

# Patient-Reported Selective Adherence to Heart Failure Self-Care Recommendations: A Prospective Cohort Study

## The Atlanta Cardiomyopathy Consortium

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Simultaneous adherence with multiple self-care instructions among heart failure (HF) patients is not well described. Patient-reported adherence to 8 recommendations related to exercise, alcohol, medications, smoking, diet, weight, and symptoms was assessed among 308 HF patients using the Medical Outcomes Study Specific Adherence Scale questionnaire (0="never" to 5="always," maximum score=40). A baseline cumulative score of  $\geq 32/40$  (average  $\geq 80\%$ ) defined good adherence. Clinical events (death/transplantation/ventricular assist device), resource utilization, functional capacity (6-minute walk distance), and health status (Kansas City Cardiomyopathy Questionnaire [KCCQ]) were compared among patients with and without good adherence. The mean follow-up was  $2.0 \pm 1.0$  years,

and adherence ranged from 26.3% (exercise) to 89.9% (medications). A cumulative score indicating good adherence was reported by 35.7%, whereas good adherence with every behavior was reported by 9.1% of patients. Good adherence was associated with fewer hospitalizations (all-cause 87.8 vs 107.6;  $P=.018$ ; HF 29.6 vs 43.8;  $P=.007$ ) and hospitalized days (all-cause 422 vs 465;  $P=.015$ ; HF 228 vs 282;  $P<.001$ ) per 100-person-years and better health status (KCCQ overall score  $70.1 \pm 24.6$  vs  $63.8 \pm 22.8$ ;  $P=.011$ ). Adherence was not associated with clinical events or functional capacity. Patient-reported adherence with HF self-care recommendations is alarmingly low and selective. Good adherence was associated with lower resource utilization and better health status. ©2012 Wiley Periodicals, Inc.

Heart failure (HF) prevalence continues to rise and is expected to worsen as the proportion of elderly population increases.<sup>1</sup> Despite advances in therapy, absolute outcomes for these patients remain suboptimal.<sup>2</sup> HF is the leading cause of hospitalization, with nearly half of all admitted patients being readmitted within 6 months of discharge.<sup>3</sup> Approximately half of HF readmissions are considered preventable, and poor adherence with recommended self-care is identified as a contributing factor in many cases.<sup>4,5</sup> Advances in therapy have resulted in an increased number of prescribed medications requiring complex daily dosing schedules.<sup>6</sup> Most HF patients are elderly with multiple comorbidities, and they may ultimately be responsible for taking more than 10 daily treatment doses.<sup>7</sup> In addition to complex medication regimens, the current guidelines include diet, exercise, and lifestyle recommendations that can be challenging for patients.<sup>8,9</sup> Adherence to some of these recommendations however, eg, medications and low-salt diet, may reduce readmissions and mortality rates.<sup>10-12</sup> Previous studies have demonstrated variable adherence to self-care depending on patient population,

specific recommendation, and the method of assessing adherence.<sup>9,13</sup> However, many prior investigations assessing adherence with HF self-care have studied only select recommendations.<sup>14,15</sup> This is concerning as many patients demonstrate selective adherence to some self-care recommendations at the expense of others.<sup>16</sup> It is possible that benefit from adherence with one, eg, medications, is neutralized by poor follow-through with another, eg, low-sodium diet or self-care behavior. In this study, we sought to comprehensively assess patient-reported adherence to 8 HF self-care recommendations, predictors of adherence, and its association with outcomes.

## METHODS

### Patient population

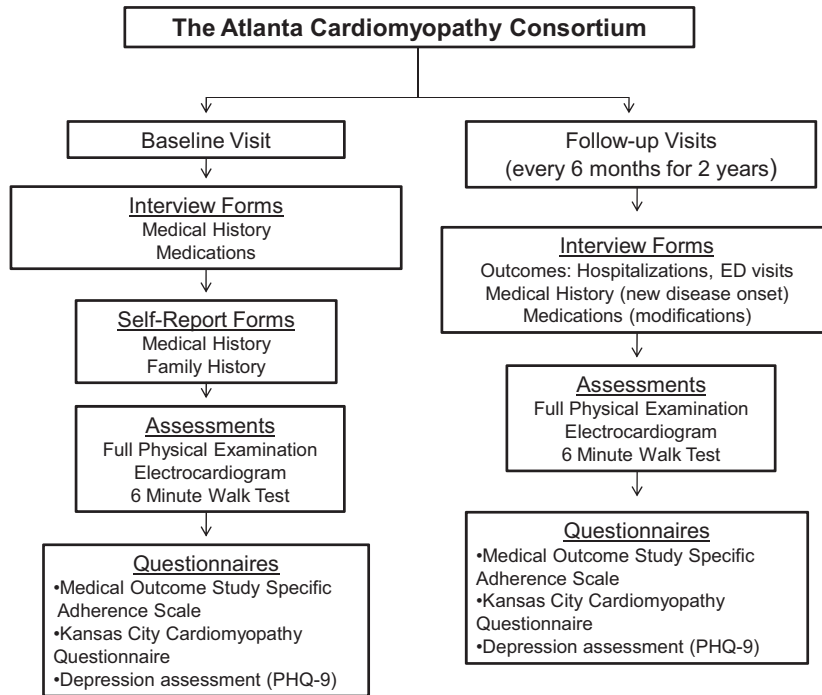
The Atlanta Cardiomyopathy Consortium is a prospective cohort study enrolling outpatients with HF from 3 university-affiliated hospitals in the greater metropolitan Atlanta area (Figure 1). Inclusion criteria included age older than 18 years, ability to understand and sign written informed consent and participate, and a diagnosis of HF with either reduced or preserved ejection fraction. The diagnosis of HF with preserved ejection fraction required, in addition to clinical diagnosis of HF, elevated B-type natriuretic peptide level  $>200$  pg/dL and/or echocardiographic evidence of diastolic dysfunction.<sup>17</sup> Exclusion criteria included congenital heart disease, previous heart transplant or awaiting

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**FIGURE 1.** The Atlanta Cardiomyopathy Consortium: study design. ED indicates emergency department; PHQ-9, Patient Health Questionnaire-9.

transplant, known cardiac infiltrative disease (eg, amyloidosis), previous other solid organ transplantation, and end-stage HF requiring outpatient continuous inotropic infusion.

### Study Procedures

All patients underwent history surveys, physical examination, electrocardiography, 6-minute walk test, several questionnaires, and collection of blood and urine samples at baseline. Race was self-reported. Education level was assessed as number of school years completed. Depression was determined based on Patient Health Questionnaire-9 (PHQ-9), which is defined below. Every 6 months, the patients were contacted to assess medication changes, procedures, new diagnoses, and hospitalizations. Mortality data were collected through medical record review, information from family members, and Social Security Death Index query. Hospitalization data were obtained from electronic health records review, outpatient notes from any specialty encounter for any admission to an outside hospital, and direct patient inquiry during follow-up. Institutional review board approved the study. Informed consent was obtained from all patients prior to enrollment. At the time of this analysis, a total of 321 patients were enrolled; of these, 308 (96.0%) completed the Medical Outcomes Study Specific Adherence Scale (MOS-SAS) for self-care behaviors at baseline and were included in the study.

### Adherence to Self-Care

Patient-reported self-care adherence was measured using the MOS-SAS questionnaire (Figure 2), an 8-item

scale that has been successfully used to measure adherence in HF, demonstrating adequate reliability and validity.<sup>18-21</sup> The self-care behaviors assessed included regular exercise, taking medication as prescribed, consuming  $\leq 1$  alcoholic beverage per day, cutting down on smoking or not smoking, following a low-salt diet or low-fat diet, weighing daily, and monitoring and paying attention to symptoms. Patients were asked how often they adhered to each behavior in the previous 4 weeks (0="none of the time," 1="a little of the time," 2="some of the time," 3="a good bit of the time," 4="most of the time," or 5="all of the time").

### Adherence Definition

There is currently no accepted standard to grade adherence for HF self-care; however, 80% level has been used to define "good" adherence to medications and is associated with an acceptable sensitivity and specificity in medication adherence studies.<sup>22</sup> We therefore used this threshold to define good adherence. Since our aim was to assess simultaneous adherence with 8 self-care measures, good adherence was defined as achieving a cumulative score of  $\geq 80\%$  (32/40 points derived from 8 questions with answer choices ranging from 0 to 5), regardless of score on individual questions. Therefore, patients could still be considered as having good adherence even if adherence was not good for any given individual behavior, as long as the overall score was  $\geq 80\%$ . We also performed a secondary analysis to assess the proportion of patients reporting  $\geq 80\%$  adherence for each of the 8 individual behaviors. For the purposes of this study, scores of 4 or 5 ("most of

	How often have you done <u>each</u> of the following in the <u>past 4 weeks</u> ?					
	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1. Exercised regularly (at least 3 times per week)	0	1	2	3	4	5
2. Took medication as prescribed (on time without skipping doses)	0	1	2	3	4	5
3. Drank 1 or less alcoholic beverage per day <i>If you don't drink, please circle number 5.</i>	0	1	2	3	4	5
4. Cut down on smoking or didn't smoke <i>If you don't smoke, please circle number 5.</i>	0	1	2	3	4	5
5. Followed a low salt diet	0	1	2	3	4	5
6. Followed a low fat diet	0	1	2	3	4	5
7. Weighed yourself every day to watch your fluid status	0	1	2	3	4	5
8. Monitored (paid attention to) your symptoms every day	0	1	2	3	4	5

**FIGURE 2.** Medical Outcomes Study Specific Adherence Scale.

the time” and “all of the time”) were combined and considered adherent for any given question.

### Patient Health Questionnaire-9

The PHQ-9 is an established reliable and valid depression screening tool, which scores each of the 9 standard (*Diagnostic and Statistical Manual of Mental Disorders—4th Edition*) criteria of depression as “0” (not at all) to “3” (nearly every day). PHQ-9 score  $\geq 10$  has 88% sensitivity and 88% specificity for major depression.<sup>23</sup>

### Self-Care Education

As part of the routine HF clinic practice, patients were educated regarding self-care behaviors at the initial consultation and each subsequent clinic visit by the nurses. During initial visit, patients and family members also watched a video describing the importance of self-care and how to best comply with it, including practical daily tips and resources. Each patient also received a copy of the patient education brochure, “A Stronger Pump: A Guide for People With All Types of Heart Failure” (Patient Education Solutions, Pritchett and Hull Associates Inc, Atlanta, GA). Additional printed reading material was given to the patients regarding low-salt diet and the sodium content in common food items. Patients were asked about self-care at each visit and given the opportunities to ask questions regarding HF self-care. Further education was provided as needed.

### Outcomes

A clinical event was defined as a composite of death, heart transplantation, or left ventricular assist device placement. Resource utilization was assessed as emergency department visits, all-cause and HF hospitalizations, and total number of days hospitalized per 100-person-year follow-up. Functional capacity was determined using the 6-minute walk test, a simple measure of functional capacity in HF patients.<sup>24</sup> Two red cones were placed 50 feet apart in a hallway adjacent to the HF clinic. Following a 2-minute rest period, baseline vital signs (heart rate, blood pressure, respiratory rate, and pulse oximetry) were taken in the right arm immediately before the test. Patients were then instructed to walk at their own pace for a total of 6 minutes and were alerted at the 3-minute mark. At the 6-minute mark, vital signs were again taken and the supervising nurse measured the distance walked and recorded the data in both meters and feet. Health status was assessed with the Kansas City Cardiomyopathy Questionnaire (KCCQ), a 23-item tool that quantifies several health status domains that include physical limitations, symptoms (frequency, severity, and recent change over time), self-efficacy, social function, and quality of life.<sup>25</sup> The KCCQ has been established as a valid, reliable, and responsive health status measure for HF.<sup>26</sup> Each scale is transformed to a score of 0 to 100, with higher scores reflecting better overall functioning, fewer symptoms,

or better quality of life. The KCCQ is also summarized into a single overall summary score ranging from 0 to 100 that reflects overall health status. It has been established that a 5-point change in the KCCQ overall summary score represents an important difference as it is related to clinical outcomes.<sup>27</sup>

### Statistical Analysis

Values are expressed as mean±standard deviation (standard deviation) for continuous and number (percentages) for categorical variables. Normality for continuous variables was assessed with normal distribution quantile graphs; non-normal variables were expressed as median and interquartile range. Descriptive analyses were performed for individual behavior as well as simultaneous adherence to all recommendations. Clinical event rates are expressed as annualized rates (total events divided by total time at risk in years) and resource utilization rates are expressed as events per 100-patient-years (total events divided by total time at risk in years multiplied by 100) to standardize for at-risk time. To identify predictors of good adherence at baseline, we first examined the association of patient characteristics with adherence in univariate logistic regression models. We then entered all univariate predictors with a *P* value of <.1 in multivariate models and used backwards elimination to identify independent predictors of good adherence. The association of baseline adherence with clinical events (death, heart transplantation, or left ventricular assist device placement) was examined with Cox proportional hazards models. The proportionality of hazards was examined using the Schoenfeld residuals. The association of adherence with health care resource utilization count data (all-cause and HF-related admissions, emergency department visits, and days in the hospital) was examined in Poisson models with time since enrollment as the exposure variable. KCCQ scores and 6-minute walk distance was compared between adherence-based groups with the non-parametric Mann-Whitney rank-sum test. A two-sided *P*<.05 was considered to be statistically significant. All analyses were performed using STATA version 11.2 (StataCorp, College Station, TX).

## RESULTS

### Study Participants

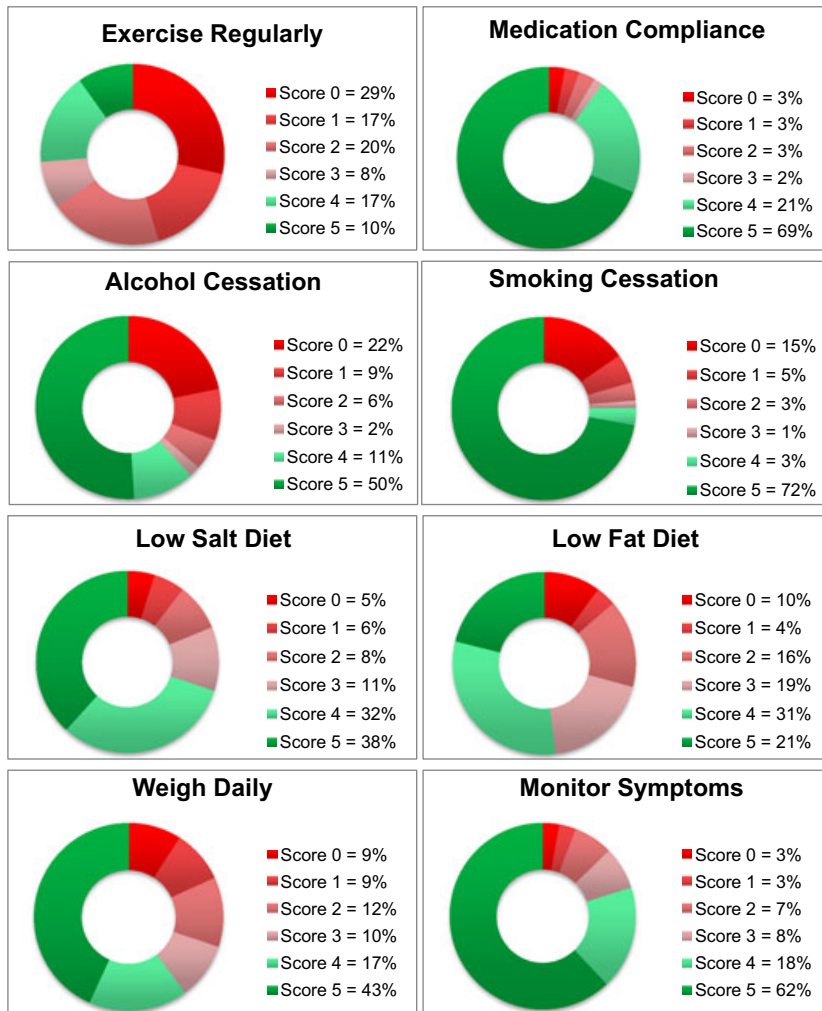
Baseline patient characteristics are presented in Table I. The mean age of patients was 57±12 years (range 25–87 years); 35.1% were female and 46.4% were black. The majority of patients had HF with reduced ejection fraction.

### Adherence

The highest adherence rates were reported with medications (89.9%), followed by symptom monitoring (79.9%). The lowest adherence rate was noted for exercise (26.3%). Good adherence was reported by

**TABLE I.** Baseline Patient Characteristics (N=308)

Characteristic	Value
<b>Demographics</b>	
Age, y	57±12
Female, No. (%)	108 (35.1)
Black, No. (%)	143 (46.4)
Insurance, No. (%)	283 (91.9)
Live alone, No. (%)	62 (20.1)
Married, No. (%)	172 (55.8)
School years, No.	14±3
Active smoking, No. (%)	41 (13.3)
<b>Heart failure characteristics</b>	
Ischemic etiology, No. (%)	124 (40.3)
Left ventricular ejection fraction, %	30.1±15.2
Ejection fraction <40%, No. (%)	217 (70.4)
<b>Comorbid conditions</b>	
Atrial fibrillation, No. (%)	45 (14.6)
Cancer, No. (%)	46 (14.9)
Chronic kidney disease, No. (%)	93 (30.2)
Coronary artery bypass surgery, No. (%)	54 (17.5)
Diabetes, No. (%)	103 (33.4)
Depression, No. (%) <sup>a</sup>	80 (26.0)
Dyslipidemia, No. (%)	159 (51.6)
Hypertension, No. (%)	207 (67.2)
Peripheral arterial disease, No. (%)	7 (2.3)
Sleep apnea, No. (%)	67 (21.8)
<b>Physical examination</b>	
Weight, kg	92.3±24.2
Waist, cm	102±16
Body mass index, kg/m <sup>2</sup>	31.0±7.3
Systolic blood pressure, mm Hg	113±20
Heart rate, beats per min	72±11
<b>Laboratory tests</b>	
Serum sodium, mEq/L	138±3
Blood urea nitrogen, mg/dL <sup>b</sup>	18 (13–26)
Creatinine, mg/dL <sup>b</sup>	1.2 (1.0–1.5)
Hemoglobin, gm/dL	13.1±1.8
B-type natriuretic peptide	208 (69, 658) <sup>b</sup>
<b>Therapy</b>	
<b>Overall</b>	
ACE inhibitor or ARB, No. (%)	242 (78.6)
β-Blocker, No. (%)	288 (93.5)
Diuretics, No. (%)	259 (84.1)
Aldosterone antagonists, No. (%)	134 (43.5)
Hydralazine and/or isosorbide dinitrate, No. (%)	78 (25.3)
Defibrillator and/or biventricular pacemaker, No. (%)	186 (60.4)
<b>Patients with ejection fraction &lt;40%</b>	
ACE inhibitor or ARB, No. (%)	178 (82.0)
β-Blocker, No. (%)	208 (95.8)
Diuretics, No. (%)	186 (85.7)
Aldosterone antagonists, No. (%)	101 (46.5)
Hydralazine and/or isosorbide dinitrate, No. (%)	60 (27.6)
Defibrillator and/or biventricular pacemaker, No. (%)	152 (70.0)
Abbreviations: ACE, angiotensin-converting enzyme; ARB, angiotensin receptor blocker. <sup>a</sup> Depression based on Patient Health Questionnaire-9 score ≥10. <sup>b</sup> Median, 25th–75th percentile.	



**FIGURE 3.** Adherence by individual self-care recommendation. Patient self-reported score 0 indicates “none of the time,” 1=“a little of the time,” 2=“some of the time,” 3=“a good bit of the time,” 4=“most of the time,” and 5=“all of the time.”

110 of 308 patients (35.7%). Adherence >80% to every single measure was reported by 28 of 308 (9.1%) patients. Figure 3 highlights adherence to the various self-care behaviors.

**Predictors of Adherence**

Among baseline patient characteristics, good adherence was positively associated with age, education, dyslipidemia, and history of coronary artery bypass surgery in univariate analysis (Table II). Depression and black race were negatively associated with adherence in univariate analysis. Marital status and insurance status were not associated with adherence. There were no sex-related differences (34.7% women vs 34.0% men; *P*=.91). In multivariate analysis, using backwards elimination, education (odds ratio [OR], 1.17 per school year; 95% confidence interval [CI], 1.07–1.28; *P*=.001) and age (OR, 1.05 per year; 95% CI, 1.02–1.07; *P*<.001) were associated with good adherence.

**TABLE II.** Association of Baseline Characteristics With Good Adherence<sup>a</sup> (N=308)

Patient Characteristics	Odds Ratio (95% Confidence Interval)	$\chi^2$	<i>P</i> Value
<b>Univariate</b>			
Age (per y)	1.04 (1.02–1.07)	18.06	<.001
Education level, per school year	1.18 (1.08–1.28)	15.02	<.001
Dyslipidemia	2.10 (1.30–3.41)	9.36	.003
Black race (vs white race)	0.52 (0.32–0.85)	7.11	.008
Coronary artery bypass grafting	2.07 (1.14–3.76)	5.72	.016
Depression	0.51 (0.29–0.90)	5.66	.021
Cancer history	2.00 (1.06–3.77)	4.57	.032
<b>Multivariate</b>			
Age (per y)	1.05 (1.02–1.07)	15.56	<.001
Education level, per school year	1.17 (1.07–1.28)	11.29	.001

<sup>a</sup>Defined as  $\geq 32/40$  points ( $\geq 80\%$ ) in the Medical Outcomes Study Specific Adherence Scale.

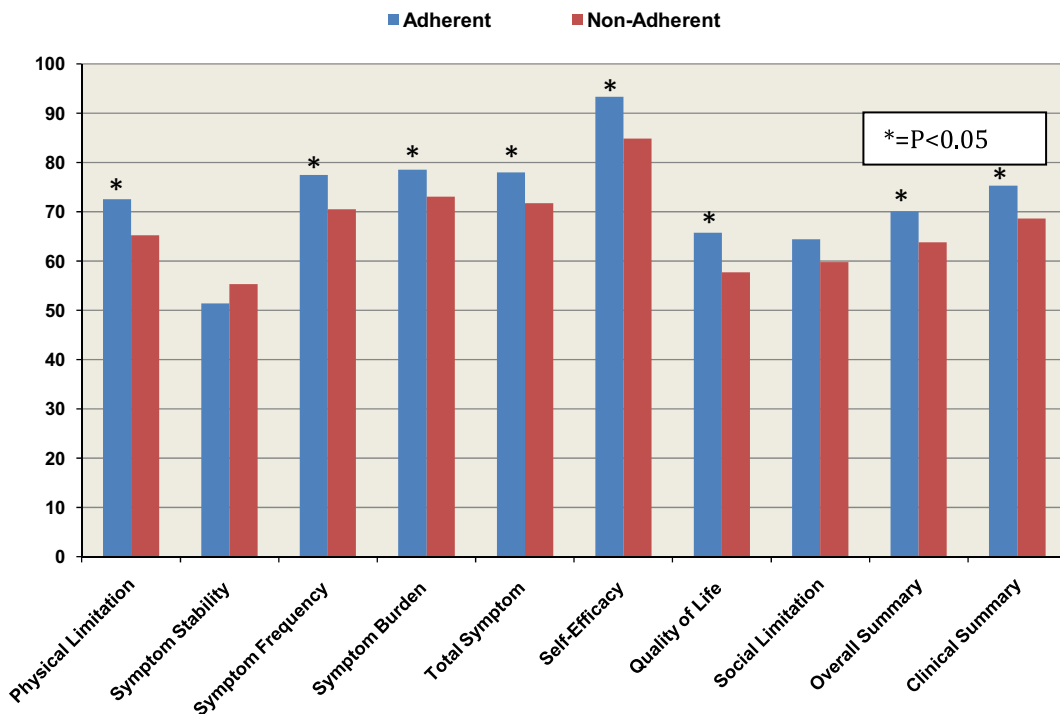
## Outcomes

During a mean follow-up of  $2.0 \pm 1.0$  years (total of 627 patient-years), 33 patients died, 5 underwent transplantation, and 2 received ventricular assist devices, for a total clinical event rate of 13.0% and annualized event rate of 6.4%. Clinical event rate was not associated with good adherence (17 of 110 [15.5%] vs 23 of 198 [11.6%]; hazard ratio, 1.36; 95% CI, 0.72–2.53;  $P=.34$ ). Good adherence was associated with reduced all-cause hospitalizations, HF hospitalizations, and number of days hospitalized as well as lower all-cause and HF-specific emergency department visits (Table III).

For the 270 patients who performed the 6-minute walk test, the mean distance was  $354 \pm 106$  m. There was no significant difference between patients with good adherence vs less optimal adherence ( $358 \pm 107$  m vs  $351 \pm 106$  m;  $P=.52$ ). Patients with good adherence had higher overall KCCQ ( $70.1 \pm 24.6$  vs  $63.8 \pm 22.8$ ;  $P=.011$ ) and clinical summary ( $75.3 \pm 22.8$  vs  $68.6 \pm 21.6$ ;  $P=.003$ ) scores. In addition, multiple KCCQ domains including physical limitation, symptom frequency, symptom burden, total symptom, self-efficacy, and quality-of-life scores were significantly better among patients with good adherence (Figure 4).

**TABLE III.** Outcomes According to Adherence Status (N=308)

Outcome	Good Adherence (N=110)	Poor Adherence (N=198)	Incidence Rate Ratio (95% Confidence Interval)	P Value
Resource utilization (per 100-person-y)				
All-cause hospitalizations	87.8	107.6	0.82 (0.69–0.97)	.018
Heart failure hospitalizations	29.6	43.8	0.68 (0.51–0.90)	.007
All-cause emergency department visits	41.4	66.9	0.62 (0.49–0.78)	<.001
Heart failure-related emergency department visits	8.2	17.2	0.48 (0.28–0.80)	.005
Total all-cause hospitalized days	422	465	0.91 (0.84–0.98)	.015
Total heart failure-related hospitalized days	228	282	0.81 (0.73–0.90)	<.001
Health Status: Kansas City Cardiomyopathy Questionnaire Scores				
Overall summary score	$70.1 \pm 24.6$	$63.8 \pm 22.8$		.011
Clinical summary score	$75.3 \pm 22.8$	$68.6 \pm 21.6$		.003



**FIGURE 4.** Health status and self care. Comparison of Kansas City Cardiomyopathy Questionnaire scores between adherent and nonadherent patients; \* $P<.05$  using the Mann-Whitney statistic.

## DISCUSSION

Less-than-desirable adherence to individual HF self-care recommendation has been described previously.<sup>28</sup> This study extends the research related to HF self-care by assessing patient-reported simultaneous adherence to 8 self-care behaviors, as opposed to assessing individual behaviors, by defining good adherence as overall a  $\geq 80\%$  cumulative score. Adherence to individual behaviors ranged from 26.3% to 89.9%; however, cumulative good adherence was alarmingly low at 35.7%, and only 9.1% of patients reported good adherence with all 8 self-care recommendations, indicating high rates of selective adherence. Older and more educated patients were more likely to be adherent, whereas active smokers were less likely. Good adherence was strongly associated with resource utilization and health status. Considering the high rate and cost of HF hospitalizations, these results are important. By studying adherence in a comprehensive fashion, we highlight the issue of selective adherence. Moreover, unlike previous literature that tended to focus on particular outcomes, we assessed a full spectrum of HF outcomes, including clinical events, resource utilization, health status, and functional capacity, thereby allowing us to globally assess the importance of self-care adherence in HF.

There is considerable variation among methods used to measure adherence to self-care. Medication adherence has been studied extensively with direct measurements, eg, observing intake or measuring drug levels.<sup>29</sup> These methods are costly and impractical for routine practice and, importantly, cannot be used for all self-care activities. Other methods include questionnaires and self-report, electronic medication monitors, and pharmacy refill data. Of these, self-report is the most widely used method, is specific, is easily employed, and is associated with outcomes.<sup>16,30,31</sup> We therefore assessed patient-reported adherence, realizing that the actual adherence may be less than self-report.

Characterization of adherence has been largely arbitrary, with most studies using an 80% threshold to define medication adherence, as this threshold has been shown to have acceptable sensitivity and specificity.<sup>22</sup> By approaching adherence in a comprehensive fashion, by defining good adherence as overall  $\geq 80\%$  adherence, we also accounted for selective adherence, which is common in HF patients. In our study, only one third of patients reported good adherence with HF self-care. Additionally, when assessed in a more rigorous fashion requiring  $\geq 80\%$  adherence to each individual recommendation,  $< 1$  in 10 patients were adherent, indicating that  $> 90\%$  of patients demonstrate selective adherence. These data suggest alarmingly low adherence with self-care and a high rate of selective adherence. These results may explain why HF self-management trials have largely failed to demonstrate significant impact on outcomes.<sup>32</sup>

Previous studies have suggested that while most HF patients have less difficulty in adhering to medications,

the majority have difficulty in adhering to exercise.<sup>33</sup> Likewise, in our study, the highest adherence was reported with medications, followed by symptom monitoring and the lowest with exercise. Although not possible to ascertain whether this is related to debilitating symptoms or lack of effort, these results are nevertheless concerning since exercise training is shown to be safe and associated with improved outcomes.<sup>34,35</sup> These results provide insight into the complex and personal nature of selective adherence and suggest the need for a deeper understanding of individuals' motivations and adherence behavior in order to inform the appropriate individualized intervention to improve outcomes.<sup>36,37</sup> It is unlikely that health care quality improvement efforts will realize their full potential without complete engagement by patients.

We found several associations between patient characteristics and self-care adherence; however, only age and education level were independently associated with good adherence. Conflicting data exist between age and adherence.<sup>39,40</sup> As the prevalence of HF increases with the aging population,<sup>1</sup> the issue of HF self-care adherence among the elderly will become even more important. Other studies have correlated higher education levels with improved adherence<sup>39,41</sup> as well as fewer emergency department visits,<sup>15</sup> and low health literacy has been associated with poor self-care and outcomes.<sup>42</sup> Other previous studies evaluating characteristics of the adherent vs nonadherent patient have reported mixed results.<sup>43-45</sup> While it is possible that adherence may vary by sex, race, and comorbidity burden, other demographic and social characteristics were not associated with good self-care in our study. We, however, highlight that younger and less-educated patients represent a particularly vulnerable population that may benefit from targeted interventions. Because adherence was related to hospitalizations, these associations are especially important because HF hospitalizations have reached an all-time high<sup>46</sup> and account for more than half of the \$39 billion annual cost of HF care.<sup>47</sup>

Although depression was not associated with adherence in multivariate analysis in our study, depression is certainly a barrier to engaging in HF self-care behaviors and is a topic deserving of special emphasis. Although few studies have evaluated the role of depression in HF self-care, some have found greater depression rates in patients with poor HF self-care.<sup>48,49</sup> As depression is the most common mood disturbance in persons with HF, ranging in prevalence from 13% to 77%, the association between depression and adherence to self-care behaviors is an important area of investigation that deserves further study.<sup>50,51</sup>

Previous studies evaluating associations between self-care and HF outcomes have shown varied results.<sup>13,52</sup> More than half of all HF hospitalizations have been linked to some form of nonadherence with self-care.<sup>4,53</sup> Some trials have demonstrated improved self-care through interventions,<sup>54</sup> with promising associations with outcomes.<sup>55</sup> However, most studies have

concentrated on only specific aspects of self-care, typically medication or dietary.<sup>5,15</sup> Our results highlight the importance of comprehensively addressing adherence in order to discourage selective focus on particular self-care measure at the expense of others.

In our study, self-care adherence was not associated with clinical event rate. We caution the interpretation of these results due to the small number of clinical events in the limited study follow-up. Other studies have demonstrated that adherence to prescribed therapy is associated with mortality reduction.<sup>56</sup> Interestingly, mortality reductions with placebo in trials likely reflect on overall pattern of self-care. We did find an association between self-care and resource utilization including emergency department visits, all-cause and HF-specific hospitalization rates, and overall number of days spent in the hospital. Also, adherent patients had improved overall health status. These results in conjunction with previous studies' suggest that better self-care is likely to improve both resource and patient-centered outcomes.

Although the problems related to suboptimal self-care are evident, how to improve them is difficult. Despite consistent education regarding proper self-care by trained HF nurses and standardized self-care instructional videos, adherence with HF self-care is low. There are no easy answers on how to change patient behavior, although there are data supporting improvement in select behaviors by certain intervention, eg, reminder systems. Future research in improving HF self-care adherence should focus on skill development, family involvement, and behavior change as well as systems of care changes. Our data regarding the poor rates of adherence with self-care highlights one of the foremost obstacles in caring for HF patients and also underscores a major hindrance in improving outcomes. Further clinical and research efforts are needed to understand reasons underlining selective adherence in order to improve self-care and associated outcomes among HF patients.

## LIMITATIONS

Our study has several limitations. Our results represent data from tertiary care specialty clinics with rigorous self-care education provided by HF nurses. It is possible that adherence is different in the community setting or that independently verified adherence is even worse than patient-reported adherence. Because eligibility for the study was contingent on the ability to comprehend and sign the written informed consent, this study does not adequately represent adherence rates among individuals who did not meet this criterion, leaving open the possibility that the adherence rates are even lower among such individuals. Also, the 80% threshold to define good adherence is arbitrary. Whether to define a different threshold, use varying threshold for various populations, or devise a modified questionnaire to quantify adherence, needs further study. Finally, all methods of assessing adherence have limitations and must be considered when interpreting

these results. This is especially true for self-report since it is particularly vulnerable to recall and selection biases.<sup>29</sup> It is likely, however, that the actual adherence to self-care is even lower and not much higher than self-report.

## CONCLUSIONS

Adherence with self-care is alarmingly low among HF patients, and selective adherence to various recommendations is common. Better adherence is associated with improved health status and reduced resource utilization. These results highlight a major opportunity for further clinical and research effort in understanding and improving self-care adherence to optimize HF outcomes.

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