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Does the Type and Frequency of Palliative Care Services Received by Patients with Advanced Heart Failure Impact Symptom Burden?

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Introduction

Patients with heart failure (HF) experience a myriad of symptoms that are associated with marked distress and impaired quality of life.[1–3] In light of their high symptom burden and poor prognosis, patients with symptomatic HF are an appropriate population in whom to introduce palliative care (PC).[4–6] However, PC referral early in the course of symptomatic HF is a relatively new practice and few data exist that describe the nature of these encounters.[7] The current study was conducted to describe the nature of outpatient PC services (i.e., type of services and care received, duration, and frequency of visits) used by patients discharged from the hospital with acute HF exacerbation, i.e., New York Heart Association (NYHA) Functional Class II–III, and to describe levels of symptom burden during the initial PC consultation and three months thereafter.

Methods

Study design, setting, and participants

This descriptive-exploratory study was conducted at a single university affiliated medical center. Participants were recruited from the inpatient setting through HF provider referrals.

Palliative care intervention

Participants met within seven days of hospital discharge with a PC specialist (e.g., physician or advanced practice nurse) who retained primary responsibility for their PC needs over three months. The PC specialist performed a comprehensive physical and psychosocial assessment, initiated discussions about advance care planning (e.g., completion of advance directives, options to take in the event of worsening health, family involvement, pain management, hydration issues, artificial nutrition, blood transfusions, advanced therapies, organ and tissue donation, and medical device donation), and worked with participants to develop a treatment plan that listed the goals of care. The treatment plan was presented to the interdisciplinary PC team during their weekly meetings, in order to support a team-based approach to providing patient-family centered care that encouraged active involvement of patients and their families in decision making involving their care.

Data collection methods

The study was approved by the appropriate institutional review board. Participants provided informed consent prior to completing the modified Edmonton Symptom Assessment Scale (ESAS),[8] a nine-item, self-reported visual analog scale numerically rated from 0 (no symptom at all) to 10 (worst possible symptom) at baseline and three months, to assess ratings of each symptom at the time that the survey was completed.[9] The severity of each individual item was categorized as none (0), mild (1–4), moderate (5–7), and severe (8–10). The reliability (Cronbach's α) of the ESAS for the current study was 0.86. Data on types of PC services received, the focus of care for each encounter, and medication use over three months were abstracted from the medical records.

Data analyses

Descriptive summaries of demographic and clinical data, symptom burden scores, and duration and frequency of PC encounters were computed using SPSS 18.0 (SPSS Inc., Chicago, IL). The paired Wilcoxon signed-rank test was used to compare symptom burden scores immediately after discharge and three months postdischarge. A symptom response rate (i.e., percentage of participants presenting a reduction of ≥ 2 points on an individual symptom of the ESAS) was computed to determine efficacy of PC in reducing symptom burden; a two-point change in individual symptom scores has been

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reported as clinically relevant in patients with cancer.[9] Statistical significance was accepted at a two-sided α level of <0.05 for all analyses.

Results

Study participants and palliative care consultation

During the five-month study recruitment period, 57 patients were referred by their HF provider; 42 (73%) provided informed consent, but only 36 (85.7%) completed the initial PC consultation. All 36 patients received support for advance care planning and care coordination from their PC specialist (see Fig. 1, Tier 1). In addition, participants received support for symptom management (81%), patient education (69%), and coping (50%). The median total time for the initial PC consultation was 75 minutes (range, 50–120; quartiles = 25th percentile: 60 minutes, 50th percentile: 85 minutes, 75th percentile: 100 minutes).

Additional palliative care services received

Following the initial PC consultation, seven (19%) felt that they did not need additional PC support. Their sociodemographic and clinical characteristics were comparable to the participants who received PC consultation plus follow-up visits (see Table 1).

All 29 patients who sought additional PC services were referred to the pharmacist (see Fig. 1, Tier 2) who worked with the PC specialist to determine a treatment regimen for reducing physical distress (e.g., pain) and psychosocial distress (e.g., depression). New medications were prescribed for 20 (69%) participants; 6 (30%) were prescribed opioids; 4 (20%) were prescribed antidepressants; and 10 (50%) were prescribed both. Seven (24%) required changes in their medications; 5 (71%) needed to uptitrate their pain medication and 2 (29%) were switched to a different antidepressant.

In addition, 20 (69%) sought the support of the social worker for case management and were given information related to community resources available to help them cope with their condition. Nineteen (66%) who complained of fatigue and dyspnea and 16 (55%) who complained of anxiety and depression were referred to the physical and occupational therapists and psychiatrist on the PC team, respectively, for further evaluation and treatment. Finally, 13 (45%) met with the chaplain; and 83%, 31%, and 7% were referred to home health, community support groups, and hospice, respectively.

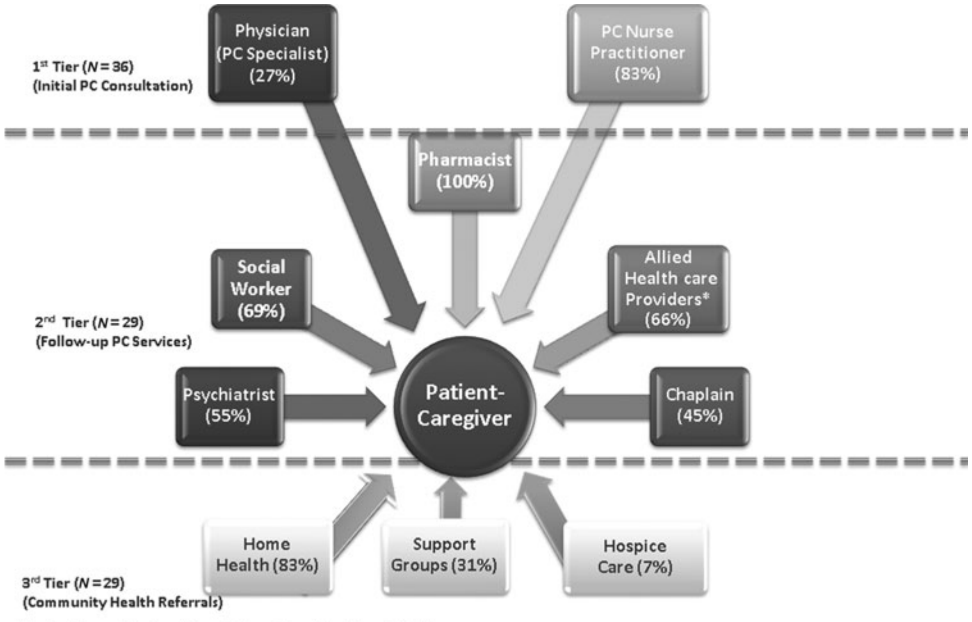
The median number of follow-up visits for each participant over three months was two days (mean, 2.21 ± 0.27; range, 1–4 days). The number of follow-up visits and telephone calls for the 29 patients totaled 64 and 45, respectively.

Symptom burden at baseline

Figure 2 illustrates the proportion of patients who reported no distress versus mild, moderate, and severe distress for each of the individual symptoms at baseline. The most common symptoms were fatigue (75%), pain (61%), anxiety (50%), depression (39%), and dyspnea (39%).

Symptom burden at three months

Table 2 reflects marked reductions in pain, anxiety, and dyspnea (all $P < 0.001$) and moderate reductions in fatigue, depression, drowsiness, appetite, and nausea (all $P \leq 0.040$) over time. More than a fifth of the participants had an SRR (i.e., $\geq$2-point decrease in 0–10 score on ESAS) for anxiety (36%), pain (32%), fatigue (25%), depression (25%), dyspnea (22%), and well-being (22%). Participants who received additional PC services following the initial PC consultation were



*Physical, Occupational, and Speech Therapist, and Registered Dietician.

FIG. 1. Palliative Care Services that participants used.

Table 1. Baseline Sociodemographic and Clinical Characteristics (*N*=36)

	All participants (N=*36*)	*Initial palliative care consultation only* (n=*7*)	*Palliative care consultation + follow-up* (n=*29*)	*Sig.*
Age, years (mean±SD)	53.9±8.0	52.7±6.3	54.1±8.4	0.850
Male, n (%)	26 (72.2)	4 (57.1)	22 (75.9%)	0.583
Race, n (%)				0.468
Hispanic	5 (13.9)	1 (14.3)	4 (13.8)	
White	22 (61.1)	3 (42.9)	19 (55.5)	
Black	9 (25.0)	3 (42.9)	6 (20.7)	
Married, ***n*** (%)	25 (69.4)	6 (85.7)	19 (65.5)	0.578
Education, ***n*** (%)				0.824
≤High school graduate	17 (47.2)	3 (42.8)	14 (48.3)	
Some college	10 (27.8)	2 (28.6)	8 (27.6)	
≥College graduate	9 (25.0)	2 (28.6)	7 (24.1)	
Ejection fraction, % (mean±SD)	25.4±5.2	23.1±4.3	25.9±5.3	0.094
Charlson Comorbidity Index (mean±SD)	3.7±1.5	2.7±1.4	3.9±1.5	0.134
NYHA class, ***N*** (%)				0.983
Class II	25 (69.4)	5 (71.4)	20 (69.0)	
Class III	11 (30.6)	2 (28.6)	9 (31.0)	
Comorbidities				
Hypertension, *n* (%)	22 (61.1)	3 (42.9)	19 (65.5)	0.523
Coronary artery disease, *n* (%)	22 (61.1)	4 (57.1)	18 (62.1)	0.957
Diabetes mellitus, type 2, *n* (%)	12 (33.3)	3 (42.9)	9 (31.0)	0.246
Overweight or obese, *n* (%)	25 (69.4)	4 (57.1)	21 (72.4)	0.575
History smoking (previous), *n* (%)	14 (38.9)	3 (42.8)	11 (37.9)	0.942
Medications used, ***N*** (%)				
Ace inhibitors	26 (72.2)	5 (71.4)	21 (72.4)	0.847
Angiotensin receptor blockers	7 (19.4)	2 (28.5)	5 (17.2)	
Beta-blockers	26 (72.2)	5 (71.4)	21 (72.4)	0.847
Diuretics	23 (63.9)	5 (71.4)	18 (62.1)	0.578
Pain medications	11 (30.6)	3 (42.9)	8 (27.6)	0.335
Antidepressants	8 (22.2)	2 (28.6)	6 (20.6)	0.430

NYHA, New York Heart Association.

more likely to show improvements in fatigue ($P<0.001$), pain ($P=0.044$), anxiety ($P=0.029$), sense of well-being ($P=0.035$), dyspnea ($P=0.008$), and nausea ($P=0.045$) than participants who only completed the initial PC consultation. Furthermore, a greater proportion of patients who only completed the initial PC consultation showed worsening symptoms of fatigue (29% versus 11%, $P<0.001$) and pain (29% versus 10%, $P=0.044$).

Discussion

The current prospective study was conducted to evaluate the types of PC services used by patients recently hospitalized for acute HF exacerbation. We also present data on the prevalence of symptoms and symptom severity during the initial PC consultation and the effects of PC services on symptom burden three months postdischarge. Our data

Table 2. Comparison between Baseline and Follow-up Symptom Scores (*N*=36)

ESAS symptoms	*Total no. of patients*	*SRR*[a] n *(%)*	*Baseline median (IQR, P25–P75)*	*Follow-up median (IQR, P25–P75)*	*Z statistic*	*P**
TSDS	36	NA	34.00 (29.00 – 40.75)	26.50 (23.25 – 32.75)	−6.895	<0.001
Fatigue	36	9 (25.0)	4.50 (3.25 – 7.00)	4.00 (3.00 – 6.00)	−2.846	0.004
Pain	36	11 (30.6)	6.00 (0.00 – 7.00)	4.00 (0.00 – 6.00)	−3.690	<0.001
Anxiety	36	13 (36.1)	4.00 (3.00 – 6.00)	3.50 (1.25 – 4.00)	−3.523	<0.001
Well-being	36	8 (22.2)	4.00 (0.00 – 6.00)	3.00 (0.00 – 4.00)	−4.148	<0.001
Depression	36	9 (25.0)	4.00 (3.00 – 6.00)	3.00 (0.00 – 5.00)	−1.640	0.038
Dyspnea	36	8 (22.2)	4.00 (3.00 – 5.00)	3.00 (0.25 – 4.00)	−3.815	<0.001
Drowsiness	36	3 (8.3)	4.00 (0.00 – 4.00)	3.00 (0.00 – 4.00)	−3.231	0.001
Appetite	36	3 (8.3)	3.00 (0.00 – 4.75)	3.00 (0.00 – 4.00)	−2.919	0.004
Nausea	36	4 (11.1)	3.00 (0.00 – 4.00)	3.00 (0.00 – 3.00)	−3.350	0.001

[a] Defined as a two-point decrease or more in 0–10 score on individual symptoms on the ESAS; NA not analyzed.

*Wilcoxon signed-rank test.

ESAS, Edmonton Symptom Assessment Scale; IQR, interquartile range; SRR, symptom response rate; TSDS, total symptom distress score.

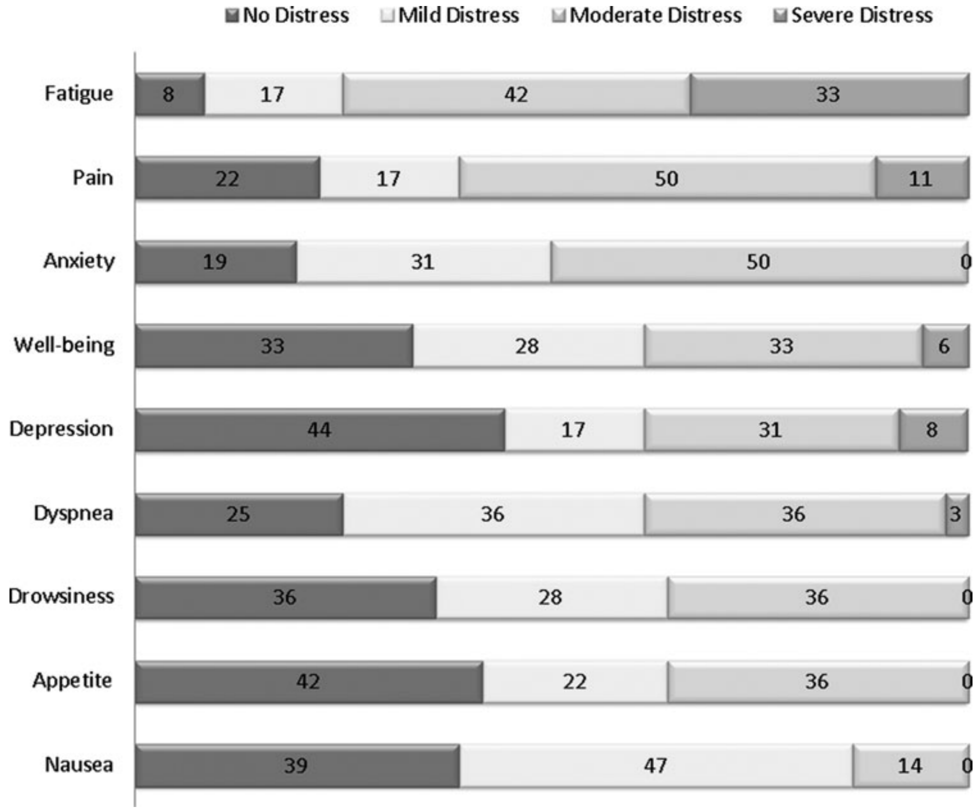


FIG. 2. Severity of Symptom Distress at baseline (N = 36).

showed moderately high symptom burden, with 92% reporting at least one symptom that was mild to moderately distressful and 61% reporting at least one severely distressful symptom. This is consistent with other studies that report high levels of both physical and psychological distress in patients with symptomatic HF.[1,10–14]

Consistent with prior research in this area, we found that a major part of the initial PC consultation was dedicated to symptom management.[4] Participants' level of symptom burden also dictated the urgency of initiating additional support from the PC team. Participants with physical and functional distress (e.g., fatigue, dyspnea) were referred for services like strength training and assistance with activities of daily living, while those with psychosocial distress (e.g., depression, anxiety) were referred for services that provided psychological support and assistance with coping. Participants with no symptoms or mild symptoms were more likely to forego additional PC support.

Earlier studies examining the effectiveness of outpatient PC services in a general medicine outpatient clinic reported improvements in dyspnea, anxiety, and spiritual well-being, but no significant impact on pain or depression.[15] In contrast, we found that ongoing PC support beyond the initial PC consultation resulted in greater reductions in symptom burden, including pain and depression, confirming that on-going PC provides clinicians with the opportunity to focus on the needs and preferences of greatest importance to patients and families are more likely to result in better outcomes.[16]

Several important limitations must be considered when interpreting the results from our study. First, as expected with descriptive, exploratory studies, causation cannot be inferred. We cannot say that the number of PC referrals actually resulted in reduced symptom burden. Second, the generalizability of our findings is limited because the sample is from a single university affiliated medical center; patients were younger on average compared to patients with HF in the community. Third, we did not have a mechanism to verify the time spent on individual PC services during the follow-up visits. Last, our study did not have a control group and it is possible that patients who had higher symptom burden were less likely to agree to participate in the study, thus leading to underestimation of the prevalence and severity of symptoms.

Conclusion

Our data supports the growing consensus that HF patients benefit from a PC referral early in the HF disease trajectory long before they qualify for hospice care, and that ongoing care resulted in greater symptom control. Future randomized controlled trials with a larger, more heterogeneous sample are warranted to better explicate the effectiveness PC services on symptom burden and clinical outcomes (e.g., readmission, self-management, quality of life) in patients with symptomatic HF. Likewise, future investigations should also examine the type and frequency of care needed by patients and families beyond the first three months following an acute hospitalization for HF exacerbation.

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Author Disclosure Statement

The authors have no disclosures to make.

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