Pain and dyspnea assessments were made using the McCorkle Symptom Distress Scale,²⁷ a commonly used instrument in palliative care populations. The PCRR includes information regarding the severity, duration, and tolerability of 11 symptoms: agitation, anorexia, anxiety, constipation, depression, diarrhea, dyspnea, fatigue, insomnia, nausea, and, pain. For pain and dyspnea, providers asked patients about both their current and maximal tolerable levels of pain and dyspnea. If current symptom severity was less than the maximum tolerable level, or if the patient reported no current symptom, we considered that patient to have adequate control. We initially modeled the three components separately (i.e., fair/good QOL, adequately controlled pain, and adequately controlled dyspnea); however, in the interest of parsimony, we chose to combine the outcomes into a single composite variable (2-3 versus 0-1 outcomes). That is, we created a binary variable (scored 0 and 1), with 1 requiring the presence of at least two of the three components: fair/good QOL, adequately controlled pain, and adequately controlled dyspnea. We performed sensitivity analyses using various permutations of the composite variable (i.e., >1 outcome, all 3 outcomes). We will refer to this composite outcome as “palliative care patient health status” or PC-PHS.

Performance status was assessed using the clinician-reported Palliative Performance Scale (PPS), version 2.0²⁸, a modification of the Karnofsky Performance Scale that has been well-validated in palliative care patients.²⁹ The PPS uses an 11-

category ordinal scale from 0-100% in 10-percentage point increments, with higher scores indicating better functioning. Recognizing that patients who receive palliative care consults while hospitalized likely differ regarding acuity, we included a binary indicator to control for location of consult. Additional control variables included patient: age, gender, race (white or non-white), sum of palliative care consultations recorded in the PCRR, and a binary indicator reflecting whether symptom assessment data were patient- versus proxy-reported.

Statistical analysis

After describing the sample, we conducted a two-step process to assess the process-outcome link. First, we regressed the composite outcome on each quality indicator, to provide unadjusted risk ratios (RRs). Next, we simultaneously adjusted for all of the quality indicators, as well as a one-variable patient adjustment score. In the second step, we did not include the quality indicator regarding dyspnea treatment, as it by definition, applies only to a small subset of our overall cohort.

We calculated RRs using modified Poisson regression with robust/sandwich standard errors.³⁰ This method has been shown to estimate relative risk consistently and efficiently in samples as low as 100. We compared RR point estimates calculated from this Poisson method and manually from 2x2 contingency tables and found them to be exact within two decimal places. Risk ratios were chosen given the frequency of our study outcome, as odds ratios may overstate relative risk in such situations.³¹

Given the limited and fixed sample size, we constructed a patient-level adjustment score to reduce the dimensionality of regression models; this technique has

been previously applied to similar studies of healthcare quality assessment.^{32,33}

Variables in the adjustment score were: (1) age at time of first palliative care consultation; (2) gender; (3) race; (4) patient versus proxy report; (5) care setting (i.e., hospital inpatient versus patient's home); and, (6) total number of palliative care consultations recorded in the PCRR. We attempted to include performance status (as a proxy for disease status and prognosis) in the adjustment model; however, it was excluded due to multicollinearity with number of palliative care consultations.

The sample size for this study theoretically provided sufficient cases to conduct the multivariable analysis, while maintaining an event per variable ratio higher than 10 to 1 in all multivariable models.^{34,35} Specifically, given the four quality indicators that applied to all patients, in addition to the single patient adjustment variable, our sample size of 85 (of which 60 experienced the composite outcome) was deemed to be sufficient. We assessed model fit by plotting fitted versus actual data points. Statistical tests were two-tailed with a critical α -level of 0.05. Analyses were conducted using Stata/IC, version 12.³⁶

RESULTS

Cohort characteristics

A total of 85 patients met all study criteria. Our predominately White cohort (93%) was almost equally split regarding gender (53% female) (Table 6.1). The median age was 85 years (range: 35-101). Median duration of palliative care enrollment was 76 days (range: 1-1,075), and 75.3% of patients died within 60 days of their last palliative care consultation (data not shown). The median number of palliative care consultations per patients was 3 (range: 2-24).

Prevalence of quality indicator adherence

Overall, we documented a 48% joint adherence rate to the four quality indicators that applied to all HF patients (Table 6.2). Taken individually, we noted highest adherence to the receipt of an initial dyspnea assessment (99%), and lowest for assessment of all eleven symptoms captured by our data collection instrument (59%). When this number was reduced to five symptoms, adherence rose to 94% (data not shown); however, for the remainder of this analysis, we refer to a “complete symptom assessment” as all eleven symptoms. Table 6.3 displays the prevalence of the PC-PHS variable, as well as its individual components.

Patient clinical and demographic adjustment

The unadjusted associations between the individual components in the one-variable adjustment score and PC-PHS (composite outcome) are displayed in Table 6.4. Overall, the unadjusted RR for the adjustment score and PC-PHS was 3.87 (95% confidence interval [CI]: 1.15-13.02) per unit increase in adjustment score. That is, for each added item in the adjustment score, patient health status improved.

Associations between quality indicator adherence and outcomes at last palliative care consultation

Of the five unadjusted RRs (Table 6.5), only dyspnea assessment at initial consultation was associated with our composite outcome of PC-PHS (unadjusted RR:

1.42, 95% CI: 1.24-1.64). In the multivariate model adjusting for palliative processes of care and patient characteristics (using the univariate adjustment score), the dyspnea assessment indicator was no longer significant (adjusted RR: 1.57, 95% CI: 0.93-2.64, $p=0.09$). However, we found a significant association between the presence of a comprehensive assessment and improved PC-PHS (adjusted RR: 1.40, 95% CI: 1.08-1.80, $p=0.01$).

DISCUSSION

Within a cohort of community-dwelling patients with HF, we describe adherence to accepted palliative care quality indicators, and assess the link between these process metrics and patient health outcomes at the end of life. To our knowledge, this study is an initial step towards understanding the relationship between type of palliative care and outcomes among patients with HF living in the community. Our work presents novel contributions to the literature by: (1) focusing on community-based palliative care for HF patients; (2) leveraging the PCRR, which to date, is the largest US database capturing prospective palliative care quality performance data at the point of care; and (3) identifying associations between the PEACE quality indicators and meaningful patient outcomes. Notably, to make our results more relevant, we sought input from a multidisciplinary and experienced group of providers within North Carolina about the quality indicators they perceived to be most important. By aligning our data source with providers of the same region, we may have addressed some regional variations in provider-related treatment patterns,^{37,38} while this may have decreased generalizability outside of North Carolina, we believe that overall this process improves the applicability of our work.

Our work highlights an initial effort to align the resources (i.e., clinical, research, and information technology) to collect and assess quality performance data in community-based palliative care. This effort is critical to our understanding of the disease experiences of patients with advanced illness living in the community, as such benchmarking affords the opportunity to set the priorities of palliative medicine. The assessment of the process-outcome link will allow future prioritization of the processes of care that hold the highest likelihood of increasing positive patient outcomes. By collecting data regarding outcomes at the patient level, the PCRR stands as a unique resource through which to assess care process and patient outcomes in a clinically-relevant and patient-oriented manner. This article is the first to assess this relationship and establishes a paradigm for future work in palliative care quality assessment work. In fact, the principal contribution of our work is the development of a framework through which we can begin to study and ultimately improve the provision of care for patients with life-limiting illness. We describe the types of data necessary to conduct palliative care quality analyses, and highlight areas where improvement is needed in future data collection systems. An important “proof-of-concept,” this article provides a structure that can be iteratively repeated over time as data quantity and quality are improved in community-based palliative care systems, such as the PCRR.

In this study, we observed that dyspnea assessment at first palliative care consultation was routinely accomplished, but was not associated with improved outcomes. However, we should not interpret the latter finding to suggest that dyspnea assessment is a task unworthy of effort. Our inability to detect an effect on patient health status is likely a function of the extremely high adherence to this indicator within our sample. In the case of complete symptom assessment and the other indicators where adherence was not at a ceiling level, we are able to assess which of these lead to

improved outcomes and focus clinical energies there. In this case, it appears to be complete symptom assessment. Future priorities should be to amass a greater patient population in the PCRR and repeat the current analyses, which may allow us to observe varying levels of quality indicator adherence.

We found that overall adherence to PEACE indicators was remarkably high for most indicators. For example, 99% of HF patients in our cohort were screened for dyspnea at their initial palliative care consultation. The primary exception was that only 44% of patients who reported dyspnea received treatment by the end of their second consultation. Our findings regarding dyspnea treatment are in contrast with those of a somewhat similar study of cancer patients, where 73% of eligible patients received treatment within 24 hours.³⁹ The Consortium is currently addressing this potential quality concern by implementing a rapid-cycling quality improvement initiative.

Of the four quality indicators applicable to our entire cohort, only one indicator - comprehensive assessment - was found to be significantly associated with improved PC-PHS, when adjusting for demographic and clinical factors. Our inability to detect statistical significance for the remaining quality indicators merits comment. One possible and likely explanation is sample size. Additionally, the high rates of adherence we found within this sample may serve as a “ceiling effect,” limiting the degree of variation in adherence. Although the PCRR is the largest repository of community-based palliative care data in the United States, the number of HF patients was small; this finding is somewhat unsurprising. However, the proportion of HF patients receiving palliative care services appears to be increasing.⁴⁰ Despite striking similarities regarding symptom burden^{4,25,41,42} and prognosis with advanced cancer patients, HF patients access supportive services at lower rates than do cancer patients. In 2008, cancer was the leading diagnosis among hospice enrollees (38.3%), whereas HF ranked 3rd (11.7%).⁴³

A growing body of literature points to a variety of potential referral barriers unique to the HF experience as impediments to palliative care referral in this population.^{18,44-46}

Nevertheless, we actively sought to leverage all available data to augment the types of analyses that we could perform. For example, we constructed a composite outcome of PC-PHS and used a patient-level summary adjustment score to reduce the number of control variables in multivariate models.

In the current study, we used indicators created for the palliative care and hospice disciplines to assess care quality. Interestingly, concurrent movements from within the cardiology community echo, in part, how quality health care for HF patients is conceptualized and defined. In 2011, the American College of Cardiology and the American Heart Association updated their set of performance measures to include symptom assessment and management.⁴⁷ Advance care planning was considered for inclusion, as well; however, it was not ultimately adopted into the final set of measures. Nevertheless, efforts to coordinate perspectives regarding the needs of HF patients and how they can be efficiently and effectively addressed amongst the constellation of medical providers whom HF patients will typically encounter is paramount, given the multimorbidity commonly experienced by this population and the complex medical management that their illness necessitates.

This study has several limitations. First, the relationship between processes of care and patient outcomes is complex, especially near the end of life and in the very elderly. Indeed, patients in our sample had a median age of 85 years, which may influence the specific processes of palliative care that they received, as well as the outcomes which they experienced. Indeed, for patients with characteristics that suggest greater vulnerability, it may be challenging to delineate process-outcome associations. Second, we were limited in our ability to control for potential confounders by both our

sample size and the data available in PCRR. Poisson regressions using sample sizes below 100 may produce wide confidence intervals.³⁰ Importantly, our estimations of process-outcome associations may be biased toward the null due to missing data. For example, QOL assessments were missing for 41% of patients at their final palliative care consultation. Third, our data come from two community-based palliative care organizations in North Carolina, which may limit generalizability to other care settings and regions. Fourth, data come from a quality-monitoring database, which are likely less accurate and consistent than research-oriented databases, although more reflective of care as actually delivered in usual practice. This may introduce measurement bias, potentially underestimating care quality. In addition, PC-PHS was a composite measure. Although it has face validity, it has not been validated and may represent another source of measurement error. Fifth, we did not include HF-specific quality indicators in this study. Finally, palliative care interventions comprise much more than the five quality indicators that we assessed in this study; therefore, our work may not capture the full effect of palliative care on patient outcomes.

Despite these limitations, this unique database provides a glimpse into adherence to palliative care quality indicators in a cohort of community-dwelling HF patients. Despite failing to identify statistically significant associations for most indicators with patient outcomes, we do not suggest abandoning such intuitively appealing care processes. The processes assessed herein are reasonable and may contribute to better end-of-life care experiences, even if through indirect pathways. With the national push towards evidence-based medicine, work such as ours stands as a cautionary note that we must be judicious in our choice of data sources. The future of understanding the healthcare needs of HF patients in the community, as well as the ability of palliative care providers to meet such demands, will require a conscious effort to expand and enrich

data repositories such as the PCRR. Rather than serving as the basis for policy or practice recommendations, we suggest that our work serves as a pilot assessment of palliative care quality in HF. Indeed, this study further demonstrates the feasibility of data collection in community-based palliative care settings for the assessment of care quality.²¹ As mandated by the Patient Protection and Affordable Care Act, hospice organizations must begin collecting quality performance data in October 2012.⁴⁸ Therefore, innovations to facilitate reliable and low-burden data capture of care quality in palliative and hospice medicine are of prime and timely interest.

FIGURES AND TABLES

Figure 6.1. PEACE Palliative care quality indicators assessable within PCRR

Indicator	Frequency selected as a top 3 indicator
<i>Selected for inclusion in regression analyses</i>	
Symptom assessment was completed during the first palliative care consultation	12
Dyspnea assessment was performed during the first palliative care consultation	6
Comprehensive assessment was completed during the first palliative care consultation	5
If patient screened positive for dyspnea during the first consultation, treatment for dyspnea was initiated by the end of consultation 2	4
Preferences for life-sustaining treatments were documented in the patient's medical record	4
<i>Not selected for inclusion in regression analyses</i>	
An advanced directive was documented in the patient's medical record	4
The designation of a healthcare surrogate was documented in the patient's medical record	4
If patient screened positive for pain during the first consultation, treatment for pain was initiated by the end of consultation 2	1
Pain assessment was performed during the first palliative care consultation	0
Bowel function assessments were performed on a weekly basis	0
Did the patient report moderate or severe pain rating in the last week of life?	0
If patient reported pain during the first consultation, was a clinical assessment completed?	0
If treatment for pain was initiated, a reduction in pain was documented in the patient's medical record	0
If patient screened positive for constipation during the first consultation, treatment for constipation was initiated by the end of consultation 2	0

Note: All indicators assessed at first palliative care consultation, unless otherwise stated. The quality indicator for the completion of a comprehensive assessment was defined as positive if the following three conditions: the clinical assessment of at least one symptom, assessment of quality of life, and the assessment of advance care planning activities. The indicators regarding advance directive documentation and healthcare surrogate designation were excluded based on clinical judgment, and because they were similar enough to the indicator regarding life-sustaining treatment preferences.

Table 6.1. Demographic and disease characteristics of study cohort

Characteristic	N (%)	
Age in years, median [range]	85 [33-101]	
Female gender	45 (53)	
Race		
White	79 (93)	
Black	3 (4)	
Other or unknown	3 (4)	
Advance care planning activities completed prior to or during initial palliative care consultation		
“Do not resuscitate” status declaration	59 (69)	
Living will completed	38 (45)	
MOST form completed	2 (2)	
Designation of healthcare surrogate	47 (55)	
Number of recorded palliative care consultations, median [range]	3 [2-24]	
Number of hospitalizations within 6 months before first palliative care consultation		
0	12 (14)	
1	28 (33)	
2	15 (18)	
3	6 (7)	
>3	9 (11)	
Not assessed/Unknown	15 (18)	
Care setting at the time of first palliative care consultation		
Hospital inpatient	46 (54)	
Nursing home or assisted living facility	21 (25)	
Patient home	8 (9)	
Unknown	10 (12)	
Respondent		
Patient	54 (64)	
Caregiver or provider	31 (37)	
	Initial Consultation, N (%)	Last Consultation, N (%)
Palliative Performance Scale, median [range]	40 [10-80]	40 [10-60]
Low (10%-30%)	24 (28)	22 (26)
Medium (40%-60%)	41 (48)	26 (31)
High (70%-100%)	4 (5)	--
Not assessed/Unknown	16 (19)	37 (44)
General quality of life rating		
Poor	38 (45)	22 (26)
Fair	35 (41)	23 (27)
Good	4 (5)	5 (6)
Not assessed/Unknown	8 (9)	35 (41)

Note: Values may not sum to 100 due to rounding and/or missing data. MOST = Medical Orders for Scope of Treatment. The Palliative Performance Scale rates functional status across five domains from 0-100% in 10-percentage point increments.

Table 6.2. Prevalence of palliative care quality indicator adherence at initial palliative care consultation

Indicator	Prevalence ^a N (%)
Full symptom assessment (i.e., 11 symptoms) at initial consultation	50/85 (59)
Comprehensive assessment at initial consultation	72/85 (85)
Dyspnea assessment at initial consultation	84/85 (99)
Dyspnea treatment initiated by consultation 2, if dyspnea present at initial consultation	20/45 (44)
Documentation of life-sustaining treatment preferences at initial consultation	74/85 (87)
Overall adherence ^b	41/85 (48)

^a Prevalence data are reported as the number of affected patients / the number of eligible patients.

^b Overall adherence does not include dyspnea treatment indicator, as this applies to only a subset of the entire cohort.

Table 6.3. Outcomes of interest assessed at final palliative care consultation

Characteristic	N (%)
Quality of life	
Fair or good	28 (33)
Poor	22 (26)
Unknown	35 (41)
Pain experience	
Adequately-controlled or no pain	68 (80)
Inadequately-controlled	6 (7)
Unknown	11 (13)
Dyspnea experience	
Adequately-controlled or no dyspnea	64 (75)
Inadequately-controlled	8 (9)
Unknown	13 (15)
Composite outcome of PC-PHS (≥ 2 of the above bolded outcomes)	60 (71)

Note: The composite outcome was defined as positive if a patient having reported at least two of the following criteria: fair/good quality of life; adequately-controlled pain; or, adequately-controlled dyspnea.

Table 6.4. Confounder adjustment variables

Variable	Unadjusted RR (95% CI)
Age per year	0.99 (0.98-1.00)
Male gender	0.86 (0.65-1.14)
Non-white race	0.94 (0.52-1.69)
Patient as source of information	0.99 (0.75-1.32)
Hospital inpatient setting of care	0.97 (0.74-1.28)
Sum of palliative care consultations	1.01 (0.98-1.04)
Confounder adjustment score ^a	3.87 (1.14-13.02)

Abbreviations: RR, risk ratio; CI, confidence interval.

^a We calculated an adjustment score for each patient by using the equation obtained from a Poisson regression model that included the variables listed, in order to reduce the dimensionality of subsequent regressions. The adjustment score (1 variable) was used in the multivariable model that assessed the relationship between palliative care processes and terminal outcomes (Table 6.5).

Table 6.5. Associations between quality indicator adherence at first palliative care consultation and palliative care patient health status at final consultation

Indicator	RR (95% CI)			
	Unadjusted	P-value	Adjusted ^a	P-value
Full symptom assessment (i.e., 11 symptoms) at initial consultation	0.95 (0.72-1.27)	0.74	0.91 (0.68-1.21)	0.53
Comprehensive assessment at initial consultation	0.98 (0.66-1.45)	0.91	1.40 (1.08-1.80)	0.01
Dyspnea assessment at initial consultation	1.42 (1.24-1.64)	<0.001	1.57 (0.93-2.64)	0.09
Dyspnea treatment initiated by consultation 2, if dyspnea present at initial consultation	1.20 (0.77-1.86)	0.42	^b	
Documentation of life-sustaining treatment preferences at initial consultation	0.89 (0.55-1.42)	0.62	0.63 (0.37-1.07)	0.09

Abbreviations: RR, risk ratio; CI, confidence interval.

^a Adjusted for all of the quality indicators (except for dyspnea treatment), as well as the unidimensional adjustment score. The adjustment score included the following factors: age, gender, race, patient versus proxy reporting, and care setting. The adjustment score had an adjusted RR (95% CI) of 3.94 (1.17-13.20), $p=0.03$. AIC of the adjusted model was 2.00, and BIC was -315.07.

^b As this indicator only represents a subset of the entire cohort, it was not assessed in the multivariate model due to reductions in sample size and power.

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CHAPTER 7: DISCUSSION

Overview

HF is a prevalent, irreversible, and progressive disease affecting approximately 5.8 million Americans, with over 550,000 annual incident cases.¹ HF patients, especially those with advanced disease, experience physical and emotional distress during their course of illness;² such distress may be addressed by palliative care. Palliative care focuses on the optimization of patient and family QOL regardless of disease stage or prognosis. Through multidisciplinary intervention, palliative care provides symptom management, psychological and spiritual support, and logistical assistance.³ Research suggests that palliative care improves satisfaction with care;⁴ decreases the risk of psychological morbidity for patients and caregivers;^{5,6} reduces patients' symptom intensity;⁷ may increase survival;⁸ and, reduces hospital expenditures.⁹ However, despite marked similarities in symptom burden and prognosis between the two diseases in their advanced stages,¹⁰ HF patients and cancer patients access supportive services at disproportionate rates.¹¹ Additionally, the role of specialist palliative care has yet to be clearly defined in cardiology, relative to the progress this discipline has made in substantiating its role in oncology. Furthermore, scant research is available to demonstrate whether palliative care improves HF patient outcomes, limiting the ability for palliative care advocates to call for its increased uptake in cardiac populations.

Study 1: Provider-related barriers impeding heart failure palliative care referral

Previous work suggests that palliative care referral may be inhibited by several factors, including provider knowledge, inter-professional territorialism, organizational structure, and perceptions of palliative care.¹²⁻¹⁴ However, all of the aforementioned studies were performed in the U.K. or Australia, and therefore may have limited generalizability to the U.S. due to differences in healthcare delivery organization, reimbursement, and policies. Our study is the first attempt to explore provider-level palliative care referral barriers for HF patients in the U.S. By interviewing a multidisciplinary and experienced group of providers, we believe to have provided a significant contribution to the literature regarding palliative care referral barriers in the U.S., some of which may not solely be specific to HF patients (and may influence discourse regarding non-HF populations and palliative care).

Overall, we found that the term “palliative care” is at best ambiguous to providers, and at worst, misleading. Providers were confused regarding the distinction between non-hospice and hospice palliative care services, and frequently used terms such as “comfort care” or “end-of-life care” when discussing palliative care, indicating that they were instead referring to hospice care. This lack of clarity about palliative care was found regardless of clinical specialty and provider type. Notably, a majority of our sample consisted of academically-affiliated providers, which given the greater likelihood of palliative care services in such locations, suggests that our findings reflect an upward bias regarding palliative care knowledge. That is, we provide a “best case scenario” relative to providers practicing in areas without specialist palliative care services.

Interestingly, providers in our study unanimously voiced interest in identifying strategies by which to integrate palliative care services into the management of their HF

patients. However, they voiced concern that attempts to increase knowledge amongst cardiology and primary care communities would need to emerge from the palliative care community. Palliative care providers were viewed as experts in “difficult communication,” and were therefore seen as the ideal agents to promote and market the role of palliative care amongst their primary care and cardiology colleagues. As such, future work is needed to understand precisely how such messages might be tailored to improve collaboration across clinical disciplines.

Study 2: Comparing the unmet needs of community-based palliative care patients with heart failure and cancer

Recognizing that barriers may exist to impede or delay the timing of palliative care referral among HF patients, we investigated how this might impact the way which HF patients ultimately present at the time of palliative care admission. That is, do HF patients have a greater symptom burden (frequency and severity) when seen by a palliative care specialist, than do cancer patients? Here, we make the assumption that cancer patients face fewer palliative care referral barriers due to the historical integration of palliative care and oncology. We capitalized on a novel quality monitoring database of community-based palliative care providers to study this question.

We noted several interesting findings. First, HF patients in this study were significantly older than were cancer patients (median age: 84 years vs. 71 years). This finding is remarkable given the frailty (as indicated by performance status) and disease burden experienced by HF patients. This suggests that these HF patients are either already hospice eligible, or very near to the threshold for hospice eligibility. This finding in and of itself does not necessarily imply a difference in care gaps between disease groups, but rather strongly motivates the need for more focused research to identify the

underlying mechanisms that explain disparities in unmet needs across subpopulations. Indeed, our findings only reflect HF and cancer patients who received palliative care referrals. For example, patients in our study may be more acutely ill and/or have more complex psychosocial needs. This may limit our ability to generalize regarding the unmet needs of other patients with advanced HF or cancer. Although difficult to conduct, population-based surveys to describe palliative care needs (met and unmet) and knowledge may be useful in understanding the experiences of broader populations that may benefit from specialist palliative care services.¹⁵

Second, and perhaps most remarkably, despite HF patients being substantially older than cancer patients, their overall symptom burden reported at the time of first palliative care consultation was similar. Due to differences in the natural histories of the diseases and in characteristics of our sample, future research is needed to explore the factors that define effective and efficient utilization of palliative care for both HF and cancer populations. Particularly for diseases with notoriously unpredictable trajectories, such as HF,¹⁶ the timing of palliative care referral should be determined by patients' needs and preferences. Future work is needed to understand how our findings translate to other contexts, in terms of region, practice setting, and local availability of palliative care services.

Study 3: Assessing the quality of palliative care received by patients with heart failure living in the community

Lastly, we sought to extend the literature by providing preliminary data regarding the association between palliative care intervention and patient-centered outcomes. Using a longitudinal approach, we used palliative care quality indicators to assess the impact of five palliative care processes performed at the first palliative care consultation

on outcomes measured at patients' last palliative care consultation. This analysis was limited to HF patients receiving community-based palliative care services from the same group of providers that comprised study 2. Our outcome measure, PC-PHS, was a composite index that captured: fair/good QOL, adequately controlled pain, and adequately controlled dyspnea.

We found remarkably high rates of adherence to most quality indicators; only one indicator (the receipt of a comprehensive assessment) was found to be associated with PC-PHS. Our inability to detect statistically significant differences may be a function of our relative small sample size (N = 85) and/or a "ceiling effect" due to the high rates of adherence seen within our sample. Ongoing efforts to improve the coverage and quality of data sources, such as the PCRR, are needed to measure the impact of palliative care services on patients with life-limiting illnesses, such as HF. Importantly, this study establishes a novel framework demonstrating how palliative care quality can be assessed through the use of patient- and proxy-reported data collected at the point-of-care in community-dwelling patients. This framework can be iteratively repeated over time as the PCRR grows and is refined, and can be leveraged to answer similar questions in different contexts (i.e., disease states, specific quality indicators, care settings).

Implications for policy, practice, and research

As seen in study 2, patients with HF living in the community possess care needs related to their disease that merit clinical attention. Without intervention, unresolved symptoms may exacerbate distress experienced by both patients and their caregivers. As such, policy structures must be reevaluated to encourage appropriate and effective

utilization of palliative care services. Naturally, we must first ensure that the specialist palliative care landscape is prepared to care for additional patients, both in terms of workforce and training. Recently, the Palliative Care and Hospice Education and Training Act was introduced to the House Committee on Energy and Commerce.¹⁷ This legislation would promote educational and career opportunities for medical, osteopathic, and nursing providers related to palliative and hospice care.

Additional policy mechanisms must be assessed in order to promote palliative care utilization by patients with advanced illness who have unmet physical and/or psychosocial needs. With the implementation of the Patient Protection and Affordable Care Act, Accountable Care Organizations (ACOs) will be responsible for the overall population health and wellbeing of their members. As such, they may consider reimbursement structures for palliative and hospice providers that address the complex reality of their patient populations (e.g., bundled payments). Another potential policy mechanism to promote palliative care would be the inclusion of palliative care providers within ACOs as a mandate for establishment as an ACO. Additionally, given that palliative care utilization may be a function of local availability, policymakers should also facilitate the development of palliative care services in currently underserved geographic regions. Furthermore, innovations in the delivery of palliative care are needed; emerging technologies, such as tele-palliative care (in the form of remote video-based consultations), may hold promise in addressing issues of geographic disparity.

This dissertation provides preliminary evidence that collaboration between palliative and non-palliative care providers is suboptimal, despite mutual agreement of the likely benefit to patients that could result from palliative co-management or consultation. Graduate, postgraduate, and continuing clinical education must first be improved to include palliative care topics. Such training should strive to: correct

misconceptions about palliative care and hospice (i.e., that hospice is a specific subset of palliative care, largely defined by policy); teach providers how to identify palliative care needs in their patients; how to refer patients for specialist or consultative palliative care services; and how, to effectively work with palliative care providers/teams to manage patient and caregiver concerns. Although palliative care (specifically, community-based palliative care) services continue to expand within the U.S., clinical providers may benefit from focused training on how to provide non-specialist palliative care services themselves. Although specialist palliative care providers possess expertise in topics such as complex symptom management and difficult communication, such skills may be imparted to primary care and cardiology colleagues in areas without formal palliative care services. Lastly, lay educational efforts must seek to inform patients and caregivers about the existence of palliative care, taking great caution to accurately portray palliative and hospice services.

Much work is still needed to create the adequate knowledge base for HF palliative care in order to promote policy and practice structures that would encourage appropriate utilization. First, given the inherent limitations of study 1 regarding sample size and generalizability, it is necessary that our work be replicated in other geographic regions and practice settings. Second, additional formative research may be needed to comprehensively understand how cardiology and primary care providers could be best educated regarding palliative care services for HF patients. Third, we explicitly focused our analysis on provider-level barriers to palliative care uptake; however, our neglect of the patient and family voice stands as its own barrier to understanding the complex decisions that underlie palliative care utilization. Research is critically needed to complement the findings we provide in study 1. Fourth, our primary outcome variable in studies 2 and 3, PC-PHS, is an index that we created specifically for the purposes of this

dissertation. An exploratory attempt to maximize the amount of information regarding patient-centered outcomes extracted from our data source, the PC-PHS variable's psychometric properties need to be rigorously tested in future work. Although it may conceptually make sense as an amalgamation of factors related to patient health in advanced illness, the PC-PHS variable must be cautiously interpreted until we further investigate its validity and reliability. Fifth, future research should be conducted to improve the measures used to assess quality of care in community-based palliative care. For example, the PEACE indicators, like most research in palliative care, inherently reflect a cancer perspective. As such, we must be sensitive to the conclusions drawn from analyses of quality of care in non-cancer diseases using these indicators. Future research is needed to develop a framework of how to assess quality of care across diseases and care settings, including indicator sets. Lastly, our work in studies 2 and 3 describe HF and cancer patients who were receiving palliative care services. As such, we cannot comment regarding the experiences of patients with HF and cancer who were not receiving palliative care from the Carolinas Consortium. It is imperative to remember that we cannot easily make conclusions regarding the care needs of patients with life-limiting illness not receiving specialist palliative care services (such as those of the Carolinas Consortium).¹⁵ For example, it cannot be assumed that the lack of palliative care uptake implies that needs are currently being met, nor that patients have unmet needs. Patients whose care needs are relatively simple may not need specialist palliative care services (i.e., needs are being met without specialist palliative care), whereas patients not currently in specialist palliative care may be located in an area without such services (i.e., needs not being met). As seen from study 1, palliative care referral may be a function of a variety of factors (e.g., provider knowledge/attitudes, local culture, availability); as such, whole-population surveillance systems to understand the

care needs of all patients with life-limiting illness are necessary, as well as to elucidate provider behavior regarding palliative care referral for these patients.

Conclusion

In this three-aim, mixed methods dissertation, I explored the role of specialist palliative care in improving outcomes for patients with HF. Whereas the qualitative study provides context regarding why HF patients might not receive palliative care, the focused quantitative analyses of studies 2 and 3 describe the unaddressed needs and the quality of care ultimately received by such patients. Additionally, the sequencing of the individual studies strengthens the overall dissertation, as study 1 was used to inform study 3, thereby conveying an inclusive message regarding palliative care in the healthcare experiences of patients with HF. This dissertation addresses and fills prior gaps in the literature, both in terms of geographic scope (i.e., by performing the first American investigation of HF palliative care referral barriers) and types of analyses (e.g., by leveraging the largest database of community-based palliative care services in the US). Our findings suggest that at current, palliative care is not being optimally leveraged to support patients and families affected by HF, and that this may largely be a function of the timing of palliative care referral. Of course, this argument presupposes that specialist palliative care indeed confers benefit to HF patients, which has yet to be conclusively demonstrated in HF. Of note, a recent landmark randomized clinical trial of early outpatient palliative care in lung cancer by Temel and colleagues suggested symptom burden and survival benefits related to palliative care utilization.⁸ Similar work is desperately needed in HF (as well as other non-cancer diseases). Nevertheless, as a first step, we found that the receipt of a comprehensive assessment (defined as the

clinical assessment of at least one symptom, quality of life, and advance care planning functions) had a modest improvement in patient outcomes, while controlling for patient characteristics. Our work stands as an initial attempt to advance our understanding of why and how to leverage specialist palliative care to reduce the suffering associated with HF morbidity and mortality.

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