

Yale University
EliScholar – A Digital Platform for Scholarly Publishing at Yale

Yale Medicine Thesis Digital Library

School of Medicine

January 2015

Symptom Burden Among Patients Hospitalized For Heart Failure

Rabeea Feroz Khan

Yale School of Medicine, rabeea.khan@yale.edu

Follow this and additional works at: <http://elischolar.library.yale.edu/ymtdl>

Recommended Citation

Khan, Rabeea Feroz, "Symptom Burden Among Patients Hospitalized For Heart Failure" (2015). *Yale Medicine Thesis Digital Library*. 1981.

<http://elischolar.library.yale.edu/ymtdl/1981>

This Open Access Thesis is brought to you for free and open access by the School of Medicine at EliScholar – A Digital Platform for Scholarly Publishing at Yale. It has been accepted for inclusion in Yale Medicine Thesis Digital Library by an authorized administrator of EliScholar – A Digital Platform for Scholarly Publishing at Yale. For more information, please contact elischolar@yale.edu.

Symptom Burden Among Patients Hospitalized for Heart Failure

A Thesis Submitted to the
Yale University School of Medicine
In Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

By Rabeea Feroz Khan

Yale School of Medicine

Class of 2015

SYMPTOM BURDEN AMONG PATIENTS HOSPITALIZED FOR HEART FAILURE

Authors: Rabeea F. Khan, Sarwat I. Chaudhry

Department of Internal Medicine. Yale University School of Medicine, New Haven, CT.

Heart failure (HF) is one of the most common reasons for hospitalization and the leading cause of 30-day readmissions. There is great interest in developing strategies to reduce hospital utilization in this large and growing patient population. Aside from classic heart failure symptoms of dyspnea and fatigue, other symptoms reported include decreased appetite, pain and anxiety. These symptoms may be amenable to treatment and patients hospitalized with heart failure may benefit from intensive symptom management in the form of palliative care. There is limited data in the heart failure population about symptom burden both during hospitalization and shortly after hospital discharge, as well as patients' perceptions of palliative care. Therefore, our aim was to evaluate if patients discharged from the hospital after acute decompensated heart failure exhibit a high burden of residual symptoms one week post-discharge. Patients hospitalized for heart failure were enrolled in this prospective cohort study. Patients were interviewed about symptom burden using the Edmonton Symptom Assessment System (ESAS) and Patient Health Questionnaire (PHQ-8) during the hospital admission and 7 to 10 days post-discharge. Patients were also questioned about existing knowledge of palliative care, and then - after a brief, standardized explanation of the goals of palliative care - patients were queried about their interest in receiving palliative care services. Ninety-one patients were enrolled; their mean age was 71.5 years (SD 12.6 years) 51.6% were female and 74.5% had NYHA class III/IV heart failure. Symptoms frequently reported during the baseline interview included decreased wellbeing (94.1%), fatigue (85.9%), shortness of breath (81.2%), anxiety (62.4%) and pain (47.1%). Frequent symptoms reported in the follow-up interview were decreased wellbeing (95.3%), fatigue (88.2%) and shortness of breath (84.7%), anxiety (60.0%) and pain (55.3%). While only 22.4% of patients had heard of 'palliative care,' after a standardized explanation, 68.2% were interested in receiving palliative care services while hospitalized. Patients hospitalized for heart failure experience a high burden of symptoms, including not only those usually associated with heart failure such as dyspnea and fatigue, but also anxiety and pain. These symptoms are common during hospitalization and the majority of patients appear to experience troublesome symptoms shortly after discharge as well. Given that patients' symptoms frequently drive health care utilization, integration of palliative care into routine heart failure management is a promising strategy to reduce readmission after heart failure hospitalization.

Acknowledgements

I would like to thank Dr. Sarwat Chaudhry, my thesis advisor, for her support throughout my research year. She is an amazing mentor and teacher, providing guidance in my career development and inspiring me to grow both professionally and personally

I would like to acknowledge the Office of Student Research for providing funding for my research year and travel for a presentation at a national meeting. Donna Carranzo and Mae Geter were very helpful with navigating logistics throughout the year.

I would not be here if it was not for the love and support of my family. I would also like to thank Carina Martin, Natalie Lastra and Olga Laur, my best friends who have been instrumental in shaping made my medical school experience. They have been there for the fun times and my rocks through the rough times, and we have shared memories that I will treasure for life.

Table of Contents

I.	Introduction.....	1
	a. Heart Failure: An Overview	1
	b. Symptom Burden in Heart Failure	4
	c. Role of Palliative Care in Heart Failure	6
II.	Study Aims and Hypotheses.....	10
III.	Methods.....	11
	a. Study Population	11
	b. Data Collection	12
	c. Data Measures	13
	d. Statistical Analysis	19
	e. Role of Student	19
IV.	Results.....	20
	a. Patient Characteristics	20
	b. Symptom Assessment	22
	c. Perception of Palliative Care	27
V.	Discussion.....	30
	a. Study Limitations	35
	b. Conclusion	36
VI.	References.....	37
VII.	Supplementary material	39
	a. Edmonton Symptom Assessment Scale (ESAS)	46
	b. Patient Health Questionnaire- 8	47
	c. Abstract accepted 37 th Annual Meeting of SGIM	48
	d. Poster presented at the 18 th Annual Meeting of HFSA	49
	e. Abstract in Journal of Cardiac Failure	50

Introduction

Heart failure is a common and costly condition. As the population of the United States has aged and survival with cardiovascular disease has increased, the number of people with heart failure has also increased considerably over the past 20 years (1). This highly prevalent disease affects patients and families, and also poses a public health concern. An estimated 5.1 million people in the United States suffer from heart failure, with 825,000 new diagnoses, 1,000,000 hospitalizations and 676,000 visits to the emergency department annually (2). Patients hospitalized for heart failure experience the highest rates of early readmissions; approximately twenty-five percent of those hospitalized with heart failure are readmitted within thirty days and half readmitted within 6 months (3). Furthermore, the 1-year mortality after hospitalization for heart failure is 30% and median life expectancy is less than five years (4). This poses a considerable economic burden that health systems are under increasing pressure to curtail (5, 6). The total cost of heart failure is driven largely by hospitalizations and was estimated to be \$30.7 billion in 2012, with a projected increase to \$69.7 billion by 2030 (7).

Heart Failure: An Overview

The American Heart Association (AHA)/American College of Cardiology guidelines define heart failure as “a complex clinical syndrome that can result from any structural or functional cardiac disorder that impairs the ability of the ventricle to

fill or eject blood” (8). Pump failure leads to inadequate blood flow to maintain oxygenation requirements. Etiologies include coronary artery disease, hypertension, valvular heart disease, genetic disorders, arrhythmias, infiltrative disorders, viruses, and cardiomyopathies. Various methodologies have been proposed for diagnosing heart failure, including the Framingham criteria, Boston criteria and the European Society of Cardiology criteria. As a clinical syndrome, heart failure is a clinical diagnosis based on various signs (edema, rales, jugular venous distention, pleural effusion, pulmonary edema, displaced point of maximal impulse, S3) and symptoms (dyspnea, fatigue, cough, paroxysmal nocturnal dyspnea, orthopnea, ascites) (9).

This chronic disease is characterized by acute decompensations, or worsening of the symptoms of disease. Treatment for acute decompensated heart failure includes correcting underlying causes (i.e., arrhythmias, valvular disease, etc.), assuring adequate oxygenation and ventilation, administering intravenous diuresis for fluid removal with loop and thiazide diuretics, restricting sodium and fluid, and vasodilator therapy (8).

An estimated 5.1 million people in the United States suffer from heart failure and the prevalence rises with age, affecting 6-10% of the population aged 65 years of age or older (8). The Rotterdam study, a prospective cohort study of inhabitants of a suburb of Rotterdam in the Netherlands, found that the prevalence of heart failure increased with age, from 0.9% in those aged 55-64 to 17.4% in those 85

years or older and estimated that 30% of people 55 years of age or older will develop heart failure (10). The Framingham study found that the prevalence of heart failure in men increases to 66 per 1000 at 80-89 years of age from 8 per 1000 at 50-59 years of age, and increases 70 per 1000 at 80-89 years of age from 8 per 1000 at 50-59 years of age in women (11). A recent large study of three million Medicare beneficiaries aged 65 years or older in the United States found that while the incidence of heart failure decreased from 1994-2003, the prevalence increased from steadily from approximately 140 000 to 200 000.

This highlights that the increased burden of the disease is not related to increased incidence in this population. The increased prevalence is due to the aging population as well as better survival from coronary heart disease such as myocardial infarctions and valvular heart disease. The population of patients 65 years of age or older in the United States is predicted to increase from 39.6 million in 2009, representing 12.9% of the population, to 72.1 million by 2030, representing 19% of the population (12). Thus there will an increase in the prevalence of heart failure over the next few decades. Improvements in primary cardiovascular prevention, including control of hypertension and hyperlipidemia, implementation of secondary prevention therapies such as usage of aspirin and beta-blockers and increasing use of percutaneous coronary intervention have translated into improved outcomes after acute myocardial infarction hospitalizations (13-20).

Symptom Burden in Heart Failure

Although improvements in therapies have decreased mortality rates in the last decades for heart failure patients (21), current guideline based therapies are not curative. Heart failure remains a fatal chronic and progressive disease, eventually characterized by multi-organ involvement, persistent symptoms and recurrent decompensations leading to hospitalizations. The conventional clinical approach to patients requiring hospitalization for decompensated heart failure focuses on improving signs of congestion and optimizing fluid status (8, 22). Objective data, such as body weight and oxygenation, are typically used to assess improvement in clinical status and patients' readiness for hospital discharge (22). However, it is increasingly recognized that patients with heart failure suffer from a range of symptoms. Aside from classic heart failure symptoms, such as dyspnea and edema, previous studies have shown that patients with heart failure often experience pain, anorexia, anxiety and depression (23-26). Dyspnea, fatigue and edema are the focus of treatment but symptoms of pain, anorexia, anxiety and depression may be amenable to palliation.

Previous studies have documented a high prevalence of symptoms not classically associated with heart failure. Small scale studies have described the prevalence of pain in those hospitalized for heart failure ranging from 60-85% (26-28) and between 52-84% in the outpatient setting (29, 30). Possible causes for pain in

these patients include impaired circulation and oxygenation, neurohormonal derangements and changes in sensation and neurological conduction (25). There has been little research done localizing sites of pain, but one survey of 349 patients with heart failure found that patients' common sources of pain include chest pain, leg pain and joint pain (28).

Depression is prevalent in this population as well, between 20-36% of those hospitalized for heart failure have met the DSM-V criteria for major depression (31-34). Heart failure patients with depression have increased fatigue and other symptoms (35) and have been shown to have worse outcomes (35, 36). Similarly, high levels of anxiety have been associated decreased quality of life in these patients (37). Furthermore, heart failure patients are an increasingly aging population whose disease burden is complicated by comorbidities, polypharmacy, and functional status that may contribute to the complexity of symptoms experienced (38). Traditional evidence-based guidelines for management of hospitalizations treat overt signs of heart failure but they do not fully address the complex signs and symptoms experienced by heart failure patients. These physical and psychosocial symptoms decrease quality of life and functional status (23, 31).

Role of Palliative Care in Heart Failure

One strategy to improve care for these patients is to integrate palliative care into heart failure disease management (39, 40). Palliative care was initially available as hospice based therapy for cancer patients who are not receiving curative treatments starting in the 1970s (41). It is now being integrated into many chronic diseases and has grown to a non-hospice model based on patient and family needs regardless of prognosis (42). Palliative care is a multidisciplinary and holistic approach with the goal of alleviating suffering and increasing the quality of life for patients and families with advanced disease by focusing on symptom management, communication, psychosocial support and coordination of care (43). Palliative care is not provided because patients are at the end of life, it is offered concurrently with medical treatment. It provides an additional layer of support to help patients cope with and navigate the impact of serious illness by addressing both patients' and families' physical, emotional, spiritual, and logistical needs (42). This is particularly relevant for older patients with heart failure, who face an ever-expanding array of invasive therapies, including implantable cardioverter defibrillators (ICDs), valve repair, and ventricular assist devices.

There have been numerous calls to include palliative care as a component of heart failure management, including from the American Heart Association, but fewer than 10% of patients with heart failure receive palliative care (44, 45). A survey of

members of the Heart Failure Society of America found that 67% majority of the physicians had not referred patients to palliative care services (46). While there is evidence that palliative care can improve patients' symptoms and satisfaction while reducing costs and health care utilization and even extending life (47-51) most of this research was done in cancer patients. There are important differences between patients with cancer and those with heart failure, making direct extrapolation of findings on the use of palliative care from oncology to heart failure difficult. Notably, patients with heart failure have a less predictable trajectory than cancer patients and it is often not clear which exacerbation will lead to death. Their course is marked by exacerbations characterized by a rapid decline in function; and although with appropriate treatments some may improve clinically, the overall course remains a downward trajectory (52, 53). This variable trajectory is a barrier for hospice referral and thus the non-hospice model of palliative care is better suited in the heart failure patient population.

The physical and psychological symptoms that heart failure patients experience are similar to that of cancer patients. One cross sectional study of 60 patients with symptomatic heart failure and 30 patients with malignancy found that both groups had similar numbers of physical symptoms, depression scores and spiritual well being, even after adjusting for demographic factors and severity of heart failure (54). Another cross sectional study of 50 heart failure patients and 50 cancer

patients found no statistical difference between symptom burden, emotional well being and quality of life scores between the two groups (55). A small survey of twenty patients with heart failure age 60 years of older reported symptom experience similar to cancer patients, such as extreme fatigue, difficulty with activities of daily living, etc. and none had access to palliative care (56). These findings highlight that palliative care has strong potential to be beneficial in patients with heart failure just as it is in patients with cancer.

Palliative care can increase quality of life alleviating symptoms that are not targeted by current guidelines. For example, current guidelines suggest appropriate dosing of loop diuretics to relieve pulmonary congestion, which also improves both dyspnea and exercise capacity (57). In contrast, a palliative care assessment recommends oral opioids as treatment for pain in heart failure which may also improve dyspnea, and benzodiazepines for alleviating anxiety as well as associated dyspnea (58). Musculoskeletal pain can also be targeted with non-pharmacologic treatments such as exercise, heat/cold treatments and joint injections (23).

A palliative care assessment for heart failure recommends evaluating fatigue broadly as it would for a patient without heart failure, with a workup to rule out causes such as anemia, dehydration, depression, thyroid dysfunction, electrolyte abnormalities etc. (59). Patients should also be screened for depression and treated appropriately (psychotherapy, pharmacologic treatment such as SSRIs if indicated).

Aside from robust symptom assessment and management, a core component of palliative care is communication about goals of care. Data from other groups demonstrate that there is a need for better communication in patients with heart failure (60-63). For instance, a study focusing on communicating with heart failure patients found that majority of hospitalized patients wanted more information on disease management and prognosis, and did not recall conversations regarding end of life during their hospital stay (63). A systematic literature review of studies involving end of life conversations with heart failure patients found that while conversations of disease management are pervasive, end of life conversations do not take place and health care providers are not comfortable with discussing disease prognosis (64). A survey of caretakers of patients with heart disease found that 63% were not aware of the prognosis of the disease, and demonstrated limited understanding of the risk of sudden cardiac death (65). These studies show that patients could benefit from palliative care services, such as better communications about disease trajectory and prognosis as well goals of care conversations to help patients make informed decisions.

Study Aims and Hypotheses

Notably lacking from our current understanding of heart failure is the prevalence and natural history of a comprehensive range of symptoms during and after heart failure hospitalization. Residual symptoms are known to be a powerful driver of recurrent health care utilization and therefore costs after hospitalization for heart failure (66). Intensive symptom management and integration of palliative care into the routine management of decompensated heart failure may therefore represent a promising approach to improve outcomes after heart failure hospitalization. However, heart failure patients' preferences regarding use of palliative care have not been described previously. Therefore, our objectives in this study were to evaluate symptom burden among patients during heart failure hospitalization and immediately post-discharge, assess the change in symptoms experienced by patients, from time of admission to one week post-discharge, and to evaluate patients' knowledge and perception of palliative care.

Hypothesis 1: Patients discharged from the hospital after an episode of acute decompensated heart failure will exhibit a high burden of residual symptoms days post-discharge.

Hypothesis 2: Patients discharged from the hospital after an episode of acute decompensated heart failure will frequently demonstrate a lack of improvement of troublesome symptoms.

Hypothesis 3: Patients admitted to the hospital for acute decompensated heart failure will demonstrate a lack of understanding of the potential role of palliative care in symptom management.

Methods

Study Population

This was a prospective cohort study in which patients hospitalized for decompensated heart failure at Yale-New Haven Hospital were enrolled from August 2013 through November 2014. Potentially eligible participants were 18 years of age or older and were identified by screening the electronic medical record for an admission diagnosis heart failure. Diagnosis of decompensated heart failure was confirmed by clinical signs and symptoms (paroxysmal nocturnal dyspnea, neck vein distention, rales, S3 gallop, increased central venous pressure, hepatjugular reflux, weight loss >4.5 kg in 5 days in response to treatment, bilateral ankle edema, nocturnal cough, dyspnea on ordinary exertion, hepatomegaly, decrease in vital capacity by one third from maximum recorded, and tachycardia) and chest radiographic findings (acute pulmonary edema, cardiomegaly and pleural effusion)

based on the Framingham Criteria (67). Exclusion criteria included hemodynamic instability requiring admission to intensive care unit or cardiac/coronary care unit, non-English speaking, decisional impairment compromising informed consent based on the University of California, San Diego Brief Assessment of Capacity (UBACC) documented dementia in electronic medical record, surgery for valve replacement during index hospitalization, active malignancy and ongoing hemodialysis (as symptom management in these patients is likely to be different from general heart failure populations). The San Diego Brief Assessment of Capacity is a validated tool for assessing decision making capacity for participating in clinical research (68) and was administered when the primary care team could not confirm the decisional capacity for informed consent.

Data Collection

Patients were approached for enrollment within two days of admission for decompensated heart failure. After a thorough explanation about the study and obtaining consent, patients were interviewed about their symptom burden using standardized survey tools (Edmonton Symptom Assessment Scale and Patient Health Questionnaire) and queried about symptom presentation and perception (see ‘Symptom Assessment’). Patients were also queried about their knowledge of palliative care during their hospital admission (“baseline interview”). A follow-up

telephone interview was conducted seven to ten days after hospital discharge to assess perception of symptoms and symptom burden using the same standardized surveys.

Data Measures

Socio-Demographics

Socio-demographic information collected from the patient interview included gender, race, ethnicity, education level, marital status and living situation. Patients were also asked about smoking history and alcohol use.

Clinical

The severity of heart failure was assessed using the New York Heart Association (NYHA) Functional Classification. This commonly used system places patients in one of four categories depending on physical limitation and symptom burden. NYHA class I patients do not have limitations of physical activity and do not exhibit symptoms with normal activity. NYHA class II is characterized by slight limitation of physical activity and mild symptoms. NYHA class III is characterized by marked limitations in activity and symptoms with less than ordinary exertion. NYHA class IV is characterized by severe limitation in physical activity and symptoms at rest (69). The NYHA class was initially assessed during the patient interview and then verified with the history and physical exam note from the inpatient cardiology team.

The electronic medical record was reviewed for age, BMI, last recorded ejection fraction, comorbid conditions, medications at discharge, length of hospital stay, medications at discharge and discharge location.

Symptom Assessment

We assessed symptoms using the Edmonton Symptom Assessment Scale (ESAS), a standardized questionnaire first described in 1991 to assess symptoms for patients in a palliative care unit (70). It was validated in cancer patients (71, 72) and has since been validated in heart failure populations by comparison with accepted heart failure tools such as Kansas City Cardiomyopathy Questionnaire (KCCQ) (23, 73, 74). The questionnaire assesses presence and severity of nine symptoms: pain, fatigue, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety and wellbeing using a visual analog scale (a 100-mm line with labels at 0 through 10). One blank scale (“other problem”) is included in the survey to capture other symptoms, which we used to collect information about “edema”.

Patients were first given an explanation of the scale used in ESAS, and were given a blank questionnaire to allow for visualization of the scale. For standardization of results, the student researcher administered the survey to all patients. Patients were asked to rate the severity of the aforementioned symptoms at the time of the interview on a scale of 0 to 10, where 0 denotes absence of the symptom and 10 denotes worst

possible severity. ESAS also provides an outline of the body to denote location of pain, which was eliminated from this study.

The Patient Health Questionnaire (PHQ-8), a widely used and well-validated screening tool, (75, 76) was utilized to screen for depression. The PHQ-8 is comprised of eight out of the nine DSM-IV criteria for diagnosis of depression, and a score of 10 or greater is defined as current depression. A large survey of 198,678 participants found no statistical difference in the prevalence of depression when defined by the DSM-IV algorithm or with a score of 10 or greater on PHQ-8 (76). The questionnaire is also a reliable and valid tool in patients with heart failure (77).

During the baseline interview, patients were asked to identify the symptoms that triggered the visit to the hospital (see Figure 1).

Figure 1: Presenting Symptoms

What symptoms did you experience before coming to the hospital?

CV	HEENT
<input type="checkbox"/> Chest pain/pressure/tightness	<input type="checkbox"/> Pain in neck or throat
<input type="checkbox"/> Ankle swelling (edema)	<input type="checkbox"/> Pain in jaw/teeth/mouth
Respiratory	<input type="checkbox"/> Pain between shoulder blades
<input type="checkbox"/> Shortness of breath	<input type="checkbox"/> Pain in shoulders and arm
<input type="checkbox"/> Cough	GI
Neurological	<input type="checkbox"/> Nausea and/or vomiting
<input type="checkbox"/> Lightheadedness	<input type="checkbox"/> Abdominal pain/pressure
<input type="checkbox"/> Confusion	<input type="checkbox"/> Indigestion or heartburn
<input type="checkbox"/> Blurry vision	Other
<input type="checkbox"/> Numbness or tingling	<input type="checkbox"/> Sweating/diaphoresis
	<input type="checkbox"/> Weakness/fatigue
<input type="checkbox"/> Other _____	<input type="checkbox"/> Anxiety/stress/agitation

This information was utilized in the follow up telephone interview when patients were then queried about their perception of the presenting symptoms (Figure 2). When administering the survey, the surveyor filled in the ‘blank space’ with symptoms the patient had reported during the baseline interview (Figure 1).

Figure 2: Perception of Presenting Symptoms

Symptom Assessment	
1. When we spoke in the hospital, you told me that _____ (symptoms reported as reason for hospitalization in baseline interview) caused you to come to the hospital. Did your _____ (symptoms) get better by the time you were discharged?	<input type="checkbox"/> Much improvement <input type="checkbox"/> Partial improvement <input type="checkbox"/> No improvement
2. Were your symptoms adequately addressed during your hospitalization?	<input type="checkbox"/> Completely addressed <input type="checkbox"/> Partially addressed <input type="checkbox"/> Not at all addressed
4. Since leaving the hospital, have your symptoms affected your day-to-day activities?	<input type="checkbox"/> Yes, very much affected <input type="checkbox"/> Somewhat affected <input type="checkbox"/> Not at all affected

Patients' Knowledge and Perceptions about Palliative Care

Patients were also queried about their existing knowledge of palliative care with the following list of questions. These questions were based on input from experts in health services research and palliative care. The questionnaire included whether

patients had heard of the term ‘palliative care,’ what services they thought palliative care provides, and who benefits the most from palliative care.

For patients who had heard of ‘palliative care’...

- 1) What kind of services does palliative care provide?
- 2) Who do you see as benefiting the most from palliative care?
- 3) Are you interested in receiving palliative care while in the hospital?
- 4) Do you think palliative care could help you feel better in the hospital?
- 5) Do you think palliative care could help you feel better at home?

For patients who had not heard of ‘palliative care’...

- 1) Do you think you would be interested in seeing a healthcare provider who specializes in symptom management?
- 2) Would you like to see this provider while hospitalized?

All patients received a brief, standardized explanation of the goals of palliative care with the following script, and were then queried about their interest in receiving palliative care services while hospitalized and at home after discharge.

“As you may already know, congestive heart failure means that your heart is not able to pump blood as well, which causes some of the symptoms that you experience such as shortness of breath. The traditional treatment for when you come into the hospital is to get rid of the fluid build up, however, some of the symptoms that you experience, such as pain and fatigue, have many different causes. Palliative care is a holistic approach, meaning providers look at the patient as a whole rather than just focusing on ‘fixing the heart.’ Palliative care is specialized care by trained doctors and nurses to provide coordinated care, focusing on symptom management and communication to improve quality of life for both you and your family. It is an additional layer of support with the care you are already receiving in the hospital to address all the symptoms you are currently having. It is not the same as hospice or end of life care. For example, if you are experiencing pain, palliative care specialists will help you feel better using both pain medications and other approaches. As you may already know, your hospitalizations for heart failure are unpredictable, and palliative care specialists can help you plan for the next time this happens, to address what you want and what your goals are care are.”

Statistical Analysis

Baseline characteristics were calculated as percentages for categorical variables (i.e. gender, race etc.) and as means with standard deviations for continuous variables (i.e. BMI, BP, etc.). Prevalence was calculated for each symptom on ESAS by dividing the total number of patients who reported a symptom score of ≥ 1 by the total number of patients. Mean values (with standard deviation) were calculated for each of the nine symptoms on the ESAS questionnaire. P values were calculated using paired t-test to compare symptoms between the baseline and follow up groups. A p-value of $< .05$ was considered statistically significant.

Data was entered into an Excel database twice, with a function set to detect mismatch and errors, to ensure accuracy of data entry. Data was analyzed using Microsoft Excel Version 14.0.0 and GraphPad Prism Version 6.0d. The study was reviewed and approved by the Yale University Human Investigation Committee. All patients signed a written informed consent prior to participation.

Role of the Student in Research Project

Under the guidance of research advisor, the student prepared the Institutional Review Board (IRB) protocol, designed the data collection forms and Excel database, developed a system within the electronic medical record system for real-time identification of patients, screened, consented and enrolled patients in the study,

conducted all baseline and follow up interviews, entered data into an Excel database, and managed and analyzed the data.

Results

Patient Characteristics

We approached 121 patients for enrollment, 91 consented and were enrolled in the study. The mean time of the baseline interview was day 2.5 (SD 1.6) of hospitalization, and the median time of the baseline interview was day 2.0 of hospitalization. The mean length of stay was 8.9 days (SD 6.6 days) and the median length of stay was 6.0 days. Four patients were lost to follow up, and two patients died during the index hospitalization from cardiac arrest. The mean time for the follow-up interview was 9.9 days (SD 4.3 days) after hospital discharge; 89.9% were interviewed within 2 weeks of discharge.

The baseline characteristics of these 91 patients are listed in Table 2. Their mean age was 71.5 (SD 12.6) years, 65.9% were 65 years of age or older, 51.6% were female, 74.7% had an ejection fraction < 50 and 74.7% had NYHA class III or IV heart failure. The most common comorbidities were hypertension (75.8%), hyperlipidemia (65.9%), and coronary artery disease (60.4%).

Age, mean (SD)	71.5 (12.6)
Female, n (%)	47 (51.6%)
Nonwhite race, n (%)	22 (24.2%)
Marital status, n (%)	
Married	40 (44.0%)
Other	51 (56.0%)
Lives alone, n (%)	22 (24.2%)
Education level, n (%)	
<High school degree	6 (6.6%)
High school graduate	43 (47.3%)
College and higher	42 (46.2%)
History of smoking, n (%)	54 (59.3%)
Current alcohol Use, n (%)	27 (29.7%)
BMI, mean (SD)	33.0 (10.1)
BMI > 30	42 (46.2%)
Blood pressure, mean (SD)	
Systolic	133.6 (26.2)
Diastolic	75.9 (20.5)
Left ventricular ejection fraction, n (%)	
LVEF <40%	56 (61.5%)
LVEF >40%	35 (38.5%)
Comorbid conditions, n (%)	
Hypertension	69 (75.8%)
Hyperlipidemia	60 (65.9%)
Coronary artery disease	55 (60.4%)
Diabetes	41 (45.1%)
Chronic kidney disease	29 (31.9%)
Chronic lung disease	24 (26.4%)
NYHA Class, n (%)	
I	1 (1.1%)
II	22 (24.2%)
III	51 (56.0%)
IV	17 (18.7%)
Length of stay, mean days (SD)	8.9 (6.6 days)
Discharge medications, n (%)	
Loop diuretic	84 (93.4%)
ACE inhibitor, angiotensin II receptor blocker	34 (37.4%)

B-blocker	75 (82.4%)
Aldosterone receptor antagonist	24 (26.4%)
Digoxin	5 (5.5%)
Disposition, n (%)	
Home	59 (64.8%)
Short term rehabilitation	29 (31.9%)
Other	3 (3.3%)

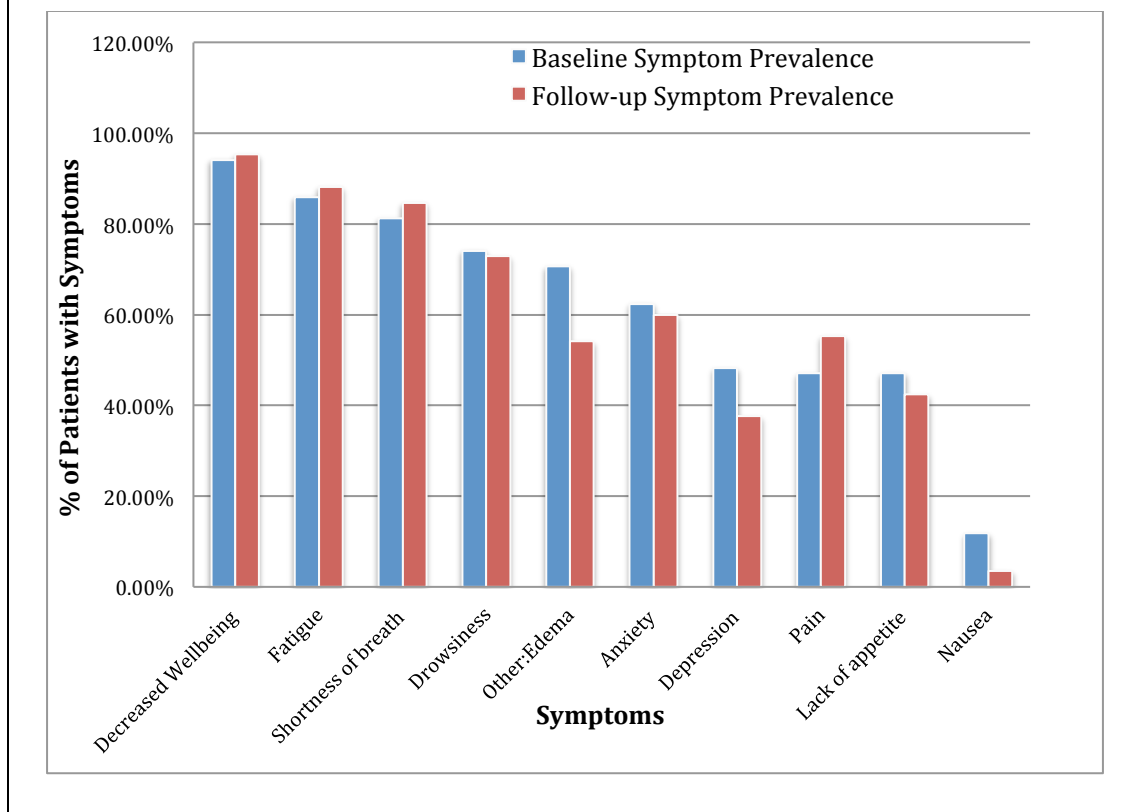
Symptom Assessment

Edmonton Symptom Assessment Scale

Figure 3 illustrates the prevalence of symptoms during the baseline interview as compared to the follow-up interview. The most frequent symptoms reported during the baseline interview based on ESAS were decreased wellbeing (80 patients, 94.1%), fatigue (73 patients, 85.9%) and shortness of breath (69 patients, 81.2%). There was a high prevalence of other symptoms not commonly associated with heart failure, such as anxiety and pain. Anxiety was reported by 53 patients (62.4%) and pain was reported by 40 patients (47.1%). The least prevalent symptom was nausea (10 patients, 11.8%).

The most frequent symptoms reported in the follow-up interview were also decreased wellbeing (81 patients, 95.3%), fatigue (75 patients, 88.2%) and shortness of breath (72 patients, 84.7%). Anxiety was reported by 51, or 60.0% of patients and pain was reported by 55.3% of patients in the follow up interview. The least prevalent symptom was nausea (3 patients, 3.5%).

Figure 3: Symptom Prevalence



Tables 2 lists the prevalence and mean scores from the ESAS scale for both the baseline and follow-up interview. The most severe symptoms during the baseline interview were decreased wellbeing (mean score 5.18, SD 2.4, $p < .0001$), fatigue (mean score 4.99, SD 2.8, $p < .0001$) and shortness of breath (mean score 4.74, SD 3.1, $p < .0001$). Anxiety was reported with a mean score of 3.36 (SD 3.3, $p < .0001$) and pain was reported with a mean score of 2.42 (SD 3.0, $p < .0001$) during the baseline interview.

The most severe symptoms in the follow-up interview were fatigue (mean score 4.93, SD 2.8, $p < .0001$), decreased wellbeing (mean score 4.52, SD 1.9, $p < .0001$), and shortness of breath (mean score 4.00, SD 2.4, $p < .0001$). Anxiety was reported with a mean score of 3.01 (SD 3.1, $p < .0001$) and pain was reported with a mean score of 2.84 (SD 3.0, $p < .0001$).

While symptoms persisted post discharge ($p < .0001$), the mean scores for nausea, lack of appetite, shortness of breath, depression, wellbeing and edema decreased in the follow up interview as compared to the baseline interview ($p < .05$, Table 2). In contrast, the mean scores for pain, fatigue, drowsiness and anxiety did not show a significant change from the baseline interview to the follow up interview ($p > .05$).

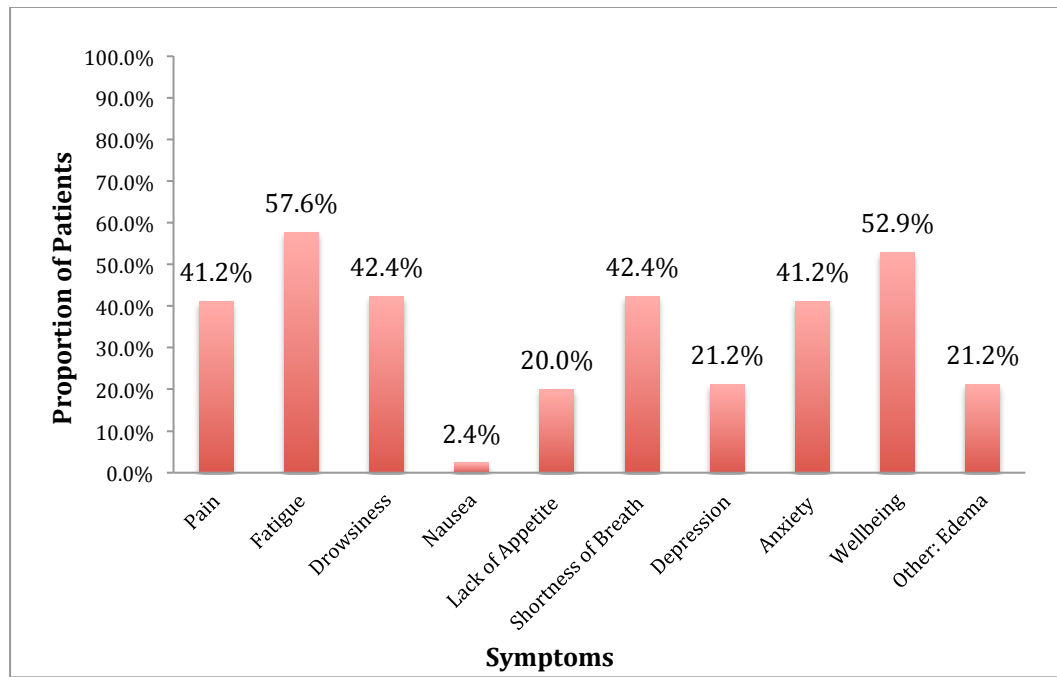
Table 2: Edmonton Symptom Assessment Scale

Symptom	Baseline Interview		Follow-up Interview		P-value
	Prevalence (%)	Mean score (SD)	Prevalence (%)	Mean score (SD)	
Pain	40 (47.1%)	2.42 (3.0)	47 (55.3%)	2.84 (3.0)	0.2135
Fatigue	73 (85.9%)	4.99 (2.8)	75 (88.2%)	4.93 (2.8)	0.8578
Drowsiness	63 (74.1%)	4.28 (3.3)	62 (72.9%)	3.79 (3.0)	0.1857
Nausea	10 (11.8%)	0.67 (2.1)	3 (3.5%)	0.14 (0.8)	0.0353

Lack of appetite	40 (47.1%)	2.45 (2.9)	36 (42.4%)	1.79 (2.4)	0.0194
Shortness of breath	69 (81.2%)	4.74 (3.1)	72 (84.7%)	4.00 (2.4)	0.0284
Depression	41 (48.2%)	2.76 (3.2)	32 (37.6%)	1.96 (3.0)	0.0153
Anxiety	53 (62.4%)	3.36 (3.3)	51 (60.0%)	3.01 (3.1)	0.2546
Decreased Wellbeing	80 (94.1%)	5.18 (2.4)	81(95.3%)	4.52 (1.9)	0.0183
Other: Edema	60 (70.6%)	4.09 (3.4)	46 (54.1%)	2.24 (2.5)	< 0.0001

Figure 4 illustrates the proportion of patients who did not report improvement in symptoms in the follow-up interview as compared to the baseline interview. Forty-nine patients (57.6%) reported the same or increased level of fatigue ($p < .0001$) and forty-five patients (52.9%) did not report increased overall wellbeing ($p < .0001$). Thirty-six patients (42.4%) reported the same or increased level of shortness of breath ($p < .0001$). Thirty-five patients (41.2%) reported the same or increased level of pain ($p < .0001$) and thirty-five (41.2%) of patients reported the same or increased level of anxiety ($p < .0001$).

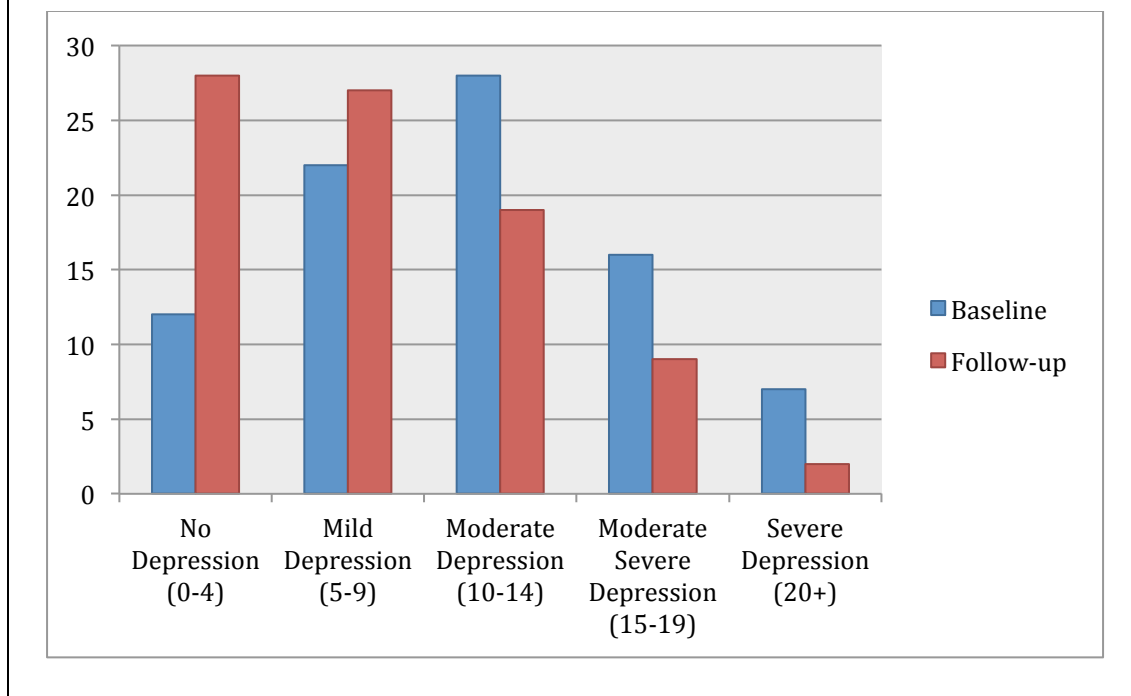
Figure 4: Proportion of Patients Who Did Reported No Improvement in Symptoms



Patient Health Questionnaire

Figure 5 illustrates the distribution of the scores on the baseline and follow-up PHQ-8. Fifty-one (60.0%) patients scored >10 on the PHQ-8 during the baseline interview and met the criteria for current depression. Thirty (35.3%) of patients scored >10 on the PHQ-8 during the follow-up interview and met the criteria for current depression.

Figure 5: Patient Health Questionnaire-8



Perception of Presenting Symptoms

Table 3 lists patients' perception of their symptoms during the follow up interview (please see Figure 1 and 2 for questionnaire). The majority of patients (52 or 61.2%) perceived symptoms to have been partially or not at all addressed by the healthcare providers during hospitalization, and (47, or 55.3%) perceived their symptoms to have only been partially ameliorated at time of discharge. Twenty-four patients (28.2%) also reported that symptoms completely affected daily activities.

	Completely, n (%)	Partially, n (%)	Not at all, n (%)
Did your (symptoms) get better by the time you were discharged?	32 (37.7%)	47 (55.3%)	6 (7.1%)
Were your symptoms adequately addressed by healthcare providers during your hospitalization?	51 (60.00%)	41 (48.2%)	11 (12.9%)
Have your symptoms affected your day-to-day activities?	24 (28.2%)	47 (54.1%)	14 (16.5%)

Perception of Palliative Care

Nineteen patients (22.4%) out of 85 had heard of the term “palliative care.” Of these patients, fourteen (73.7%) were interested in receiving palliative care services in the hospital. Shown in Table 4 are quotes illustrating patients’ perspectives of palliative care. Sixty-six patients (77.6%) had not heard of the term “palliative care.” After a brief, standardized explanation of what palliative services are designed to do (see Methods), forty-four (51.8%) were interested in receiving palliative care services while hospitalized. Twenty-two patients (25.9%) were ‘undecided’ about whether they wanted to receive palliative services.

<i>Table 4: Perceptions of Palliative Care</i>
“Takes care of very ill patients and make them comfortable”
“Visiting nurse, home care”
“Home care for elderly and sick”
“Pain relieve, patient comfort, support for family”
“The kind to help support people who aren’t feeling well”
“Helping patients get along and cope with symptoms”
“Comfort to dying patient and family, relieve family from care”
“Help with day to day activities, not in hospital setting”
“Keeping people comfortable as they end their lives”
“Outpatient basic services that help with day to day care”
“Useful for older people at end of life when they need lots of medical care”
“For cancer patients in extreme pain”
“For dying patients”
“The patient who’s departure is eminent”
“Semi-holistic teach approach to care”
“Comfort care”
“When someone comes in and helps make decisions”
“Visiting nurse who gives medications”
“Hospice care when end is coming”
“Nurses coming in to help at home”
“Hospice care right before people die”
“Team effort towards the patient to provide everything the patient needs”
“Helps cancer patients”
“Scientific care combined with nontraditional care”
“Not hospice care, pre-hospice care”

Discussion

We found that patients hospitalized for heart failure experience a high burden of symptoms during hospitalization and shortly after discharge. These symptoms include not only those classically associated with heart failure such as dyspnea and edema, but also anxiety, pain and depression. Symptoms often persisted after hospital discharge despite intensive inpatient treatment for heart failure. Furthermore, while there was improvement in shortness of breath, depression, nausea, lack of appetite, edema and overall wellbeing, patients did not report a significant change in symptoms of pain, fatigue, drowsiness and anxiety after hospital. The majority of patients surveyed perceived that their presenting symptoms did not get better by time of discharge, and that presenting symptoms effected daily activities shortly after discharge. We also found that the majority of patients were unfamiliar with palliative care. Patients who had heard of palliative care often were not able to demonstrate a complete or accurate understanding of its meaning or implications.

There are relatively few studies evaluating symptom burden during and after hospitalization. The Pain Assessment, Incidence & Nature in Heart Failure study, which evaluated pain in 347 outpatients with advanced heart failure, reported pain in 84% of patients (78). Another recent study which evaluated symptom burden in 100 patients hospitalized for heart failure found that 60% of patients reported pain; decreased well-being (95%), fatigue (94%), and shortness of breath (91%) were the

most commonly reported symptoms during an acute heart failure decompensations (24). Notably, this study did not follow patients after hospital discharge to assess change in symptom burden or severity. One study (n=62) evaluating the prevalence and severity of pain in the outpatient setting found that 52% of patients reported pain (mean pain score of 2.5 ± 3.1), with higher pain scores correlated with lower EF (29). Several other studies have demonstrated symptom burden using various questionnaires (30, 79-83). However, to our knowledge, this is the only study that includes a longitudinal assessment of symptom burden during heart failure hospitalizations and shortly after discharge. While there are studies demonstrating limited knowledge of palliative care among clinicians (46, 55), there has been little prior work on perceptions of palliative care in the heart failure population.

The high symptom burden immediately after heart failure hospital discharge, as well as patients' perception that presenting symptoms did not get improve by time of discharge, suggests that our current approach to decompensated heart failure does not adequately address patients' symptoms. There are many potential reasons for the inadequacy. First, the existence of multiple comorbid medical conditions is common in the aging heart failure population, and these comorbidities may be contributing to symptoms. Dyspnea and fatigue may arise not just from decreased cardiac output and pulmonary congestion but rather from a combination of systemic effects of heart failure, as well as impact from comorbid conditions such as depression and obesity

(23, 37, 84, 85). Patients with severe kyphosis or COPD may have residual dyspnea even after euvolemia is achieved (23, 37, 84, 85). Sleep related breathing abnormalities causing oxygen desaturation stimulating sympathetic drive may increase daytime fatigue (86). Hormonal changes and pro-inflammatory cytokine releases in heart failure result in a catabolic state (87) (i.e., increased insulin resistance), muscle remodeling, and respiratory and skeletal muscle atrophy and weakness (23, 88).

Second, clinicians caring for patients hospitalized for heart failure may not be prepared to thoroughly assess and treatment symptoms such as pain, anxiety, depression, and fatigue (38). For example, pain may be undertreated since traditional therapies such as nonsteroidal anti-inflammatory drugs are avoided in heart failure as they can cause renal damage (89). Finally, there is growing pressure on health systems to reduce length of stay and once patients no longer meet criteria for hospitalization (such as requiring supplemental oxygen or intravenous diuretics) there is an impetus to discharge them even if they have remaining symptoms. These residual symptoms may be driving health care utilization (23, 90, 91).

We found that symptoms of pain, anxiety, fatigue, and drowsiness did not improve after hospital discharge. Unlike alleviations of symptoms of shortness of breath and edema that are goals of hospital admissions, these symptoms may not be targeted by traditional heart failure therapy. The etiology of pain in heart failure is not

clearly understood and most likely multifactorial in etiology, and treatment is difficult without full understanding of mechanism.

The progressive nature of heart failure, coupled with high mortality rates and poor quality of life, makes it ideally suited for the incorporation of palliative care. There have been numerous calls to include palliative care as a component of heart failure management, including from the American Heart Association, but fewer than 10% of patients with heart failure receive palliative care (44, 45). We found that the majority of patients had not heard of palliative care, and those who had heard of the term were not able to articulate a complete understanding. The gap in patient knowledge base may be because palliative care is underutilized and not a standard of care in the heart failure population. Obstacles to integrating palliative care into heart failure may include a prevailing and untrue perception among both clinicians and care providers that palliative care and life-prolonging therapies are mutually exclusive, the belief that heart failure is a chronic and manageable illness, unpredictable trajectory of heart failure, a shortage of specialty-trained palliative care clinicians, and a lack of training for cardiology clinicians in the basic elements of palliative care (23, 24, 42, 92, 93).

Patients with heart failure have an unpredictable trajectory and variable prognosis. Their course is marked by exacerbations characterized by a rapid decline in function; with appropriate treatments some may improve clinically, although the

overall course remains a downward trajectory (52, 53). Because it is not clear which exacerbation will lead to death, earlier integration of palliative care is important. Furthermore, patients and families are often not aware of poor prognosis that heart failure carries (94). Early integration of palliative care can lead to open communication about goals of care, helping patients understand their disease and make informed decisions.

In addition to improving patient care, integration of palliative care has the potential to decrease healthcare costs. Eighty-four percent of the total healthcare spending is on chronic conditions which includes heart failure (95). As a tertiary prevention measure, integration of palliative care can decrease readmissions. It can also decrease healthcare costs by decreasing the length of stay in hospital and number of interventions performed near end of life, the length of stay. A large multi-hospital system based study demonstrated that inpatient palliative care resulted in \$279 to \$374 in direct cost savings per day (96). To date, there are limited interventional studies evaluating the effects of implementation of palliative care in the heart failure population. One small interventional study (n=36) found that heart failure patients reported greater symptom control after three months of outpatient based palliative care following an acute decompensation (83), consistent with other studies (97). Larger trials are needed to evaluate what barriers exist to integrating palliative care in

routine care, and whether palliative care will be effective in reducing symptom burden and outcomes (i.e., readmission and healthcare costs).

Study Limitations

There are several limitations to our study. First, this is single system study with a small sample size, and thus it is possible that the results are not generalizable to the population as a whole. However, Yale-New Haven Hospital is the fourth largest hospital system in the nation and demographics are comparable to national averages (98). Second, patients' description and experience of symptoms may fluctuate with time but symptoms were assessed at two points, the baseline and discharge interview. Furthermore, there was variation between patients in terms of when the baseline and follow up interviews were conducted. For example, some patients were interviewed immediately after admission before initiation of treatment, and their reported symptom burden could have been higher at baseline than if the baseline interview was conducted closer to discharge. However, the mean time of the baseline interview was day 2.5 (SD 1.6) of hospitalization whereas the mean length of stay was 8.9 days (SD 6.6 days). The utilization of the Edmonton Symptom Assessment System helps in standardizing the quantification of symptom burden. Importantly, we do not have data on treatment for symptoms (i.e., pain medication prescribed during or after hospitalization). Therefore, we cannot comment on

adequacy of treatment for symptoms, only on presence and severity of symptoms during and after hospitalization.

Conclusion

Patients hospitalized for heart failure experience a high burden of symptoms, including not just dyspnea and fatigue but also anxiety and pain. These symptoms are common during hospitalization, but the majority of patients experience troublesome symptoms shortly after discharge as well. Given that symptoms frequently drive health care utilization, early integration of palliative care into routine heart failure management is a promising strategy to reduce hospital utilization.

1. Wong CY, Chaudhry SI, Desai MM, Krumholz HM. Trends in Comorbidity, Disability, and Polypharmacy in Heart Failure. *American Journal of Medicine*. 2011;124:136-43.
2. Go AS, Mozaffarian D, Roger VL, Benjamin EJ, Berry JD, Blaha MJ, et al. Heart disease and stroke statistics--2014 update: a report from the American Heart Association. *Circulation*. 2014;129(3):e28-e292.
3. Dharmarajan K, Hsieh AF, Lin Z, Bueno H, Ross JS, Horwitz LI, et al. Diagnoses and timing of 30-day readmissions after hospitalization for heart failure, acute myocardial infarction, or pneumonia. *JAMA*. 2013;309(4):355-63.
4. Stewart S, MacIntyre K, Hole DJ, Capewell S, McMurray JJ. More 'malignant' than cancer? Five-year survival following a first admission for heart failure. *Eur J Heart Fail*. 2001;3(3):315-22.
5. Keenan PS, Normand SL, Lin Z, Drye EE, Bhat KR, Ross JS, et al. An administrative claims measure suitable for profiling hospital performance on the basis of 30-day all-cause readmission rates among patients with heart failure. *Circ Cardiovasc Qual Outcomes*. 2008;1(1):29-37.
6. Jencks S, Williams M, Coleman EA. Rehospitalizations among patients in the Medicare fee-for-service program. *New Eng J Med*. 2009;360:1418-28.
7. Heidenreich PA, Albert NM, Allen LA, Bluemke DA, Butler J, Fonarow GC, et al. Forecasting the impact of heart failure in the United States: a policy statement from the American Heart Association. *Circ Heart Fail*. 2013;6(3):606-19.
8. Yancy CW, Jessup M, Bozkurt B, Butler J, Casey DE, Jr., Drazner MH, et al. 2013 ACCF/AHA guideline for the management of heart failure: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. *J Am Coll Cardiol*. 2013;62(16):e147-239.
9. Longo DL, Fauci AS, Kasper DL, Hauser SL, Jameson JL, Loscalzo J. *Harrison's principles of internal medicine*. McGraw-Hill's AccessMedicine. 19th ed. New York, N.Y.: McGraw-Hill Medical,; 2014:2000 p.
10. Bleumink GS, Knetsch AM, Sturkenboom MC, Straus SM, Hofman A, Deckers JW, et al. Quantifying the heart failure epidemic: prevalence, incidence rate, lifetime risk and prognosis of heart failure The Rotterdam Study. *Eur Heart J*. 2004;25(18):1614-9.
11. Ho KK, Pinsky JL, Kannel WB, Levy D. The epidemiology of heart failure: the Framingham Study. *J Am Coll Cardiol*. 1993;22(4 Suppl A):6A-13A.
12. *Aging Statistics*. Washington, DC: Administration for Community Living.

13. Spencer FA, Lessard D, Yarzebski J, Gore JM, Goldberg RJ. Decade-long changes in the use of combination evidence-based medical therapy at discharge for patients surviving acute myocardial infarction. *American heart journal*. 2005;150(4):838-44.
14. Rogers WJ, Canto JG, Lambrew CT, Tiefenbrunn AJ, Kinkaid B, Shoultz DA, et al. Temporal trends in the treatment of over 1.5 million patients with myocardial infarction in the US from 1990 through 1999: the National Registry of Myocardial Infarction 1, 2 and 3. *Journal of the American College of Cardiology*. 2000;36(7):2056-63.
15. Mehta RH, Montoye CK, Gallogly M, Baker P, Blount A, Faul J, et al. Improving quality of care for acute myocardial infarction: The Guidelines Applied in Practice (GAP) Initiative. *JAMA : the journal of the American Medical Association*. 2002;287(10):1269-76.
16. Fornasini M, Yarzebski J, Chiriboga D, Lessard D, Spencer FA, Aurigemma P, et al. Contemporary trends in evidence-based treatment for acute myocardial infarction. *The American journal of medicine*. 2010;123(2):166-72.
17. Burwen DR, Galusha DH, Lewis JM, Bedinger MR, Radford MJ, Krumholz HM, et al. National and state trends in quality of care for acute myocardial infarction between 1994-1995 and 1998-1999: the medicare health care quality improvement program. *Archives of internal medicine*. 2003;163(12):1430-9.
18. Goldberg RJ, Spencer FA, Steg PG, Flather M, Montalescot G, Gurfinkel EP, et al. Increasing use of single and combination medical therapy in patients hospitalized for acute myocardial infarction in the 21st century: a multinational perspective. *Archives of internal medicine*. 2007;167(16):1766-73.
19. Khera S, Kolte D, Palaniswamy C, Mujib M, Aronow WS, Singh T, et al. ST-elevation myocardial infarction in the elderly--temporal trends in incidence, utilization of percutaneous coronary intervention and outcomes in the United States. *International journal of cardiology*. 2013;168(4):3683-90.
20. Chen J, Normand SL, Wang Y, Drye EE, Schreiner GC, Krumholz HM. Recent declines in hospitalizations for acute myocardial infarction for Medicare fee-for-service beneficiaries: progress and continuing challenges. *Circulation*. 2010;121(11):1322-8.
21. MacIntyre K, Capewell S, Stewart S, Chalmers JW, Boyd J, Finlayson A, et al. Evidence of improving prognosis in heart failure: trends in case fatality

- in 66 547 patients hospitalized between 1986 and 1995. *Circulation*. 2000;102(10):1126-31.
22. Francis GS, Greenberg BH, Hsu DT, Jaski BE, Jessup M, LeWinter MM, et al. ACCF/AHA/ACP/HFSA/ISHLT 2010 clinical competence statement on management of patients with advanced heart failure and cardiac transplant: a report of the ACCF/AHA/ACP Task Force on Clinical Competence and Training. *J Am Coll Cardiol*. 2010;56(5):424-53.
 23. Goodlin SJ. Palliative care in congestive heart failure. *J Am Coll Cardiol*. 2009;54(5):386-96.
 24. Shah AB, Udeoji DU, Baraghoush A, Bharadwaj P, Yennurajalingam S, Schwarz ER. An evaluation of the prevalence and severity of pain and other symptoms in acute decompensated heart failure. *Journal of palliative medicine*. 2013;16(1):87-90.
 25. Goodlin SJ, Wingate S, Albert NM, Pressler SJ, Houser J, Kwon J, et al. Investigating pain in heart failure patients: the pain assessment, incidence, and nature in heart failure (PAIN-HF) study. *Journal of cardiac failure*. 2012;18(10):776-83.
 26. Nordgren L, Sorensen S. Symptoms experienced in the last six months of life in patients with end-stage heart failure. *Eur J Cardiovasc Nurs*. 2003;2(3):213-7.
 27. Shah AB, Udeoji DU, Baraghoush A, Bharadwaj P, Yennurajalingam S, Schwarz ER. An evaluation of the prevalence and severity of pain and other symptoms in acute decompensated heart failure. *J Palliat Med*. 2013;16(1):87-90.
 28. Goodlin SJ, Wingate S, Albert NM, Pressler SJ, Houser J, Kwon J, et al. Investigating pain in heart failure patients: the pain assessment, incidence, and nature in heart failure (PAIN-HF) study. *J Card Fail*. 2012;18(10):776-83.
 29. Udeoji DU, Shah AB, Bharadwaj P, Katsiyiannis P, Schwarz ER. Evaluation of the prevalence and severity of pain in patients with stable chronic heart failure. *World J Cardiol*. 2012;4(8):250-5.
 30. Rustoen T, Stubhaug A, Eidsmo I, Westheim A, Paul SM, Miaskowski C. Pain and quality of life in hospitalized patients with heart failure. *J Pain Symptom Manage*. 2008;36(5):497-504.
 31. Bekelman DB, Havranek EP, Becker DM, Kutner JS, Peterson PN, Wittstein IS, et al. Symptoms, depression, and quality of life in patients with heart failure. *J Card Fail*. 2007;13(8):643-8.

32. Freedland KE, Rich MW, Skala JA, Carney RM, Davila-Roman VG, Jaffe AS. Prevalence of depression in hospitalized patients with congestive heart failure. *Psychosom Med*. 2003;65(1):119-28.
33. Havranek EP, Ware MG, Lowes BD. Prevalence of depression in congestive heart failure. *Am J Cardiol*. 1999;84(3):348-50, A9.
34. Jaarsma T, Johansson P, Agren S, Stromberg A. Quality of life and symptoms of depression in advanced heart failure patients and their partners. *Curr Opin Support Palliat Care*. 2010;4(4):233-7.
35. Sullivan MD, Newton K, Hecht J, Russo JE, Spertus JA. Depression and health status in elderly patients with heart failure: a 6-month prospective study in primary care. *Am J Geriatr Cardiol*. 2004;13(5):252-60.
36. Rutledge T, Reis VA, Linke SE, Greenberg BH, Mills PJ. Depression in heart failure a meta-analytic review of prevalence, intervention effects, and associations with clinical outcomes. *J Am Coll Cardiol*. 2006;48(8):1527-37.
37. Heo S, Doering LV, Widener J, Moser DK. Predictors and effect of physical symptom status on health-related quality of life in patients with heart failure. *Am J Crit Care*. 2008;17(2):124-32.
38. Light-McGroary K, Goodlin SJ. The challenges of understanding and managing pain in the heart failure patient. *Curr Opin Support Palliat Care*. 2013;7(1):14-20.
39. Allen LA, Stevenson LW, Grady KL, Goldstein NE, Matlock DD, Arnold RM, et al. Decision Making in Advanced Heart Failure: A Scientific Statement From the American Heart Association. *Circulation*. 2012.
40. Yancy CW, Jessup M, Bozkurt B, Masoudi FA, Butler J, McBride PE, et al. 2013 ACCF/AHA Guideline for the Management of Heart Failure: A Report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines. *J Am Coll Cardiol*. 2013.
41. Connor SR. Development of hospice and palliative care in the United States. *Omega (Westport)*. 2007;56(1):89-99.
42. Adler ED, Goldfinger JZ, Kalman J, Park ME, Meier DE. Palliative care in the treatment of advanced heart failure. *Circulation*. 2009;120(25):2597-606.
43. Morrison RS, Meier DE. Clinical practice. Palliative care. *N Engl J Med*. 2004;350(25):2582-90.
44. Hunt SA, Abraham WT, Chin MH, Feldman AM, Francis GS, Ganiats TG, et al. ACC/AHA 2005 Guideline Update for the Diagnosis and Management of Chronic Heart Failure in the Adult: a report of the American College of Cardiology/American Heart Association Task Force on Practice

- Guidelines (Writing Committee to Update the 2001 Guidelines for the Evaluation and Management of Heart Failure): developed in collaboration with the American College of Chest Physicians and the International Society for Heart and Lung Transplantation: endorsed by the Heart Rhythm Society. *Circulation*. 2005;112(12):e154-235.
45. Liu L. Changes in cardiovascular hospitalization and comorbidity of heart failure in the United States: findings from the National Hospital Discharge Surveys 1980-2006. *Int J Cardiol*. 2011;149:139-45.
 46. Riegel B, Moser DK, Powell M, Rector TS, Havranek EP. Nonpharmacologic care by heart failure experts. *J Card Fail*. 2006;12(2):149-53.
 47. Jordhoy MS, Fayers P, Loge JH, Ahlner-Elmqvist M, Kaasa S. Quality of life in palliative cancer care: results from a cluster randomized trial. *J Clin Oncol*. 2001;19(18):3884-94.
 48. El-Jawahri A, Podgurski LM, Eichler AF, Plotkin SR, Temel JS, Mitchell SL, et al. Use of video to facilitate end-of-life discussions with patients with cancer: a randomized controlled trial. *J Clin Oncol*. 2010;28(2):305-10.
 49. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363(8):733-42.
 50. Back AL, Li YF, Sales AE. Impact of palliative care case management on resource use by patients dying of cancer at a Veterans Affairs medical center. *J Palliat Med*. 2005;8(1):26-35.
 51. Elsayem A, Swint K, Fisch MJ, Palmer JL, Reddy S, Walker P, et al. Palliative care inpatient service in a comprehensive cancer center: clinical and financial outcomes. *J Clin Oncol*. 2004;22(10):2008-14.
 52. Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM. Patterns of functional decline at the end of life. *JAMA*. 2003;289(18):2387-92.
 53. Goldstein NE, Lynn J. Trajectory of End-Stage Heart Failure: the influence of technology and implications for policy change. *Perspectives in Biology and Medicine*. 2006;49(1):10-8.
 54. Bekelman DB, Rumsfeld JS, Havranek EP, Yamashita TE, Hutt E, Gottlieb SH, et al. Symptom burden, depression, and spiritual well-being: a comparison of heart failure and advanced cancer patients. *J Gen Intern Med*. 2009;24(5):592-8.
 55. O'Leary N, Murphy NF, O'Loughlin C, Tiernan E, McDonald K. A comparative study of the palliative care needs of heart failure and cancer patients. *Eur J Heart Fail*. 2009;11(4):406-12.

56. Horne G, Payne S. Removing the boundaries: palliative care for patients with heart failure. *Palliat Med.* 2004;18(4):291-6.
57. Bayliss J, Norell M, Canepa-Anson R, Sutton G, Poole-Wilson P. Untreated heart failure: clinical and neuroendocrine effects of introducing diuretics. *Br Heart J.* 1987;57(1):17-22.
58. West RL, Hernandez AF, O'Connor CM, Starling RC, Califf RM. A review of dyspnea in acute heart failure syndromes. *Am Heart J.* 2010;160(2):209-14.
59. Shah AB, Morrissey RP, Baraghoush A, Bharadwaj P, Phan A, Hamilton M, et al. Failing the failing heart: a review of palliative care in heart failure. *Rev Cardiovasc Med.* 2013;14(1):41-8.
60. Apatira L, Boyd EA, Malvar G, Evans LR, Luce JM, Lo B, et al. Hope, truth, and preparing for death: perspectives of surrogate decision makers. *Ann Intern Med.* 2008;149(12):861-8.
61. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Jama.* 2008;300(14):1665-73.
62. Fried TR, Bradley EH, O'Leary J. Prognosis communication in serious illness: perceptions of older patients, caregivers, and clinicians. *J Am Geriatr Soc.* 2003;51(10):1398-403.
63. Howie-Esquivel J, Dracup K. Communication with hospitalized heart failure patients. *Eur J Cardiovasc Nurs.* 2012;11(2):216-22.
64. Barclay S, Momen N, Case-Upton S, Kuhn I, Smith E. End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis. *Br J Gen Pract.* 2011;61(582):e49-62.
65. McCarthy M, Hall JA, Ley M. Communication and choice in dying from heart disease. *J R Soc Med.* 1997;90(3):128-31.
66. Retrum JH, Boggs J, Hersh A, Wright L, Main DS, Magid DJ, et al. Patient-identified factors related to heart failure readmissions. *Circ Cardiovasc Qual Outcomes.* 2013;6(2):171-7.
67. McKee PA, Castelli WP, McNamara PM, Kannel WB. The natural history of congestive heart failure: the Framingham study. *New England Journal of Medicine.* 1971;285(26):1441-6.
68. Jeste DV, Palmer BW, Appelbaum PS, Golshan S, Glorioso D, Dunn LB, et al. A new brief instrument for assessing decisional capacity for clinical research. *Arch Gen Psychiatry.* 2007;64(8):966-74.

69. New York Heart Association. Criteria Committee., New York Heart Association. *Nomenclature and criteria for diagnosis of diseases of the heart and great vessels*. 8th ed. Boston: Little, Brown; 1979.
70. Bruera E, Kuehn N, Miller MJ, Selmsler P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care*. 1991;7(2):6-9.
71. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. *Cancer*. 2000;88(9):2164-71.
72. Watanabe SM, Nekolaichuk CL, Beaumont C. The Edmonton Symptom Assessment System, a proposed tool for distress screening in cancer patients: development and refinement. *Psychooncology*. 2012;21(9):977-85.
73. Opasich C, Gualco A, De Feo S, Barbieri M, Cioffi G, Giardini A, et al. Physical and emotional symptom burden of patients with end-stage heart failure: what to measure, how and why. *Journal of cardiovascular medicine (Hagerstown, Md)*. 2008;9(11):1104-8.
74. Walke LM, Byers AL, Gallo WT, Endrass J, Fried TR. The association of symptoms with health outcomes in chronically ill adults. *Journal of Pain & Symptom Management*. 2007;33(1):58-66.
75. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med*. 2001;16(9):606-13.
76. Kroenke K, Strine TW, Spitzer RL, Williams JB, Berry JT, Mokdad AH. The PHQ-8 as a measure of current depression in the general population. *Journal of Affective Disorders*. 2009;114(1-3):163-73.
77. Pressler SJ, Subramanian U, Perkins SM, Gradus-Pizlo I, Kareken D, Kim J, et al. Measuring depressive symptoms in heart failure: validity and reliability of the patient health questionnaire-8. *Am J Crit Care*. 2011;20(2):146-52.
78. Goodlin SJ, Wingate S, Albert NM, Pressler SJ, Houser J, Kwon J, et al. Investigating pain in heart failure patients: the pain assessment, incidence, and nature in heart failure (PAIN-HF) study. *Journal of Cardiac Failure*. 2012;18(10):776-83.
79. Goebel JR, Doering LV, Shugarman LR, Asch SM, Sherbourne CD, Lanto AB, et al. Heart failure: the hidden problem of pain. *J Pain Symptom Manage*. 2009;38(5):698-707.
80. Evangelista LS, Sackett E, Dracup K. Pain and heart failure: unrecognized and untreated. *Eur J Cardiovasc Nurs*. 2009;8(3):169-73.

81. Godfrey C, Harrison MB, Medves J, Tranmer JE. The symptom of pain with heart failure: a systematic review. *J Card Fail.* 2006;12(4):307-13.
82. Zambroski CH, Moser DK, Bhat G, Ziegler C. Impact of symptom prevalence and symptom burden on quality of life in patients with heart failure. *Eur J Cardiovasc Nurs.* 2005;4(3):198-206.
83. Evangelista LS, Liao S, Motie M, De Michelis N, Ballard-Hernandez J, Lombardo D. Does the type and frequency of palliative care services received by patients with advanced heart failure impact symptom burden? *J Palliat Med.* 2014;17(1):75-9.
84. Komajda M, Hanon O, Hochadel M, Lopez-Sendon JL, Follath F, Ponikowski P, et al. Contemporary management of octogenarians hospitalized for heart failure in Europe: Euro Heart Failure Survey II. *Eur Heart J.* 2009;30(4):478-86.
85. Witte KK, Clark AL. Why does chronic heart failure cause breathlessness and fatigue? *Progress in Cardiovascular Diseases.* 2007;49(5):366-84.
86. Arzt M, Bradley TD. Treatment of sleep apnea in heart failure. *Am J Respir Crit Care Med.* 2006;173(12):1300-8.
87. Anker SD, von Haehling S. Inflammatory mediators in chronic heart failure: an overview. *Heart.* 2004;90(4):464-70.
88. Clark AL. Origin of symptoms in chronic heart failure. *Heart.* 2006;92(1):12-6.
89. NSAIDs and heart failure. *Prescribe Int.* 2001;10(56):182-3.
90. Parshall MB, Welsh JD, Brockopp DY, Heiser RM, Schooler MP, Cassidy KB. Dyspnea duration, distress, and intensity in emergency department visits for heart failure. *Heart Lung.* 2001;30(1):47-56.
91. Friedman B, Lyness JM, Delavan RL, Chunyu L, Barker WH. Major depression and disability in older primary care patients with heart failure. *J Geriatr Psychiatry Neurol.* 2008;21(2):111-22.
92. Hanratty B, Hibbert D, Mair F, May C, Ward C, Corcoran G, et al. Doctors' understanding of palliative care. *Palliat Med.* 2006;20(5):493-7.
93. Kavalieratos D, Mitchell EM, Carey TS, Dev S, Biddle AK, Reeve BB, et al. "Not the 'grim reaper service'": an assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. *J Am Heart Assoc.* 2014;3(1):e000544.
94. Allen LA, Yager JE, Funk MJ, Levy WC, Tulskey JA, Bowers MT, et al. Discordance between patient-predicted and model-predicted life expectancy among ambulatory patients with heart failure. *JAMA.* 2008;299(21):2533-42.

95. Foundation RWJ. Chronic Care: Making the Case for Ongoing Care. . Robert Wood Johnson Foundation. Princeton, NJ; 2010.
96. Morrison RS, Penrod JD, Cassel JB, Caust-Ellenbogen M, Litke A, Spragens L, et al. Cost savings associated with US hospital palliative care consultation programs. Arch Intern Med. 2008;168(16):1783-90.
97. Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. Arch Intern Med. 2004;164(1):83-91.
98. American Fact Finder. United States Census Bureau.

Supplementary Materials

a. Edmonton Symptom Assessment System

Edmonton Symptom Assessment System:												
Please circle the number that best describes how you feel NOW:												
No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness <i>(Tiredness = lack of energy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness <i>(Drowsiness = feeling sleepy)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression <i>(Depression = feeling sad)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety <i>(Anxiety = feeling nervous)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing <i>(Wellbeing = how you feel overall)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No _____ Other Problem <i>(for example constipation)</i>	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____
Patient's Name _____						Completed by (check one):						
Date _____ Time _____						<input type="checkbox"/> Patient <input type="checkbox"/> Family caregiver <input type="checkbox"/> Health care professional caregiver <input type="checkbox"/> Caregiver-assisted						

b. Patient Health Questionnaire-8

Patient Health Questionnaire (PHQ-8):				
Over the <u>last two weeks</u> , how often have you been bothered by any of the following problems? (Use "✓" to indicate your answer)	Not at all	Several days	More than half the days	Nearly every day
	1. Little interest or pleasure in doing things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Feeling down, depressed, or hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Trouble falling or staying asleep, or sleeping too much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Feeling tired or having little energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Poor appetite or overeating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Trouble concentrating on things, such as reading the newspaper or watching television	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If you checked off <u>any</u> problems, how <u>difficult</u> have these problems made it for you to do your work, take care of things at home, or get along with other people?				
Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

c. Abstract accepted at the 37th Annual Meeting of the Society of General Internal Medicine. April 2014.

JGIM

ABSTRACTS

S217

SUSTAINABLE PATIENT-CENTERED MEDICAL HOME TRANSFORMATION IN SAFETY-NET CLINICS: LESSONS LEARNED FROM THREE CASE STUDIES *Rashmi Gupta*¹; Edward Wagner²; Katie Coleman³. ¹University of Seattle, Washington, Seattle, WA; ²McColl Center of Health Care Innovation, Group Health, Seattle, WA. (Tracking ID #1933680)

BACKGROUND: Although only 6 years have passed since the Patient-centered Medical Home (PCMH) was first proposed to reinvigorate primary care, thousands of practices have engaged in transformation activities. However, practice transformation has proven to be difficult and requires wholesale changes to the practice. The Commonwealth Fund sponsored a 5 year demonstration project, the Safety Net Medical Home Initiative (SNMHI), to help clinics become PCMHs. Despite the high level of support made available to each practice, practices varied widely in their transformation success. More intensive study of three successful SNMHI practices confirmed lessons learned in the larger project about: what motivates practices to demolish old ways of organizing and delivering care; what changes enable practices to see a better future and sustain the effort; and how do successful practices go about making changes?

METHODS: The goal of the SNMHI was to develop and test a replicable model for supporting PCMH transformation among 65 safety net practices in five states. Participating practices in each state were supported by a Regional Coordinating Center (RCC) that employed medical home facilitators (MHFs) who worked closely with individual clinics. Transformation was guided by an explicit PCMH model that consisted of eight high level areas for change process (Wagner). Measurement of the transformation process involved multiple instruments including the Patient-centered Medical Home Assessment (PCMH-A), a 33 item self-assessment (Daniels). To study the transformation process more intensively, we selected three practices of different sizes, geographic locations, and organizational structures among those that had made major progress in becoming PCMHs as measured by change in PCMH-A scores. The sites selected included clinic A (an urban FQHC in Oregon), clinic B (a small single-site rural clinic in Colorado), and clinic C (multi-site urban and rural FQHC in Idaho). Data collected included bi-annual PCMH-A and Key Activity Checklists, MHF bi-annual evaluation, PCC narrative reports about each practice, and clinical data from each site. To gain a deeper understanding of the transformation process, we identified individuals at each practice who played key roles in practice transformation. We then conducted semi-structured one hour long qualitative interviews either in person or by phone during February and March, 2013 with these practice leaders. We addressed domains including motivation to change, initial approach to change, role of leadership, key beneficial approaches to change, key barriers to change, and reflection on change process. Data analysis involved coding transcriptions of interviews and identifying themes within and across cases.

RESULTS: The mean overall PCMH-A score across the 65 sites rose from 7 to 9 (out of 12) over 3 years. The scores for clinics A, B, and C rose from 7.0 to 9.0, 5.3 to 10.0, and 6.9 to 9.3, respectively. Prior to the SNMHI, Clinic A had a long history of practice transformation initiatives, but progress had stalled. Clinics B and C had not previously been engaged in practice transformation. Following involvement in the SNMHI all three clinics generated the will or motivation to change, found attractive ideas to guide change, and developed a strategy and infrastructure that facilitated the execution of system changes. Medical and administrative leaders made transformation an organizational priority and visibly drove change. Intrinsic motivators such as concerns about quality of care or community reputation had

SYMPTOM BURDEN IN PATIENTS HOSPITALIZED FOR DECOMPENSATED HEART FAILURE *Rabees Khan*¹; Shelli L. Feder²; Nathan Goldstein³; Sarwat Chaudhry¹. ¹Yale School of Medicine, New Haven, CT; ²Mount Sinai School of Medicine, New York City, NY; ³Yale University School of Nursing, New Haven, CT. (Tracking ID #1930389)

BACKGROUND: Heart failure is one of the most common reasons for hospitalization among older adults, and is the leading cause of readmissions within 30 days after hospital discharge. Consequently, there is great interest in developing strategies to reduce hospital utilization in this large and growing patient population. Aside from the classic heart failure symptoms of dyspnea and fatigue, other symptoms that have been reported in patients with heart failure include pain, decreased appetite, anxiety, as well as difficulty sleeping. These symptoms may be amenable to treatment, and as such, patients hospitalized with heart failure may benefit from intensive symptom management in the form of palliative care. However, there is limited data in the heart failure population about symptom burden both during hospitalization and shortly after hospital discharge, as well as patients' perceptions of palliative care.

METHODS: Patients hospitalized with a primary diagnosis of decompensated heart failure at Yale-New Haven Hospital were enrolled in this prospective cohort study. Exclusion criteria included non-English speaking, severe cognitive impairment, and ongoing hemodialysis. Patients were interviewed about their symptom burden using the Edmonton Symptom Assessment System (ESAS) and the Patient Health Questionnaire (PHQ-8) during their hospital admission ("baseline interview"). A follow-up telephone interview was conducted seven to ten days after hospital discharge, assessing symptom burden using the same standardized instruments. Patients were also questioned about their existing knowledge of palliative care, and then—after a brief, standardized explanation of the goals of palliative care—patients were queried about their interest in receiving palliative care services.

RESULTS: Thirty-five patients were enrolled in the study from September–December 2013. Their mean age was 71.3 years (SD 13.5 years) 54 % were female, and 71.4 % had NYHA class III or IV heart failure. The most frequent symptoms reported during the baseline interview were tiredness (82.9 %), drowsiness (82.9 %), shortness of breath (62.9 %), anxiety (57.1 %) and pain (45.7 %). The most frequent symptoms reported in the follow-up interview were tiredness (93.9 %), drowsiness (81.8 %), shortness of breath (81.8 %), anxiety (57.6 %) and pain (57.6 %). While only 14.3 % of patients had heard of the term "palliative care," after a brief, standardized explanation of what palliative services are designed to do, 45.7 % were interested in receiving palliative care services while in the hospital.

CONCLUSIONS: Patients hospitalized for heart failure experience a high burden of symptoms, including not just dyspnea and fatigue but also anxiety and pain. These symptoms are common during hospitalization, but the majority of patients experience troublesome symptoms shortly after discharge as well. Given that symptoms frequently drive health care utilization, integration of palliative care into routine heart failure management is a promising strategy to reduce hospital utilization.

TACKLING HEALTH EQUITY: LEADERSHIP'S PERCEPTIONS OF HEALTH CARE PERSONNEL AND ORGANIZATIONS *Rebecca A. Cunningham*

d. Poster presented at the 18th Annual Scientific Meeting of the Heart Failure Society of America (HFSA) on September 15th, 2014 in Las Vegas, NV. I received a ‘Young Investigator’ award for this poster.



SYMPTOM BURDEN IN PATIENTS HOSPITALIZED WITH DECOMPENSATED HEART FAILURE

Rabeya F. Khan, Sarwat I. Chaudhry MD; Department of Internal Medicine

WHAT WE LEARNED

- Patients hospitalized for heart failure experience a high burden of symptoms, including not only those usually associated with heart failure such as dyspnea and fatigue, but also anxiety, pain and depression.
- These symptoms are common both during hospitalization and shortly after discharge.

BACKGROUND

Heart failure (HF) is one of the most common reasons for hospitalizations and 30-day readmissions. It is increasingly recognized that heart failure patients suffer from a range of symptoms, not just classic heart failure symptoms such as dyspnea and edema. These symptoms may drive readmissions, and patients hospitalized with HF may benefit from intensive symptom management in the form of palliative care.

OBJECTIVE

To measure symptom burden in patients admitted with acute decompensated heart failure, as measured by the Edmonton Symptom Assessment System and Patient Health Questionnaire, both during hospitalization and shortly after discharge.

METHODS

- Patients hospitalized with a primary diagnosis of decompensated heart failure at Yale-New Haven Hospital were enrolled in this prospective cohort study.
- Patients were interviewed about symptom burden using the Edmonton Symptom Assessment System (ESAS) and Patient Health Questionnaire (PHQ-8) during the hospital admission.
- A follow-up telephone interview was conducted seven to ten days after hospital discharge, assessing symptom burden using the same standardized instruments.

RESULTS

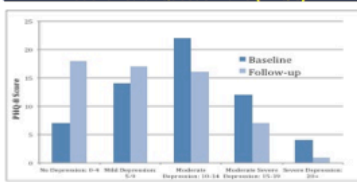
Baseline Characteristics of Patients

	Patients (n=59)
Age, mean (SD)	72 (13)
Female Sex, n (%)	30 (50.8%)
Nonwhite Race, n (%)	15 (25.4%)
Education ≤ High School	32 (54.2%)
LVEF < 50, n (%)	41 (69.5%)
NYHA Class, n (%)	
I	0 (0.0%)
II	16 (27.1%)
III	32 (54.2%)
IV	11 (18.6%)
Comorbid Diseases	
Coronary Artery Disease	35 (59.3%)
Diabetes Mellitus	29 (49.2%)
Renal Insufficiency	22 (37.3%)
Chronic Lung Disease	17 (28.8%)

Edmonton Symptom Assessment Scale Mean Scores

Symptom	Baseline (SD)	Follow-up (SD)
Pain	2.42 (3.1)	3.22 (3.0)
Fatigue	5.20 (2.9)	5.27 (2.8)
Drowsiness	4.71 (3.3)	4.17 (2.8)
Nausea	0.42 (1.6)	0.14 (0.8)
Lack of appetite	1.93 (2.5)	1.66 (2.5)
Swelling	4.15 (3.3)	2.54 (2.7)
Shortness of breath	4.27 (3.2)	4.00 (2.4)
Depression	2.75 (3.0)	2.08 (2.8)
Anxiety	3.20 (3.1)	2.78 (2.7)
Decreased wellbeing	5.12 (2.6)	4.44 (2.0)

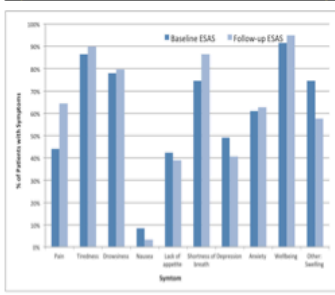
Patient Health Questionnaire (PHQ-8)



SUMMARY

- Patients hospitalized for HF experience a high burden of symptoms during hospitalization and shortly after discharge.
- These symptoms include not only those usually associated with HF such as dyspnea and fatigue, but also anxiety, pain and depression.
- Given that symptoms frequently drive health care utilization, integration of palliative care into routine HF management is a promising strategy to reduce hospital utilization.

Symptom Prevalence: Hospitalization v. Discharge



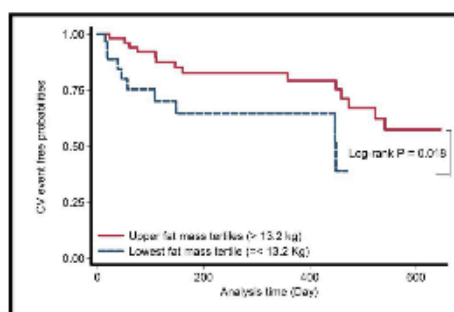


Figure 1.

(NT-proBNP) and greater strength capacities in chronic HF patients. We investigated the prognostic role of body fat mass and related anthropometric measurements in ADHF patients. **Methods:** We prospectively evaluated 121 consecutive ADHF patients. Patients underwent echocardiography, cardiopulmonary exercise, blood analysis, right knee extension strength measurement, and evaluation of body fat and muscle mass using bioimpedance analysis (BIA, available in 93 patients). Cardiovascular (CV) event was defined as composite of all-cause mortality, readmission due to heart failure aggravation, and heart transplantation. **Results:** Mean age of study population was 59.8 ± 15.1 years (61 male, 65.6%). Compared with patients in lowest fat mass tertile (< 13.3 kg), those in upper fat mass tertiles had higher body mass index (BMI), waist circumference (WC), hip circumference (HC), muscle strength, lower ventilation to carbon dioxide production slope (VE/VCO₂), and lower NT-proBNP level. Fat mass showed strong correlation with BMI ($r=0.735$, $P < 0.001$), WC ($r=0.705$, $P < 0.001$), waist-hip ratio (WHR, $r=0.804$, $P < 0.001$) and moderate correlation with muscle strength ($r=0.251$, $P=0.018$), VE/VCO₂ ($r=-0.252$, $P = 0.018$) but no correlation with muscle mass ($r=0.105$, $P = 0.316$) and peak oxygen uptake (VO₂, $r = 0.112$, $P = 0.297$). CV event occurred in 24 patients (25.8%) during median follow-up of 157 days (interquartile range 42-449). Kaplan-Meier plot showed that lowest fat mass tertile was associated with higher CV event rate compared to upper tertiles (32.3% vs 22.6%, Log rank $P = 0.018$, Figure 1). In age and sex adjusted Cox proportional hazard model, fat mass, WHR, and BMI predicted CV event but muscle mass did not. The prognostic value of fat mass (HR 0.90 [0.82-0.99], $P = 0.049$) and WHR (HR 0.88 [0.77-0.99], $P=0.042$) remained significant after further adjustment for potential predictors including peak VO₂, VE/VCO₂, muscle strength, hemoglobin level, and log-transformed NT-proBNP. **Conclusion:** Decreased fat mass and waist-hip ratio were independently associated with poor prognosis in ADHF patients whereas muscle mass was not. In context of cardiac cachexia and obesity paradox, adiposity may provide protective role in prognosis

149

Symptom Burden in Patients Hospitalized for Decompensated Heart Failure
Rabea F. Khan¹, Nathan E. Goldstein², Sarwat I. Chaudhry¹; ¹Yale School of Medicine, New Haven, CT; ²Mount Sinai School of Medicine, New York, NY

Background: Heart failure (HF) is one of the most common reasons for hospitalization and the leading cause of 30-day readmissions. There is great interest in developing strategies to reduce hospital utilization in this large and growing patient population. Aside from classic HF symptoms of dyspnea and fatigue, other symptoms reported include decreased appetite, pain and anxiety. These symptoms may be amenable to treatment and patients hospitalized with HF may benefit from intensive symptom management in the form of palliative care. There is limited data in the HF population about symptom burden both during hospitalization and shortly after hospital discharge, as well as patients' perceptions of palliative care. **Hypothesis:** Patients discharged from the hospital after acute decompensated HF will exhibit a high burden of residual symptoms one week post-discharge. **Methods:** Patients hospitalized for HF were enrolled in this prospective cohort study. Patients were interviewed about symptom burden using the Edmonton Symptom Assessment System (ESAS) during the hospital admission and 7 days post-discharge. Patients were also questioned about existing knowledge of palliative care, and then - after a brief, standardized explanation of the goals of palliative care - patients were queried about their interest in receiving palliative care services. **Results:** Fifty-nine patients were enrolled; mean age was 71.6 (SD 12.8 years) 50.8% were female and 72.9% had NYHA class III/IV HF. Frequent symptoms reported during the hospital interview were fatigue (86.4%; mean 5.20, SD 2.9), shortness of breath (74.6%; mean 4.27, SD 3.2), anxiety (61.0%; mean 3.20, SD 3.1) and pain (44.1%, mean 2.42, SD 3.1). Frequent symptoms reported in the follow-up interview were fatigue (89.8%; mean 5.27, SD 2.8), shortness of breath (86.4%; mean 4.00, SD 2.4), pain (64.4%; mean 3.22, SD 3.0), and anxiety (62.7%; mean 2.78, SD 2.7). While only 20.3% of patients had heard of 'palliative care,' after a standardized explanation, 49.2% were interested in receiving palliative care services while hospitalized. **Conclusions:** Patients hospitalized for HF experience a high burden of symptoms, including not only those usually associated with HF such as dyspnea and fatigue, but also anxiety and pain. These symptoms are common during hospitalization and the majority of patients appear to experience troublesome symptoms shortly after discharge as well. Given that symptoms frequently drive health care utilization, integration of palliative care into routine HF management is a promising strategy to reduce hospital utilization.

150

Heart Failure and Palliative Care: Not Always a Good Fit

Birgit A. Siceloff¹, Corrine Jurgens²; ¹New York Presbyterian at Cornell, New York, NY; ²Stony Brook University, Stony Brook, NY

Background/Purpose: Despite evidence that palliative care reduces high symptom burden of heart failure (HF), few patients are referred to or receive palliative services. The purpose of this study was to explore HF health professional's knowledge, attitude and experience integrating palliative care with this population. **Method:** Focus groups were conducted with 28 interdisciplinary health care professionals caring for HF patients in a large urban medical center. Focus groups lasted 35-60 minutes