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Abstract

Introduction: There is a paucity of research about the impact of palliative care (PC) on perceived control (i.e. one's perceived influence over outcomes or events in the environment) and activation (i.e. ability to self-manage) in patients with symptomatic heart failure (HF). Likewise, little is known about the association between perceived control, activation, and symptom distress in this patient population. We hypothesized that patients with advanced HF who received ongoing PC services (i.e. ≥ 2 PC consultations) vs no access or a single PC consultation would have greater improvements in perceived control and activation and greater reductions in symptom distress three months post-discharge for HF exacerbation.

Methods: Forty-two patients (average age 53.9 ± 8.0 years; predominantly male (72%), White (61%) and married (69%)) participated in the study. However, only 36 (85.7%) patients completed an outpatient PC consultation of which 29 (69%) patients returned for additional follow-up visits with the PC team. Data on perceived control, activation, and symptom distress were collected at baseline and three months. Parametric statistical models were applied to draw conclusions.

Results: Findings showed that the patients who received ≥ 2 PC consultations had greater improvements in perceived control and activation than their counterparts; these increases were associated with greater reductions in symptom distress.

Conclusion: Our findings suggest that on-going PC interventions enhance perceived control and activation in patients with advanced HF and open up the possibility of planning larger studies to assess the effect of PC on these variables as possible mediators to improvements in self-management and clinical outcomes.

Keywords

Heart failure, palliative care, perceived control, activation, self-care

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Introduction

Chronic heart failure (HF) is a health care epidemic characterized by progressive decline of cardiac performance and functional status with frequent decompensation of the chronic state resulting in recurrent hospitalizations.¹ Despite tremendous advances achieved in medical management, HF continues to present patients with challenges that lead to marked physical, psychological, social, and

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extreme distress; furthermore, amongst these patients diverse symptoms are common and result in feelings of loss of control over their own health outcomes (i.e. perceived control) or inadequate self-management knowledge, skills, and self-efficacy, which are expressed by the composite construct of patient activation (i.e. activation).² Self-management is the ability of the patient to deal with symptoms, treatment, complications, and lifestyle changes; it goes beyond traditional knowledge-based patient education to include processes that enhance self-advocacy, improve self-efficacy, and support application of knowledge to maintain a satisfactory quality of life. Since patient self-management is so critical to health outcomes, greater attention to symptom management earlier in the HF trajectory may potentially reduce suffering from both physical and psychological symptoms and lessen the distress associated with this incurable condition.³

One approach to addressing the needs of patients living with HF is the integration of palliative care (PC) with standard HF care.⁴⁻⁶ Likewise, guidelines advocate for PC, referral to hospice, and end of life support for patients suffering with terminal illness.⁷ Palliative care is 'an interdisciplinary team approach to optimizing QOL (quality of life) and symptom management that does not necessarily exclude any medical therapy and takes into account physical, psychosocial, and spiritual needs and patient/family preferences.'⁸ A substantial literature calls for PC in older adults and caregivers suffering with HF. Moreover, recent position statements and health care delivery models emphasize several critical needs to enhance a new protocol for PC in this vulnerable group of chronically ill patients that includes: (a) *Interdisciplinary team evaluation and symptom management* with the integration of psychosocial, functional, and behavioral support; (b) *Multidimensional assessment* to identify, prevent, and alleviate suffering; and (c) *Early integration of PC* with updates based on changes in clinical status.⁹⁻¹¹ However, research that focuses on the impact of PC on symptom control in HF is still in its infancy. Likewise, although there is increasing advocacy for timely symptom control in patients with HF, there is limited research examining the efficacy of PC services on perceived control and activation.¹²

The primary objective of the current descriptive correlational study was to obtain preliminary data on the efficacy of PC services on enhancing perceived control and activation in patients with symptomatic HF. The specific aims of the study were to: (a) assess levels of perceived control and activation immediately after discharge with acute HF decompensation and three months thereafter; (b) compare the impact of no access or limited access to PC services (i.e. single PC consultation) vs access to on-going PC services (i.e. ≥ 2 PC consultations) on perceived control and activation in a sample of patients with symptomatic HF; and (c) determine the association between perceived control, activation, and symptom distress in patients immediately after and three months post-discharge

for HF exacerbation. We hypothesized that patients with advanced HF who received on-going PC services would have greater improvements in perceived control and activation and consequently, greater reductions in symptom distress three months post-discharge for HF exacerbation than their counterparts.

Methods

Study design and setting

This prospective, single-cohort, study was conducted at a single, tertiary care medical center with both a specialized HF disease management program led by seven heart failure specialist and four nurse practitioners with expertise in HF disease management and a PC clinic comprised of two board certified PC physicians, a nurse practitioner with expertise in PC, and PC support staff (e.g. pharmacist, psychiatrist, social worker, physical, occupational, and speech therapist, and chaplain).¹³ The appropriate Institutional Review Board reviewed and approved the research protocol; all participants gave written informed consent.

Study participants

Participants were recruited from the inpatient setting during an episode of acute HF exacerbation through HF provider referrals. Eligible participants were at least 18 years old, able to read, write, and speak English or Spanish; and were willing to be referred for a PC consultation. Patients were precluded from study participation if they had: (a) cognitive decline (e.g. dementia); (b) other co-morbid terminal illness (e.g. malignancy); (c) surgically implanted left ventricular assist device; and (d) currently receiving PC services for symptom management.

Procedures

Prior to hospital discharge, a member of the research team provided the patient with a packet containing: (a) a PC program brochure; (b) a cover letter explaining the purpose of the PC consultation with a date and time of their PC appointment; the letter encouraged participants to bring their spouse, partner, or other family member to the initial visit; and (c) an information sheet to instruct the study participant to schedule a telephone interview with a member of the research team; the purpose of the 20-30 min interview was to obtain baseline information from participants prior to their initial PC consultation (~7-10 days after discharge). After completion of the baseline telephone interview, the research staff conducted chart reviews to extract data about participants' medical history and current clinical status and treatment regimen. A follow-up telephone interview was scheduled three months after the initial PC consultation and was conducted by the same research staff.

The initial PC consultation was scheduled a week following hospital discharge, and in conjunction with participants' follow-up visit with their HF provider. During this initial consultation, the PC specialist (e.g. physician or advance practice nurse) completed a standardized intake summary (e.g. current health status, treatment regimen), assessed physical and psychological symptoms, determined illness understanding, established goals of care with the patient and family, and assisted with treatment decision making and coordination of care. The intervention is described in greater depth in another paper.¹³ All patients were encouraged to avail themselves of on-going PC services based on their identified goals of care; they were given the number for the 24-hour on-call service staffed by the PC team and were encouraged to call for additional PC support (e.g. worsening of symptoms, support for care coordination, etc.).

Measures

During the baseline interviews, participants were asked to provide information related to their sociodemographic (i.e. personal characteristics—age, gender, race/ethnicity, marital status, level of education, employment status, occupation) and clinical status (i.e. medical history and current treatment regimen). Participants were also asked to complete a series of surveys at baseline and three-months later.

To measure perceived control, participants completed the revised Control Attitude Scale (CAS-R),¹⁴ an eight-item tool designed to measure a person's belief that he or she has the resources to cope with the negative events associated with cardiac illness; sample items are 'I can do a lot of things myself to cope with my heart condition' and 'Regarding my heart problems, I feel lots of control.'¹⁵ The total score is obtained by reversing the ratings on negatively phrased items and adding the item scores—each item is rated on a scale of 1 (totally disagree) to 5 (totally agree); scores range from 8–40 with higher scores indicating greater perceived control.¹⁴ Cronbach's alpha values for the CAS-R in patients with coronary heart disease, acute myocardial infarction, and HF were all greater than 0.70.¹⁴

The participants also completed the Patient Activation Measure (PAM), a 13-item, interval-level, unidimensional tool, developed by Hibbard and colleagues¹⁶ to assess patient's self-rated ability to take preventive actions, manage symptoms, access medical care, and work with health care providers to make decisions about care.² A four-point Likert scale that ranges from 1 (strongly agree) to 4 (strongly disagree) is used for each item and these scores are added to derive a single score previously shown to be reliable and valid.¹⁷ Hibbard & colleagues describe four levels of activation, viewed as sequential across a hierarchical continuum: 1 (low level of activation)—believing the patient role is important (score \leq 47); 2 (also a low level)—having the knowledge and confidence to take action (score=47.1–55.1); 3 (medium)—taking action to

maintain or improve health (score=55.2–67); and 4 (high)—maintaining healthy lifestyle changes under stress (score \geq 67.1).¹⁸ A study conducted in the target population of HF patients suggest that the PAM is highly reliable at the individual patient level and a valid instrument for assessing activation and individualizing care in HF patients with a Cronbach's α of 0.88.¹⁹

Finally, to measure symptom distress, participants completed the Edmonton Symptom Assessment Scale (ESAS), a self-reported visual analog scale developed for use in assessing the symptoms of patients receiving palliative care.²⁰ It includes nine common symptoms of advanced cancer (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath); scores range from 9–90 with higher scores indicating greater symptom distress.²¹ It is designed to enable repeated quantitative measurements of multidimensional symptom intensity with minimal patient burden, numerically rated from zero (no symptom at all) to 10 (worse possible symptom).²² Since its original inception by Bruera et al. in 1991,²⁰ the ESAS has been adopted in diverse palliative and cancer care programs and countries.²¹ The reliability of the modified ESAS was previously established in patients with chronic illness with a Cronbach's alpha coefficient of 0.86.²⁰ In a group of patients with HF, the ESAS was highly correlated with quality of life measures.²³

Data analysis

Data analysis was performed using SPSS for Windows Statistical Program (version 18, 1.0, SPSS, Inc., Chicago, Illinois, USA). Descriptive statistics including means, ranges, standard deviations and chi-square statistics were used to characterize the study population and summarize distribution of perceived control, activation scores, and symptom distress. Data were analyzed using both parametric and non-parametric statistics; data were fairly similar so only parametric data are presented in the paper. Differences in sociodemographic and clinical variables and variables of interest were examined using independent sample *t*-tests or chi-squared tests depending on levels of measurement. Bivariate analyses examined correlations between sociodemographic characteristics, PC group, perceived control, activation, and symptom distress scores. Reported *p*-values are two-sided and adjusted for multiple comparisons.

Results

Patient characteristics

A total of 42 patients provided informed consent for participation in the study at the time of hospital discharge; 85.7% came for the initial PC consultation. Of the 36 patients who came for the PC consultation, 29 (69%) received additional PC services beyond the initial consultation (Figure 1). The median number of follow-up visits

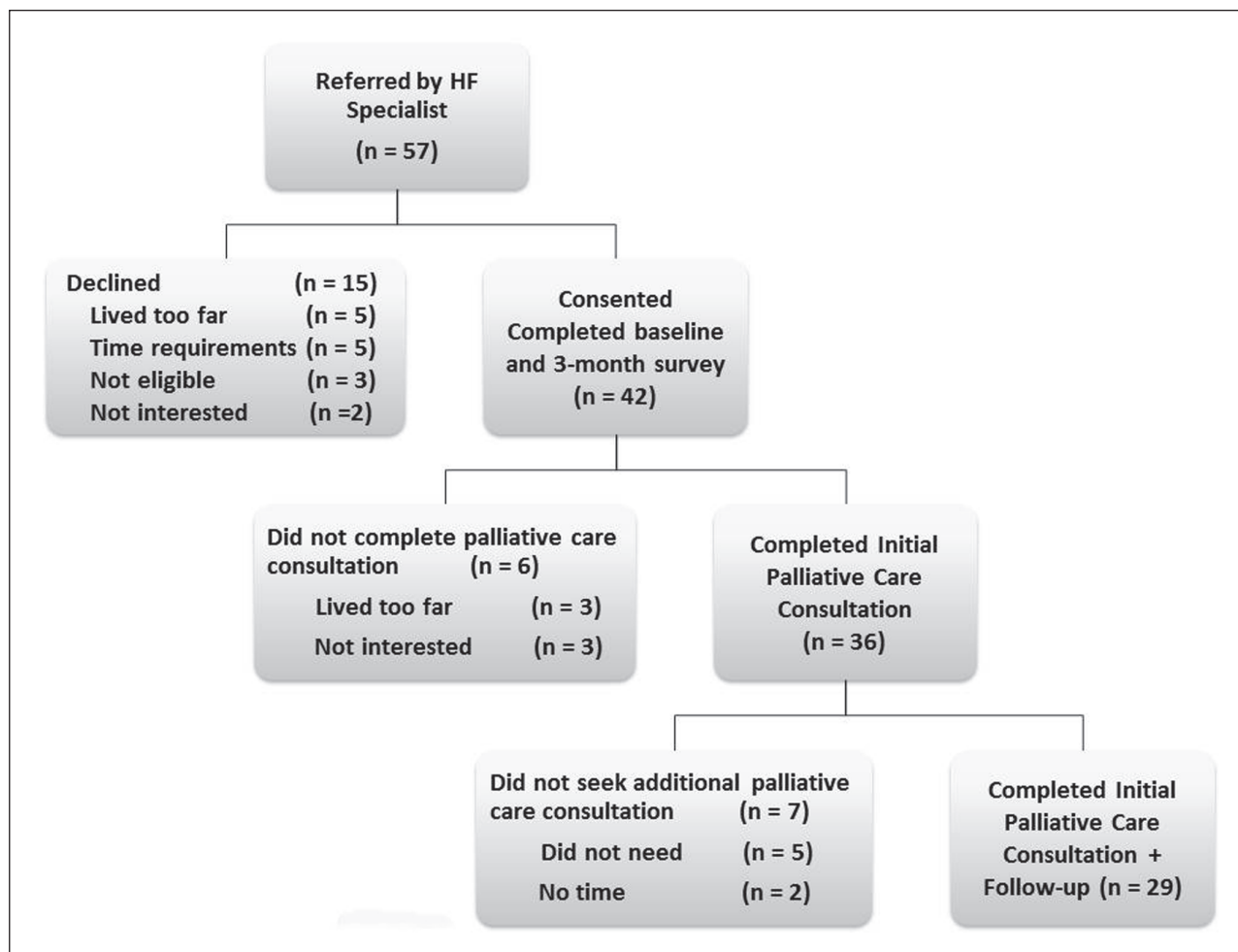


Figure 1. Flow diagram of study process. HF: heart failure.

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 who availed themselves of ≥ 2 PC consultations totaled 64 and 45, respectively.¹³ Table 1 shows the sociodemographic and clinical characteristics of participants who reported ≤ 1 PC consultation vs ≥ 2 PC consultations; no significant differences between the two groups were observed.

Perceived control, activation, and symptom distress

Data showed that perceived control and activation levels were fairly low at baseline in both groups (Table 2). Using a repeated measures general linear model, and assessing the total study population, time was a statistically significant predictor of perceived control ($F=65.1, p<0.001$), activation ($F=27.0, p<0.001$), and symptom distress ($F=68.3, p<0.001$). No differences were observed in perceived control, activation, and symptom distress at baseline between the two groups; however, participants who received on-going

PC care reported significantly greater improvements in perceived control ($F=26.5, p<0.001$) and activation scores ($F=14.4, p<0.001$) and greater reductions in symptom distress ($F=4.5, p=0.040$) compared to their counterparts.

Table 3 shows the proportion of participants who reported increased activation levels at three months and the corresponding average increase at three months according to the baseline activation level and number of PC services accessed. A significantly greater proportion of participants who attended two or more PC consults showed increases in their activation levels ($p<0.001$) following the intervention compared to their counterpart.

Bivariate analyses

Table 4 illustrates the correlation between the key variables. In the entire sample, race was associated with increased perceived control at baseline ($r=0.430, p<0.001$); Hispanics had the lowest perceived control scores followed by Blacks. On-going PC was related to perceived control ($p<0.001$); activation levels ($p=0.006$); and

Table 1. Baseline sociodemographic and clinical characteristics (n=42).

	All participants (n=42)	Participants receiving ≤1 palliative care consultation (n=13)	Participants receiving > 2 palliative care consultations (n=29)	Sig.
Age, years (mean±SD)	53.7±7.9	52.5±7.6	53.3±7.3	0.930
Male, n (%)	30 (71.4)	8 (61.5)	22 (84.6)	0.383
Race, n (%)				0.168
Hispanic	7 (16.7)	3 (23.1)	4 (13.8)	
White	24 (57.1)	5 (38.5)	19 (55.5)	
Black	11 (26.2)	5 (38.5)	6 (20.7)	
Married, n (%)	29 (69.0)	10 (76.9)	19 (65.5)	0.578
Education, n (%)				0.664
<High school graduate	18 (42.9)	4 (30.8)	14 (48.3)	
Some college	12 (28.6)	4 (30.8)	8 (27.6)	
>College graduate	12 (28.6)	5 (38.5)	7 (24.1)	
Ejection fraction, % (mean±SD)	26.1±6.2	30.5.14±9.7	23.1±4.3	0.094
Charlson Comorbidity Index	3.7±1.5	3.5±1.0	2.7±1.4	0.134
NYHA class, n (%)				0.983
Class II	29 (69.0)	9 (69.2)	20 (69.0)	
Class III	13 (31.0)	4 (30.8)	9 (31.0)	
Comorbidities				
Hypertension, n (%)	26 (61.9)	7 (53.8)	19 (65.5)	0.823
Coronary artery disease, n (%)	23 (54.8)	5 (38.5)	18 (62.1)	0.365
Diabetes mellitus, type 2, n (%)	16 (38.1)	7 (53.8)	9 (31.0)	0.246
Overweight or obese, n (%)	29 (69.0)	8 (61.5)	21 (72.4)	0.875
History of smoking (previous), n (%)	15 (35.7)	4 (30.8)	11 (37.9)	0.842
Medications use, n (%)				
ACE inhibitors	31 (73.8)	10 (76.9)	21 (72.4)	0.747
Angiotensin receptor blockers	8 (19.0)	3 (23.1)	5 (17.2)	0.649
Beta-blockers	31 (73.8)	10 (76.9)	21 (72.4)	0.847
Diuretics	28 (66.7)	10 (76.9)	18 (62.1)	0.178
Pain medications	14 (33.3)	6 (46.1)	8 (27.6)	0.335
Antidepressants	11 (41.0)	5 (38.5)	6 (20.6)	0.430

p<0.05; ACE: Angiotensin Converting Enzyme; NYHA: New York heart Association; SD: standard deviation.

Table 2. Comparison of perceived control and activation levels at baseline and three months for participants receiving ≤1 palliative consultation (n=13) and those receiving >2 palliative care consultations (n=29).

Participants	≤1 Palliative consultation		>2 Palliative care consultations		p value (time)	p value (G×T)
	Baseline	3-month	Baseline	3-month		
Perceived control (CAS-R)	26.5±5.9	29.2±5.0	24.9±7.4	37.4±9.1	<0.001	<0.001
Patient activation (PAM)	39.3±6.4.3	41.4±7.5	37.3±7.3	50.2±10.4	<0.001	<0.001
Symptom distress (ESAS)	27.6±11.4	23.1±10.2	35.7±7.1	28.2±5.5	<0.001	0.040

CAS-R: Control Attitude Scale-Revised; PAM: Patient Activation Measure; ESAS: Edmonton Symptom Assessment Score.

symptom distress ($p=0.038$) at three-month follow-up. Perceived control at baseline was associated with perceived control at three-month follow-up and activation scores at baseline and three-month follow-up (all

p 's<0.001), but not symptom distress at either time points. Activation scores at baseline were related to activation scores ($p=0.001$), perceived control ($p=0.007$), and symptom distress ($p=0.026$) at three-month follow-up.

Table 4. Correlational matrix for the key variables ($n=42$).

Variable	1	2	3	4	5	6	7	8
1. Race	1.000							
2. Palliative care	-0.222	1.000						
3. Perceived control (baseline)	-0.430 ^a	-0.107	1.000					
4. Patient activation (baseline)	-0.259	-0.069	0.618 ^a	1.000				
5. Symptom distress (baseline)	0.285	0.203	-0.057	-0.219	1.000			
6. Perceived control (3-months)	0.157	0.432 ^a	0.604 ^a	0.487 ^a	0.089	1.000		
7. Patient activation (3-months)	0.087	0.383 ^b	0.417 ^a	0.412 ^a	-0.057	0.838 ^a	1.000	
8. Symptom distress (3-months)	0.221	0.352 ^b	-0.298	-0.371 ^a	0.915 ^a	0.344 ^b	0.348 ^b	1.000

^a $p < 0.001$, ^b $p < 0.05$.

and activation compared to Whites.²⁶ Future research examining relationships between sociodemographic variables, perceived control, and activation in a larger sample are warranted to better explicate the impact of personal characteristics on self-management.

As the concept of patient-centered care gains momentum, health care providers need to be proactive in providing patients with the tools necessary to make informed decisions about their health care and to solve problems encountered daily from living with a chronic condition. Palliative care interventions have been seen as a means for reducing disability and promoting quality of life through more proactive measures to enhancing access to care, increasing patient involvement in managing their health, and promoting better symptom control.²⁷ The current study provides researchers and clinicians with a better understanding of the potential role of PC interventions in enhancing perceived control and care activation and promoting patient's readiness, willingness, and ability to manage their own care. We also demonstrate the potential benefits of initiating PC earlier in the HF trajectory as reflected in the data that a large proportion of our sample (69%) was New York Heart Association functional class II.

Study limitations and future work

There are several important limitations to our findings. First, we had a small, heterogeneous sample which limits the strength and generalizability of our conclusions. For example, we observed a trend for higher comorbidity scores in patients with no or limited PC access; however, the sample size was too small to detect any significant differences. Second, enrollment in the study was based on a convenience sample of patients willing to participate in the study and be referred for PC services resulting in a sample that was probably skewed toward patients with a more favorable view toward PC even before their participation. Likewise, it is possible that patients who had higher symptom distress were less likely to agree to participate in the study, thus leading to the underestimation of the prevalence and severity of symptoms. Third, because of the lack

of a true control group and the possibility of selection bias, our findings should be viewed as hypothesis-generating and in need of testing in a long-term, randomized, controlled trial. Additionally, future work designed to draw conclusions about perceived control and activation should incorporate a larger sample. Investigating other relevant outcomes, such as social support, may also be useful for future research.

Conclusion

Our findings suggest that on-going PC interventions show promise in being able to enhance perceived control and activation in patients with advanced HF and open up the possibility of planning larger studies to assess the effect of PC on these variables as possible mediators to improvements in self-management and clinical outcomes. Measuring perceived control and activation and using the information to improve PC programs and processes that support patient self-management could be an important key to reducing symptom distress and improving outcomes of care in patients with symptomatic HF.³⁻⁴ Thus, developing PC programs to promote active self-management and determining the mechanisms by which they influence outcomes warrant additional investigation.

Implications for Practice

- On-going palliative care interventions may potentially enhance perceived control and activation and warrant further investigation in a larger clinical trial.
- Integrating measures to increase perceived control and activation to support self-management may be key to implementing effective palliative care programs in heart failure patients.

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Conflicts of interest

The authors declare that they have no conflicts of interest.

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