Symptom Burden, Depression, and Spiritual Well-Being: A Comparison of Heart Failure and Advanced Cancer Patients

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BACKGROUND: A lower proportion of patients with chronic heart failure receive palliative care compared to patients with advanced cancer.

OBJECTIVE: We examined the relative need for palliative care in the two conditions by comparing symptom burden, psychological well-being, and spiritual well-being in heart failure and cancer patients.

DESIGN: This was a cross-sectional study.

PARTICIPANTS: Sixty outpatients with symptomatic heart failure and 30 outpatients with advanced lung or pancreatic cancer.

MEASUREMENTS: Symptom burden (Memorial Symptom Assessment Scale-Short Form), depression symptoms (Geriatric Depression Scale-Short Form), and spiritual well-being (Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being scale).

MAIN RESULTS: Overall, the heart failure patients and the cancer patients had similar numbers of physical symptoms (9.1 vs. 8.6, $p=0.79$), depression scores (3.9 vs. 3.2, $p=0.53$), and spiritual well-being (35.9 vs. 39.0, $p=0.31$) after adjustment for age, gender, marital status, education, and income. Symptom burden, depression symptoms, and spiritual well-being were also similar among heart failure patients with ejection fraction ≤ 30 , ejection fraction >30 , and cancer patients. Heart failure patients with worse heart failure-related health status had a greater number of physical symptoms (13.2 vs. 8.6, $p=0.03$), higher depression scores (6.7 vs. 3.2, $p=0.001$), and lower spiritual well-being (29.0 vs. 38.9, $p<0.01$) than patients with advanced cancer.

CONCLUSIONS: Patients with symptomatic heart failure and advanced cancer have similar needs for palliative care as assessed by symptom burden, depression, and spiritual well-being. This implies that heart failure patients, particularly those with more severe heart failure, need the option of palliative care just as cancer patients do.

KEY WORDS: heart failure; quality of life; palliative; symptoms; spirituality; depression.

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INTRODUCTION

Morbidity and mortality in chronic heart failure are high, with a median survival of 1.6 years after a hospitalization¹ and a 44% risk of readmission within six months.² Overall, the long-term survival rate is worse in patients with heart failure than for men with bowel cancer or women with breast cancer.³ Moreover, heart failure can have a major impact on patients' health status, directly contributing to their symptom burden (e.g., shortness of breath and fatigue) and functional limitations, which, in turn, can substantially diminish quality of life.^{4,5} Comorbid depression is prevalent. About 30% of inpatients and outpatients with heart failure have significant depressive symptoms, and this further contributes to worse patient health status.^{6,7}

Advanced cancer is similarly associated with high mortality and diminished patient health status. For example, less than 40% of lung cancer patients survive more than one year after diagnosis.⁸ Fatigue, shortness of breath, cough, and pain are common in lung cancer, as are limitations in physical, emotional, and role functioning.⁹ Patients with pancreatic cancer similarly have significant impairments in multiple domains of quality of life and suffer from fatigue, loss of appetite, pain, nausea/vomiting, and other symptoms.^{10,11}

Palliative care, defined as care devoted to improving quality of life and reducing suffering for patients with severe, life-threatening illnesses and their families, is often utilized in advanced cancer patients.¹² Typical domains addressed in palliative care include symptom burden, depression, and spiritual well-being. To date, however, palliative care has been markedly under-utilized in heart failure patients. For example, in a national survey of heart failure specialists, 67% of respondents referred no patients to palliative care in the previous six months.¹³ Heart failure patients' unmet needs for palliative care and lack of access to palliative care are described in multiple qualitative studies.^{14–16} One potential reason for the under-utilization of palliative care in heart

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failure is the perception that patients with cancer may have more symptoms, more depression, and lower spiritual well-being compared to patients with heart failure. However, the symptom burden, level of depression, and spiritual well-being of heart failure and cancer patients have not been directly compared.

Accordingly, the goals of this study were the following: 1) to compare prototypical palliative care domains, including symptom burden, depression, and spiritual well-being, between patients with heart failure and patients with advanced cancer, and 2) to determine how these domains may differ among the heart failure patients based on ejection fraction and level of heart failure-specific health status. Similar burdens in these domains in heart failure and in advanced cancer would support the broader employment of palliative care interventions among heart failure patients. Furthermore, this knowledge may help identify for which patients with heart failure palliative care approaches should be considered.

METHODS

Study Population and Design

Heart Failure Patients. Sixty outpatients with heart failure were recruited from cardiology clinics at Johns Hopkins Hospital and Bayview Medical Center in Baltimore, Maryland between August 2004 and April 2005. Descriptions of this study population have been published.¹⁷ Eligible study participants had 1) a cardiologist's diagnosis of heart failure, 2) New York Heart Association (NYHA) functional class II, III, or IV according to a cardiologist, and 3) were age 60 years or older. We chose heart failure patients age 60 or older to narrow the variability in our sample and to make the age distribution of heart failure patients more similar to the cancer patients. Patients were excluded if they were diagnosed with dementia, unable to understand the study protocol or provide informed consent, or listed on a heart transplant list.

Advanced Cancer Patients. Thirty outpatients with advanced lung or pancreatic cancer were recruited from oncology clinics at Johns Hopkins Hospital between February 2005 and December 2006. Eligible study participants 1) had non-resectable Stage IIIB and IV non-small cell lung cancer, or primary nonresectable pancreatic adenocarcinoma; 2) were aware of their diagnosis and prognosis; 3) were over age 18; and 4) had been to clinic at least once. Patients were ineligible for study participation if they 1) were unable to complete surveys due to a language barrier; 2) were unable to give informed consent; or 3) had a diagnosis of dementia. Advanced non-small cell lung cancer and pancreatic adenocarcinoma were chosen because they are both highly lethal malignancies with limited treatment options and high palliative care needs.^{9,10} In addition, non-small cell lung cancer is one of the most common malignancies.⁸ Clinical guidelines recommend palliative care at various stages in both malignancies.¹⁸

Both patient populations were recruited the same way: treating providers approached eligible patients and asked them if they would be interested in participating. Neither the heart failure patients nor the cancer patients were part of a larger study. At the study visit, patients with heart failure and cancer completed the same surveys to assess symptoms, depression,

and spiritual well-being. Patients with heart failure also completed a heart failure-specific health status questionnaire. This study was approved by the Institutional Review Board at the Johns Hopkins Bloomberg School of Public Health.

Measurements

Symptom presence during the prior week was assessed with the Memorial Symptom Assessment Scale-Short Form (MSAS-SF).¹⁹ This scale includes 28 physical symptoms (number of symptoms range, 0–28; higher number indicates more physical symptoms) and has been validated in patients with cancer¹⁹ and heart failure.²⁰ Respondents are asked to report if they have a symptom, and if so, how “distressing or bothersome” the symptom is on a 5-item Likert scale. Some examples of symptoms asked about include: lack of energy, pain, dry mouth, constipation, nausea, shortness of breath, cough, and numbness/tingling in hands or feet. The psychological symptoms from the MSAS-SF were not included in this analysis, since we used a separate, validated measure to specifically measure depression. We counted the number of symptoms for each patient because we believe this was the most clinically relevant and understandable metric.

Depression symptoms were assessed using the Geriatric Depression Scale-Short Form (GDS-SF). The GDS-SF is a self-report, reliable and valid screening tool for current depression.^{21,22} The GDS is widely used in elderly and medically-ill populations because it excludes somatic symptoms of depression while maintaining sensitivity.²³ It has been validated in non-geriatric adults.^{24–26} The scale range is from 0 to 15, with a higher score indicating a greater number of depressive symptoms. A score of 5 or higher is 60% sensitive and 89% specific for a diagnosis of depressive disorder.²⁷ The scale has high internal consistency (Cronbach's alpha 0.80).²⁷

We chose to measure spirituality rather than religiosity because the notion of spirituality is meaningful to a broader population of patients. Measures of religiosity are often less inclusive in their questions, focusing on a notion of God or relationship with God that is most relevant to specific faith traditions. We measured spiritual well-being with the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACIT-Sp) scale. The FACIT-Sp uses words such as “faith” and “beliefs” rather than the word “God,” and is thus broadly meaningful, including to the growing population of people who identify themselves as spiritual but not religious.²⁸ The FACIT-Sp is a 12-item self-report measure that assesses overall spiritual well-being (scale range, 0–48; higher scores signifying greater spiritual well-being). Respondents are asked to rate how true statements are on a 5-item Likert scale such as, “I feel peaceful” and “I find strength in my faith or spiritual beliefs.” This instrument was developed and validated in a large sample of medically-ill patients and has high internal consistency (Cronbach's alpha for total scale, 0.87).^{28,29}

Among the heart failure patients, heart failure-specific health status was measured using the overall summary score of the Kansas City Cardiomyopathy Questionnaire (KCCQ). The KCCQ is a valid, reliable, and responsive measure developed for patients with heart failure.^{30,31} The overall score (range, 0–100; higher score indicates better heart failure-related health status) predicts future cardiovascular mortality and rehospitalization.³² Cronbach's alpha ranges from 0.78–0.90 for the subscales making up the overall score. The most

recent ejection fraction at the time of study participation was obtained by medical record review. Ejection fraction was based on echocardiography in all patients with documented ejection fractions. The mean time interval between the measured ejection fraction and survey completion was 6 months.

Statistical Analysis

Population characteristics of the patients with heart failure and advanced cancer were examined. The Wilcoxon rank sum statistic was used to compare age, treated as a continuous variable, in the two populations, while the Cochran-Mantel-Haenszel statistic was employed for education and income. Chi-square or Fisher's exact statistics tested for differences in gender, ethnicity (white vs. non-white) and relationship status (married/significant other).

To evaluate differences in reported symptom burden, depression symptoms, and spiritual well-being according to cancer and heart failure diagnosis, we used three comparisons: i) cancer vs. heart failure group, ii) cancer vs. heart failure with EF $\leq$ 30 vs. heart failure with EF $>$ 30, and iii) cancer vs. heart failure with KCCQ overall score $\leq$ 50 vs. heart failure with KCCQ overall score $>$ 50. We used a KCCQ cutoff of 50 since a score of $<$ 50 among chronic heart failure outpatients was associated with more than twice the increased risk of hospitalization or death in the following year.³² The first analysis provided an overall comparison of number of symptoms, depression score, and spiritual well-being between the two patient populations. To test whether ejection fraction was associated with symptom burden, depression symptoms, and spiritual well-being, we then divided the heart failure group into three categories, ejection fraction $\leq$ 30, between 30 and 50, and $\geq$ 50. No differences in symptom burden, depression symptoms, or spiritual well-being were found between the two latter ejection fraction groups so they were combined because of the small number of patients in these groups.

Using separate ANOVA models, we compared the least-squares means for number of symptoms, depression scores, and level of spiritual well-being between the heart failure and cancer groups according to the three comparison strategies. T-test *p*-values were used to assess differences in means according to comparison groupings. The folded form of the F-statistic and Levene's test confirmed equality of variance for the 2-group and 3-group comparisons, respectively. To address non-normality, we examined square root and rank transformations. These transformed models resulted in the same inferences as the models without transformation. For interpretability, the untransformed model results are presented. In order to improve the likelihood that differences in symptom burden, depression, and spiritual well-being were related to disease characteristics (heart failure versus cancer), rather than non-disease characteristics, we decided a priori to adjust for sociodemographic differences between the two populations including age, gender, marital status, education, and income. Adjustments by age were mean-centered. All analyses employed SAS software (Version 9.1, SAS Institute, Cary, North Carolina).

RESULTS

Patients with heart failure were older and more likely to be male, less likely to have a spouse or significant other, and more

likely to have less education and lower household income compared to the patients with advanced cancer (Table 1). After adjustment for these demographic characteristics, patients with heart failure had similar levels of symptom burden, depression symptoms, and spiritual well-being compared to patients with advanced cancer (Table 2). Both populations experienced a mean of approximately nine physical symptoms in the prior week. More than half of heart failure patients reported shortness of breath, lack of energy, pain, feeling drowsy, or dry mouth. More than half of cancer patients reported lack of energy, cough, feeling drowsy, shortness of breath, pain, difficulty sleeping, and numbness/tingling in hands/feet. Thirty percent of heart failure patients (*n*=18) had probable depressive disorder compared to 33.3% of advanced cancer patients (*n*=10) using the cutoff score of five on the GDS (*p*=0.75). Symptom burden, depression symptoms, and spiritual well-being were also similar between heart failure patients with ejection fraction $\leq$ 30, ejection fraction $>$ 30, and cancer patients (Table 3).

Patients with worse heart failure-specific health status (KCCQ score $<$ 50) had a greater overall symptom burden, more depression symptoms, and worse spiritual well-being compared to patients with better heart failure-specific health status after adjustment for age, gender, marital status, education, and income (Table 4). Patients with worse heart failure-specific health status had a mean of 13.2 physical symptoms in the prior week compared to 7.6 symptoms in the better heart failure-specific health status group (*p* $<$ 0.001). The mean number of depression symptoms in the worse heart failure-specific health status group was above the cutoff for probable depression and was significantly higher than the mean number of depression symptoms in the better heart failure-specific health status group (6.7 versus 2.8, *p* $<$.0001).

Finally, patients with worse heart failure-specific health status had more symptom burden and depression symptoms and worse spiritual well-being compared to patients with advanced cancer after adjustment for demographic factors (Table 4). Symptom burden, depression symptoms, and spiritual well-being were not significantly different between the

Table 1. Characteristics of Patients with Heart Failure and Advanced Cancer

Characteristic	Heart failure (n=60)	Advanced cancer (n=30)	P-value
Age (median, [IQR])	75 [70, 81]	64 [53, 71]	$<$ 0.0001
Female gender (n, %)	22 (36.7)	18 (60.0)	0.04
Non-white (n, %)	7 (11.7)	6 (20.0)	0.35
Married/significant other or partner (n, %)	30 (50.9)*	24 (80.0)	0.01
Highest grade completed in school (n, %)			$<$ 0.0001
Less than high school graduate	25 (42.4)*	1 (3.5)†	
High school graduate	20 (33.9)*	6 (20.7)†	
Additional education	14 (23.7)*	22 (75.9)†	
Total household income (n, %)			0.01
Less than or equal to \$20,000	20 (35.7)‡	5 (18.5)§	
\$20,001–\$30,000	19 (33.9)‡	4 (14.8)§	
More than \$30,000	17 (30.4)‡	18 (66.7)§	

*n=59; †n=29; ‡n=56; §n=27

Table 2. Adjusted (Age, Gender, Marital Status, Education, Income) Measures According to Heart Failure and Advanced Cancer Populations

	Heart failure	Advanced cancer	P-value
	Mean $\pm$ SE	Mean $\pm$ SE	
Number of physical symptoms*	9.1 $\pm$ 0.9	8.6 $\pm$ 1.4	0.79
Depression score [†]	3.9 $\pm$ 0.5	3.2 $\pm$ 0.8	0.53
Spiritual well-being score [‡]	35.9 $\pm$ 1.4	39.0 $\pm$ 2.3	0.31

SE: standard error

* Measured using the Memorial Symptom Assessment Scale, short form (range, 0–28; higher number indicates more physical symptoms)

[†] Measured using the Geriatric Depression Scale, short form (range, 0–15; higher score indicates a greater number of depressive symptoms)[‡] Measured using the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being scale (scale range, 0–48; higher scores signifying greater spiritual well-being)

patients with advanced cancer and the patients with better heart failure-specific health status after adjustment.

DISCUSSION

This study compared three prototypical palliative care domains, symptom burden, psychological well-being, and spiritual well-being, between patients with heart failure and patients with advanced lung and pancreatic cancer. We found that patients with heart failure and advanced cancer reported similar levels of symptom burden, depression, and spiritual well-being. Stratifying heart failure patients by ejection fraction did not reveal significantly different levels of symptom burden, depression or spiritual well-being. However, patients with worse heart failure-specific health status had significantly greater overall symptom burden, more depression symptoms, and lower spiritual well-being compared to patients with advanced cancer.

No previous studies have directly compared symptom burden, depression, and spiritual well-being in heart failure and cancer patients. In one study, both patients with heart failure and patients with cancer reported substantial symptom burden, with cancer patients reporting more moderate or

severe symptoms.³³ The cancer patients had a variety of different cancers, and that study compared severity of symptoms rather than overall number of symptoms, as measured in our study. Depression is common in both populations.^{7,34} A recent qualitative study found that spiritual distress tended to occur at distinct points in the illness trajectory in advanced cancer, such as at diagnosis and progression of disease, while spiritual well-being in heart failure gradually decreased. Participant interviews revealed that this gradual decrease in spiritual well-being in patients with heart failure was associated with a loss of identity and increasing dependence.³⁵

There are several limitations to this study. While we adjusted for sociodemographic characteristics, unmeasured confounding factors could account for some of the similarities and/or differences in palliative care domains among advanced cancer and heart failure patients. We originally chose heart failure patients age 60 or older to narrow the variability in our sample and this limits generalizability. However, since older adults report lesser decreases in quality of life compared to younger adults,³⁶ the effects we found might have been greater if we included younger patients with heart failure. Our choice to enroll patients with lung and pancreatic cancer and not other cancers may also limit generalizability. Finally, the small sample that was recruited from one area may limit generalizability, although our findings about the prevalence of symptoms and depression are similar to other studies suggesting that our patient population was similar.

Our findings support the notion that patients with symptomatic heart failure have palliative care needs. For example, patients with heart failure had a number of symptoms that were “quite a bit” or “very much” distressing. Little research-based evidence exists to guide practitioners on which patients with heart failure might be appropriate to receive palliative care, and when it should be provided, especially given the association of palliative care with end of life care.^{16,37–48} The ACC/AHA 2005 Guideline Update for the Diagnosis and Management of Chronic Heart Failure in the Adult generally equates palliative care with hospice and primarily discusses it in the context of end of life care.⁴⁹ However, palliative care can be understood as care that should be provided from the time of diagnosis of a serious illness, which is often much earlier than when patients are eligible for hospice or at the end of life.⁵⁰ In our study, outpatients with symptomatic heart failure had similar palliative care needs in terms of symptom burden,

Table 3. Adjusted (Age, Gender, Marital Status, Education, Income) Measures According to Heart Failure and Advanced Cancer Populations; The Heart Failure Group was Dichotomized by Ejection Fraction

	Heart failure		Advanced cancer	P-value		
	I	II	III			
	EF $\leq$ 30 (n=33)	EF>30 (n=26)	(n=30)	I vs. II	I vs. III	II vs. III
	Mean $\pm$ SE	Mean $\pm$ SE	Mean $\pm$ SE			
Number of physical symptoms*	9.4 $\pm$ 1.1	8.7 $\pm$ 1.2	8.7 $\pm$ 1.5	0.64	0.72	0.99
Depression score [†]	3.6 $\pm$ 0.6	4.3 $\pm$ 0.6	3.2 $\pm$ 0.8	0.42	0.70	0.32
Spiritual well-being score [‡]	35.2 $\pm$ 1.8	36.3 $\pm$ 1.9	39.1 $\pm$ 2.3	0.68	0.25	0.39

SE: standard error

* Measured using the Memorial Symptom Assessment Scale, short form (range, 0–28; higher number indicates more physical symptoms)

[†] Measured using the Geriatric Depression Scale, short form (range, 0–15; higher score indicates a greater number of depressive symptoms)[‡] Measured using the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being scale (scale range, 0–48; higher scores signifying greater spiritual well-being)

Table 4. Adjusted (Age, Gender, Marital Status, Education, Income) Measures According to Heart Failure and Advanced Cancer Populations; The Heart Failure Group was Dichotomized by Health Status Measured by The Kansas City Cardiomyopathy Questionnaire Overall Summary Score

Instruments	Heart Failure		Advanced cancer	P-value		
	I	II	III			
	KCCQ 0 – 50 (n=17)	KCCQ 50.1 – 100 (n=43)	(n=30)			
	Mean ± SE	Mean ± SE	Mean ± SE	I vs. II	I vs. III	II vs. III
Number of physical symptoms*	13.2±1.4	7.6±0.9	8.6±1.3	<0.001	0.03	0.58
Depression score†	6.7±0.7	2.8±0.4	3.2±0.7	<0.0001	0.001	0.65
Spiritual well-being score‡	29.0±2.2	38.4±1.4	38.9±2.1	<0.001	0.004	0.85

SE: standard error

* Measured using the Memorial Symptom Assessment Scale, short form (range, 0–28; higher number indicates more physical symptoms)

† Measured using the Geriatric Depression Scale, short form (range, 0–15, higher score indicates a greater number of depressive symptoms)

‡ Measured using the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being scale (scale range, 0–48; higher scores signifying greater spiritual well-being)

depression, and spiritual well-being to outpatients with advanced cancer. The heart failure patients enrolled in this study were all able to attend a clinic visit and complete questionnaires and were not enrolled in hospice. Thus, patients with heart failure have a variety of palliative care needs perhaps long before they are in hospice that are on par with the needs of advanced cancer patients.

Our study found that heart failure-specific health status, as measured by the KCCQ, better reflected the burden of illness on patients' symptoms, mood, and spiritual well-being than patients' measured ejection fractions. The instrument we used to measure heart failure-specific health status, the KCCQ, is a useful marker of prognosis³² and can monitor changes in clinical status over time.³¹ This study demonstrates its use in identifying disease burden in three palliative care domains. Patients with KCCQ scores ≤50 had a large number of bothersome symptoms, an average depression score indicating a probable depressive disorder, and worse spiritual well-being compared to patients with better heart failure-specific health status. Based on these results, KCCQ scores ≤50 may be used to identify patients who may benefit from palliative care assessment and treatment, with the caveat that heart failure is an illness whose severity often fluctuates over time. Furthermore, low KCCQ scores should be one of a number of clinical status indicators that may alert health care providers to palliative care needs.

The study results reveal the need to address symptom burden, depression, and spiritual well-being in patients with heart failure. Heart failure patients often have persistent prototypical symptoms, such as shortness of breath and fatigue, despite optimal medical management and device therapy.^{51,52} Many also have concurrent symptoms such as pain, constipation, and dry mouth that contribute to diminished quality of life.⁵ Palliative care approaches can reduce both persistent prototypical and concurrent symptoms in patients with heart failure through pharmaceutical and behavioral approaches.^{53–56} While we do not have data on whether attempts were made to address these domains in the study population, the presence of burdens in these domains implies unmet needs. This suggests that heart failure patients, particularly those with more severe heart failure, need the option of palliative care treatment just as cancer patients do.

Depression in patients with heart failure may be treated best with an approach that targets both persistent physical symptoms and depression concurrently since physical symptoms and

psychological symptoms are often interrelated. SSRIs and cognitive behavioral psychotherapy may improve depression in patients with heart failure.^{57–59} In addition, clinicians should not underestimate the potential benefits of supportive communication. Empathy may help reduce distress in patients who are depressed.⁶⁰ While these strategies may help heart failure patients with depression, symptoms and depression are strongly linked⁵ and depression is more resistant to treatment in patients with more medical comorbidities^{61,62} as is common in heart failure.⁶³ Thus, after disease management is optimized, palliation of physical symptoms and treatment of depression concurrently may lead to greater reductions in depression and concomitant improvements in quality of life.

Addressing patients' spiritual well-being is important because patients want health care providers to address it,⁶⁴ it is associated with depression¹⁷ and quality of life,⁶⁵ and patients with low spiritual well-being are more likely to be suicidal and desire help in hastening their death.²⁹ Several interventions that have been tested primarily in patients who have advanced cancer enhance spiritual well-being, including dignity therapy⁶⁶ and meaning-centered psychotherapy.⁶⁷ These interventions should be evaluated in patients with heart failure, particularly those with poor heart-failure specific health status, given our finding that heart failure patients with poor heart failure-specific health status had lower spiritual well-being than patients with advanced cancer.

In summary, patients with symptomatic heart failure and advanced cancer had a similar burden of symptoms, depression, and low spiritual well-being. Heart failure patients with worse heart failure-specific health status had more symptoms, more depression, and lower spiritual well-being compared to advanced cancer patients. This suggests that heart failure patients, particularly those with more severe heart failure, may benefit from palliative care treatment just as cancer patients do.

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