

Heart failure self-care interventions to reduce clinical events and symptom burden

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Background: Lack of adherence to prescribed therapies and poor symptom recognition are common reasons for recurring hospitalizations among heart failure (HF) patients. The purpose of this literature review is to examine the effectiveness of HF self-care interventions in relation to clinical events and symptom burden.

Methods: A systematic review of randomized controlled trials with a HF self-care measure was conducted. The PubMed, CINAHL, and Medline databases were searched between 2010 and 2014, using the keyword “heart failure” in combination with the terms “self-care”, “self-management”, “self-care maintenance”, “self-care confidence”, “symptoms”, and “hospitalizations”. Outcomes of interest were clinical events and/or symptom burden.

Results: Nine studies met the inclusion criteria. HF education was the core of all interventions examined. Dose and strategies varied across studies. All interventions that effectively decreased clinical events included education on how to respond to worsening HF symptoms.

Conclusion: Knowledge alone does not improve HF self-care behaviors or reduce the risk of clinical events and/or symptom burden. Interventions that augment self-confidence or self-efficacy to perform optimal self-care management and self-care maintenance may be useful.

Keywords: heart failure, self-care, self-management, self-care maintenance, self-care confidence, symptoms, hospitalizations

Introduction

Heart failure (HF) is a major public health concern worldwide in terms of morbidity, mortality, and cost. Currently, an estimated 5.8 million Americans are diagnosed with HF, with associated costs estimated at over \$30 billion dollars annually.¹ The incidence of HF increases with age, and the prevalence of HF is predicted to increase by 46% by 2030. Despite advances in pharmacological and medical management, mortality rates remain high, with 50% of patients dying within 5 years of diagnosis.¹ In terms of morbidity, HF is responsible for more than one million hospitalizations annually. Importantly, many hospitalizations are for symptom management and considered preventable.² Efforts to decrease hospitalization risk include providing guideline-based treatment which involves maximizing pharmacotherapy and improving self-care.³

Patients with HF require education in order to adapt to their chronic condition and perform self-care behaviors. Despite receiving HF education and perceiving HF information as important, patients often have low levels of knowledge and lack a clear understanding of the causes of HF.^{4,5} Similarly, patients with HF often do not understand how and when self-care behaviors should be performed.⁶ The most favorable strategy for promoting HF self-care should be straightforward, standardized,

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and practical for a variety of health care providers and patient populations.⁷

Self-care strategies are a vital link empowering patients to take responsibility for their health. Consequently, self-care strategies are patient-centric as opposed to provider-centric.⁸ It is important to note that terminology related to self-care varies across the literature. For the purpose of this review, operational definitions of self-care are based on the work by Riegel and Dickson.⁹ Accordingly, self-care encompasses self-care maintenance and self-care management behaviors that are moderated by self-care confidence.^{9–11} Self-care maintenance is defined as daily activities that maintain clinical stability. Typically, these are adherence behaviors, such as taking medications, limiting dietary sodium, and daily monitoring of symptoms and weight. Self-care management involves recognizing a change in symptoms and responding to this change by taking an extra diuretic, limiting fluids, or calling one's health care provider. Self-care confidence is the belief in one's ability to perform self-care behaviors effectively. Although self-care confidence is an important determinant of self-care, it is not self-care per se.^{9,11} Symptom monitoring is a challenge for HF patients. In particular, determining the meaning or importance of symptoms and differentiating HF symptoms from other comorbid illnesses is difficult for patients.^{12,13} For example, early symptoms signaling impending decompensation (eg, increasing fatigue and weight gain) are not specific to the syndrome, and only 33% of patients weigh themselves frequently or always.¹⁴ Patients also commonly attribute these symptoms to less threatening illness, and symptoms may increase insidiously, impeding early recognition.^{4,13} Timely reporting of symptoms and or self-management can lead to early intervention, improving quality of life and decreasing hospitalization risk.⁷

Effective management of HF is a major challenge for both HF patients and their health care providers for several reasons. Patients with HF are generally older in age and often have complex comorbid illness profiles. As a result, polypharmacy related to both HF and comorbid illnesses further complicate management by providers and the patient's ability to achieve effective self-care.^{15,16} In addition, cognitive dysfunction is common among patients with HF, potentially affecting self-care capacity.^{17–19} Published HF guidelines emphasize the importance of self-care behaviors to decrease clinical events requiring hospitalization.^{3,20} Consequently, the importance of HF patients using self-care strategies to maintain and manage their illness is critical.

Limitations of prior HF reviews include inconsistent differentiation of self-care maintenance versus self-care

management, inclusion of telehealth studies, and omission of outcomes (eg, symptom burden and clinical events).^{8,21,22} Self-care maintenance behaviors are important to maintain clinical stability, but when employed alone are insufficient in preventing clinical events such as hospitalization.^{23–26} In addition, HF management decisions using telehealth is not the equivalent of self-care management as providers rather than patients are managing the illness. Symptom burden and clinical events were not included as outcome measures in the review by Barnason et al.²¹ A review by Ditewig et al examined the effectiveness of self-management interventions with regard to clinical events and quality of life. Although the authors reported a positive if not always significant improvement in clinical events and quality of life, some studies in the review were not true self-management interventions.⁸ As symptoms drive health care utilization, interventions that address skill in self-management of symptoms are needed to avert hospitalization. Therefore, the purpose of this review was to identify effective HF self-care management interventions that decrease clinical event risk and reduce symptom burden.

Methods

A systematic review of randomized controlled trials was conducted.^{27–29} Electronic databases (PubMed, CINAHL, and Medline) were searched using the key word “heart failure” in combination with the terms “self-care”, “self-management”, “self-care maintenance”, “self-care confidence”, “symptoms”, and “hospitalizations”. A hand search was conducted on studies retrieved. The inclusion criteria were: randomized controlled trials with a HF self-care measure, specific self-management component in the intervention, reported outcomes of interest which were clinical events and/or symptom burden, and studies published in English for the years 2010–2014. Clinical events were defined as unplanned contact with health care providers, emergency department admission, and hospitalization. Years were limited as prior reviews examined self-care interventions published for years 1996–2010.^{8,21,22} Intervention studies targeting self-care knowledge alone were excluded because our outcome of interest focused on actual self-care behaviors. The authors reviewed abstracts followed by a full text review to support the reliability and validity of studies selected for the review. Consensus was reached among the authors on studies selected for inclusion. Two hundred and seventy citations were evaluated for inclusion. Duplicate citations (n=29), nonrandomized clinical trials, studies that did not address self-care behaviors or outcomes of interest, and studies not available in English

were excluded (n=232; Figure 1). Nine studies (n=1,415 participants) met the inclusion criteria for this review.

Results

Self-care interventions and clinical events

Eight of the nine randomized trials meeting the inclusion criteria reported on the relationship between self-care management and clinical events (Table 1). Interventions varied across studies in relation to educational content, educational dose, and timeframe to event. Most of the studies used written materials such as a HF booklet.^{7,30–33} One investigator also created an audiotape of the HF education session for participants³⁰ and one provided a DVD on HF self-management.³³ All but one study specified use of one-on-one education.^{7,30–36} Instrumental support included provision of weight scales,^{7,30–33} pill boxes and measuring cups,³⁰ and a telemonitoring system with weight and blood pressure capability.³⁶ Monitoring and reinforcement of education was done with follow-up telephone calls,^{30,31,33–35} home visits,^{7,35} and daily symptom and weight diaries.^{7,34,35} Few studies specified teaching patients in use of extra diuretic doses for worsening symptoms.^{7,31,34} Most studies limited the self-management component to recognizing and responding to worsening symptoms by contacting health care providers. Interestingly, six of eight studies reported improved self-care or knowledge scores,^{7,30–32,35,36} but only three studies reported a significant decrease in clinical events.^{32–34}

The dose of the intervention did not consistently relate to frequency of clinical events. Among the interventions effective in reducing clinical events, the number of contacts

ranged from a one-time one-hour educational session³² to six contacts.^{33,34} The study by Kommuri et al had the largest sample (n=265) and the shortest intervention (one hour).³² The interventions in the studies by Lee et al and Shively et al used six sessions either in-person or by telephone.^{33,34} Lee et al instructed participants (n=44) in use of a symptom diary, evaluation of symptoms as clusters, and how to weigh themselves daily.³⁴ Risk for a clinical event was higher in the usual care group at the 90-day follow-up (hazards ratio 3.17, 95% confidence interval 1.09–9.16). The intervention (symptom graph, symptom clusters, weighing instructions) was similar to that used by Jurgens et al that did not reduce events at 90 days.⁷ The interventions differed in dose. Lee et al conducted five booster sessions via telephone over 90 days, whereas Jurgens et al used one home visit to reinforce the education. Shively et al employed a patient activation intervention which addressed information, motivation, and behavioral skills necessary for self-management. Participants received a tailored education intervention based on their level of activation and self-selected goals. Participants also received instrumental support, including a blood pressure cuff, a pedometer, and a weight scale along with the DVD and booklet. Shively et al reported fewer hospitalizations in the low activation and high activation groups, but not the medium activation group.³³ All interventions that effectively decreased clinical events included education on how to respond to worsening HF symptoms.

The intervention dose ranged from one contact to nine contacts in studies reporting little or no effect on clinical events.^{7,30,31,35,36} The study by De Walt et al (n=605) reported that a multisession intervention did not decrease clinical events over 12 months compared with a single session (incidence rate ratio 1.01, 95% confidence interval 0.83–1.22).³¹ However, the multisession intervention was beneficial in reducing HF-related hospitalizations for participants with low literacy. The usual care group received a single education session on salt avoidance and medication adherence, in addition to an educational manual and digital weight scale. The intervention group received usual care plus specific instructions on daily weights, diuretic self-adjustment, and five to eight follow-up telephone calls over 4 weeks. All participants in the study by Jurgens et al similarly received educational booklets and weight scales, which potentially blunted identification of differences in clinical events between the usual care and intervention groups.⁷ Seto et al reported no difference in number of clinical events among intervention group participants who received an individual educational session and a telemonitoring system to

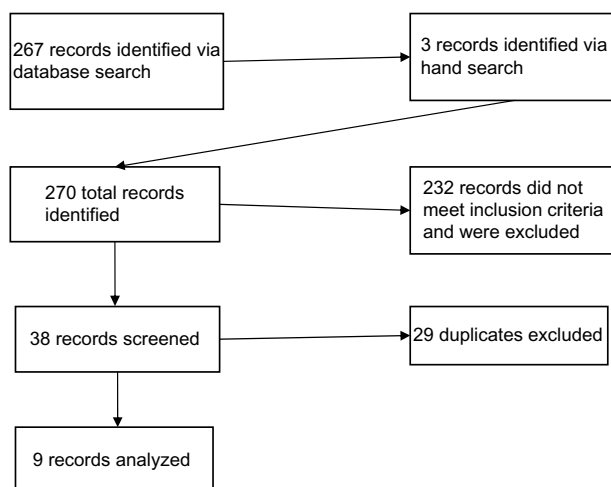


Figure 1 PRISMA flowchart for selection of evidence.

Abbreviation: PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Table 1 Self-care and clinical events

Reference and aim	Sample/method/interventions	Clinical events	Strengths and limitations
Davis et al ³⁰ Aim To test the effect of a targeted intervention on self-care, HF knowledge, and 30-day readmissions USA	n=125 UC n=62 IG n=63 Mean age 59 (SD 13) years 53% male 31% white Measures 1. SCHFI $\alpha=0.65-0.76$ 2. Dutch HF knowledge Scale $\alpha=0.39$ Interventions UC 1. Standard discharge teaching (verbal review of a HF education booklet with symptom recognition, management, exercise, dietary and fluid restriction, medication adherence) IG	No difference in readmission rates between the groups: IG 22%, UC 19% at 30 days Self-care IG had greater but not statistically significant improvement in self-care for all subscales Dutch HF knowledge scores increased significantly in IG ($P<0.001$), but decreased in UC	Strengths Heterogeneous sample in terms of gender and ethnicity Limitations Short intervention time Age 21 years and older Depression scale not validated in young adults Small sample size Young mean age Single academic center Sample mainly black patients; not representative of diverse populations
DeWalt et al ³¹ Aim To compare two different self-care methods; single-session versus multisection literacy-sensitive self-care intervention and effect on all-cause hospitalization and death USA	n=605 UC n=302 IG n=303 Mean age 60.7 (SD 13.1) years 52% male 39% white 16% Hispanic 38% black Measures 1. HF quality of life: improving chronic illness care evaluation HF symptom scale (self-care education and symptom burden)* 2. Clinical events (all-cause hospitalization or death)	1. Standard discharge teaching plus targeted self-care teaching intervention while hospitalized tailored to personal routine a. Workbook with pictograms b. Personalized self-care schedule (medications, appointments, symptom documentation) c. Problem-solving session audio-taped and given to patient d. Weight scale e. Pill box f. Measuring cups g. Salt substitute h. Follow-up telephone call 24–72 hours after discharge to conduct teach back session IG (multisection intervention) did not decrease all-cause hospitalization and death at 1 year IRR 1.01 (95% CI 0.83–1.22) Self-care IG (multisection group) had significantly greater improvement in self-care at 1 and 6 months, but not at 12 months Effect of multisection differed by literacy group Low literacy had lower hospitalization and death with IRR 0.75; 95% CI (0.45–1.25)	Strengths Large sample Limitations Cannot attribute the effects to any single element of the intervention Information on dosages of medications not collected nor number of outpatient visits

Intervention UC	High literacy had higher IRR 1.22; 95% CI 0.99–1.50 ($P=0.0048$) HF-related hospitalization	Randomization did not result in even distribution between groups on HF quality of life scores (predictor of hospitalization) Conducted at only four academic centers, which may limit generalizability
IG	Among low literacy, IG had a lower incidence rate 0.53; 95% CI 0.25–1.12 high literacy had a higher rate of 1.32 (95% CI 0.92–1.88; $P=0.005$) An intensive multisection intervention did not change clinical outcomes compared with a single-session intervention. People with low literacy appear to benefit more from multisection intervention than people with high literacy	
UC	1. 40-minute training session on daily self-assessment, action plan for exacerbation, salt avoidance, exercise, medication adherence 2. Educational manual 3. Digital weight scale	
IG	1. 40-minute training session on daily self-assessment, action plan for exacerbation, salt avoidance, exercise, medication adherence 2. Educational manual 3. Digital weight scale 4. Instruction on daily weights to guide diuretic self-adjustment 5. 5–8 follow-up 10-minute phone calls over 4 weeks to reinforce education and guide patient toward better self-care skills	
Jurgens et al ⁷	n=99	Early but not sustained benefit on clinical events
Aim	UC n=51 IG n=48 Mean age 67.7 (SD 12.1) years 67.7% male 88.9% white	Evaluated components of intervention Limitations Small sample Primarily white, male sample Inability to blind the individual collecting telephone data
To test the efficacy of an HF training program on a patient's ability to recognize and respond to changes in HF symptoms	USA	
Measures	1. SCHFI at baseline and 3 months, $\alpha=0.43-0.83$ 2. HF somatic perception scale (symptom burden), $\alpha=0.87$ 3. Clinical events (HF hospitalization, emergency department visit, death)	No difference between UC and IG in 90-day event-free survival ($\chi^2=1.53$, $P=0.216$) Self-care IG had statistically significant improvements in self-care maintenance, self-care management and self-care confidence from baseline to 90 days UC had statistically significant improvements in self-care maintenance and management from baseline to 90 days IG had greater but not statistically significant improvements in self-care maintenance and self-care confidence compared with UC UC had greater but not statistically significant improvement in self-care management scores
Intervention	UC	
UC	1. Booklet on HF self-care 2. Weight scale	
IG	1. Booklet on HF self-care 2. Weight scale 3. HF symptom training intervention: one time one-on-one training by advanced practice nurse using 6-minute walk Test to increase effort for detecting differences in dyspnea and fatigue	
1. Booklet on HF self-care	2. Weight scale	
2. Weight scale	3. HF symptom training intervention: one time one-on-one training by advanced practice nurse using 6-minute walk Test to increase effort for detecting differences in dyspnea and fatigue	
3. HF symptom training intervention: one time one-on-one training by advanced practice nurse using 6-minute walk	Test to increase effort for detecting differences in dyspnea and fatigue	
Test to increase effort for detecting differences in dyspnea and fatigue	4. Daily symptom graph of weight, dyspnea, fatigue, and presence of edema	
4. Daily symptom graph of weight, dyspnea, fatigue, and presence of edema	5. Meaning of symptoms (eg, when to call provider or take an extra diuretic)	
5. Meaning of symptoms (eg, when to call provider or take an extra diuretic)	6. Follow-up visit 1 week after training to review instruction	
6. Follow-up visit 1 week after training to review instruction	Primary endpoint: time to first HF hospitalization, ED visit for HF, or HF-related cause and death	
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(Continued)

Table 1 (Continued)

Reference and aim	Sample/method/interventions	Clinical events	Strengths and limitations
Kommuri et al ² Aim To assess changes in HF knowledge assessments between a control group and a nurse educator education session USA	n= 265 UC n=137 IG n=128 Mean age 67 years 61% male 78% white Measures 1. HF knowledge questionnaire at discharge, 30 days, 60, 90, and 180 days to assess HF disease management knowledge, self-care management behaviors and medications, diet recommendations, and salt content* Intervention UC 1. Standard discharge information IG 1. Standard discharge information 2. One hour face-to-face nurse educator delivered HF program a. Principles of HF b. Dietary sodium c. Limiting fluids d. Diuretic mechanisms e. Rationale for medication f. Daily weight monitoring g. Self-care behaviors h. Medication compliance i. Smoking cessation j. Avoid nonsteroidal medications k. Response to worsening symptoms l. Avoid alcohol m. HF guidelines in lay terms Primary endpoint: clinical events of hospitalization or death within 180 days Change in HF knowledge scores from baseline to 30 days and 180-day follow up	IG had significantly higher knowledge scores at 3 months compared with UC. Clinical events associated with lower HF knowledge (10 versus 11, $P=0.002$) and HF management scores (4 versus 5, $P=0.001$) when compared with patients without clinical events HF nurse education at the time of hospital discharge results in improved patient knowledge and reduced risk of readmission Self-care Strong association between HF knowledge and adherence to HF self-care measures (median, IQR 1.0 to 4 versus 0, -2 to 2, $P=0.007$) Significant improvement in IG disease management knowledge scores ($P<0.001$) No improvement or difference between groups for dietary and sodium knowledge	Strengths Large sample Limitations HF knowledge questionnaire lacks reliability and validity data Unable to show improvements in dietary knowledge due to weakness in educational program

Lee et al ³⁴	n=44 UC n=21 IG n=23	IG participants experienced longer event-free survival ($P=0.03$) at 3 months UC had higher risk for a clinical event (HR 3.17, 95% CI 1.09–9.16) controlling for NYHA functional class Self-care	Strengths Heterogeneous sample in terms of gender Limitations Small sample size
Aim	Mean age 60 (SD 12) years 52.3% male 61.4% white	No difference between groups at baseline Self-care at 1 and 3 months not reported	
To test the effect of a comprehensive daily symptom diary intervention (education and counseling about HF symptoms, how to recognize symptoms and what to do with escalating symptoms) on event-free survival and health-related quality of life	Measures	1. Event-free survival assessed at 1 month and 3 months 2. SCHFI (two items assessing weight and edema monitoring)* 3. MLHF (physical symptom subscale)* 4. Symptom diary	
USA	Intervention	1. Discharge education booklet describing HF, a low sodium diet, and medication instructions	
	UC	IG	
	1. One face-to-face education and counseling session in patient's home	1. One face-to-face education and counseling session in patient's home	
	a. How HF symptoms are related to fluid retention and diet	a. How HF symptoms are related to fluid retention and diet	
	b. How to monitor symptoms	b. How to monitor symptoms	
	c. What to do for worsening symptoms (eg, when to call provider or take an extra diuretic)	c. What to do for worsening symptoms (eg, when to call provider or take an extra diuretic)	
	d. Review of medication regimen	d. Review of medication regimen	
	e. Use of symptom diary using symptom clusters	e. Use of symptom diary using symptom clusters	
	f. How to weigh daily	f. How to weigh daily	
	2. Five booster sessions via biweekly phone calls for 3 months	2. Five booster sessions via biweekly phone calls for 3 months	
Sero et al ³⁶	n=100 UC n=50 IG n=50	No differences between groups for HF hospitalizations, ED visits, or number of nights in hospital at 6 months IG group had higher number of HF clinic visits ($P=0.04$) related to the cardiologist asking them to come in based on telemonitoring alerts Self-care	Limitations Study inadequately powered to detect effects of telemonitoring on mortality and hospitalization Sample included patients new to HF clinic and stable HF patients Homogeneous population in terms of gender and ethnicity Young mean age
Aim	Mean age 53.7 (SD 13.7) years 79% male 72% white	Both IG and UC had significant improvements in self-care maintenance scores. IG had greater improvement than UC on self-care maintenance ($P=0.03$) Both IG and UC had significant improvements in self-care management, but no significant differences between groups ($P=0.7$)	
To investigate the effects of a mobile phone-based telemonitoring system on HF management and outcomes	Measures	Both IG and UC had significant improvements in self-care maintenance scores. IG had greater improvement than UC on self-care maintenance ($P=0.03$) Both IG and UC had significant improvements in self-care management, but no significant differences between groups ($P=0.7$)	
Canada	1. SCHFI* 2. MLHF* 3. Clinical events	Both IG and UC had significant improvements in self-care maintenance scores. IG had greater improvement than UC on self-care maintenance ($P=0.03$) Both IG and UC had significant improvements in self-care management, but no significant differences between groups ($P=0.7$)	
	Intervention	Both IG and UC had significant improvements in self-care maintenance scores. IG had greater improvement than UC on self-care maintenance ($P=0.03$) Both IG and UC had significant improvements in self-care management, but no significant differences between groups ($P=0.7$)	
	UC	Both IG and UC had significant improvements in self-care maintenance scores. IG had greater improvement than UC on self-care maintenance ($P=0.03$) Both IG and UC had significant improvements in self-care management, but no significant differences between groups ($P=0.7$)	
	1. Standard care which included	Both IG and UC had significant improvements in self-care maintenance scores. IG had greater improvement than UC on self-care maintenance ($P=0.03$) Both IG and UC had significant improvements in self-care management, but no significant differences between groups ($P=0.7$)	
	a. Visits to clinic once every 2 weeks to once every 3–6 months, depending on severity of HF	Both IG and UC had significant improvements in self-care maintenance scores. IG had greater improvement than UC on self-care maintenance ($P=0.03$) Both IG and UC had significant improvements in self-care management, but no significant differences between groups ($P=0.7$)	
	b. Education during preliminary visits to clinic	Both IG and UC had significant improvements in self-care maintenance scores. IG had greater improvement than UC on self-care maintenance ($P=0.03$) Both IG and UC had significant improvements in self-care management, but no significant differences between groups ($P=0.7$)	
	c. Use of telephone clinic as necessary	Both IG and UC had significant improvements in self-care maintenance scores. IG had greater improvement than UC on self-care maintenance ($P=0.03$) Both IG and UC had significant improvements in self-care management, but no significant differences between groups ($P=0.7$)	

(Continued)

Table 1 (Continued)

Reference and aim	Sample/method/interventions	Clinical events	Strengths and limitations
Shao et al ³⁵ Aim To determine the effectiveness of a self-management program based on the self-efficacy construct in older people with HF Taiwan	IG 1. Standard care 2. Telemonitoring system a. Daily morning weight b. BP readings c. Weekly ECG 3. Answered daily morning symptom questions on mobile phone 4. Individual training session on how to use system, provided technical support n=93 UC n=46 IG n=47 Mean age 72 (SD 5.5) years 68% male Measures 1. Self-efficacy for salt and fluid control, $\alpha=0.94-0.96$ 2. HF self-management behavior scale (lower scores indicate better self-management), $\alpha=0.71$ 3. HF symptom distress scale, $\alpha=0.67$ 4. Health service use (include patient clinical, ED visits, and hospitalization) Intervention UC 1. Educated on improving general knowledge of HF, causes, signs and symptoms, complications, medications, and activity and dietary recommendations 2. Phone calls at weeks 3, 7, and 11 IG 1. Educated on improving general knowledge of HF, causes, signs and symptoms, complications, medications, and activity and dietary recommendations 2. Home visit within 3 days after enrollment 3. Phone calls at weeks 1, 3, 7, and 11 4. Diary of daily sodium and fluid intake and daily weight Primary endpoint: HF-related symptoms, hospitalization at 12 weeks n=84 UC n=41 IG n=43 Mean age 66 (SD 11) years 99% male 77% white	No significant differences between groups in health service use at 12 weeks Self-care Self-management behavior improved significantly in IG versus UC (mean 27.15 versus 30.13, $P<0.001$)	Limitations Short follow-up for measuring outcomes Lack of objective measures to support difference between IG and UC Homogenous population Two medical centers limits generalizability Unable to conclude which intervention was effective because the effectiveness of four information sources could not be determined
Shively et al ³³ Aim To determine the efficacy of a patient activation intervention compared with UC on patient activation, self-management, hospitalization, and ED visits in patients with HF	IG 1. Educated on improving general knowledge of HF, causes, signs and symptoms, complications, medications, and activity and dietary recommendations 2. Home visit within 3 days after enrollment 3. Phone calls at weeks 1, 3, 7, and 11 4. Diary of daily sodium and fluid intake and daily weight Primary endpoint: HF-related symptoms, hospitalization at 12 weeks n=84 UC n=41 IG n=43 Mean age 66 (SD 11) years 99% male 77% white	IG had fewer hospitalizations in low/high activation group at 6 months ($F=2.57$, $P=0.041$) IG had more hospitalizations in medium activation group	Limitations Small sample size Homogeneous sample in terms of gender and ethnicity Small number of clinical events

USA	Measures 1. Patient activation measure 2. SCHFI, $\alpha=0.42-0.88$ 3. Medical outcomes study specific adherence scale 4. Hospitalization and ED visits Intervention UC 1. Routine medical care in primary care or non-HF specialty clinic IG 1. Routine medical care in primary care or non-HF specialty clinic 2. Activation assessed and individualized health behavior goals set 3. Six sessions one-to-one education by telephone or in person by advanced practice nurse 4. Educational booklet 5. BP cuff 6. HF self-management DVD 7. Weight scale 8. Pedometer Measures taken at baseline, and at 3 and 6 months	Self-care No significant differences in group-by-time interactions for SCHFI maintenance, management or confidence scores IG had significant increase in patient activation scores
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Note: *Cronbach's alpha not reported.

Abbreviations: BP, blood pressure; CI, confidence interval; HF, heart failure; ECG, electrocardiogram; ED, emergency department; UC, usual care group; IG, intervention group; IQR, interquartile range; IRR, incidence rate ratio; SCHFI, Self-Care of HF Index; MLHF, Minnesota Living with HF Questionnaire; HR, hazard ratio; NYHA, New York Heart Association (functional class); α , Cronbach's alpha; SD, standard deviation.

monitor weight, blood pressure, and electrocardiograms for 6 months.³⁶ Finally, among investigators using symptom diaries or some form of symptom tracking,^{7,30,34,35} only the study by Lee et al had a significant effect on clinical events.³⁴

Self-care interventions and symptom burden

Symptom burden, as a predictor of quality of life and hospitalization, is an important outcome of interest in relation to the effectiveness of self-care interventions.^{37,38} Symptom burden was reported as an outcome in four studies (Table 2).^{34-36,39} In some cases, measurement was extrapolated from quality of life measures with physical symptom subscales.^{34,36} Two studies reported significant improvement in symptom burden in relation to instituting a self-management intervention.^{35,39}

Baker et al compared a brief educational intervention (usual care group) compared with a teach-to-goal intervention on self-care behaviors and HF quality of life.³⁹ Both groups received a 40-minute educational session on self-care maintenance and self-care management. All participants ($n=605$) also received an educational manual and a digital scale. The intervention group was provided with specific instructions on daily weights and diuretic self-adjustment followed by five to eight phone calls over 4 weeks to reinforce the education. The intervention group had significant improvement in symptoms and self-efficacy whereas symptom burden was unchanged in the usual care group. Both groups had significantly improved self-care scores; however, the improvement in the intervention group was significantly greater. Strengths of this study were its large sample size and heterogeneity in terms of gender and ethnicity. Limitations include high baseline HF knowledge and younger mean age than typically found among samples of patients with HF.

The intervention group in the study by Shao et al received the same intervention as the usual care group, supplemented by a home visit, one extra phone call, and a diary for daily sodium, fluid intake, and weight.³⁵ Self-care management and symptom scores improved in the intervention group. The intervention by Lee et al was similar; however, the symptom burden did not differ between groups at 3 months.³⁴

Discussion

This review was limited to studies with a self-management component in the intervention. We found the majority of self-care interventions increased knowledge and improved self-care scores, but were inconsistent in relation to decreasing clinical events or reducing symptom burden. The core

Table 2 Self-care and symptom burden

Reference and aim	Sample/method/interventions	Symptom burden	Strengths and limitations
<p>Baker et al³⁹</p> <p>Aim To examine the effect of two different levels of self-care learning on the adoption of key self-care behaviors and on HF-related quality of life USA</p>	<p>n=605 UC n=302 IG n=303 Mean age 60.7 (SD 13.1) years 52% male 39% white Measures 1. S-TOFHLA 2. ICICE* 3. Heart Failure Symptoms Scale (used as measure of quality of life)* Intervention UC Brief Educational Intervention 1. 40-minute educational session on daily self-assessment, action planning in case of exacerbations, salt avoidance, and medication adherence 2. Educational manual 3. Digital weight scale IG Teach to goal 1. 40-minute educational session on daily self-assessment, action planning in case of exacerbations, salt avoidance, and medication adherence 2. Educational manual 3. Digital weight scale 4. Specific instructions on daily weights to guide diuretic self adjustment 5. 5–8 phone calls over 4 week period to reinforce education and guide patient towards better self-care skills Time frame of 4 weeks</p>	<p>IG had significant improvement in HF symptoms compared with UC ($P<0.001$) Symptoms were unchanged in UC group Self-care IG had a significant increase compared with UC 0.70 versus 0.30; $P=0.008$ Changes in self-efficacy Teach-to-goal group had a significant increase compared with brief educational intervention group (1.0 versus 0.4; $P=0.006$)</p>	<p>Strengths Large sample Heterogeneous sample in terms of gender and ethnicity Limitations High baseline knowledge of study participants Young mean age of sample</p>
<p>Lee et al³⁴</p> <p>Aim To test the effect of a comprehensive daily symptom diary intervention (education and counseling about HF symptoms, how to recognize symptoms, and what to do with escalating symptoms) on event-free survival and health-related quality of life USA</p>	<p>n=44 UC n=21 IG n=23 Mean age 60 (SD 12) years 52.3% male 61.4% white Measures 1. Event-free survival assessed at 1 and 3 months 2. MLHF (physical symptom subscale)* 3. Symptom diary Intervention UC 1. Discharge education booklet describing HF, a low sodium diet, and medication instructions</p>	<p>MLHF physical subscale scores (proxy for symptom burden) were not significantly different between groups over 3 months Self-care No difference between groups at baseline Self-care at 1 and 3 months not reported</p>	<p>Strengths Heterogeneous sample in terms of gender Limitations Small sample size Young mean age of sample</p>

<p>IG</p> <p>1. One face-to-face education and counseling session in patient's home</p> <ol style="list-style-type: none"> How HF symptoms are related to fluid retention and diet How to monitor symptoms What to do for worsening symptoms Review of medication regimen Use of symptom diary using symptom clusters How to weigh daily <p>2. Five booster sessions via biweekly phone calls for 3 months</p> <p>n=100</p> <p>UC n=50</p> <p>IG n=50</p> <p>Mean age 53.7 (SD 13.7) years</p> <p>79% male</p> <p>72% white</p> <p>Measures</p> <ol style="list-style-type: none"> SCHF* MLHF* <p>Intervention</p> <p>UC</p>	<p>No difference between groups on symptom burden (MLHF physical subscale)</p> <p>IG had greater improvement on MLHF emotional subscale ($P=0.05$)</p> <p>Self-care</p> <p>Both IG and UC had significant improvements in self-care maintenance scores. The IG had greater improvement than UC on self-care maintenance ($P=0.03$)</p> <p>Both IG and UC had significant improvements in self-care management, but no significant differences between groups ($P=0.7$)</p>	<p>Limitations</p> <p>Study inadequately powered to detect effects of telemonitoring on mortality and hospitalization</p> <p>Primarily white male sample</p> <p>Sample included patients new to HF clinic and stable HF patients</p> <p>Young mean age of sample</p>
<p>Seto et al¹⁶</p> <p>Aim</p> <p>To investigate the effects of a mobile-based telemonitoring system on HF self-care and clinical management</p> <p>Canada</p>	<p>1. Standard care including</p> <ol style="list-style-type: none"> Visits to clinic once every 2 weeks to once every 3–6 months, depending on severity of HF Education during preliminary visits to clinic Use of telephone clinic as necessary <p>IG</p> <ol style="list-style-type: none"> Standard care Telemonitoring system <ol style="list-style-type: none"> Daily morning weight BP readings Weekly ECG Answered daily morning symptom questions on mobile phone Given individual training session on how to use system, provided technical support during trial <p>n=93</p> <p>UC n=46</p> <p>IG n=47</p> <p>Mean age 72 (SD 5.5) years</p> <p>68% male</p> <p>Measures</p> <ol style="list-style-type: none"> Self-efficacy for salt and fluid control, $\alpha=0.94-0.96$ HF self-management behavior scale, $\alpha=0.71$ 	<p>Limitations</p> <p>Short follow-up for measuring outcomes</p> <p>Lack of objective measures to support difference between IG and UC</p> <p>Homogenous population</p> <p>Two medical centers limits generalizability</p>
<p>Shao et al³⁵</p> <p>Aim</p> <p>To determine the effectiveness of a self-management program based on the self-efficacy construct in older people with HF</p> <p>Taiwan</p>	<p>IG had lower symptom distress scores than the UC at time 2 and time 3, indicating improvement in HF symptom distress</p> <p>Self-care</p> <p>Self-management behavior improved significantly in IG versus UC (mean 27.15 versus 30.13, $P<0.001$), with lower scores indicating better self-management</p>	<p>Limitations</p> <p>Short follow-up for measuring outcomes</p> <p>Lack of objective measures to support difference between IG and UC</p> <p>Homogenous population</p> <p>Two medical centers limits generalizability</p>

(Continued)

Table 2 (Continued)

Reference and aim	Sample/method/interventions	Symptom burden	Strengths and limitations
	3. HF symptom distress scale, $\alpha=0.67$ 4. Health service use (include patient clinical, ED visits, and hospitalization) UC 1. Educated on improving general knowledge of HF, causes, signs and symptoms, complications, medications, activity, and dietary recommendations 2. Phone calls at weeks 3, 7, and 11 IG 1. Educated on improving general knowledge of HF, cause, signs and symptoms, complications, medications, and activity and dietary recommendations. 2. Home visit within 3 days after enrollment 3. Four phone calls at weeks 1, 3, 7, and 11 4. Diary of daily sodium and fluid intake and daily weight Primary endpoint: HF-related symptoms, hospitalization at 12 weeks		Unable to conclude which intervention was effective because the effectiveness of four information sources could not be determined

Note: *Cronbach's alpha not reported.

Abbreviations: BP, blood pressure; HF, heart failure; ECG, electrocardiogram; ED, emergency department; UC, usual care group; ICICE, Improving Chronic Illness Care Evaluation; IG, intervention group; SCHFI, Self-Care of HF Index; MLHF, Minnesota Living with HF Questionnaire; α , Cronbach's alpha; SD, standard deviation; S-TOFHLA, Short-Test of Functional Health Literacy in Adults.

of each intervention was patient education, and educational content was similar across studies. Other components of interventions such as use of symptom diaries or instrumental support (eg, provision of weight scales) also were inconsistent in relation to the outcomes of interest. Only one investigator evaluated the self-care intervention components to identify those that were most effective. Provision of a weight scale and conducting a home visit were the two components associated with statistically significant improved self-care.⁴⁰ Without additional responder analysis data, we are unable to conclusively identify which self-care interventions are most effective in reducing clinical event risk and symptom burden. However, interventions focused on improving skill in symptom monitoring and timely response to escalating symptoms are important.^{5,11}

Self-care, an integral component of HF disease management, is beneficial in terms of reducing morbidity, mortality, and symptom burden, and improving quality of life.⁴¹⁻⁴³ Considering HF is a chronic and progressive illness, need for oversight by health care providers will presumably increase over time. However, it is preferable to maximize self-care capacity to assist patients in maintaining clinical stability and independence for as long as possible.

Self-care capacity is known to vary among patients.⁴⁴ Several factors affect self-care capacity, including but not limited to cognitive status,^{17,18,45} health literacy,^{46,47} depression,⁴⁸⁻⁵⁰ and self-efficacy or self-confidence.^{39,51} Consequently, determining which self-management interventions are effective for improving outcomes in different populations is challenging. Attention to modifiable factors affecting self-care capacity is therefore warranted. In particular, self-efficacy and self-confidence are important targets for self-management interventions because of a moderating and mediating effect on self-care. Lee et al reported that higher levels of self-care were associated with better health status, but only if self-confidence was high.⁵¹ A case in point is a lack of difference in clinical events in the study by Jurgens et al. The intervention group had a statistically significant improvement in self-care confidence from baseline to 90 days (from 54.3 to 65.2, $P \leq 0.01$); however, Self-Care of HF Index scores were below 70, which is the cutoff score considered adequate.⁷ Exploring use of interventions that improve self-efficacy and self-care confidence may support increased effectiveness of many of the interventions currently in use. Motivational interviewing and similar cognitive behavioral interventions may be a useful strategy for increasing confidence and subsequent self-management skills.^{52,53}

Limitations of studies in this review include both methodological concerns and sampling. Treatment fidelity to ensure consistency in delivery of interventions is an important aspect of research. Only one study specifically reported treatment fidelity procedures.⁷ In other studies, fidelity was implied by delivery of the intervention by the same person^{31–33,39} or not reported.^{30,34–36} Limitations to generalizability of the studies also include small sample sizes,^{7,30,33,36} homogenous samples with respect to ethnicity,^{7,30,32,33,35,36} and limited time to follow-up.³⁰ Lastly, reporting instrument reliability coefficients affects the interpretation of study results. Only four of the nine studies^{7,30,33,35} reported reliability coefficients.

Research implications

This review highlights several implications for future conduct of research on HF self-care interventions. First, differentiating the components of self-care, particularly in relation to maintenance and management, is important. Studies in this review support the usefulness of HF education to improve patient knowledge. However, knowledge alone is insufficient to improve outcomes. Knowledge of self-care maintenance or adherence behaviors plus skill in HF self-management is needed to reduce clinical event risk and symptom burden. The evidence also suggests the importance of self-efficacy and self-confidence for effective self-care management. Second, all interventions evaluated in this review incorporated several components, but little is known about which components are most important. As health care resources are limited, conducting responder analyses would assist in filling gaps in knowledge regarding which component(s) to emphasize in terms of outcomes and cost. Third, self-care capacity and effectiveness of interventions varies across individuals and populations. Therefore, analyses of interventions in relation to their effectiveness in subpopulations are needed to guide choice and dose of interventions.^{5,44,54} Finally, research is needed to examine the effect of self-care on health outcomes important to patients, insurance providers, and health care systems. Outcomes of interest include but are not limited to symptom burden, quality of life, morbidity, mortality, and hospitalization.

Implications for practice

Self-care is an essential component of HF management, but patient education frequently occurs in the time-limited process of hospital discharge. As a result, self-care interventions need to be standardized and feasible for clinicians across health care settings.^{55,56} Consideration of patient factors such as adequacy of social support, health literacy, cognition,

depression, socioeconomic status, and advanced age is also important when choosing an intervention.^{11,21} Importantly, patients with HF seek information on how to negotiate all the components of self-management in addition to understanding medications, dietary restrictions, and symptom monitoring.⁶ Consequently, a focus on skill-building educational tactics is needed in addition to basic self-care information. Timely self-management is challenging for patients due to difficulty in detecting an increase over baseline symptoms.⁴ As a result, delay in seeking care for symptoms is common, because symptoms such as weight gain and increasing fatigue are not perceived as important or related to HF.^{12,57} To support effective self-management, patients need specific instruction on the importance of symptoms and what to do when symptoms occur (eg, weight gain). Inclusion of family members or other support persons in education and skill building is recommended as they can assist with many components of self-care, including detecting a change in status.¹¹

Conclusion

Self-management of HF is a complex proposition for patients and their families based on the skills required to maintain clinical stability as well as skills for symptom management. The most effective dose for self-care interventions is unknown. Strategies that increase self-care confidence may be a key factor in determining the frequency and amount of oversight needed over time.^{50,51} Finally, patients need to understand the importance of acting when a change in status occurs. Patients with HF are known to wait to see if symptoms improve.¹² Understanding the importance of self-management of the early symptoms of HF, such as weight gain, increasing fatigue, decreasing activity tolerance, and dyspnea on exertion, is particularly important. If the early symptoms of impending decompensation are recognized and treated, hospitalization for symptom management may be averted.

Disclosure

The authors report no conflicts of interest in this work.

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