Patient "Activation" of Patients Referred for Advanced Heart Failure Therapy

Kristen M. Tecson, PhD[a,b,*], Kyle Bass, MD[c], Joost Felius, PhD[b,d], Shelley A. Hall, MD[d], Aayla K. Jamil, MS[d], and Sandy A. Carey, PhD[e]

Advanced heart failure (HF) is a devastating chronic illness requiring complex treatment regimens and patient engagement. Having the information, motivation, and skills to live with a medical condition are conceptualized by the term, "activation." Patients referred for advanced HF therapy and their unpaid family caregiver were invited to participate in this study by completing the 10-item patient activation measure (PAM) questionnaire. Anxiety and depression were assessed via the hospital anxiety and depression scale. We compared activation, anxiety, and depression between those selected versus not selected for advanced HF therapy (left ventricular assist device or heart transplantation). We analyzed those who subsequently underwent advanced HF therapy in regards to activation and 1-year survival. There were 133 (68%) patients selected for therapy. Neither depression nor anxiety differed by selection status, but PAM levels did (p = 0.02). Those not selected for therapy were approximately 4 times more likely to have lower activation than those who were selected (8% vs 2%). Of the 133 selected patients, 110 (84%) subsequently underwent advanced HF therapy and 15 (14%) of those died within 1 year. Survival was independent of baseline anxiety (p = 0.92) and depression (p = 0.70), as well as patient and caregiver PAM (p = 0.50 and 0.77, respectively). In conclusion, patients with higher activation were more likely to be selected for advanced HF therapy. **(Am J Cardiol 2019;123:627−631)**

Heart failure (HF) is a devastating chronic illness affecting more than 26 million people and poses tremendous physical and financial burdens.[1−4] Advanced therapy (i.e., orthotopic heart transplantation [OHT] or left ventricular assist device [LVAD]) may be offered to HF patients; however, clinical teams are tasked with selecting only the best subset of candidates, those who have the self-awareness and engagement in personal care to adhere to these demanding treatments.[5−7] Having the necessary information, motivation, and skills to live with a medical condition has been conceptualized by a single term, "activation."[8] Specifically, activation refers to the patient's ability and readiness to engage in the health behaviors needed to maintain or improve his or her health.[9] Low activation has been associated with anxiety, depression, and worse clinical course[10] and high activation has been associated with better health behaviors and more favorable outcomes.[11] Hence, the purpose of this manuscript is to evaluate the association between a quantifiable measure of activation (i.e., the patient activation measure [PAM]) and mortality following advanced HF therapy referral.

Methods

This prospective study was approved by the Baylor University Medical Center's Institutional Review Board. Due to the observational nature of this survey study, the informed consent requirement was waived; however, participants were provided a written explanation of the study's goals. Patients referred for advanced HF therapy at the Center for Advanced Heart and Lung Disease at Baylor University Medical Center and their unpaid family caregiver were invited to complete the 10-item PAM questionnaire, a written survey in which respondents indicate on a 4-point Likert scale their level of agreement with statements regarding knowledge of their condition, feelings of responsibility, sense of playing an active role, and confidence in ability to follow a treatment regimen.[12] PAM results are reported as raw scores (0 to 100) and as levels ranging from 1 to 4 as follows: (1) disengaged and overwhelmed, (2) becoming aware, but still struggling, (3) taking action, (4) maintaining behaviors and pushing forward.[13] Additionally, study participants' anxiety and depression levels were assessed via the hospital anxiety and depression scale (HADS).[14] HADS anxiety and depression measures are reported as normal, borderline, or high. The selection committee that provided the final ruling on approval for advanced therapy was blinded to all survey results. Patients' decisions to participate or not participate did not influence their care.

We compared differences in patient characteristics between those selected vs those not selected for advanced HF therapy using two-sample *t* tests, Wilcoxon Rank Sum tests, Chi-square tests, and Fisher's Exact tests, as appropriate. We analyzed those who subsequently received advanced HF therapy using the same methods. Continuous

[a]Baylor Heart and Vascular Institute, Baylor Scott & White Research Institute, Dallas, Texas; [b]Department of Internal Medicine, Texas A&M University College of Medicine Health Science Center, Dallas, Texas; [c]Soltero Cardiovascular Research Center, Baylor University Medical Center, Dallas, Texas; [d]Annette C. and Harold C. Simmons Transplant Institute, Baylor Scott & White Research Institute, Dallas, Texas; and [e]Abbott, Saint Paul, Minnesota. Manuscript received July 25, 2018; revised manuscript received and accepted November 1, 2018.

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*Corresponding author: Tel: (214)820-5451; fax: (214)820-7393
E-mail address: kristen.tecson@bswhealth.org (K.M. Tecson).

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variables are reported as mean ± standard deviation, or as median [quartile 1, quartile 3], if skewed. Categorical variables are presented as frequencies (percentages). Analyses were conducted in SAS (Cary, NC) version 9.4 assuming a type I error rate of 5%.

Results

There were 133 (68%) patients selected for advanced HF therapy and 63 (32%) who were not (Table 1, Figure 1). There were no statistically significant relationships detected between PAM levels and patient characteristics (p's >0.28), with the exception of chronic obstructive pulmonary disease (p = 0.04), which was associated with higher rates of low activation. Neither race nor age differed by selection status, with the majority of patients being white and the middle half of respondents aged in 48 to 65 years. There was a significantly higher proportion of males accepted for therapy than women (p = 0.04). Whereas neither anxiety nor depression levels differed by selection status (p = 0.30, 0.40, respectively), we observed significantly different PAM levels between those selected for advanced therapy and those who were not (p = 0.02). Particularly, those who were not selected for therapy were approximately 4 times more likely to be in the lowest level of activation compared with those who were selected (i.e., 8% of nonselected patients vs 2% of selected patients showed signs of disengagement or being overwhelmed; Table 1). Further, those who were selected had a higher prevalence of being categorized as either of the two highest activation levels when compared with those who were not selected. Interestingly, whereas the caregivers' PAM levels did not differ significantly by selection status, patients who were selected for therapy were more likely to have a caregiver complete the PAM questionnaire (97% vs 83%). Individuals who were not selected for advanced therapy were not regularly followed-up; however, 28 such participants' mortality status was fully known at 1 year following baseline; 29% of those participants died within 1 year, compared with 15% of those who were approved for advanced therapy (p = 0.10).

Of the 133 patients selected for therapy, 110 (84%) had undergone advanced HF therapy (i.e., LVAD or OHT) at the time of analysis (Table 2). Fifteen (14%) died within 1 year of surgery, with men faring significantly better than

Table 1
Characteristics of patients evaluated for advanced heart failure therapy (n = 196)

Variable	Selected (n = 133)	Not selected (n = 63)	p Value
Men	110 (83%)	44 (70%)	0.04
Age (years)	58 [49, 65]	57 [48, 65]	0.80
Race			0.06
Asian	1 (1%)	1 (2%)	
Black	23 (17%)	19 (30%)	
White	109 (82%)	43 (68%)	
Hispanic	8 (6%)	7 (11%)	0.25
Insurance			0.27
Medicare/Medicaid	70 (53%)	41 (65%)	
Private	58 (44%)	20 (32%)	
Uninsured	5 (4%)	2 (3%)	
Chronic obstructive pulmonary disease	7 (5%)	5 (8%)	0.53
Diabetes mellitus	42 (32%)	22 (35%)	0.64
Chronic kidney disease	13 (10%)	18 (29%)	<0.001
Prior sternotomy*	95 (71%)	19 (33%)	<0.001
Ischemic etiology**	54 (42%)	29 (50%)	0.30
PAM Score	66 [59, 76]	63 [53, 76]	0.07
PAM Level			0.02
1	2 (2%)	5 (8%)	
2	15 (11%)	14 (22%)	
3	74 (56%)	28 (44%)	
4	42 (32%)	16 (25%)	
Caregiver PAM Level***			0.79
1	2 (2%)	1 (2%)	
2	9 (7%)	6 (11%)	
3	56 (43%)	23 (42%)	
4	62 (48%)	25 (46%)	
Anxiety Level			0.30
Abnormal	21 (16%)	14 (22%)	
Borderline	27 (20%)	8 (13%)	
Normal	85 (64%)	41 (65%)	
Depression Level			0.38
Abnormal	11 (8%)	7 (11%)	
Borderline	19 (14%)	13 (21%)	
Normal	103 (77%)	43 (68%)	

*Missing 5; **Missing 9; ***Missing 12.

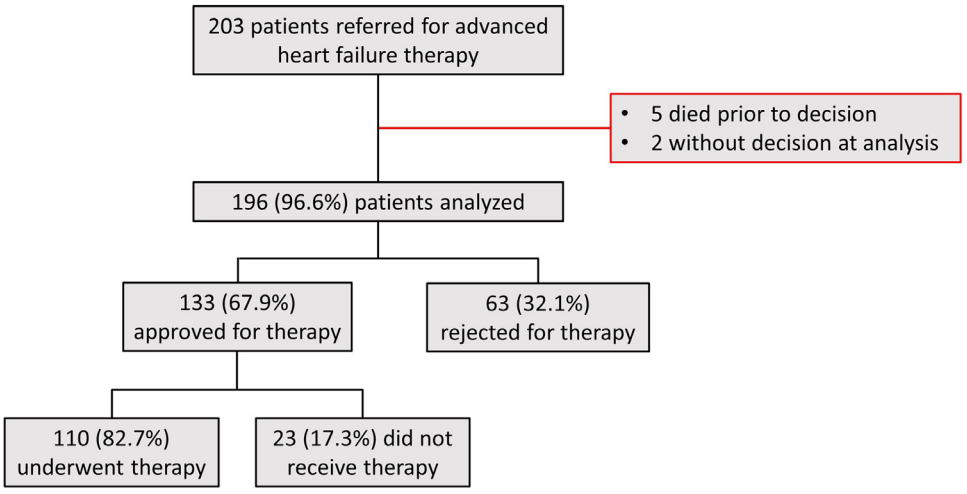

Figure 1. Patient flow diagram.

Table 2
Characteristics of patients who received advanced heart failure therapy (n = 110)

Variable	Living		p Value
	Yes (n = 95)	No (n = 15)	
Men	82 (86%)	9 (60%)	0.02
Age (years)	60 [52, 65]	52 [44, 60]	0.07
Race			0.20
Asian	1 (1%)	0 (0%)	
Black	18 (19%)	0 (0%)	
White	76 (80%)	15 (100%)	
Insurance			0.01
Medicare/Medicaid	51 (54%)	6 (40%)	
Private	43 (45%)	6 (40%)	
Uninsured	1 (1%)	3 (20%)	
Chronic obstructive pulmonary disease	5 (5%)	1 (7%)	1.00
Diabetes mellitus	25 (26%)	8 (53%)	0.06
Chronic kidney disease	10 (11%)	0 (0.0%)	0.35
Prior sternotomy	70 (74%)	9 (60%)	0.35
Ischemic etiology*	41 (44%)	7 (47%)	0.83
PAM Score	66 [59, 79]	63 [56, 72]	0.30
PAM level			0.50
1	2 (2%)	0 (0%)	
2	12 (13%)	1 (7%)	
3	47 (50%)	11 (73%)	
4	34 (36%)	3 (20%)	
CG PAM Level*			0.77
1	2 (2%)	0 (0%)	
2	5 (5%)	0 (0%)	
3	40 (42%)	8 (57%)	
4	48 (51%)	6 (43%)	
Anxiety			0.92
Abnormal	15 (16%)	2 (13%)	
Borderline	19 (20%)	4 (27%)	
Normal	61 (64%)	9 (60%)	
Depression			0.70
Abnormal	7 (7%)	2 (13%)	
Borderline	15 (16%)	2 (13%)	
Normal	73 (77%)	11 (73%)	

*Missing 1.

women (p = 0.02). Those who survived had a median age approximately 7 years greater than those who died; however, this was not significantly different (p = 0.07). Patients' survival status at 1-year was independent of PAM level for both the patient and caregiver. Survival status was also not associated with anxiety or depression.

Discussion

In this study of HF patients referred for advanced HF therapy, we found that those who were selected for therapy had significantly higher activation than those who were not selected. Further, those who subsequently received advanced HF therapy were primarily in the highest 2 activation categories (86% in level 3 or 4). We did not detect a significant relation between PAM (score or level) and 1-year mortality among the patients who received treatment.

Because patients with lower activation have poor health literacy and often require skilled care, the PAM may be an important tool to aid clinicians in identifying patients at high-risk for mortality.[15,16] Indeed, the PAM may be a good proxy for clinical judgment, as approval for therapy by the selection committee (unaware of PAM results) was associated with higher levels of activation. Thus, these results indicate that the selection committee successfully identified patients with high engagement and self-care abilities, even without the use of standardized tools. Higher activation in patients has been associated with better health outcomes, healthier behaviors, higher preventive testing compliance, and more positive interactions with health care providers, all of which are critically important skills for the recovery from advanced HF therapy.[11,17]

In a study of approximately 100 adults hospitalized for HF with an average age of 57 years, higher patient activation was associated with better self-care behaviors, perceived control, and self-efficacy.[18] Similarly, a study of participants spanning a wide age range (20 to 80 years old) reiterated that self-management factors, namely cognition and adherence, were predictive of quality of life for these individuals after LVAD implantation.[19] Conversely, nonadherence has been associated with higher rates of mortality.[20] Following advanced HF therapy, patients likely require physical therapy, which places demands on scheduling, transportation, financial, and physical abilities.[21]

As our study reiterated, patients with higher activation were more likely to be approved for advanced HF therapy. Further, those who were not approved for therapy (and had lower activation) had a mortality rate nearly twice that of participants who were approved for therapy. For this reason, it is critical for patients to be highly engaged and activated, even in early stages of the evaluation process. In many cases, it is possible to increase activation through patient education programs, which may lead to improved patient outcomes.[22] Greene and colleagues conducted a trial regarding an activation intervention and saw improvements in activation level, which were associated with desirable health outcomes and decreases in medical costs.[23] Similarly, Shivley and colleagues randomized participants to either a usual care or a usual care + activation intervention group, which included individual meetings and phone calls. Participants in the intervention group had significant increases in PAM scores from baseline to 6 months and had fewer hospitalizations, reiterating the need for targeted interventions to improve patient activation, and engagement.[24] Hibbard and Greene showed that patients with the lowest levels of activation who participate in interventions experience the largest increases in activation.[25]

Patient activation has been repeatedly associated with clinical course and quality of life; however, we did not detect associations between PAM and 1-year mortality among patients who received advanced therapy. The reason for this is likely twofold. First, the variability in PAM levels/scores effectively disappeared after the selection process; participants who received approval for therapy had high levels of activation (in our sample of patients who received therapy, 86% had level 3 or 4 activation). Conversely, a sample of frail adults by Overbeek and colleagues yielded a highly variable PAM distribution with 39% of respondents having level 1 activation, 31% with level 2, 26% level with 3, and 5% with level 4.[26] In that study, patient activation was positively associated with mental competence and quality of life, whereas a negative association with frailty was observed.[26] Secondly, there was a small number of events (deaths) in our study, yielding low statistical power. Alternatively, although we did not detect a statistically significant difference in caregivers' PAM results, patients who survived were more likely to have had a caregiver participate in the PAM study than those who died. As such, the caregiver activation results observed in this study were likely artificially inflated for the patients who were not selected for therapy (assuming that nonparticipation may be a proxy for less engagement/activation).

As the results of this study were from self-reporting, there may be presence of bias. Some participants who were not approved for advanced HF therapy had incomplete follow up information. Due to small event rates in this single center, we were unable to adjust for potential confounders and the generalizability of results may be limited. A larger study is needed to more fully understand the relation between PAM scores and the risk for mortality following advanced HF therapy. Neither education nor socioeconomic data were recorded for this study, so we were unable to assess their relations with PAM levels

In this study, patient activation was significantly higher for patients who were accepted for advanced HF therapy compared with those who were not selected. Additionally, because being approved for advanced therapy conferred a higher 1-year survival rate than not receiving approval, patients with higher engagement and activation were more likely to have favorable clinical trajectories than those who were less activated. The PAM may be a useful quantitative, objective tool to incorporate into the selection process.

Disclosures

The authors have nothing to disclose.

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