

## State of the Science Promoting Self-Care in Persons With Heart Failure A Scientific Statement From the American Heart Association

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Self-care is advocated as a method of improving outcomes from heart failure (HF), the final common pathway for several prevalent illnesses, including hypertension and coronary artery disease. HF is widespread in aging populations across the world.<sup>1</sup> The burden of HF is manifested in poor quality of life (QOL)<sup>2,3</sup> and early mortality.<sup>4</sup> In addition, there are >3 million ambulatory care and emergency department visits<sup>5</sup> and well over 1 million hospitalizations for HF in the United States annually,<sup>6</sup> which contributes to the exorbitant costs associated with HF. Much of this healthcare utilization is thought to be preventable if patients engage in consistent self-care.<sup>7,8</sup>

This scientific statement seeks to highlight concepts and evidence important to the understanding and promotion of self-care in persons with HF. Specifically, the document describes what is known about (1) the self-care behaviors required of HF patients, (2) factors that make self-care challenging for patients, (3) interventions that promote self-care, and (4) the effect of self-care on HF outcomes. The review ends with evidence-based recommendations for clinicians and direction for future research.

### Self-Care Defined

Self-care is defined as a naturalistic decision-making process that patients use in the choice of behaviors that maintain physiological stability (symptom monitoring and treatment adherence) and the response to symptoms when they occur.<sup>9</sup> The term *naturalistic decision making* is used to describe how people make decisions in real-world settings. Naturalistic decision makers focus on process rather than outcomes, make decisions based on the situation, let the context influence their decision-making processes, and base practical decisions on the information available at the moment.<sup>10</sup>

In HF, self-care maintenance requires following the advice of providers to take medications, eat a low-sodium diet, exercise, engage in preventive behaviors, and actively monitor themselves for signs and symptoms. Self-care management refers to decision making in response to signs and symptoms. In HF, self-care management requires that patients recognize a change (such as increasing edema), evaluate the change, decide to take action, implement a treatment strategy (eg, take an extra diuretic dose), and evaluate the response to the treatment implemented. Self-care is not

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synonymous with treatment adherence or compliance but instead subsumes treatment adherence as 1 component of self-care.

Patients themselves, often supported by their families and caregivers, are responsible for the vast majority of HF care (self-care). Even those who are seen in the office at relatively frequent intervals or who are telephoned at home are required to engage actively in self-care. Because self-care involves behaviors such as taking medications, monitoring and interpreting symptoms, keeping appointments, and contacting healthcare providers when needed, it is impossible for a community-dwelling patient to avoid self-care.

## Specific Self-Care Behaviors

### Medication Taking

Medication adherence is generally expressed as the percentage of prescribed doses that are actually taken or taken on time. A recent review catalogued rates of medication adherence in patients with HF.<sup>11</sup> Widely varying rates (2% to 90%) have been reported, depending on the method used to measure adherence and the sample studied. One of the largest studies is that by Butler et al,<sup>12</sup> who monitored the pharmacy records of nearly 1000 patients with HF for 1 year after hospital discharge. Only 80% of patients with a prescription for an angiotensin-converting enzyme inhibitor at discharge filled the prescription during the 30 days after discharge; this rate declined further to 60% and remained roughly stable over the remainder of the year after discharge.

Depression is an important contributor to poor medication adherence.<sup>13</sup> Other common reasons for nonadherence to medications include cost, attitudes about taking medicines, and the effect of certain medicines on sexual function. In a sample of 202 HF patients newly discharged from the hospital, Moser and colleagues<sup>14</sup> found a high rate of medication nonadherence. Reasons given by patients for nonadherence (more than 1 reason could be chosen) were a lack of understanding about the discharge instructions (57%), confusion about apparently conflicting instructions given by different physicians (22%), medication cost (18%), not being convinced of the utility of the medication (9%), and worry about potential side effects (7%). Patients took medications that had not been prescribed because they had been taking them previously (68%), they lacked confidence in the new prescription (19%), they did not realize that 2 medications were the same (eg, generic versus trade name; 8%), or they confused medications of others in the household with their own (7%).

It is common in the literature to classify patients as *adherent* when  $\geq 80\%$  of doses are taken and *nonadherent* when  $< 80\%$  are taken, but the basis for this threshold is obscure.<sup>15</sup> In some situations, such as after cardiac transplantation, levels of adherence significantly greater than 80% are required to produce optimal results.<sup>16</sup> In a study in which cyclosporine adherence was monitored electronically for a 3-month period and posttransplantation outcomes were assessed for 3 years, overall medication-taking behavior was

categorized as either excellent (99.9% of medicines taken), minor nonadherence (97.0%), or moderate nonadherence (93.2%).<sup>16</sup> Those patients who excelled in adherence had significantly fewer late acute rejection events than those with minor or moderate nonadherence. These results suggest that for some drugs, higher adherence rates are needed than we may realize. In a recent study, adherence rates of greater than 88% to common HF medications were associated with better event-free survival than lower adherence rates.<sup>17</sup>

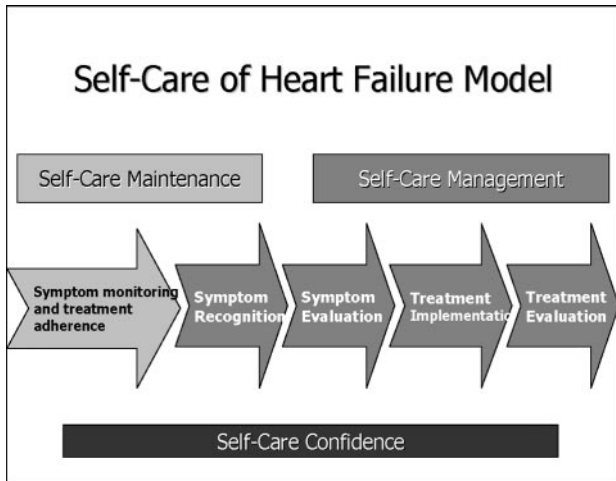
Although unproven, lower rates of medication-taking adherence are thought to be adequate in lower-risk situations or with medications with a long duration of action. In contrast, high rates of adherence are probably necessary with neurohormonal blockers, which minimize the cardiocirculatory burden of elevated norepinephrine and mediators of the renin-angiotensin-aldosterone system,<sup>18–20</sup> decrease myocardial oxygen demand<sup>21</sup> and inflammatory cytokine levels,<sup>22,23</sup> and improve myocardial function.<sup>24</sup> Because it is common to instruct HF patients to vary diuretic doses in response to changes in body weight, adherence targets are even more difficult to define for diuretics. Regardless of the medication regimen, self-care in this domain includes decisions and plans to incorporate medication taking into daily activities, obtaining initial and refill prescriptions, and managing a change of routine brought about by appointments, travel, and other illnesses.

### Symptom Monitoring

Several investigators have demonstrated that patients delay for days before seeking care for symptoms of HF.<sup>25–27</sup> This delay may be due to a failure to routinely monitor symptoms or an inability to recognize and interpret symptoms when they occur. Unfortunately, symptom-monitoring behaviors are performed infrequently by HF patients.<sup>28</sup> Fewer than half of HF patients report weighing themselves daily.<sup>29</sup> Even among patients recently discharged from a hospital for an exacerbation of HF, few weigh themselves daily even in the first week after discharge.<sup>14</sup> Of those who do weigh at least intermittently, few consider weight gain to be a significant problem.<sup>30</sup> Failure to weigh may be due to the misconception that daily weighing is a method of monitoring for gains in adipose tissue rather than fluid status.<sup>31</sup> It also may be due to the poor correlation between increases in body weight and other signs and symptoms, such as dyspnea or edema.<sup>32</sup> Thus, a gain in weight in the absence of HF symptoms may be interpreted by patients as being insignificant or unrelated to HF.

An inability to recognize early symptoms as being related to HF has been documented repeatedly<sup>9,30,33–36</sup> (Figure). Even if recognized, the interpretation of symptoms can be a challenge. In 1 study, patients were asked the importance of specific symptoms, should they occur.<sup>30</sup> The symptoms judged to be of little importance were unintentional weight loss of 3 or more pounds, sudden weight gain of 3 or more pounds, and increased severity or frequency of chest pain, all symptoms that could indicate significant clinical deterioration.

Efforts to improve patients' abilities to recognize, interpret, and act on their early symptoms may be facilitated by



**Figure.** Model illustrating that symptom monitoring and treatment adherence are a function of self-care maintenance. Self-care management requires the ability to recognize symptoms, evaluate those symptoms, implement an appropriate self-help remedy, and evaluate the effectiveness of that treatment's effect. Confidence is believed to mediate and/or moderate the effect of self-care on outcomes.<sup>33</sup> Reprinted with permission of Lippincott Williams & Wilkins.

repeated or serial assessments of specific symptoms; however, even routine and repeated queries by providers will probably not be successful until HF patients know what symptoms are most important and how to monitor for those symptoms. Those adept at early symptom recognition are relatively more likely to engage in self-initiated treatment strategies such as restricting fluid or sodium intake or taking an additional diuretic dose.<sup>37</sup> Small additional doses of a diuretic in response to worsening symptoms can decrease the risk of reactive increases in neurohormonal activation that can occur when high-dose diuretics are required during acute hospitalization.<sup>38</sup> The difficulty patients have in detecting and interpreting their symptoms has led to interest in remote monitoring and devices to monitor fluid accumulation, which may improve outcomes in the future.

### Dietary Adherence

Guidelines on the recommended intake of sodium are inconsistent, as is the terminology (eg, sodium, salt, sodium chloride). Published HF guidelines have recommended 2 to 3 g of sodium per day, 3 to 4 g/d, or have not made any specific range or upper limit.<sup>39–41</sup> Lennie<sup>42</sup> observed that both the US Department of Agriculture and the American Heart Association (AHA) Nutrition Committee recommend an upper limit of 2.3 g of sodium per day for healthy adults, which is more restrictive than that asked of persons with HF. The inconsistency in sodium recommendations reflects a striking dearth of evidence from well-controlled trials in HF patients.

Numerous investigators have documented that excess sodium intake is a precipitating factor for acute hospitalization<sup>43–45</sup>; however, many of the studies were conducted 15 to 20 years ago and may not reflect current dietary and phar-

maceutical management.<sup>42</sup> In addition, an inherent bias in these studies was the inclusion of only those patients who were hospitalized for an acute exacerbation of HF. A newly published study evaluated the effect of a normal-sodium diet compared with a low-sodium diet on rehospitalization for HF. Compensated HF patients (n=232) on a stable regimen of high-dose oral furosemide (250 to 500 mg twice daily), spironolactone, and fluid restriction (1000 mL/d) were randomized to receive a normal-sodium (120 mmol or  $\approx$ 3 g of sodium) diet or a low-sodium (80 mmol or  $\approx$ 2 g of sodium) diet beginning 30 days after hospital discharge and continuing for 6 months.<sup>46</sup> The normal-sodium group had a lower incidence of rehospitalization during follow-up and a significant decrease in plasma brain natriuretic peptide, aldosterone levels, and plasma renin activity. These findings suggest that sodium depletion may have detrimental renal and neurohormonal effects that worsen clinical outcomes in compensated HF patients; however, because of the unusually high diuretic dose, which was not titrated downward in the setting of a reduced sodium intake, the clinical relevance of this trial is uncertain. Further research is needed before practice can be changed.

In the absence of evidence from appropriately designed trials in HF patients, we recommend a sodium intake of no more than 2.3 g/d, which is the recommended upper limit of intake in the general population.<sup>47</sup> Still, we acknowledge that recommendations for sodium intake should be individualized given HF severity and the patient's current condition and medical regimen. Furthermore, extreme changes in sodium intake should be avoided, because they cause reactive increases in neurohormonal activation.<sup>48</sup> Given these considerations, a sodium intake much lower than 2.3 g/d might be appropriate in recently hospitalized or unstable patients. In contrast, among stable patients on a complicated medical regimen who are acclimated to a higher sodium intake, aggressive attempts to lower sodium intake might not be warranted.

Sodium intake in HF patients is likely high. Although survey data on sodium intake in HF patients are unavailable, it is reasonable to speculate that their intake is similar to sodium intake in the general population. According to the National Health and Nutrition Examination Survey (NHANES) III, median sodium intake among individuals 70 years of age and older was 2.3 g/d in women and 3.1 g/d in men.<sup>49</sup> In the general adult population, one quarter of adult men exceed 5200 mg of sodium per day, and one quarter of women exceed 3500 mg/d. Approximately 95% of adult men and 75% of adult women exceed the upper limit of 2300 mg of sodium per day. Similar to the general population, most HF patients have difficulty following a low-sodium diet.<sup>8,44,45,50,51</sup> In 1 HF sample, mean daily sodium intake ranged from 1398 to 5807 mg; 58% had a sodium intake  $>$ 2 g daily.<sup>52</sup> In the EuroHeart Failure survey, only 58% of patients reported receiving advice to decrease their sodium intake, and only 36% of patients reported following this advice.<sup>53</sup> In 1 study, fewer than half of the participants reported always avoiding salty foods.<sup>51</sup> The statement, "I do not eat canned soups or TV dinners" was endorsed by only a few respondents in another study.<sup>28</sup> To limit sodium intake, patients should choose

lower-sodium versions of foods that are typically rich in sodium, that is, cheese, processed meats, canned products, and baked products.

### Fluid Restriction

The 2 US HF guidelines recommend a fluid restriction <2 L/d, especially in patients with severe hyponatremia or persistent or recurrent fluid retention despite sodium restriction and use of diuretics.<sup>39,40</sup> Adherence to fluid restriction was 73% in 1 sample of HF patients.<sup>54</sup> In another sample, the statement, "I am careful not to drink 'too many' fluids" was ranked low in importance.<sup>28</sup> Only 44% of the chronic HF patients with a sudden weight gain decreased their fluid intake in response to weight gain in another study.<sup>30</sup> Unfortunately, many HF patients believe that drinking water is helpful,<sup>31,51,55,56</sup> perhaps because of the general advice given to elders and in the lay press to maintain hydration when ill.

A recently published randomized, controlled trial of fluid intake in HF patients demonstrated that it is safe and beneficial to recommend a liberal fluid prescription based on body weight in stable HF patients.<sup>57</sup> The European Society of Cardiology has just revised its guideline recommendation to state that fluid intake should be restricted to 1.5 to 2.0 L/d in patients with severe symptoms and hyponatremia, noting that routine fluid restriction in patients with mild to moderate symptoms does not confer clinical benefit.<sup>41,58</sup> In patients with severe symptoms and hyponatremia, neurohormonal activation limits the body's ability to excrete ingested sodium and water.<sup>59</sup> Thus, in select patient groups, adherence to dietary fluid and sodium restrictions can help balance sodium and water and minimize the risk of acute congestive episodes.

### Alcohol Restriction

Advice to restrict alcohol in HF is traditional, despite the fact that few data are available to guide the recommendation. The custom probably began with the recognition that a prolonged and substantial intake of alcohol can cause cardiomyopathy. There are conflicting reports of the effects of alcohol ingestion on ejection fraction.<sup>60</sup> Other potential problems associated with alcohol intake include nutritional and vitamin deficiencies. It was hoped that the SOLVD (Studies Of Left Ventricular Dysfunction) trials would clarify these issues; however, although a positive relationship was found between light to moderate alcohol intake and significant increases in serum markers of inflammation,<sup>39</sup> mortality rates were lower among light to moderate drinkers than among nondrinkers.<sup>61</sup>

Current guidelines recommend limiting intake of alcohol to no more than 1 to 2 glasses (6 to 8 oz per glass) of wine per day,<sup>41</sup> or no more than 2 glasses for men and 1 glass for women per day.<sup>39</sup> Persons with alcoholic cardiomyopathy should not drink any alcohol. Although a growing body of research acknowledges that alcohol in low to moderate amounts may prevent heart disease, alcohol is toxic to the liver, has detrimental effects on other organs, decreases motivation to limit sodium and food intake, and is an

**Table 1. Cachexia in Adults: Diagnostic Criteria**

|  |
|--|
| Underlying disease   |
| and  |
| Weight loss of $\geq 5\%$ in 12 months or less (or BMI <20 kg/m <sup>2</sup> ) |
| plus   |
| $\geq 3$ of 5 criteria:  |
| Decreased muscle strength  |
| Fatigue  |
| Anorexia   |
| Low fat-free mass index  |
| Abnormal biochemistry:   |
| Inflammation   |
| Anemia   |
| Low serum albumin  |

addictive substance. Thus, it cannot be recommended as a self-care therapy.<sup>62,63</sup>

### Weight Loss

Public opinion is focused on the obesity epidemic rather than on unhealthy weight loss; hence, most providers emphasize the need to reduce body size.<sup>64</sup> In HF patients, however, dieting is potentially harmful. A recent meta-analysis demonstrated that obese persons with HF have lower mortality and hospitalization rates than patients with a body mass index (BMI) within the normal range, a phenomenon known as the *obesity paradox*.<sup>65</sup> For reasons that are not entirely clear, obesity is a marker of the absence of significant catabolism.

Weight loss may reflect cachexia, the clinically important and terminal phase of body wasting found as a complication of several chronic illnesses, including HF. The prevalence of cardiac cachexia has been estimated at 8% to 15% in patients in New York Heart Association class II to IV. Approximately 10% of patients with advanced HF develop cachexia. The diagnosis of cardiac cachexia independently predicts a worse prognosis, apparently as an indicator of significant neuroendocrine and immune activation.<sup>66,67</sup> After heart transplantation, both preoperative cachexia and obesity are associated with decreased survival.<sup>68</sup>

A recent consensus definition for cachexia in chronic illness specifies that symptomatic cachexia is diagnosed in adults with (1) evidence of weight loss due to chronic illness of at least 5% within a 12-month period or, in cases in which weight loss cannot be documented, those whose BMI is <20 kg/m<sup>2</sup>, and (2) if they also fulfill at least 3 of the 5 clinical and laboratory criteria shown in Table 1.<sup>69</sup> General muscle wasting of the limbs along with a significant loss of fat tissue are key features of cardiac cachexia. In New York Heart Association class II or III HF, leg-muscle wasting is observed in 50% of patients, even in the absence of weight loss.<sup>70,71</sup>

The presence of obesity signifies an intact appetite and a functioning metabolism. Although the evidence is not conclusive at this point, the writing group consensus is that if BMI is >40 kg/m<sup>2</sup>, weight loss should be encouraged in

individuals with HF to bring the BMI down to  $<40 \text{ kg/m}^2$ . If BMI is  $<30 \text{ kg/m}^2$ , the writing group believes that weight loss should not be encouraged. Rather, patients should be encouraged to monitor for loss of appetite, unexpected weight loss, and muscle wasting. Our rationale for this recommendation is that weight loss is a powerful independent variable that predicts mortality in patients with chronic HF, as well as those with cancer, chronic obstructive pulmonary disease, or chronic kidney disease; elderly people discharged from a hospital; elderly nursing home patients; and persons with infections such as HIV/AIDS.<sup>69</sup> Generally, the risk of death increases with increasing magnitude of weight loss and with decreasing BMI, a phenomenon well documented for patients with systolic HF<sup>72,73</sup> and those with acute HF after myocardial infarction.<sup>74,75</sup> Recently, these findings were extended to patients with nonsystolic HF in the CHARM trial (Candesartan in Heart failure: Assessment of Reduction of Mortality and morbidity).<sup>76</sup> Furthermore, there is no evidence that weight loss prolongs life in elderly people or in patients with chronic illnesses such as HF, chronic obstructive pulmonary disease, or chronic kidney disease. The best survival has been found for patients with a BMI between 30 and 32 (to 35)  $\text{kg/m}^2$ . Considering the adverse effects of obesity on QOL and morbidity and the adverse effects of severe obesity on mortality in HF patients,<sup>77</sup> we selected a BMI of  $<30 \text{ kg/m}^2$  for our recommendation. Further research is needed before recommendations can be made for persons with a BMI between 30 and 40  $\text{kg/m}^2$ .

### Exercise

Routine exercise is a potent way to improve oxygen delivery and decrease inflammation. Exercise increases the anaerobic threshold,<sup>78</sup> increases peak oxygen uptake in persons with HF,<sup>79</sup> and increases coronary flow reserve in persons with coronary artery disease.<sup>80</sup> In moderate HF, clinical trials have shown that exercise improves  $\dot{V}_{O_2\text{max}}$ , ventilatory response, heart rate variability, and blood flow.<sup>81</sup> Exercise can decrease depression, which is common in HF. The effect of exercise on mortality is not yet clear.

Even patients with severe, symptomatic left ventricular dysfunction can benefit from an individually tailored exercise program based on the results of formal exercise testing.<sup>82</sup> In their most recent guidelines, the AHA and the American College of Cardiology (ACC) recommend exercise as a beneficial adjunctive treatment in patients with current or prior symptoms of HF and reduced left ventricular ejection fraction on the basis of level 1B evidence.<sup>40</sup>

A modest benefit was found by the Heart Failure and A Controlled Trial Investigating Outcomes of exercise training (HF-ACTION) investigators, who randomized 2331 HF patients into groups of supervised training or usual care with a recommendation to maintain physical activity.<sup>83</sup> In an intention-to-treat analysis, exercise training reduced the primary outcome of all-cause mortality and all-cause hospitalization (hazard ratio [HR] 0.93, 95% confidence interval [CI] 0.84 to 1.02,  $P=0.13$ ; adjusted for highly predictive baseline

characteristics, HR 0.89, 95% CI 0.81 to 0.99,  $P=0.03$ ). As presented at the 2008 AHA Scientific Sessions, a modest benefit was found in QOL (1.9 relative risk increase for exercise training versus usual care,  $P<0.001$ ).

Preliminary QOL results from the HF-ACTION study show that at 3 months, patients in the exercise group had a 5-point improvement in score on the Kansas City Cardiomyopathy Questionnaire, which was significantly higher than that seen in the usual-care group; however, Kansas City Cardiomyopathy Questionnaire scores did not improve further after 3 months in the exercise program. The investigators speculated that a possible reason for the lack of continued improvement was that the transition from supervised exercise to home exercise meant that patients received less social support after the early months. It is noteworthy, though, that the scores remained stable and did not decline during the home exercise period. Many patients in the usual-care group also did not experience decreased scores after the first 3 months, which might be attributable to the social support they received as part of a clinical trial.<sup>83</sup> An analysis of the number needed to treat to see a benefit revealed that 5 patients needed to be referred for exercise training to obtain a significant change (5 points or greater) in QOL. This number is lower than what has been found in most evaluations of recommended treatments for cardiovascular conditions, which suggests that exercise could be an important self-care approach to HF care.

In spite of the evidence of benefit, few persons with HF report engaging in exercise.<sup>28</sup> In 1 study, 53.2% admitted to not doing any physical activity.<sup>30</sup> In another study, 35% of patients responded to a question about physical activity by admitting that they were active somewhere between 2 times each month and never.<sup>51</sup> In HF-ACTION, adherence to the exercise regimen was difficult to maintain. At 10 to 12 months after enrollment, the median exercise duration was 74 minutes per week (interquartile range 0 to 180 minutes) despite a training goal of 120 minutes per week. This duration further decreased to a median of 50 minutes per week in the third year of follow up.

No universal prescription for a particular exercise regimen for HF patients exists, but the regimens used in the various studies suggest a few possibilities. A recent study demonstrated that waltz dancing (1 hour 3 times per week for 8 weeks at 70% peak  $\dot{V}_{O_2}$ ) was safe and improved functional capacity and endothelium-dependent dilation to an extent similar to other forms of aerobic exercise in HF patients.<sup>84</sup> Other tested regimens have varied in intensity (eg, 50%, 70%, and 80% of maximal capacity), duration, and type (eg, cycling, walking, treadmill, and circuit weight training). The results of HF-ACTION support past research and the current AHA recommendations for adequate warm-up (10 to 15 minutes) and cool-down periods and 3 to 5 exercise sessions per week, with supplemental walking on nontraining days.<sup>81,85</sup>

A recent review highlighted the importance of recognizing multiple potential barriers to exercise before trying to help patients develop a state of readiness for exercise.<sup>31</sup> Lapses in physical activity should be expected and addressed as an opportunity to look more closely at the patient's unique situation and to establish a suitable program that the patient is

likely to sustain. One of the major areas of focus for future research will be the evaluation of strategies to improve adherence, such as those used in HF-ACTION.

### Smoking Cessation

Smoking cessation advice or counseling is one of the Joint Commission's national quality measures for HF.<sup>86</sup> The rationale behind smoking cessation in HF is that nicotine has vasoconstrictor and proinflammatory activity.<sup>87,88</sup> Smoking cessation has been shown to reduce adverse outcomes and decrease mortality in HF,<sup>89</sup> yet a surprising number of people with HF continue to smoke. In a recent survey of 3778 German adults with a smoking history, more than half (52%) of those with a circulatory disorder, including HF, were current smokers.<sup>90</sup> Among those with 3 or more circulatory disorders, 28% were current smokers. Fonarow and colleagues<sup>91</sup> found that counseling on smoking cessation was documented in only 50% of individuals discharged after hospitalization in the United States for acute decompensated HF.

A recent Cochrane review of self-help interventions for smoking cessation failed to find evidence of benefit from the addition of written self-help materials to face-to-face advice or to nicotine replacement therapy.<sup>92</sup> When tailored interventions were delivered to smokers, the meta-analysis supported a small benefit of tailored information compared with no intervention. In another study that tested a tailored approach, 27% of eligible known smokers given tailored information based on lung function as tested by respiratory spirometry gave up smoking and remained nonsmokers 1 year later.<sup>93</sup> The rationale was that smokers with signs of accelerated respiratory decline may be more motivated to quit if given tailored smoking cessation advice. In a recent review of self-help quit lines, multiple call-back counseling improved long-term cessation for smokers who contacted quit-line services. Although no effect of the type of counseling or the type of self-help materials supplied to callers was found, offering more calls appeared to improve success rates.<sup>94</sup>

Tobacco quit rates appear to increase as the number of interventions provided increases.<sup>95</sup> Thus, rather than depending purely on self-help interventions, nicotine replacement therapy and antidepressants are recommended. Nicotine replacement therapy, no longer contraindicated in patients with heart disease,<sup>96</sup> increases the odds of success in quit attempts by 50% to 70%.<sup>97</sup> Newer, centrally acting medications such as varenicline also may increase smoking cessation success rates.<sup>98</sup>

### Preventive Behaviors

Routine hand washing, dental health, and maintenance of scheduled immunizations may limit inflammation and infection, which have the potential to cause tissue ischemia in persons with HF.<sup>99,100</sup> Poor dental health is linked to the development of cardiovascular disease and mortality,<sup>78</sup> although little research has been done linking dental health to HF. In 1 study, the number of missing teeth was significantly higher in nursing home patients with a history of HF.<sup>101</sup> Those with a history of atherosclerotic vascular disease, HF,

ischemic heart disease, and joint disease were most likely to be without teeth. More research is needed in this important area of self-care.

The risk of hospitalization for HF is increased during influenza season,<sup>79</sup> a risk that can be minimized by taking the influenza vaccine.<sup>80</sup> There is evidence of a significant knowledge gap regarding the risk of influenza in that HF patients do not know that a viral illness may cause rapidly worsening HF.<sup>54</sup> Thus, it is not surprising that in a European study, only 68% of community-dwelling HF patients received an influenza immunization.<sup>102</sup> In another study, factors such as age, respiratory problems, diabetes mellitus, and HF were associated with greater rates of immunization, whereas low education, smoking, and poor medication adherence were negatively associated with influenza immunization.<sup>103</sup> These results suggest that self-care maintenance behaviors (eg, diet, exercise, and medication taking) may cluster, but further research is needed before this can be said definitively.

Similarly, poor HF outcomes during the winter months may be mitigated by pneumonia immunization.<sup>104</sup> A recent report from the Centers for Disease Control and Prevention demonstrated that only 58% of adults  $\geq 65$  years had ever received a pneumococcal vaccination.<sup>105</sup> Rates were particularly low in the Hispanic population.

Attitudes and expectations may explain in part the failure by patients to pursue preventive measures. In an important recent article, a group of ambulatory HF patients surveyed about their expectations regarding their own survival were consistently optimistic.<sup>106</sup> This optimism illustrates one reason why it is difficult to engage patients who are inordinately optimistic to the point of feeling less obligated to be actively engaged in their own care. Unless motivated to actively participate in self-care, patients may not directly associate dental health, prevention of influenza and pneumonia, or symptom monitoring with prevention of HF hospitalization or other untoward HF outcomes.

### Nonprescription Medications

A self-care behavior that many HF patients engage in is the taking of nonprescription medications such as herbal remedies, alternative medicines, and over-the-counter drugs. A 1997 survey estimated that 12.1% of all adults in the United States had used an herbal medicine in the previous 12 months, up from 2.5% in 1990.<sup>107</sup> In a European study of the use of nonprescription therapy by persons with chronic HF, the vast majority (84.3%) used some drug that had not been prescribed by their physician (over-the-counter drugs were used by 75.8%, herbal remedies by 21.3%, and vitamins and minerals by 20.9%). Importantly, the patients were unaware of the possible interaction with HF therapies and seldom informed their physicians they were using these agents.<sup>108</sup> Among 252 patients with HF, one third had used complementary and alternative medicine in the past 6 months to treat a number of conditions, the most common being heart problems, weight loss, arthritis, and anxiety.<sup>109</sup>

A specific group of over-the-counter medications known to pose a significant risk to patients with HF is nonsteroidal antiinflammatory drugs (NSAIDs). Arthritis is 1 of the top 10

**Table 2. Self-Care Behaviors Recommended for Patients With HF**


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|   |
|---|
| Maintain current immunizations, especially influenza and <i>Streptococcus pneumoniae</i>  |
| Develop a system for taking all medications as prescribed   |
| Monitor for an unexpected decline in body weight and for signs/symptoms of shortness of breath, swelling, fatigue, and other indicators of worsening HF |
| Restrict dietary sodium   |
| Restrict alcohol intake   |
| Avoid other recreational toxins, especially cocaine   |
| Cease all tobacco use and avoid exposure to second-hand smoke   |
| Do not ignore emotional distress, especially depression and anxiety. Seek treatment early   |
| Tell your provider about sleep disturbances   |
| Achieve and maintain physical fitness   |
| Visit your provider at regular intervals  |
| Talk to a pharmacist or other provider about herbal medicines   |
| If diabetic, achieve diabetes mellitus treatment goals  |

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comorbid conditions in persons with HF<sup>110,111</sup> and directly influences self-care by interfering with exercise. Many patients with arthritis manage their pain and joint stiffness with NSAIDs. These agents have been shown to increase the risk of renal insufficiency and of hospitalization in persons with HF.<sup>112</sup> In a recent study, the estimated adjusted relative risk of a first hospitalization for HF was 1.3 (95% CI 1.1 to 1.6) in current users of NSAIDs relative to control subjects, after controlling for major confounding factors.<sup>113</sup> The relative risk of hospitalization in current NSAID users with a history of prior HF hospitalization was 8.6 (95% CI 5.3 to 13.8) compared with patients who did not use NSAIDs and who had no prior clinical diagnosis of HF. Therefore, guidelines state that NSAIDs should be avoided in persons with HF. It is unclear, however, what drug should be substituted for persons with inflammatory diseases such as arthritis. Aspirin cannot be recommended,<sup>114</sup> and acetaminophen may not be effective.<sup>115</sup>

Routine querying of HF patients regarding alternative and complementary therapies (to manage HF or other illness) is essential. If patients are taught to maintain a written record of all medications they are taking, including prescription, over-the-counter, and herbal supplements, it will assist in the evaluation of possible interactions. Patient interest in alternative and complementary therapies should motivate providers to stay abreast of the knowledge accumulating about the potential beneficial or detrimental effects of such therapeutics. Advocated self-care behaviors are summarized in Table 2.

### Factors That Make Self Care Difficult for Patients

Self-care management is a decision-making process. As such, factors that complicate the situation and those that interfere with the ability to make decisions interfere with self-care management, as described below.

### Comorbid Conditions

Virtually all individuals with HF have other illnesses. In a large, multicenter population admitted with acute decompensated HF, the prevalence of hypertension was 73%, whereas there was a 57% prevalence of coronary artery disease, a 44% prevalence of diabetes mellitus, and a 30% prevalence of renal insufficiency.<sup>116</sup> Both clinicians and patients have difficulty managing HF in the context of comorbid conditions. The presence of comorbidities contributes to difficulties in self-care in 4 major areas: Medication taking, dietary adherence, symptom monitoring, and decision making about how to manage multiple conditions.<sup>31</sup>

With regard to medication taking, patients with HF must cope with taking multiple medications, which is compounded by comorbidities. It is common for patients with HF and comorbidities to be taking 9 to 12 pills per day and to lack even a simple understanding of the medications taken.<sup>102,117,118</sup> Surprisingly, in prior reports, up to 12% of patients taking multiple medications did not understand the purpose or effect of the diuretic they were taking, and 50% to 77% did not understand the purpose or effects of their other medications.<sup>102,119</sup> Furthermore, adherence to prescribed medications is lower in patients with HF who have multiple comorbidities.<sup>14,102,117–120</sup> This is not to say, however, that patients should be prescribed fewer medications to increase adherence. In fact, medication adherence has been found to be higher in patients taking more medications than in those taking fewer medications.<sup>121</sup> However, it is essential that clinicians take patients' multiple comorbidities into account when counseling them about medication taking.

It becomes increasingly difficult to adhere to a low-sodium diet when comorbid conditions exist, each with different dietary requirements. As many as one third of HF patients are trying to follow 2 different diets, another third follow 3 different diets, and 11% are attempting to follow 4 diets.<sup>30</sup> Healthcare providers have not been adept at clarifying or simplifying instructions for multiple diet requirements, with the result that dietary confusion is very common among patients with HF, and adherence to this aspect of self-care is generally poor.<sup>122</sup>

Comorbidities make symptom monitoring difficult for many HF patients. Persons with comorbid lung disease find it difficult to distinguish between dyspnea caused by HF and that caused by their lung condition. Patients with diabetes often have difficulty determining the source of their symptoms and interpreting them. Those with chronic renal failure may not benefit from self-care behaviors aimed at limiting fluid retention as much as those without renal disease. As the number of comorbidities increases with age, so does the tendency of patients to attribute their symptoms to aging.<sup>118,120</sup>

Finally, lack of knowledge about how to manage comorbidities interferes with decision making in HF patients. Confusion about the various comorbid conditions and difficulty interpreting healthcare providers' instructions for multiple illnesses present barriers to effective self-care decision making.<sup>30,123,124</sup>

## Depression

Depression, the most common mood disturbance in persons with HF, ranges in prevalence from 13% to 77% depending on the method of diagnosis and the timing of assessment.<sup>125,126</sup> As many as 35% of patients with HF have clinical depression.<sup>127</sup> Among ambulatory patients with HF, the incidence and prevalence of depression are higher than in the general population.<sup>2,128–132</sup> Both depression and depressive symptoms are independently associated with hospitalization and mortality in persons with HF.<sup>131,133–135</sup> Depressive symptoms predict worse health status, and physical and social functioning, symptom burden, and QOL are poorer in outpatients with HF and depressive symptoms.<sup>132</sup>

Depression is a barrier to engaging in HF self-care behaviors, which may in part explain the observed association between depression and adverse outcomes in this population. Although few studies have evaluated the role of depression in HF self-care, some have found greater depression in patients with poor HF self-care.<sup>13,34</sup> Among persons with coronary disease, depression is associated with nonadherence to medications, decreased participation in exercise, lower adherence to diet recommendations, and lower rates of smoking cessation.<sup>136,137</sup>

Depression may hinder self-care through several mechanisms. Particularly in elders, depression is associated with impaired cognition, even when depression is in remission.<sup>138–140</sup> Depression is characterized by slowed information processing and substantial deficits in all domains of cognition, including memory, executive function, and processing speed. Thus, depression may interfere with the ability to learn, perceive symptoms, judge severity of symptoms, and make decisions about symptoms. Additionally, depression adversely affects functional status, limiting physical activity and the ability to act on worsening symptoms, independent of HF severity.<sup>141</sup> Depression often leads to social isolation<sup>141</sup> and thus poor social support, which is important in self-care skill development.<sup>34</sup> Finally, hopelessness or lack of optimism may lead to ineffective or even harmful coping mechanisms.

Although the effect of depression interventions on survival and hospitalizations is unknown in persons with HF, evidence suggests that interventions that target depression can help modify dietary behaviors and increase physical functioning.<sup>129,142</sup> Therefore, HF self-care interventions that incorporate screening for and treatment of depressive symptoms may achieve greater success than interventions that focus on education and self-care skills alone.<sup>143</sup>

## Anxiety

The paucity of research related to anxiety in patients with HF makes estimation of the prevalence of anxiety difficult. Limited evidence to date suggests that self-reported anxiety may be present in up to 50% to 70% of HF patients.<sup>7,14,144</sup> Older adults with HF report anxiety levels 60% higher than those without cardiac disease, and 40% of all persons with HF have major anxiety.<sup>145,146</sup> HF is associated with anxiety levels as high as or worse than those seen in cardiac patients without HF or in patients with cancer or lung disease.<sup>144,145,147</sup> In 1 study of clinically diagnosed anxiety disorders, panic disorder

was present in 9.3% of 258 outpatients with HF, and a comorbid anxiety disorder was present in 29% of those with panic disorder.<sup>148</sup> When a clinical diagnostic interview schedule was used, the prevalence of all clinical anxiety disorders in 100 patients with HF was 29%.<sup>149</sup> Thus, it appears that the prevalence of anxiety among patients with HF is high and covers the range of clinical anxiety disorders and self-reported symptoms of anxiety.

Anxiety may affect patients' willingness and ability to engage in self-care, because it impairs cognition, energy, and motivation.<sup>150</sup> Patients who are anxious may be unable to learn or act on new information about making necessary lifestyle changes.<sup>151</sup> They can have difficulty coping with challenges and have relatively more problems during cardiac rehabilitation.<sup>151–153</sup> Anxiety predicts worse disability, more physical symptoms, and poorer functional status even in studies that controlled for disease severity.<sup>81,154,155</sup> Thus, anxiety is expected to be associated with poor uptake of self-care behaviors.

Few investigations of the relationship between anxiety and self-care behaviors in HF exist, however, and those that do have conflicting findings.<sup>150</sup> In an Australian study in which depression, anxiety, and self-efficacy were examined as predictors of adherence to medical therapy and lifestyle change recommendations, self-efficacy was the strongest predictor, followed by anxiety, whereas depression was not predictive.<sup>156</sup> Anxiety was 1 component of a mental health instrument that was associated with overall, dietary, and exercise adherence in patients with HF.<sup>157</sup> Among HF patients recently discharged from a hospitalization for an exacerbation of HF who had a high level of anxiety (50%), adherence to a number of self-care behaviors was extremely poor.<sup>14</sup> Only 14% of patients were weighing themselves daily, 9% of patients reported monitoring for symptoms of worsening HF, 31% could not name even 1 symptom of HF, and only 34% of patients were taking all medications as prescribed.<sup>14</sup> The direct association of anxiety with self-care behaviors, however, was not measured in this study.

To date, more than 200 tools have been developed to measure anxiety, which is indicative of the considerable differences in its conceptualization and targeted patient populations.<sup>158</sup> These instruments have significant variability in their psychometric properties, which is important to researchers and clinicians seeking to identify patients at risk for poor self-care. The choice of a tool to measure anxiety should consider characteristics of specific HF subpopulations, psychometric validity, and clinical utility. Similar to depression, HF self-care interventions that incorporate screening for and treatment of anxiety may achieve greater success than those that focus on self-care education and skills alone.

## Age-Related Issues

### Young Adults

There is a growing population of adolescents with HF now surviving to adulthood.<sup>159</sup> These individuals face unique challenges, particularly related to the transition to adulthood, a time when self-care becomes a societal expectation; some have a developmental delay or a genetic syndrome that makes



self-care even more challenging. Typical adolescent milestones such as graduating from high school and leaving home can be particularly overwhelming when added to medical issues and developmental delays.<sup>160,161</sup> Many are unaware of the effects of risky behavior such as sex, competitive sports, and use of alcohol and recreational drugs on their cardiac condition.<sup>162–164</sup> Nearly one third of adolescent and young adult heart transplant recipients do not adhere to their medication regimens.<sup>163</sup> Many patients with complex disease are lost to follow-up.<sup>164</sup>

Studies of successful self-care interventions with adolescents and young adults with chronic conditions are lacking. Most research in this population is qualitative, small-sample patient and family surveys, or focus groups that evaluate the process of transition to adult care, medication adherence, and successful self-care. Determinants of success in this young population include developmental maturity and independence, recognition of the desire for normalcy, egocentrism, concrete thinking, parental involvement in care planning, short-term successes, a positive attitude and sense of self, and knowledge of the disease process.<sup>163,165–167</sup> A strong support network appears to be especially important in adolescent and young adult groups when the goal is to improve self-care.

#### Older Adults

The vast majority of persons with HF seen in clinics and hospitals are older adults. Self-care is an issue for all HF patients, regardless of age, yet the very elderly and those at the end of life may believe, “I’m too old to do this,” or, “At my age, when it’s time for me to die, it’s time.” As a general statement, treatment should be individualized on the basis of prognosis and QOL. Someone dying in hospice may not wish to eat a low-sodium diet or limit alcohol. However, self-care can improve QOL for persons with HF.<sup>168</sup>

#### Impaired Cognition

Diminished cognitive function affects 25% to 50% of patients with HF.<sup>169–171</sup> Patients with cognitive dysfunction have less knowledge about HF than those with intact cognitive function.<sup>172</sup> Impaired cognition has been shown to be associated with poor HF self-care.<sup>34,37</sup>

Compared with age-matched healthy individuals, HF patients have cognitive deficits in multiple domains, including attention/concentration, language, working memory, long-term memory, psychomotor speed, problem solving, and executive function. These cognitive deficits, found on neuropsychological testing, have been validated by studies using neuroimaging techniques in which HF patients have been found to have diminished gray matter volume in the insular cortex, frontal cortex, parahippocampal gyrus, cingulate, cerebellar cortex, and deep cerebellar nuclei compared with age-matched healthy individuals.<sup>173,174</sup> Additionally, HF patients have been shown to have significantly reduced regional blood flow in the precuneus and cuneus, the right lateral temporoparietal cortex, and the posterior cingulate gyrus compared with age-matched healthy individuals.<sup>175</sup> Self-care is a decision-making process that uses the prefrontal cortex. Thus, it is not surprising that deficits in memory, attention,

and executive function may impair the perception of, interpretation of, and reasoning about early symptoms.<sup>176</sup>

The search for reversible causes of impaired cognition is currently under way. The most likely cause of diminished cognitive function not associated with dementia in HF is low cardiac output that leads to inadequate cerebral perfusion and cerebral hypoxia.<sup>177–179</sup> Silent stroke is another potential cause of diminished cognitive function.<sup>180</sup> A third potential explanation is serum apolipoprotein E genotype, a risk factor for cognitive impairment in other populations.<sup>181</sup> Adverse effects of individual medications, drug interactions, and other comorbid conditions may also contribute to cognitive impairment in this population.

#### Sleep Disturbances

A recent Institute of Medicine report called national attention to the devastating effects of poor sleep, including potential problems with treatment adherence.<sup>182</sup> Poor sleep is associated with deficits in sustained attention, memory, executive function, and psychomotor speed.<sup>183,184</sup> With attention to the numerous factors that impair the sleep of persons with HF, it may be that sleep can be improved, which may improve cognition and thereby improve HF self-care. Sleep and HF self-care are just beginning to be examined, but in 1 study describing how expertise in HF self-care develops, those poor in HF self-care had more daytime sleepiness and worse cognition, whereas experts in HF self-care had less daytime sleepiness.<sup>34</sup> Especially in the 25% to 50% of HF patients known to have impaired cognition, poor sleep may contribute to and accentuate problems with cognition and thereby contribute to poor self-care.

Persons with HF have numerous reasons for poor sleep. HF increases the odds of having mild or severe sleep disturbance.<sup>185</sup> When sleep-disordered breathing is defined as an apnea-hypopnea index (number of apnea and hypopnea events per hour of sleep)  $\geq 15$ , approximately one third of persons with HF have sleep-disordered breathing.<sup>186</sup> When an apnea-hypopnea cut point of  $\geq 10$  is used, 60% of adults with systolic HF have sleep-disordered breathing.<sup>187</sup> A recent scientific statement from the AHA recommends an apnea-hypopnea cut point of  $\geq 5$ , which would result in most HF patients being diagnosed with sleep-disordered breathing.<sup>185</sup> And, it is not just those with systolic HF who are affected; obstructive sleep apnea has been found in  $>50\%$  of HF patients with preserved systolic function.<sup>188</sup> Early recognition and treatment of sleep-disordered breathing are important, because the episodic hypoxia that occurs with sleep-disordered breathing may cause irreversible decrements of executive function.<sup>189</sup>

Several other causes of poor sleep in persons with HF should be considered. Diuretic administration is often associated with nocturia, which may cause sleep fragmentation. Many HF patients are elderly, and insomnia is quite common in older adults.<sup>190</sup> Data from a recent study provided evidence that older subjects had less capacity for sleep and had sleep cycles that were 1.5 hours shorter than younger subjects.<sup>191</sup> Additionally, several common comorbid diagnoses are associated with poor sleep, including diabetes mellitus, chronic

obstructive pulmonary disease, nasal problems, thyroid disease, stroke, and arthritis.<sup>192</sup> Impaired sleep may also be a primary diagnostic indicator of comorbid depression.<sup>193</sup> Symptoms of nocturnal dyspnea may cause patients to rise, feeling unable to breathe, or to sleep in a recliner. Finally, a common but frequently overlooked contributor to poor sleep is the medication regimen, including drugs commonly prescribed for HF.<sup>194,195</sup>  $\beta$ -Blockers, for example, impair sleep; the mechanism appears to be a decrease in nocturnal production of melatonin.<sup>196</sup>

### Poor Health Literacy

The terms *literacy* and *health literacy* are often used interchangeably but reflect 2 different constructs. According to the National Literacy Act, literacy is the ability to read, write, and speak the language of the society, reason with numbers, and understand mathematical concepts at a level necessary to function in society. In contrast, *Healthy People 2010* defined health literacy as the ability to read and understand prescription medication instructions, appointment cards, and health materials and to process and understand basic health information and services in order to function successfully in the patient role and to make effective health decisions.

Health literacy influences patients' ability to perform self-care so substantially that the Institute of Medicine included the improvement of health literacy as 1 of 20 priority areas that could transform healthcare.<sup>197</sup> Although there have been few investigations of the impact of health literacy on HF patients' self-care, several lines of evidence converge to suggest that low health literacy is a fundamental barrier to effective self-care. Many individuals with heart disease have low health literacy,<sup>198</sup> and those most likely to have HF commonly have low health literacy.<sup>199</sup> Health literacy is lower in older than in younger people, and the health literacy of 27% of older adults receiving Medicare was below the basic level.<sup>200</sup> In a study of 653 new Medicare enrollees with at least 1 chronic disease that required self-care (ie, asthma, diabetes mellitus, HF, or hypertension), 24% had inadequate health literacy, and 12% had marginal health literacy.<sup>201</sup>

Surprisingly, formal education is not synonymous with literacy or health literacy in that one can be literate without possessing health literacy. Many clinicians believe that if patients can read and write, they are sufficiently literate to engage in effective self-care. Although persons with higher education are more likely to engage in self-care than those who are poorly educated,<sup>202</sup> a low education level does not preclude one from attaining the health literacy necessary to engage in effective self-care.<sup>203,204</sup>

As many as 90 million Americans have poor health literacy,<sup>197</sup> and this is probably a worldwide issue.<sup>205</sup> Poor health literacy impairs self-care by making it difficult for the patient to negotiate our complex healthcare system, as well as to understand and act on essential health-related information.<sup>206</sup> Approximately 14% of participants in a national survey of the health literacy of American adults did not possess basic health literacy and could not understand even simply written health information.<sup>207</sup>

**Table 3. Healthcare System Problems That Limit Self-Care**

|  |
|--|
| Deficiencies in mandated self-care education for persons with only HF                  |
| CMS Hospital Quality Alliance measures   |
| Professional society performance standards   |
| Clinical practice guidelines   |
| Hospital discharge plans   |
| For patients with HF and multiple comorbidities  |
| No quality measures, performance standards, or guidelines exist                        |
| Policy considerations in fee-for-service payer systems                                 |
| Little or no reimbursement for patient education, counseling, and coordination of care |
| Reimbursement tied to individual diseases rather than complexity                       |
| Medical care systems   |
| No common medical record   |
| Multiple providers   |
| Poor communication between providers   |
| Gaps and conflicts in current knowledge  |
| Healthcare providers   |
| Inadequate knowledge base for HF   |
| Inadequate instruction in self-care and its teaching                                   |
| Inadequate provider communication skills   |
| Inadequate or incorrect information from providers                                     |
| Poor communication between providers   |
| Inadequate training for treatment of chronic conditions                                |
| Inadequate treatment of depression and anxiety   |
| Lack of time or remuneration for self-care education                                   |
| Inadequate skill in behavioral counseling  |
| CMS indicates Centers for Medicare & Medicaid Services.                                |

In the few studies of health literacy conducted among persons with HF, health literacy was poor and was associated with poor outcomes. In a trial of a pharmacist-based intervention designed to increase adherence to HF medications, health literacy was inadequate or marginal in 28% of patients.<sup>206</sup> Cognitive impairment was predictive of low health literacy in this sample.<sup>208</sup> In another study of HF patients, 38% of the sample was unable to read and understand their own medication labels.<sup>209</sup> Importantly, this low level of health literacy predicted increased emergency department visits for cardiac-related problems.

### Problems With the Healthcare System

Virtually every component of the healthcare system fails in the goal of promoting self-care for patients with HF (Table 3). Education about HF is mentioned briefly in clinical practice guidelines,<sup>40,41,210,211</sup> but only 1 guideline provides recommendations to promote decision-making or self-care skills.<sup>39</sup> Hospital discharge plans generally reflect Centers for Medicare and Medicaid Services performance measures and ACC/AHA performance standards, but only 1 of 4 Centers for Medicare and Medicaid Services performance measures for patients discharged after an HF admission addresses self-care by requiring that discharge instructions include "written instructions or educational

material given to patient or caregiver at discharge during the hospital stay. These instructions must address all of the following: activity level, diet, discharge medications, follow-up appointment, weight monitoring and what to do if symptoms worsen.<sup>212</sup> This same performance measure is the only self-care measure of 5 performance measures recommended by the ACC/AHA Task Force on Performance Measures.<sup>213</sup>

Another issue is that each of the quality or performance measures or guidelines is directed at HF as an isolated disease process. Yet, most HF patients have multiple comorbid conditions. Therefore, providers currently are left with little guidance about the incremental benefit versus harm of multiple medications, the type and time course of benefit, and how to incorporate patient preferences and expectations into treatment plans.<sup>214,215</sup> HF performance measures, quality indicators, and clinical practice guidelines would be significantly more helpful if they addressed multiple comorbidities in the same patient, especially older patients.

Fee-for-service insurers, such as Medicare, rarely reimburse for patient education, counseling, and coordination of care. These reimbursement policies detract from important aspects of care.<sup>216</sup> Primary care providers report dealing with 3.9 medical problems per visit, which leaves little time left for patient education or self-care instruction.<sup>217</sup> Reimbursement is often based on quality indicators for individual diseases and rarely accounts for the complexity of care provided.<sup>214</sup> Although not necessarily linked directly to successful implementation of self-care programs, these reimbursement issues nevertheless influence how much education is provided in the clinical setting. As a case in point, patient education has been demonstrated to improve self-care and outcomes in diabetes mellitus.<sup>218–222</sup> As a result of this evidence, diabetes education is reimbursed.

Despite recent improvements, physicians continue to demonstrate significant deficits in adherence to both chronic and acute HF guidelines and performance measures.<sup>223,224</sup> Common deficiencies in the medical care system that discourage self-care are the lack of a common medical record and the existence of multiple providers. The average Medicare beneficiary with HF sees an average of 15 providers per year, with 8 of these prescribing medications.<sup>225</sup> Even with a common medical record, this large number of providers is likely to confuse patients. Indeed, 17% of patients with chronic conditions report receiving conflicting advice from different providers.<sup>226,227</sup>

Patients are often confused by conflicting or incomplete information.<sup>224</sup> In 1 population study, only slightly more than half (54%) of all patients and 66% in the 60- to 90-day follow-up cohort received complete discharge instructions.<sup>224</sup> These deficits are largest for use of warfarin in atrial fibrillation and for discharge instructions, the performance measure most likely to influence self-care.<sup>228</sup> Patients often perceive that they have received inadequate information from their providers and report a lack of time for adequate education. In a study of patients with HF treated in a tertiary referral center, 20% reported poor communication skills on

the part of the provider, 16% reported receiving inadequate information, and 9% reported poor communications between providers.<sup>228</sup> Furthermore, few HF providers assess health literacy and appropriately tailor information when interacting with HF patients.<sup>229</sup>

Even if self-care education were reimbursed, physician education about self-care and how to instruct patients in self-care is rarely provided in either medical school or house staff curricula. Other disciplines, especially nursing, have a high level of expertise in the education of patients and families about self-care, but the time to provide this education is often unavailable.

## Interventions That Promote Self-Care

### Skill Development

Adequate self-care requires skill in performing routine self-care maintenance behaviors (eg, meal preparation, ordering low-salt food in a restaurant) and skill in the self-care management behaviors of recognizing and making decisions about signs and symptoms and evaluating those decisions (Figure). Knowledge is important for this process, but patients require both tactical skills (eg, “how to”) and situational skill (or “what to do when”) for adequate self-care.<sup>230</sup> In some patients, these skills evolve over time and with practice.<sup>34</sup> Most patients, however, need assistance to master self-care skills.

Building self-care skill requires focusing on skill deficits and helping patients learn how to manage unique situations, yet we know little about which self-care skills are most problematic for HF patients. Neily et al<sup>231</sup> found that 42% of HF patients were poor at reading food labels, and most were unable to sort foods into high- and low-sodium foods. Hope et al<sup>209</sup> found that 62% of HF patients who accessed an emergency department were unable to read their prescription medication label. Determining what situations are challenging to patients (eg, vacation, restaurants) can illustrate special situations that might be taught with role-playing and other active exercises. Dickson and Riegel<sup>230</sup> argue that a skill-building paradigm must include the critical element of coherence, which links the individual’s unique symptoms, the HF mechanism, the cause of symptoms, and the specific action needed to avert an exacerbation of HF. Without that link, patients will continue to tell us that they know they need to follow a low-salt diet, but they are not sure how to do it.

### Behavior Change

Only a few investigators have tested interventions that are focused on changing patients’ perceptions about the benefits of self-care<sup>232</sup> and helping patients to achieve their self-care goals.<sup>233–235</sup> Techniques evaluated include individualized patient or patient and family teaching,<sup>232,235–238</sup> group educational sessions,<sup>233,234</sup> and mailed written materials.<sup>239,240</sup> Although education that increases HF knowledge and understanding is essential,<sup>54,241</sup> knowledge is not sufficient, and self-care is often unrelated to knowledge.<sup>242</sup>

Self-care requires active decision making and concerted behavior change. Guidelines and a framework for promot-

ing and continuing behavior change were developed by the National Heart, Lung, and Blood Institute and published in 2003.<sup>243</sup> A key conclusion from this effort was the importance of using theory-based interventions for enhancing self-care. Both social cognitive theory<sup>244</sup> and the stages of motivational readiness for change model<sup>245</sup> have been used to guide such interventions in community, workplace, and primary care settings, each with promising results.<sup>246–249</sup>

Counseling techniques such as motivational interviewing incorporate both social cognitive theory and the stages of motivational readiness for change model. Motivational interviewing has been shown to produce potent behavior change even in challenging substance abuse and dependence populations, as well as among those with health problems that require modifications in diet and exercise.<sup>250,251</sup> Motivational interviewing emphasizes the humanistic proposition that people are naturally motivated for growth and self-direction. The underlying premise of the approach is that with unconditional positive regard (acceptance), accurate empathy, a collaborative approach, and genuineness, people will eventually actualize their full potential to live a fulfilling life.<sup>252–254</sup>

In a pilot study of an adapted brief form of motivational interviewing, 71.4% of participants improved in HF self-care after receiving the intervention.<sup>255</sup> In a study comparing 2 motivational strategies (supportive-educative and mutual goal setting) provided by home healthcare nurses to promote self-care, no difference was found between the 2 motivational strategies, but patients in both treatment groups showed more confidence in their understanding of HF than those in a placebo group who received instruction on health-promotion activities.<sup>256</sup> More research is needed to evaluate motivational interviewing as an effective approach to improving HF self-care and outcomes.

### Family Support

Evidence for the beneficial effects of social support on outcomes of cardiovascular disease and HF is growing, along with evidence that social isolation and living alone are associated with poor self-care. Unmarried or unpartnered HF patients report greater depression,<sup>130</sup> a risk factor for poor self-care, whereas those in partnered relationships exhibit lower levels of emotional problems over time.

Social support from family, friends, and providers is associated with better medication adherence and lower readmission rates.<sup>257,258</sup> Lack of social and emotional support is related to psychosocial distress in HF patients, a factor that contributes to poor self-care.<sup>259,260</sup> In 1 prospective, multidisciplinary intervention trial, living with another person was associated with medication adherence.<sup>261</sup> In a recent study of 74 community-dwelling HF patients, perceived social support was moderately associated with better self-reported medication and dietary adherence and daily weighing.<sup>262</sup> In another study, decision making that was shared between a couple was positively related to HF self-care maintenance ( $r=0.65$ ) and self-care confidence ( $r=0.52$ ).<sup>263</sup> Family members may be particularly helpful in promoting exercise in HF patients. In a

recent review of the HF-ACTION exercise trial, the point was made that caregivers need to be aware of the multiple barriers to exercise that exist before they can help their loved ones develop a state of readiness for this important self-care behavior.<sup>264</sup>

Family-focused intervention studies in HF are limited in number, and most are still in development. In a randomized trial using a family partnership framework, Dunbar and colleagues compared a patient-family education intervention with a family partnership intervention on dietary sodium self-care in 61 HF patient–family member dyads.<sup>265,266</sup> All dyads received in-depth education, and the dyads randomized to the family partnership intervention received additional counseling on how to enhance family support, improve family communication concerning HF self-care, and provide HF patients with choice and empathy. The family partnership intervention was more effective than patient-family education alone in reducing dietary sodium intake after 3 months; however, the change was not sustained at 6 months, which indicates the need for a stronger intervention, and this is now being tested.

Few of the telemonitoring, telephone, and electronic World Wide Web–enhanced approaches to HF care have incorporated the family or caregiver. In a feasibility study, Piette et al<sup>267</sup> reported that weekly automated assessment and behavior change telephone calls to patients and family caregivers ( $n=52$  dyads) improved self-care. In contrast, a randomized controlled trial of telemonitoring for patient and caregiver dyads ( $n=102$ , 84 of whom completed the trial) found little evidence that caregiver mastery, informal social support, or electronic home monitors predicted hospital readmission.<sup>268</sup> Given the paucity of data on family interventions, more research is needed to improve the effectiveness and efficiency of family interventions and to better understand the influence of the family context on self-care.

### Systems of Care

Systems of care such as disease management and care coordination can promote self-care, because they typically are designed to focus on facilitating transitions across settings.<sup>269,270</sup> Disease management is defined by the National Library of Medicine as a systematic process of managing the care of patients with specific chronic diseases or conditions across the spectrum of outpatient, inpatient, and ancillary services. True disease management includes population identification processes, comprehensive needs assessment, proactive health promotion, patient-focused health management goals and education, self-care education, routine reporting and feedback, and ongoing evaluation of outcomes.<sup>271</sup> In 1 pretest-posttest study of 108 hospitalized HF patients enrolled in a 6-month outpatient disease-management program, self-care knowledge improved, as did the proportion of patients who weighed themselves daily. The frequency of cardiovascular hospitalizations and emergency department visits decreased, and QOL improved over time.<sup>272</sup> In a recent meta-analysis, programs that focused on enhancing patient self-care abilities reduced HF hospitalizations (relative

risk 0.66, 95% CI 0.52 to 0.83) and all-cause hospitalizations (relative risk 0.73, 95% CI 0.57 to 0.93) but had no effect on mortality (relative risk 1.14, 95% CI 0.67 to 1.94).<sup>273</sup>

Telehealth is a specific form of disease management that holds promise for improving the self-care abilities of persons with HF. The Weight monitoring in Heart Failure (WHARF) trial demonstrated that daily reporting of weight and symptoms in patients with advanced HF reduced mortality (by 56.2%;  $P < 0.003$ ) but not hospitalizations in the intervention group compared with the control group.<sup>274</sup> More sophisticated technology such as video conferencing and telephone-line transmission of weight, blood pressure, and electrocardiograms (telehealth) has been shown to be even more effective, reducing hospitalizations and days spent in the hospital.<sup>275</sup> Dansky et al<sup>276</sup> demonstrated that telehealth can reduce HF symptoms. A clinical trial by Kathryn H. Bowles, PhD, RN, et al, ongoing at this time, will provide data on whether or not improved self-care is the mechanism by which HF outcomes are improved with telehealth.

Care coordination has received relatively less attention in HF than in diabetes mellitus, although Naylor and colleagues<sup>277–279</sup> have demonstrated in a series of studies that the use of advanced practice nurses to facilitate the transition from hospital to home can improve outcomes and decrease cost in persons with HF. A fixed or bundled payment for this type of approach is being advocated to provide incentives for hospitals and providers to coordinate care.<sup>280</sup> The promotion of self-care is fundamental to the success of such an approach.

### Effect of Self-Care on Outcomes

There is surprisingly little empirical evidence of the direct relationship between HF self-care and health outcomes. In studies attempting to establish the effect of HF self-care on health outcomes, problems include the following: (1) Reciprocity of relationships between HF self-care and health outcomes and (2) temporal assignment. That is, it is often difficult to establish whether a poor outcome is driving improvements in HF self-care, or if HF self-care is driving improvements in health outcome. Without longitudinal data, it is difficult to establish which occurred first.

### All-Cause Hospitalization

Readmission rates for HF have been reported to be as high as 31% 2 months after discharge and 59% 19 months after discharge.<sup>281</sup> As part of a systematic review of randomized trials of multidisciplinary management programs in HF, McAlister and colleagues<sup>273</sup> analyzed the impact of interventions that focused on enhancing HF self-care. They concluded that self-care activities significantly reduced HF hospitalizations (relative risk 0.66, 95% CI 0.52 to 0.83) and all-cause hospitalizations (relative risk 0.73, 95% CI 0.57 to 0.93). Similarly, in a systematic review of the effect of self-care interventions on outcomes, Jovicic et al<sup>282</sup> found a decrease in

HF readmissions (odds ratio 0.44, 95% CI 0.27 to 0.71) and all-cause hospital readmissions (odds ratio 0.59, 95% CI 0.44 to 0.80). Despite an apparent benefit of self-care on hospital readmission, improvements in self-care were only implied; little or no actual measurement of self-care was included in these studies.

### Mortality

The 5-year survival rate for patients with HF has increased over time to approximately 50%, an increase attributed to more efficacious therapies for acute and chronic HF.<sup>283</sup> In the reviews described above by McAlister et al<sup>273</sup> and Jovicic et al,<sup>282</sup> no measurable effect of self-care on mortality alone was observed.

### Composite Risk of Mortality and Hospital Admission

DeWalt and colleagues evaluated the effect of a self-care program designed for HF patients with low literacy<sup>284</sup>; the intervention group had a lower rate of hospitalization or death (adjusted incident rate ratio 0.53, CI 0.32 to 0.89). In another study, Lee and colleagues<sup>285</sup> estimated the importance of HF self-care management or decision making about symptoms in explaining the risk of mortality, first hospitalization, or emergency department admission in 195 HF patients followed up for an average of 364 days. With control for common confounders, including treatment adherence, HF patients who performed above-average self-care management were much less likely to die or to be admitted to the hospital than patients who performed below-average self-care management (adjusted HR 0.44, 95% CI 0.22 to 0.88). Taken together, the results of these studies suggest an advantageous relationship between HF self-care and reduced risk of death or hospitalization.

### Cost of Care

Lee and colleagues<sup>286</sup> evaluated the influence of HF self-care on direct inpatient costs over a 6-month period in 134 self-identified Hispanic patients with HF. Measures of HF self-care explained part of the variance in direct HF inpatient cost. HF patients who were more engaged in HF self-care and who were confident in their self-care skills had markedly lower direct HF inpatient costs than those who practiced poor self-care or who lacked confidence in their self-care skills.

### Quality of Life

It is difficult to draw strong conclusions about the benefits of self-care on QOL in patients with HF; however, a recent review of the literature from 1995 to 2008 found that a predominance of studies reported a QOL benefit.<sup>287</sup> The review included 22 HF reports that tested a self-care intervention with QOL measured as an outcome. Two of the articles focused only on improving self-care.<sup>284,288</sup> In the other 20 articles, self-care was emphasized as a part of a disease-management program. Only 18 of the 22 studies

used a randomized design. When these 18 studies were reviewed, the effect of self-care interventions on QOL in HF patients was equivocal, with only 10 trials finding greater improvement in QOL in the intervention group than in the control group. In the 2 trials that tested self-care as the primary intervention, 1 reported improved QOL in the intervention group,<sup>288</sup> whereas the other reported no differences in QOL between groups.<sup>284</sup> Interestingly, QOL differences were found in studies that included relatively younger patients, predominantly men, and primarily New York Heart Association class III and IV patients.<sup>287</sup> One study that followed up patients for an additional year after the intervention ended reported a similar deterioration in QOL in patients randomized to both the intervention and control groups.<sup>266</sup> Thus, no definitive conclusion about the effect of self-care on QOL can be made.

### Recommendations for Clinicians and Directions for Future Research

At this point in time, we know the following about HF self-care: It is important to strongly encourage individuals with HF to devise systems that will help them remember to take their medications regularly and on time. Patients should monitor routinely for changes in their signs and symptoms of HF. A daily diet with 2 to 4 g of sodium is recommended. Alcohol should be discouraged or limited to 1 to 2 drinks per day of alcohol such as unfortified (ie, not port) wine for men (1 for women). Fluids probably do not need to be restricted unless patients are severely symptomatic and hyponatremic. Weight loss should be advised only when BMI exceeds 40 kg/m<sup>2</sup>. Routine exercise at levels based on prescriptions derived from the results of exercise testing is recommended for all HF patients, even those with severe, symptomatic left ventricular dysfunction, if they are currently stable and compensated. Smoking cessation, routine hand washing, daily dental hygiene, and annual vaccination against influenza are advocated. Persons over the age of 65 years should be immunized against pneumonia unless contraindicated. It is difficult for most patients to achieve all of these behaviors, with the lowest adherence rates occurring with regard to diet and exercise. Specific recommendations, based primarily on expert opinion, are summarized in Tables 2 and 4; those in Table 2 are for patients, whereas those in Table 4 are for families and healthcare providers.

Not detailed in these recommendations but essential in terms of promotion of self-care is the need for better assessment of patients by providers. The HF patient population is characterized by multiple comorbid conditions. A significant proportion is depressed, anxious, and cognitively impaired. Sleep deprivation and poor health literacy are relatively common and have been documented to compromise efforts to perform self-care. We recommend that the breadth of issues assessed by providers be expanded to include the self-care behaviors discussed in this article and the numerous factors that influence these issues. Routine, repeated, and ongoing assessment of anxiety, depression, cognition, sleep quality, finances, and availability of a family caregiver would help identify individuals who need relatively

more support. Patients found to be anxious, depressed, or cognitively impaired should be referred for further testing and treatment.

### Future Research

Further research is needed in several key areas. Accurate and consistent methods of symptom monitoring need to be developed. Patients are encouraged to weigh themselves daily, but the fact that they frequently fail to do so suggests that daily weighing is not helpful to them. A better way to detect early fluid retention is needed. Implanted devices may provide such information in the near future.

Research is needed to establish guidelines for the dietary advice given to persons with HF. At this time, dietary sodium and fluid restriction advice is still vague and generic. Recommendations about alcohol are based on logic rather than evidence. Accumulating data on the obesity paradox have illustrated that weight loss is not always the best advice for persons with HF. The experts on this panel were able to agree that weight loss should not be recommended if BMI is <30 kg/m<sup>2</sup> and that weight loss should be recommended for those with a BMI >40 kg/m<sup>2</sup>. The group between 30 and 40 BMI kg/m<sup>2</sup>, however, remains a quandary. Research is needed to clarify the BMI cut point at which weight loss should be advocated.

An important aspect of dietary advice that needs further study relates to foods thought to be proinflammatory that raise C-reactive protein levels. Examples of these foods include simple sugars, saturated fats, and excess alcohol. Foods that counteract the inflammatory response, such as fish oil supplements, olives, walnuts, flaxseed oil, fruits and vegetables, garlic, ginger, sunflower seeds, herring, and nuts, might be useful in these patients, but much more research is needed before they can be advocated.<sup>88</sup>

Other comorbid conditions that need to be studied include depression and anxiety. Research evaluating the role of depression and anxiety in self-care and the effect of interventions addressing these emotions on self-care behavior and other important outcomes is needed.

Impaired cognition is an important issue with the potential to significantly impair self-care. To date, studies have focused on determining the prevalence of cognitive impairment in HF, understanding the cognitive domains that are impaired, and elucidating the mechanisms responsible for impairment. Research is urgently needed to identify the mechanisms responsible for diminished cognitive function in HF. These studies may lead to novel interventions to treat the deficits and perhaps prevent them in the future. Limited evidence is available in HF that could be used to design testable interventions. The need to assist patients whose care is complicated by cognitive impairment, as well as their family members, remains a priority. Few prospective longitudinal studies have been conducted in representative samples that characterize the changes in cognitive function over time in HF using valid neuropsychological tests.<sup>170,171,288</sup> Without such longitudinal studies, interventions may not target the problematic areas, which makes them less likely to be efficacious.

**Table 4. Ways in Which Families and Healthcare Providers Can Promote HF Self-Care**

| Family Members   | Healthcare Providers   |
|--|--|
| Provide support by making low-sodium foods available, preparing low-sodium meals, quitting smoking or smoking elsewhere, reducing alcohol intake, and joining in the patient's exercise regimen.   | Provide structured and individually reinforced education during all clinical encounters. Consider literacy level and cultural background.  |
| Be sensitive to the need for a particularly strong support network for adolescents, young adults, and older adults with HF.  | Teach skills (eg, how to choose a low-sodium diet, how to monitor and evaluate symptoms when they occur) rather than simply providing information.                                       |
| Assist the patient in developing a system for taking all medications as prescribed. Periodically check on the success of the system and modify as needed. Assist with refills, reminders, and other cues as needed.  | Simplify the medication regimen whenever possible. Use once-daily medicines and fixed-dose combinations whenever possible.   |
| Watch for changes in HF symptoms and help patients monitor for these changes. Help HF patients practice the decision-making skills needed to plan what to do when symptoms occur.  | Assess for use of OTC medications and herbal remedies; involve a pharmacist if necessary to determine whether drug interactions are a problem.   |
| Watch for changes in cognition, depression, and anxiety that can occur with chronic HF. Patients may not notice these changes.   | Discourage NSAID use and help patients to identify alternatives.   |
| Watch for changes in appetite, weight loss, and muscle wasting.  | Treat comorbid conditions aggressively.  |
| Request referral to home care or an advanced practice nurse after discharge from the hospital or if the treatment regimen changes significantly. <sup>282,283</sup> Consider enrolling the patient in an HF disease-management program if such a program is available. | Individualize treatment on the basis of prognosis and QOL. For example, alcohol intake may be acceptable for an HF patient in hospice.   |
| Work with the patient to monitor for signs of worsening HF.  | Screen routinely for depression and anxiety. Treat depression and anxiety immediately, without waiting for symptoms to wane on their own.  |
|  | Screen routinely for barriers to self-care (eg, inability to afford medicines) so that solutions can be developed before poor self-care is evident.                                      |
|  | Encourage dental hygiene by inquiring about routine flossing and dental cleaning.  |
|  | Ask about sleep quality. Refer patients who report poor sleep, who are obese, and whose bed partner reports snoring for screening for sleep-disordered breathing.                        |
|  | Strongly encourage use of CPAP in patients with sleep-disordered breathing.  |
|  | Eliminate medications with daytime sleepiness as a side effect when possible (including as-needed medicines and OTC and herbal remedies).  |
|  | Assess cognitive abilities on an ongoing, routine basis using an approach that is sensitive to known defects in memory, executive function, and processing speed. <sup>170,171,289</sup> |
|  | Include family and friends in education and counseling activities.   |
|  | Refer to social worker if social isolation is a problem.   |
|  | Consider ways to create a more seamless system from inpatient to outpatient care.  |

OTC indicates over-the-counter; NSAID, nonsteroidal antiinflammatory drugs; and CPAP, continuous positive airway pressure.

There is a pressing need to establish the direct effect of HF self-care on clinical outcomes, including survival and QOL. Physiological research is needed to establish the mechanism by which HF self-care influences outcomes using measures of neurohormonal, inflammatory, and hemodynamic function. Intervention research is greatly needed, and those studies should incorporate assessment of the cost-effectiveness of the interventions studied. Although clinicians freely acknowledge the importance of including families and caregivers in intervention approaches, the cost-effectiveness of doing so has not been addressed.

Sorting out the appropriate approach to improving self-care is essential for future research. The efficacy of family-focused behavioral and psychosocial interventions in other chronically ill populations suggests that these might be useful for HF patients in improving self-care, yet more remains to be learned about the most advantageous approaches and doses

and the influence of patient gender and age on intervention outcomes.<sup>290</sup> Interventions that promote self-care are needed among those with low health literacy. In addition, more research on the available technology, such as telehealth, is needed.

Finally, a more seamless healthcare system from inpatient to outpatient care is greatly needed. Every aspect of the medical care system requires improvement if patients with HF are to achieve adequate self-care. In a seamless healthcare system, patients could begin self-care education in the hospital and be supported in the transition to the outpatient setting. Skilled providers would be available to address the complexities described in the present scientific statement, such as a patient population with increasing age and multiple comorbid illnesses. Support from the healthcare system for this large and compromised patient population is needed urgently.

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## State of the Science: Promoting Self-Care in Persons With Heart Failure: A Scientific Statement From the American Heart Association

Barbara Riegel, Debra K. Moser, Stefan D. Anker, Lawrence J. Appel, Sandra B. Dunbar, Kathleen L. Grady, Michelle Z. Gurvitz, Edward P. Havranek, Christopher S. Lee, JoAnn Lindenfeld, Pamela N. Peterson, Susan J. Pressler, Douglas D. Schocken and David J. Whellan on behalf of the American Heart Association Council on Cardiovascular Nursing, Council on Clinical Cardiology, Council on Nutrition, Physical Activity, and Metabolism, and Interdisciplinary Council on Quality of Care and Outcomes Research

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