

Comparing Unmet Needs between Community-Based Palliative Care Patients with Heart Failure and Patients with Cancer

Dio Kavalieratos, PhD,¹⁻³ Arif H. Kamal, MD,^{3,4} Amy P. Abernethy, MD,²⁻⁴
Andrea K. Biddle, PhD,² Timothy S. Carey, MD, MPH,⁵ Sandesh Dev, MD,⁶
Bryce B. Reeve, PhD,² and Morris Weinberger, PhD^{2,5,7}

Abstract

Background: As the role of palliative care (PC) has yet to be clearly defined in patients with heart failure (HF), such patients may face barriers regarding PC referral. In order to maximally meet the needs of HF patients, it is necessary to understand how they compare to the classic PC population: patients with cancer.

Objective: To characterize the unresolved symptom and treatment needs with which patients with HF and those with cancer present to PC.

Methods: We used data from the Palliative Care Research Registry (PCRR), a repository of quality improvement data from three community-based PC organizations. We abstracted first PC visit data from the PCRR for patients with primary diagnoses of HF or cancer seen between 2008 and 2012. We assessed the association of primary diagnosis (i.e., HF or cancer) on three outcomes: unresolved symptoms, treatment gaps, and a composite indicator of symptom control and quality of life. Analyses included descriptive statistics and multivariate Poisson regression.

Results: Our analytic sample comprised 334 patients with HF and 697 patients with cancer, the majority of whom were white and male. Compared to patients with cancer, patients with HF presented with fewer unresolved symptoms, both overall and at moderate/severe distress levels. Patients with HF more commonly reported moderately/severely distressful dyspnea (25% versus 18%, $p=0.02$), and more commonly experienced dyspnea-related treatment gaps (17% versus 8%, $p<0.001$).

Conclusions: Patients with HF possess care needs that are squarely within the purview of PC. Future work is needed to delineate how PC referral policies should be refined to optimize PC access for patients with HF.

Introduction

HISTORICALLY, palliative care (PC) in the United States has largely served patients with cancer.¹ Nevertheless, patients with other serious illnesses, including heart failure (HF), may benefit from PC. HF is a progressive condition that affects more than 5,000,000 Americans,² and is associated with significant physical and psychosocial distress for patients and caregivers.³⁻⁷ Given its prevalence and

improved survival resulting from life-prolonging therapies, the burden of chronic HF is greater than ever and is expected to grow.⁸

Internationally, numerous consensus statements support PC for patients with HF, ranging from specialist PC consultation to comanagement models.^{7,9-11} In the United States, the American College of Cardiology recommends PC for patients with advanced disease,⁹ however, patients with HF access palliative services far less often than patients with

¹Center for Research on Health Care, Division of General Internal Medicine, Department of Medicine, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania.

²Department of Health Policy and Management, Gillings School of Global Public Health, ⁵Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina.

³Center for Learning Health Care, Duke Clinical Research Institute, ⁴Division of Medical Oncology, Duke University School of Medicine, Duke University Medical Center, Durham, North Carolina.

⁶Phoenix VA Health Care System, Phoenix, Arizona.

⁷Center for Health Services Research in Primary Care, Durham Veterans Affairs Medical Center, Durham, North Carolina.

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cancer.¹ Although patients with HF and those with cancer exhibit similar disease-related burdens,¹² patients with HF with worse health status experience greater physical and psychological symptom burdens.⁶ Patients with HF and those with cancer (and their caregivers) may differ in other ways. First, patients with HF may be less engaged in health care decision-making and have less information regarding their illness and treatment options.^{13,14} Second, patients with HF experience poorer care coordination.^{13,15,16} Third, the pattern of decline in physical and psychological well-being vastly differs between patients with HF and patients with cancer.¹³ Last, the unpredictable trajectory of HF may impede PC referral.¹⁵⁻¹⁸ Moreover, because provider-related factors may delay PC referral among patients with HF,¹⁶ they may present with more advanced symptoms than patients with cancer.

Community-based PC is expanding in the United States,^{19,20} and holds promise to increase PC access for patients with HF. As such, it is important for community-based PC providers to understand the unmet palliative needs of patients with HF at first consultation, and how they differ from those of patients with cancer. Our goals are to: (1) describe patients with HF and patients with cancer receiving community-based PC; (2) determine the impact of having HF versus cancer on unresolved symptoms and treatment gaps; and (3) assess associations between primary diagnosis and outcomes. We seek to provide potential priorities for initial community-based PC consultations of patients with HF and those with cancer.

Methods

Data

We analyzed data from the Palliative Care Research Registry (PCRR), the repository of retrospective quality improvement data for the Carolinas Palliative Care Consortium. Established in 2008, the Consortium is a community-academic partnership between three North Carolina PC organizations and Duke University.^{21,22} We extracted data from patients' initial PC visits between June 1, 2008 and January 1, 2012.

At each PC visit, Consortium providers collected patient- or proxy-reported data on the distress of 11 symptoms: agitation, anorexia, anxiety, constipation, depression, diarrhea, dyspnea, fatigue, insomnia, nausea, and pain using the McCorkle Symptom Distress Scale.²³ Symptom tolerability was also assessed.

Measures

Our dependent variables were: (1) number of unresolved symptoms; (2) number of treatment care gaps; and, (3) palliative care patient health status (PC-PHS), a composite indicator of adequate symptom control and QOL. Unresolved symptoms are those rated as causing moderate or severe distress for each of the 11 symptoms in the PCRR (range, 0–11). Thus, “unresolved” signifies symptom distress persisting at the initial PC consultation—likely reflecting care received prior to PC referral. Somatic symptom burden (i.e., frequency and severity) may be a reasonable indicator of latent emotional distress and poor quality of life in cardiovascular disease.^{24,25} A treatment gap was defined as the lack of a documented pharmacologic or nonpharmacologic intervention for a symptom whose distress was rated as moderate or severe. As interventions were documented for pain, dyspnea,

TABLE 1. DIAGNOSTIC CODES USED TO IDENTIFY PATIENT COHORTS

| <i>Cohort</i> | <i>ICD-9-CM Diagnostic Codes</i> |
|-----------------------------|---|
| Heart failure ²⁹ | 428.xx (heart failure); 429.3 (cardiomegaly); 402.01 (malignant hypertensive heart disease with HF); 402.11 (benign hypertensive heart disease with HF); 402.91 (unspecified hypertensive heart disease with HF); and, 425.xx (cardiomyopathy). |
| Cancer | 140-239.9 |

constipation, and depression, treatment gap counts ranged between 0–4. Similar to unresolved symptoms, our measure reflects care received prior to PC referral.

Finally, PC-PHS is a composite indicator of symptom control and quality of life. We focused on pain and dyspnea, which are relevant to patients with HF and those with cancer^{26,27} and are often targets of PC interventions. Providers asked patients about both current and maximum tolerable levels of each symptom. Patients were considered to have adequate control if current symptoms were less than the maximum tolerable level, or the patient reported no current symptom. Although this may not constitute the ideal goal for symptom resolution, it represents a minimum standard of control. Furthermore, it is a patient-centered approach, assessing treatment effectiveness based on a specific patients' symptom experience. Quality of life was assessed with a single item (poor, fair, good).²⁸ Given that only 5% of patients reported good quality of life, we created a binary measure (poor versus fair/good QOL). The resulting PC-PHS variable is a binary indicator with 1 (better health status) indicating all 3 criteria were met (i.e., controlled pain, controlled dyspnea, and fair/good quality of life), and 0 otherwise.

Our independent variable was primary diagnosis (i.e., HF or cancer). Diagnostic codes used to identify cohorts are provided in Table 1.

Control variables included: patient age, gender, race, care setting, and respondent (i.e., patient-reported, proxy-reported). Performance status was assessed using the Palliative Performance Scale (PPS).^{30,31} We transformed PPS into a three-category variable for clinical relevance (i.e., 0–30, low; 40–60, medium; 70–100, high).^{32,33}

Statistical analysis

All analyses were cross-sectional, patient-level, and assessed at the time of first PC visit. First, we used Pearson's χ^2 tests, Student's *t* tests, and Wilcoxon-Mann-Whitney tests to examine bivariate differences by primary diagnosis. Next, we estimated risk ratios (RRs) to assess the effect of primary diagnosis on the probability of the PC-PHS outcome. We calculated RRs using modified Poisson regression with robust errors.^{34,35} Statistical tests were two-tailed with a critical α -level of 0.05. We conducted numerous sensitivity analyses, as well as assessments of model fit (e.g., Akaike's Information Criterion [AIC], deviance). Analyses were conducted using Stata/IC, version 12 (StataCorp, College Station, TX).³⁶ This study was approved by the Institutional Review Boards of Duke University and the University of North Carolina.

Results

Of 1031 patients meeting study criteria, 334 (32%) had a primary diagnosis of HF; their characteristics are presented in Table 2. Most patients had a do-not-resuscitate order. The median PPS score for all patients was 40%, indicating predominantly bedridden patients with extensive evidence of disease. Approximately half of each disease group reported fair/good quality of life. Compared to patients with cancer, patients with HF were significantly older (84 versus 71 years, $p < 0.001$), had one or more prior hospitalization in the preceding 6 months (81% versus 63%, $p < 0.001$), and likelier to reside in a nursing home (18% versus 4%, $p < 0.001$).

Patients with HF presented with fewer moderately and severely distressful unresolved symptoms than did patients with cancer (1.77 versus 2.24, $p = 0.0001$) and overall (3.36 versus 3.87, $p = 0.0002$), patients with HF, relative to patients

with cancer, less frequently rated the following symptoms as moderately/severely distressful: anorexia (29% versus 46%, $p < 0.001$), pain (19% versus 32%, $p < 0.001$), insomnia (14% versus 20%, $p = 0.02$), anxiety (12% versus 20%, $p = 0.002$), constipation (8% versus 15%, $p = 0.004$), and nausea (4% versus 13%, $p < 0.001$). Only dyspnea was more commonly reported by patients with HF than patients with cancer as moderately/severely distressful (25% versus 18%, $p = 0.02$; Fig. 1). Patients with HF experienced more dyspnea treatment gaps (17% versus 8%, $p < 0.001$; Fig. 2); cancer patients had more constipation-related treatment gaps (11% versus 6%, $p = 0.008$).

In bivariate analysis, diagnosis was not associated with PC-PHS (unadjusted RR: 1.20, 95% confidence interval [CI]: 0.96, 1.50, Table 3). However, after adjusting for clinical and demographic factors, patients with HF had lower probability of positive health status (adjusted RR: 0.70, 95% CI: 0.55, 0.90).

TABLE 2. DEMOGRAPHIC AND DISEASE CHARACTERISTICS OF STUDY COHORT

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

Values may not sum to 100 due to rounding and/or missing data. The Palliative Performance Scale rates functional status across five domains from 0%–100% in 10-percentage point increments, with greater scores indicating higher performance. χ^2 tests of independence were calculated for categorical variables, Student's *t* tests were used for normally distributed continuous variables, and Wilcoxon-Mann-Whitney tests calculated for interval or non-normally distributed continuous outcomes.

MOST, Medical Orders for Scope of Treatment.

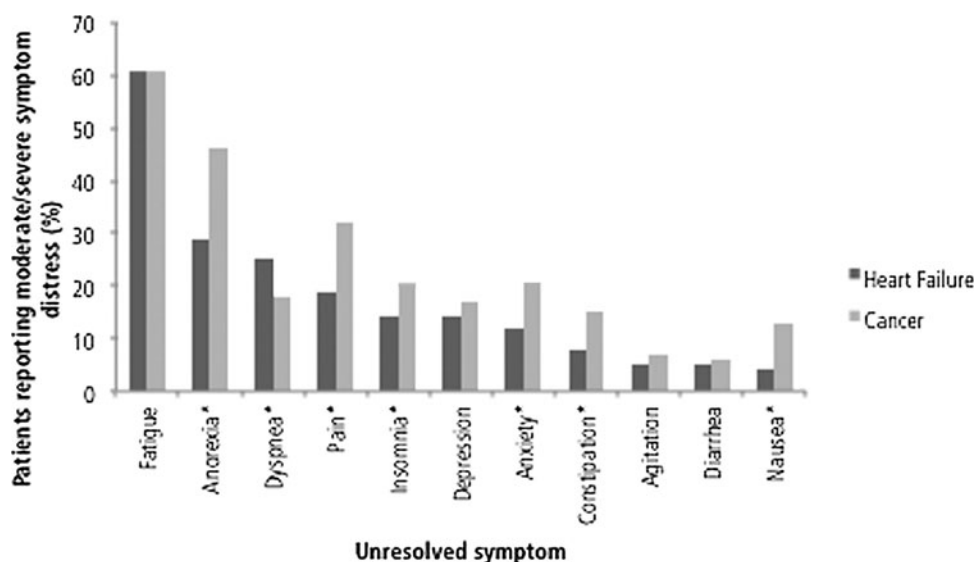


FIG. 1. Prevalence of unresolved symptoms at first palliative care consultation. A symptom was defined as unresolved when the distress that it caused was rated as either moderate or severe. *Pearson's χ^2 test indicates significant difference in unresolved symptom prevalence between heart failure patients and patients with cancer at the $\alpha=0.05$ level.

Discussion

Patients with HF possess care needs that are clearly within the purview of PC. Prior work comparing the physical and psychosocial needs of patients with HF and those with cancer found the groups to be indistinguishable vis-à-vis symptom burden, despite differences regarding specific symptom prevalence.^{6,37} Our conclusions generally support these findings. We found that patients with cancer reported more unresolved moderately/severely distressful symptoms (2.24 versus 1.77). Whether this difference is sufficient to affect clinical decisionmaking is unknown; our experience suggests that symptom prioritization becomes paramount when people

suffer from multiple problems simultaneously. Nevertheless, the question remains whether cumulative symptom burden or distress from a specific symptom prompts provider intervention. Echoing previous work,^{37,38} we found greater dyspnea in patients with HF than in patients with cancer; dyspnea, like pain, is a high-priority symptom that must be addressed, otherwise quality of life degrades and caregiver burden escalates.³⁸⁻⁴² Last, having HF was associated with poorer health, even after controlling for the advanced age of our patients with HF. Our findings suggest that patients with HF and patients with cancer are appropriate for PC, however, the pattern of burden appears to differ between the two illnesses. Therefore, the portfolio of palliative interventions must be appropriately tailored.

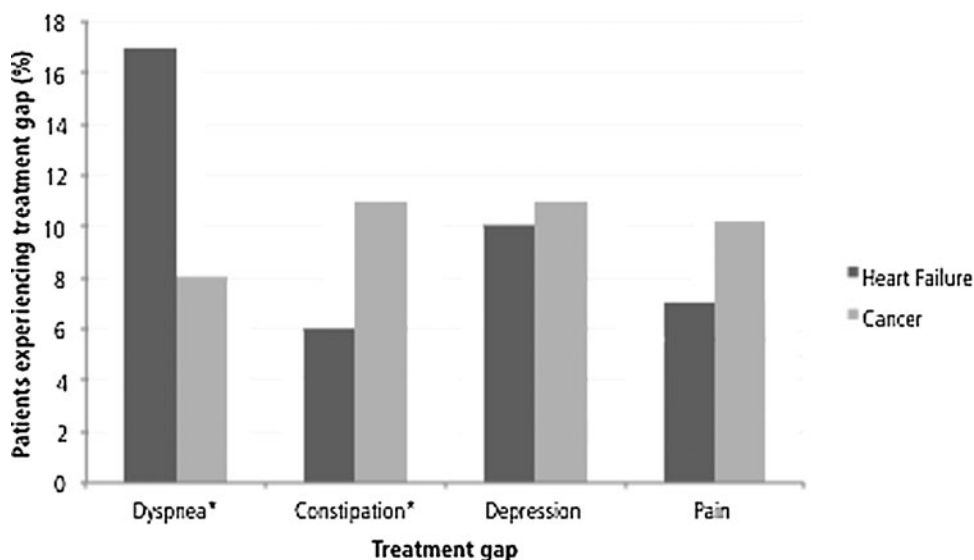


FIG. 2. Prevalence of treatment gaps at first palliative care consultation. We defined a treatment gap as the lack of a documented intervention for a symptom whose distress was rated as moderate or severe. *Pearson's χ^2 test indicates significant difference in treatment gap prevalence between heart failure patients and patients with cancer at the $\alpha=0.05$ level.

TABLE 3. ASSOCIATIONS BETWEEN VARIOUS DEMOGRAPHIC AND CLINICAL VARIABLES AND PALLIATIVE CARE PATIENT HEALTH STATUS AT FIRST PALLIATIVE CARE CONSULTATION

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

^aSignificant at the 1% level.

^bSignificant at the 5% level.

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

Akaike's Information Criterion (AIC) of adjusted model: 1.24.

RR, risk ratio; CI, confidence interval.

Several limitations merit comment. First, PC-PHS is an exploratory composite measure. Although it has not yet been formally validated, it has face validity based on clinical and intuitive logic. Second, our cross-sectional study means that conclusions be judiciously interpreted. Third, data come from a community-based PC consortium in North Carolina and our patients were referred for PC; these factors may limit generalizability.

Ours is the first HF-focused analysis of community-based PC in the United States. We hope that it will serve to further describe a model of care through which we may expect a growing number of patients with HF to receive supportive services.^{7,19} With an estimated additional 3,000,000 Americans to be diagnosed with HF by 2030,⁴³ our work can spark discussion regarding PC workforce planning, ensuring that PC teams have the skills and resources necessary to care for people with HF.

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Address correspondence to:
Dio Kavalieratos, PhD
Center for Research on Health Care
Division of General Internal Medicine
Department of Medicine
University of Pittsburgh
230 McKee Place, Suite 600
Pittsburgh, PA 15213
E-mail: diok@pitt.edu