Brief Report: Patient Activation Among Urban Hospitalized Patients With Heart Failure

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Abstract

Background—Patient activation influences patients' ability to meaningfully engage in critical heart failure self-care. The purpose of this study was to identify whether patient activation is associated with patient-reported health outcomes in an urban and racially diverse inpatient sample of patients with heart failure.

Methods—We prospectively recruited patients with heart failure hospitalized at an urban academic medical center from October 2016 to May 2017 and measured patient activation, physical and affective symptoms, physical function, self-care, perceived control, and self-efficacy. Differences in patient-reported health outcomes between low and high activation groups were compared with the use of linear regression models adjusting for age, sex, education, left ventricular ejection fraction, and New York Heart Association functional classification.

Results—A total of 96 patients completed the study (mean age 57 ± 12.4 y); 39% identified as black and 35% as Latino, 35% were female, and 50% reported not having enough income to make ends meet. Based on the 4 levels of activation defined by the Patient Activation Measure–13, 22% of patients reported being "disengaged and overwhelmed," 14% were "becoming aware, but still struggling," 39% were "taking action," and 26% were "maintaining behaviors and pushing further." Higher patient activation was associated with better applied cognitive abilities, self-care behaviors, perceived control, and self-efficacy.

Conclusion—Patient activation can be easily measured in hospitalized patients with heart failure and is associated with clinically meaningful patient-reported health outcomes.

Keywords

Heart failure; self-care; patient activation; self-efficacy; perceived control

Heart failure (HF) is a chronic life-limiting syndrome that affects more than 6.5 million Americans and is increasing in prevalance.[1] The optimal management of HF relies on patients being able to participate in their own self-care, including being able to manage progressive symptoms of HF. Patient activation entails having knowledge, skills, and confidence to manage ones' own health, and it positively influences patient outcomes,[2]

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disease management,[3] and health care utilization.[4] Patient activation has also been described as one's self-concept of self-management, or the feeling of being in charge of one's own health.[5] Despite recommendations in clinical guidelines and the importance of routine patient engagement in self-care, many patients struggle to manage symptoms effectively. More activated patients may be better equipped to handle the complexity of managing symptoms of HF. The purpose of the present study was to identify whether patient activation is associated with patient-reported outcomes (ie, physical and affective symptoms, physical function, self-care, perceived control, and self-efficacy) in an urban racially diverse inpatient sample of patients with HF. The hypothesis was that higher activation would be associated with better patient-reported outcomes.

Methods

Study Design and Setting

We conducted a prospective cross-sectional study measuring patient activation and patient-reported outcomes in patients with HF at an academic urban medical center in Upper Manhattan from October 2016 to May 2017.

Participants

Patients were included in the study if they (1) had chronic HF, (2) were currently hospitalized with HF, and (3) were 20 years old. Patients were excluded if they were incapable of completing the survey questions because of psychosis or dementia. The study was approved by the Institutional Review Board and all of the participants provided written consents to participate.

Patient Characteristics

Demographic characteristics, health literacy, patient activation, and patient-reported outcomes were collected with the use of the Qualtrics web application on a tablet.

Patient-Reported Health Outcomes

Patient activation was measured by means of the Patient Activation Measure (PAM)–13, which has been validated in Spanish[6] and among hospitalized HF patients.[7] PAM scores range from 0 to 100 (higher scores indicating higher activation) and are converted to 4 levels and labeled as follows: 1) Disengaged and overwhelmed, 2) Becoming aware, but still struggling, 3) Taking action, and 4) Maintaining behaviors and pushing further.[8]

Consistent with other research,[7] we categorized patient activation as low (levels I and II) or high (levels III and IV). Self-care behavior related to HF was measured with the use of the European Heart Failure Self-Care Behavior Scale (EHFSC-9), a 9-item measure with scores that range from 9 to 45 (lower scores indicating better self-care).[9] Self-care management behavior was measured with the use of the Self-Care of Heart Failure Index v6.2.[10] Perceived control was measured with the use of the Control and Attitudes Scale,[11] and health status was measured with the use of the Kansas City Cardiomyopathy Questionnaire.[12] Health literacy was measured with 3 health literacy questions that identify

patients with "inadequate health literacy."[13] Clinical characteristics were abstracted from the electronic health record.

Physical and affective symptoms were collected with the use of a web application, mi.Symptoms, specifically designed for this study. Physical HF symptoms were measured with the use of the Heart Failure Somatic Perception Scale, which has a total score and a dyspnea subscale, both of which are associated with survival in HF.[14] Other patient-reported health outcomes included the Patient-Reported Outcomes Measurement Information System short-form questionnaires for Physical Function, Depression, Anxiety, Fatigue, Applied Cognition, and Sleep Disturbance, many of which have been validated in patients with HF.[15]

Statistical Analysis

Descriptive statistics were used to summarize baseline demographic and clinical characteristics by low and high activation (PAM levels I/II vs III/IV). Differences in baseline characteristics between the 2 activation groups were assessed with the use of t, Fisher exact, or χ^2 tests. The differences in patient-reported health outcomes between low and high activation groups were compared with the use of linear regression models with adjustment for confounding factors such as age, sex, education, left ventricular ejection fraction, and New York Heart Association Functional functional classification. Internal consistency (reliability) of the PAM was assessed with the use of Cronbach alpha. All analyses were performed with the use of SAS (v9.3).

Results

Characteristics of the 96 patients enrolled are presented in Table 1. The mean age was 57 years (range 23–77 years), 36% were female, 35% Latino, and 19% completed the study in Spanish. Regarding self-identified race, 39% were black, 28% white, 29% other, and 4% Asian.

The PAM had sufficient internal consistency (Cronbach alpha 0.92). Patient activation scores ranged from 31.7 to 100 (median 55.6, interquartile range (IQR) 51.0–72.5). Overall, 22% of patients reported being "disengaged and overwhelmed," 14% "becoming aware, but still struggling," 39% "taking action," and 26% "maintaining behaviors and pushing further."

As presented in Table 2, after adjusting for demographic and clinical characteristics in models 1 and 2, we found that patients with higher patient activation self-reported better applied cognition (β coefficient 4.6, standard error (SE) 2.2; $P = .038$) than the lower activation group. Patients in the higher activation group also reported better self-care behavior scores, measured with the use of the EHFSC-9, than the lower activation group (β coefficient −4.8, SE 1.9; $P = .016$). Patients in the higher activation group reported better self-care management (β coefficient 10.5, SE 5.5; $P = .059$). Higher activation was also associated with better self-efficacy (β co-efficient: 9.2, SE 4.7; $P = .052$) and perceived control (β coefficient 2.7, SE 1.4; $P = .056$).

Discussion

We performed a prospective study of hospitalized patients with HF to identify patient activation levels in an urban and racially diverse sample of patients with HF. More than one-third of the patients reported having low patient activation. Higher activation was associated with better self-reported cognitive abilities after adjustment for demographic and clinical factors. Patients with impaired cognition may feel less activated to participate in disease self-management. In this study, patients who reported higher activation also reported scoring higher on self-management behaviors, including reducing dietary salt, reducing fluid intake, taking an extra diuretic, or calling a doctor or nurse for guidance in response to worsening symptoms. Higher activation was also associated with better self-care behaviors, including adherence to medication, diet, and exercise, as well as self-management of symptoms. These positive changes in patients' self-management are consistent with the other studies that associate a higher PAM score with better chronic disease self-management.[16,17]

One of the goals of self-care is to help patients increase their own perception of control over the emotional adjustment of their diagnosis, ongoing prognosis, health behaviors, and responses to symptoms. In this study, there were trends toward higher activation being associated with more perceived control and self-efficacy.

The patient activation levels reported in this sample varied from others from more homogeneous hospitalized patients with HF.[18,19] Overall, one of the primary differences between our study and others is that in our study patient activation was measured in a racially diverse cohort of HF patients. In addition, the mean age in our study was 20 years younger than in a study conducted in southeastern Minnesota by Dunlay et al.[19] Like others who have reported patient activation among patients with HF, we found that patients with more education were also more likely to self-report higher activation.[19] Given the conceptual similarity, we expected that higher activation would also be associated with trends in higher perceived control and self-efficacy.

The primary limitations of this study are that it had a small sample size and was conducted as a cross-sectional study. Next steps include longitudinal data collection with the use of the mi.Symptoms tool that we developed for this project.

Conclusion

This study demonstrates that patient activation can be measured in hospitalized patients with HF and is associated with clinically meaningful patient-reported health outcomes, including applied cognition, self-care, perceived control, and self-efficacy. Measuring patient activation could aid in the identification of higher-risk patients who may need additional self-care support after discharge. This also underscores the value of supporting patients with low patient activation, especially for patients with HF who have a chronic condition that requires active self-care.

Acknowledgments

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Table 1

Baseline Demographics and Clinical Characteristics

Variable	Overall (n = 96)	Low Activation (n = 34)	High Activation (n = 62)	P Value
Age, y	56.9 ± 12.4	56.4 ± 12.9	57.2 ± 12.1	.659
Sex, female	34 (35.4%)	12 (35.3%)	22 (35.5%)	.804
Race				.930
Black or African American	37 (38.5%)	14 (41.1%)	23 (37.1%)	
Other or prefer not to answer	28 (29.2%)	9 (26.5%)	19 (30.7%)	
White	27 (28.1%)	10 (29.4%)	15 (27.4%)	
Asian or Pacific Islander	4 (4.2%)	1 (1.0%)	3 (3.1%)	
Hispanic ethnicity	34 (35.4%)	12 (35.3%)	22 (35.5%)	.985
Country of origin				.278
Dominican Republic or Puerto Rico	20 (20.8%)	9 (26.5%)	11 (17.7%)	
United States	55 (57.3%)	19 (55.9%)	36 (58.1%)	
Other	21 (21.8%)	6 (7.0%)	15 (17.4%)	
Education				.005 *
Some high school or less	24 (25.0%)	8 (23.5%)	16 (25.8%)	
High School/some college/Associate's degree	47 (49.0%)	21 (61.7%)	26 (41.9%)	
College or more	25 (26.0%)	5 (14.7%)	20 (32.3%)	
Spanish language preference	16 (18.6%)	6 (17.7%)	12 (19.4%)	.840
Income				.691
Comfortable	12 (12.6%)	5 (14.7%)	7 (11.5%)	
Have enough to make ends meet	36 (37.9%)	11 (32.4%)	25 (41.0%)	
Not enough to make ends meet	47 (49.5%)	18 (52.9%)	29 (47.5%)	
Partner				.936
Single	33 (34.4%)	9 (26.5%)	24 (38.7%)	
Married/partnered	40 (41.7%)	18 (52.9%)	22 (35.5%)	
Divorced/separated	14 (14.6%)	5 (14.7%)	9 (14.5%)	
Widowed	9 (9.4%)	2 (5.9%)	7 (11.3%)	
Inadequate health literacy				
Completing medical forms by yourself	84 (87.5%)	29 (85.3%)	55 (88.7%)	.749
Difficulty with written information	24 (25.0%)	11 (32.4%)	13 (21.0%)	.218
Reading hospital materials	15 (15.6%)	8 (23.5%)	7 (11.3%)	.114
NYHA functional classification				.349
I/II	21 (21.9%)	6 (17.7%)	15 (24.2%)	
III/IV	75 (78.1%)	28 (82.4%)	47 (75.8%)	
Left ventricular ejection fraction (%)	29.7 (±17.3)	30.3 (±16.4)	29.3 (±17.9)	.807
Medications				.817 *
Beta-blocker	56 (73.7%)	21 (77.8%)	35 (71.4%)	
ACEI/ARB	6 (7.9%)	2 (7.4%)	4 (8.2%)	
Diuretic	14 (18.4%)	4 (14.8%)	10 (20.4%)	

Results are presented as n (%) unless otherwise specified. Low activation is defined as a patient activation level of I or II and high activation as level III or IV. For continuous variables, P values were calculated with the use of 2-sample t tests. For categoric variables, P values were calculated with the use of chi-square tests. ACEI, angiotensin-converting enzyme inhibitor; ARB, angiotensin receptor blocker; NYHA, New York Heart Association.

*
Fisher exact test.

Table 2

Patient-Reported Outcomes Comparing High Patient Activation and Low Patient Activation

Outcome	Overall (n = 96)	Low-PAM (n = 33)	High-PAM (n = 61)	P Value	Model 1	Model 2
HFSPS total	44.8 ± 21	46.5 ± 20.6	43.9 ± 21.7	.579	−1.5 (4.5), .737	0.1 (4.5), .980
Dyspnea	16.5 ± 9.3	17.1 ± 8.3	16.2 ± 9.9	.655	−0.5 (6.5), .798	−0.3 (2.0), .895
PROMIS						
Physical Function	35.9 ± 8.0	33.5 ± 6.6	37.3 ± 8.4	.027	3.5 (1.7), .040	3.2 (1.7), .064
Depression	56.5 ± 11.1	56.9 ± 11.0	56.3 ± 11.2	.818	0.3 (2.3), .902	0.8 (2.2), .703
Anxiety	57.7 ± 10.6	58.5 ± 10.3	57.3 ± 10.9	.610	−0.6 (2.3), .775	0.6 (2.3), .811
Fatigue	57.6 ± 11.0	59.1 ± 10.2	56.8 ± 11.5	.321	−1.8 (2.3), .437	−1.5 (2.1), .479
Applied Cognition–Abilities	49.9 ± 9.3	47.3 ± 9.0	51.3 ± 9.2	.044	3.8 (6.6), .060	4.6 (2.2), .038
Sleep disturbance	56.4 ± 11.9	56.2 ± 10.7	56.6 ± 12.6	.892	1.1 (2.5), .673	2.3 (2.4), .340
Self-care management	72.8 ± 23.6	67.2 ± 22.5	76.0 ± 24.0	.084	8.7 (5.1), .090	10.5 (5.5), .059
Self-care behaviors	18.9 ± 8.7	21.5 ± 10.3	17.6 ± 7.4	.034	−3.4 (1.8), .058	−4.8 (1.9), .016
Control and attitudes scale	30.7 ± 6.3	28.4 ± 6.8	31.9 ± 5.8	.007	3.7 (1.3), .007	2.7 (1.4), .056
KCCQ Clinical Summary	43.1 ± 26.6	39.5 ± 27.6	45.0 ± 26.1	.335	3.6 (5.5), .513	2.0 (4.6), .657
KCCQ Self-Efficacy	78.5 ± 23.1	70.6 ± 23.8	82.9 ± 21.6	.012	11.5 (4.8), .019	9.2 (4.7), .052

Results are presented as mean ± SD. P values were calculated with the use of 2-sample t tests. Models 1 and 2 report the β coefficient (SE) for PAM group and P value adjusted, respectively, for age, sex, and education and for age, sex, education, left ventricular ejection fraction, and New York Heart Association functional classification. HFSPS, Heart Failure Somatic Perception Scale, range 0–100; KCCQ, Kansas City Cardiomyopathy Questionnaire; PAM, Patient Activation Measure; PROMIS, Patient-Reported Outcomes Measurement Information System.